Quality in Ageing and Older

Building relational research capacity in care homes in the covid-19 era: applying Recognition Theory to the research agenda

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Title

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Abstract

Purpose: Research can be an influential driver in raising care home standards and the wellbeing and human rights of residents. We present a case for how a relational research capacity building programme could advance this agenda.

Approach: We use Axel Honneth's Recognition Theory as a lens through which to explore organisational and institutional factors (such as research capacity and investment) that can either enable or limit 'recognition' in the context of research in care homes. We draw on recent evidence from the COVID-19 pandemic in the United Kingdom and worldwide, to argue that such a relational capacity building agenda is even more pressing in the current context, and that it resonates with evidence from existing relational capacity building initiatives.

Findings: A lack of relevant research arguably contributed to the crisis experienced by the care home sector early in the pandemic and there are only tentative signs that residents, care home providers and staff are now informing the COVID-19 research agenda. Evidence from pre COVID-19 and insights from Honneth's Recognition Theory suggest that relational approaches to building research capacity within the care home sector can better generate evidence to inform practice.

Originality: This is a novel application of Recognition Theory to research in the care home sector. Drawing on theory as well as evidence has enabled us to provide a rationale as to why relationship-based research capacity building in care homes warrants further investment.

Keywords:

Care Homes, Nursing Homes, Residential Homes, Research Capacity Building, Pandemic, COVID-19, Axel Honneth, Recognition Theory

Introduction

In 2016 there were approximately 410,000 care home residents in the United Kingdom (UK: Competitions and Markets Authority, 2017) and this number is projected to rise (Lam *et al.*, 2018). All UK nations have health and social care policies that endorse the importance of research in informing good care and enhancing wellbeing (Scottish Government, 2016; Welsh Government, 2015, 2014; Department of Health and Social Care, 2014; Health and Social Care Board, 2013; Department of Health and Social Care, 2012). Care home research can drive practice change and improve care standards by informing good practice (Jonker *et al.*, 2020; Jenkins *et al.*, 2016). It can also promote staff professional development (Jenkins *et al.*, 2016), drive up prestige and improve the perception of care homes (Johnstone and Donaldson, 2019). In recognition of this, the care regulator in England explicitly encourages providers to participate in research (Smith *et al.*, 2019).

In 2014, however, the Older Peoples Commissioner for Wales concluded that too many older people living in care homes in Wales had an unacceptable quality of life and their dignity was insufficiently protected, whilst in 2017, 30% of care homes in England received 'inadequate' or 'requires improvement' ratings from the Care Quality Commission (Competitions and Markets Authority, 2017). Similarly, we see reports and inquiries about quality in aged care in other countries, for example, the Australian Royal Commission into Aged Care Quality

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and Safety that is due to report in November 2020. Knowledge production can be a powerful driver for raising quality standards, expectations, experiences and attention to human rights, but we argue this needs to be grounded in recognition of the value of care homes and informed by the perspectives of care home residents, their families, and the workforce.

The COVID-19 pandemic has had (and will continue to have) profound impacts on the care home population. Research is needed to inform how the sector can best protect residents' health and emotional wellbeing and promote their quality of life within the new world environment. For instance, COVID-19 social distancing restrictions have meant that the way care is provided in care homes has had to change. It is therefore imperative to generate the evidence needed to inform new ways of working. In pressurised contexts it can seem expedient to take a top-down approach to evidence building. We argue that such an approach to care home research would be detrimental in the immediate and longer-term. We draw on existing evidence and Recognition Theory (Honneth, 1996) to outline our argument that taking into account the urgency of the situation, there needs to be an ongoing investment in relational research capacity building with care home stakeholders. We have written this paper primarily to engage an audience of researchers, academics and policy makers and commissioners involved in the long term residential care of older adults. We draw on evidence predominately from the UK experience, but our argument has relevance to other countries with similar research and care infrastructures.

Our case for relational research capacity building

In establishing a case for a relational research capacity building approach, we draw on our interpretation of ideas central to Axel Honneth's Recognition Theory (1996). A social theorist, Honneth (1996) published a seminal work *The Struggle For Recognition: The Moral Grammar of Social Conflict*, about recognition, non-recognition and misrecognition and the constitution of social conflicts and social change. Honneth (1996) builds on Hegels' (1807, 1821) conceptualisation of an intersubjective 'struggle for recognition'. Hegel (1807, 1821) argued that the need to be seen and recognised as a valued subject by others-to be visible and affirmed- is a driving force for human agency and social change. Honneth (1996) integrated these understandings with George Mead's (1934) social psychology about the formation of human identity and self in the child/caregiver relationship (Honneth, Chapter 5: 14). When Honneth talks of recognition he is referring to an individual experiencing that they are 'visible' to others, listened to, that their rights and dignity are respected, and that their social community values them. Recognition is a thread that runs across intersecting domains of self, social relationships and societies. Worth, esteem and respect are central in several contemporary recognition theories which have sought to explain identity movements and struggles for power and justice (Taylor, 1992; Fraser, 1998).

For Honneth (1996), this validation through mutual recognition is a prerequisite for the attainment of a 'positive relation to self', relationships with others and for justice (Honneth, 1996; Houston, 2016). Individuals achieve (or are thwarted from achieving) recognition through the various dynamics of contextual factors. Honneth (1996) outlines three patterns or forms of recognition- love, rights and solidarity: love and friendship developed in primary relationships; legal recognition as the experience of rights and duties backed by laws, and solidarity or 'social relations of symmetrical esteem' as the recognition of others and by

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others of what the self-offers and brings to the social world (Honneth, Chapter 5: p.45). In Honneth's schema, being afforded respect involves having one's legal rights upheld and people can attain self-esteem when their society values them and their contribution to the community (Honneth, 1996). Disrespect (or misrecognition and non-recognition) at the relational level and through processes of social exclusion (including at an infrastructural level) and social denigration, can negatively impact on physical and social integrity and dignity (Honneth, 1996: Chapter 5, p.45). Those who are not recognised, as Mattias (2019) summarises, are particularly motivated to resist, that is, to engage in a 'struggle for recognition'.

Based on Honneth's (1996) Recognition Theory, Laitinen and Pirhonen (2018) outline ten forms of recognition versus misrecognition for older people in long term care, where '…the minimal core is the recognition of biological, social and institutional existence, lack of invisibilization' (2018, p.4). These ten forms of recognition/misrecognition are profound and cover aspects of day to day care, how respect and visibility of a care home resident's unique personhood is made manifest or not, and the social domains of recognition/misrecognition of long-term care settings. Banks (2018, p.167) in an Australian study used Honneth's (1996) work to explore recognition of aged care workers and finds study participants are '…compromised by external signals of mistrust and devaluing forms of misrecognition', as are the people with whom they work. These works illustrate the potency of Honneth's (1996) Recognition Theory as a lens through which to explore complex power relations at micro-macro levels. In the discussion that follows we turn to focus on research in care home settings using this relational based theoretical perspective.

The current evidence base

The current evidence base of research in care homes in the UK upon which evidence creation during and after the COVID-19 pandemic can be built is weak. This can be accounted for by the relatively small number of high quality studies taking place in care homes in the UK before the COVID-19 crisis, an absence of a coordinated research agenda for care homes and, the limited processes for the dissemination of research knowledge to inform care home practices.

The lack of research undertaken in care home settings can be partially explained by the dearth of a support and delivery infrastructure to assist care home research engagement (Shepherd *et al.*, 2015). Furthermore, the care home industry is not professionalised. Many posts are occupied by people without professional qualifications (Lam *et al.*, 2018) and many professionals who work alongside care homes, such as social workers, may have received limited research training as part of their qualification (Orme and Powell, 2007). Unsurprisingly care home staff can struggle to understand their role in the research process (Goodman *et al.*, 2011). Some providers can view research as a threat and irrelevant to their work, especially if the researcher is viewed as an 'outsider' (Lam *et al.*, 2018; Jenkins *et al.*, 2016). Moreover, care home research presents methodological challenges for researchers. For quantitative studies it is suggested that researchers need to approach at least 40% more care homes to achieve their recruitment targets (Davies *et al.*, 2014), thereby increasing the costs of undertaking research in care homes compared to non-care home settings (Lam *et al.*, 2018). Other reported challenges include time-consuming participant recruitment and high attrition rates (Lam *et al.*, 2018).

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The knowledge mobilisation infrastructure of care home research is also deficient. Care staff often fail to access the training and knowledge available that could inform their work. For example, in 2104 it was estimated that only 60% of care staff in Wales had undertaken mandatory training (Older Peoples Commissioner, 2014, p.71). Social work colleagues may not know where to access the latest research evidence or have the requisite skills to interpret and assess the quality of this evidence (McLaughlin, 2012). Equally, staff training and the development of the social care workforce continues to be underfunded (Trigg, 2018). This lack of knowledge mobilisation also impacts on residents and their families as a lack of knowledge has led to many people accepting 'good enough' care believing that 'good' care is impossible (Older Peoples Commissioner, 2014; Competitions and Markets Authority, 2017).

It must be acknowledged that care home research requires thoughtful, sensitive and specific approaches because of the multifarious issues experienced by the care home population. Care home residents often have complex care needs and up to three quarters of this population experience some degree of cognitive impairment (Gordon *et al*., 2013). It is rare to include older adults with high support needs in co-producing knowledge and social care staff report feeling similarly disempowered (Andrews *et al.*, 2020). When opportunities are available, care home residents, especially those from minority groups, are often unwilling to participate as support for their engagement is unavailable (Lam *et al*., 2018). Family members can be reluctant to support research activities in care homes if their relative has dementia or if they perceive the research to invade privacy (Lam *et al*., 2018). In addition, some care home providers may act as 'gate keepers', with the intention of protecting their residents, as there is a general lack of understanding that residents who lack capacity should have equal access to research participation (Shepherd, 2020).

Despite the well documented understanding that care home residents would benefit from interventions to improve their wellbeing including their confidence, self-esteem, respect and rights (e.g. Goodman and Davies, 2013; Older Peoples Commissioner, 2014), we contend that misrecognition and non-recognition of the care home population, as seen through the lens of Honneth's (1996) Recognition Theory, is a further contributory factor to the limited body of current care home research.

Misrecognition and non-recognition

We highlight three structural faces of misrecognition and non-recognition in the care home sector that have implications for research infrastructures.

Political climate: Welfare provision is inherently political (MacKenzie *et al*., 2013) and research agendas are formed within a political context. Whilst care home residents, their families and friends, and the care home workforce know the importance of the care home sector, the dominant political discourse has paid scant attention to the role it plays (Burton, Goodman and Quinn, 2020): instead care homes are increasingly perceived by many to be a 'last resort' for care and support (Mason, 2012). In addition, in contrast to the National Health Service (NHS), care in residential homes is considered a private, rather than a public responsibility (Mason, 2012). These political factors, and the normative perception of care homes, have a bearing on how the sector is recognised, with implications for the construction of research processes and knowledge generation about care home issues.

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Social discourses and ageism: Commentators have raised concern about the rhetoric of older adult vulnerability and paternalistic attitudes. They have asserted that older adults can also be resilient and adaptive (Pereyra *et al.*, 2020). Banks (2018, p.196) suggests that '…discursive constructions of older people (as frail, vulnerable, passive 'others') are likely to impact on both older people themselves, and on the dynamics of activities or services connected with them'. Cultural change is also needed in attitudes towards ageing and dying (Mason, 2012). For instance, most people do not plan for their care in later years and there is a lack of public understanding about the care system (Competitions and Markets Authority, 2017) and the rights that care home residents have under the law (Ivory *et al.*, 2020). As many care homes have limited interactions with their local communities (Older People's Commissioner, 2014) it is difficult to challenge prevailing perceptions, lack of awareness and non-recognition of the care home population, which is perpetuated in social discourses (Burton *et al.*, 2020). Consequently, when COVID-19 arose in the UK at the beginning of 2020, care homes did not have intuitive appeal for the UK public and this was arguably one reason why the government focused on the NHS to galvanise community support (Pereyra *et al.*, 2020). Several commentators have claimed that an NHS focus during this time to the exclusion of support for care homes, negatively impacted on care home residents (e.g. Birt *et al.*, 2020) and has led to a high court claim (Booth, 2020). Consistent with Honneth's ideas (1996), this court action alleges that, amongst other failings, the government was negligent in its duty to protect the 'rights' of care home residents and staff.

The relationship of the care sector with the NHS: Arguably the care home sector suffers from its complex interfaces with the NHS (Oliver, 2015). As well as benefitting from its public profile and its single provider status, the NHS also has a well-established and coordinated research infrastructure. This infrastructure enables evidence-informed practice, contributes additional investment and facilitates recognition of NHS staff and patients. It is hard for the diverse care home sector to compete with the NHS for parity of esteem and respect, and it certainly does not have the same level of research investment or infrastructure, as indicated above.

Towards recognition

Honneth's (1996) Recognition Theory indicates a route towards better recognition at an interpersonal, community and infrastructural level. In research terms, we argue 'recognition' would translate to a process whereby those involved engage with, listen to and respond to the needs, experiences and views of care home stakeholders, particularly care home residents, their families/ friends and care staff in all components of research activity and development. It would also mean an infrastructure that renders visible care home residents and the care home sector, respects the rights of all involved and the knowledge they hold through lived experience and practice wisdom. Relational research capacity building takes this approach and there is evidence that it can generate positive impacts for the care home community.

The supporting evidence

A systematic review on the challenges of conducting research in care homes recommended that researchers develop long-term relationships with care home providers, that a research network be established and that research education for providers is improved (Lam *et al.*,

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2018). Others have emphasised that fostering and sustaining relationships is essential and there is a need to work collaboratively (Jenkins *et al*., 2016). Policy makers are proposing similar agendas. There is also evidence from allied sectors that collaborative approaches to research capacity building can be successful (e.g. Gradinger *et al.*, 2019).

A key example in the UK of a relational capacity building approach in care homes is the Enabling Research in Care Homes (ENRICH) network, established in England in 2012 (Davies *et al*., 2014) and in Wales in 2017. This network aims to connect care homes and researchers. There is initial evidence that the network has been effective at sustaining research partnerships and facilitating care home participation in research (Davies *et al.*, 2014). The network has changed how care home staff perceive research and how researchers view the prospect of conducting research in care homes (Iliffe *et al*., 2017). In Wales, the Welsh Government has recently committed funds to support the growth of the ENRICH Cymru network to build research capacity in a relational way with care providers.

The relevance of relational research capacity building in care homes in the COVID-19 era

Recognition Theory (Honneth, 1996) is particularly pertinent to the pressing concerns the care home community is facing in the current COVID-19 pandemic. The initial response to the pandemic in the UK has highlighted a lack of 'recognition' for this diverse community, especially in terms of a visible and co-produced research agenda. In a public health emergency good guidance and data are essential pre-requisites. The lack of care home research on which to base a response and the lack of an infrastructure to quickly acquire it arguably exacerbated the problems care homes faced and will continue to face unless we see a marked change.

A comparison of early international data suggests that high death rates among care home residents were not inevitable (Comas-Herrera *et al.*, 2020). Dynamic real-time data from the care home sector which could have facilitated an intelligence-led response to COVID-19 was lacking (Burton *et al.*, 2020). The UK outbreak accelerated in March 2020, but it was not until 20th April 2020 that care home deaths could be sufficiently collated to be included in the UK COVID-19 statistics (Pereyra *et al.,* 2020). Some commentators argued that even in May the precise care home death rate remained unclear due to the lack of suitable surveillance systems (The Health Foundation, 2020). This problem was not UK specific. Countries such as Argentina and South Africa reported that care home fatality data remained missing from their national statistics in June 2020 (Pereyra *et al.*, 2020).

The task of understanding and characterising the presentation of COVID-19 in care home residents was also severely delayed. Following the 2012 Middle East Respiratory Syndrome Coronavirus it was recognised that the effectiveness of a response to a pandemic threat depended critically on the speed of developing an understanding of the clinical characteristics of the illness. As a result, the UK developed and maintained a 'sleeping' pre-pandemic suite of documents, agreements and protocols in preparation for future outbreaks (Simpson *et al.*, 2019). At the core of this was the clinical characterisation protocol for emerging infections developed by the International Severe Acute Respiratory and Emergency Infections Consortium. While hospitals and other acute settings are the focus of this protocol, long-term care facilities are entirely absent.

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Furthermore, guidance for care homes has been slow to emerge. It was not until 15th May 2020 that the UK government published care home specific COVID-19 guidance and most of this guidance was derived from other sectors. Guidance from the Department of Health and Social Care (2020) and organisations such as the British Society for Gerontology (2020) transposed recommendations developed for acute NHS hospitals into care homes. Again, this was not unique to the UK. For instance, health experts reportedly dominated COVID-19 care home decision-making in the Netherlands (Pereyra *et al.*, 2020). As care establishments are people's homes not hospitals (Birt *et al.*, 2020), guidance concerning social distancing, personal protective equipment and health surveillance (British Geriatrics Society, 2020) will have led to an institutional feel in homes if not adapted appropriately. Indeed, feedback from care homes in Wales to the Older Peoples Commissioner (2020) suggested that the information provided was difficult to implement. Care homes require bespoke evidence on which to base decisions (Jenkins *et al*., 2016). Unfortunately, a rapid review by Goodman (2020) found limited care-home specific research that was ready to implement during COVID-19 and a rapid review by Embregts *et al.* (2020) found no evidence-based interventions to support long-term care staff during infectious outbreaks. Again, this problem is not UK-specific: the WE-THRIVE (worldwide elements to harmonize research in long-term care living environments) deplored the lack of meaningful data to monitor and develop practice in care homes during COVID-19 (McGilton *et al.*, 2020).

The care home sector voice remains muted in the emerging COVID-19 research agenda. More research in care homes is now being funded but there is limited evidence about how this research agenda is being informed by residents and families, care home providers or staff. Some commentators have claimed the response to developing the agenda has been paternalistic and has implied that care homes need to be 'told' what to do (Ivory *et al.*, 2020). Supporting Recognition Theory (Honneth, 1996), the lack of attention to the specific needs of care homes has had negative wellbeing impacts. In South Africa the lack of government responsiveness was reportedly one factor that impacted on the wellbeing of care home staff and residents (Pereyra *et al.*, 2020). Similarly, in Wales the government response led families, residents and staff to believe that public bodies had limited understanding about what care homes need (Older Peoples Commissioner, 2020). Several commentators (e.g. Ivory *et al.*, 2020) have suggested that the COVID-19 response in care homes violated residents' human rights and there have been calls for public enquiries (Barbarino *et al.*, 2020).

Implications: a faster route to research recognition

Increasing relational research capacity during and post the COVID-19 crisis will strengthen care home research and would signify a stronger commitment to evidence-informed practice. We propose that a future research agenda must take into account 'recognition' of the care home population and workforce and not be driven by a top-down or paternalistic agenda. Instead we suggest that efforts must be made to increase research capacity within the care home sector by fostering relationships between residents, families, care staff and researchers. These relationships need to ensure that care home stakeholders drive the research agenda going forward. If this agenda remains solely in the hands of academics, or set by government funding bodies, care homes will remain 'unrecognised' and care staff will remain an afterthought (McGilton *et al.*, 2020).

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The implication of our argument is that researchers, academics and policy makers need to embark on a project of engaging and working with care homes to discover which research questions need to be answered and how research findings can best be implemented (Goodman, 2020). To enable people to thrive and to enhance their wellbeing, Recognition Theory (Honneth, 1996) requires mutual respect for residents' rights by putting in place necessary protections and conditions (Schwehr, 2020). Equally research should highlight the resilience and adaptiveness of care home residents and staff thereby promoting a balanced discourse that counters the current agenda which tends to focus exclusively on resident frailty and disability. We contend that involving the people who the research is designed to impact increases the chance of new approaches and insights emerging (Knapp, 2020).

There are initial signs that some researchers and administrations are embarking on a relational research capacity building agenda. The Older People's Commissioner in Wales (2020) is now advocating a policy approach which positions the voices of older people living in care homes, their friends and family, and care home workers as central *'Experts by Experience'*. This paper recommends policy makers take heed of the lessons illuminated during the COVID-19 pandemic in care homes, especially the importance of collaborative research that takes a genuinely relational approach by recognising and valuing care home communities as equal 'experts' in setting the research agenda and informing research development. Another example is the work of the NIHR Academic Research Collaboration (ARC) network in England. The ARC facilitated an online platform for care homes to put forward their most pressing questions during the COVID-19 crisis (Goodman, 2020). This responsive process allowed the development of an evidence-based resource to support staff and ensured that the voice of the care home community guided the resource development. A final example is the consultation undertaken by the Older Peoples Commissioner (2020) for Wales with care home staff, residents and family members to gain an insight into people's experiences between May and June 2020.

Conclusion

Honneth (1996) argued in Recognition Theory that society will remain unjust if some of its members are systematically denied their deserved recognition. We have argued that the lack of research capacity within the care home sector in the UK and internationally is an example of a failing to recognise a significant part of our society. We have presented evidence that ensuring the care home community is 'recognised' in the research agenda, through a relational research capacity programme, can yield better informed care home research. This approach respects resident, family and care staff/ provider perspectives and the questions that matter most to them. We have also presented evidence that indicates a lack of research 'recognition' has had a detrimental impact on the care home community during COVID-19 and argued that COVID-19 expediates the need for real investment in this area. A well-resourced infrastructure based upon relationships and so valued by commissioners, care homes and the public will support real change in care homes into the future. This is consistent with emergent policy recommendations (Older People's Commissioner, 2020) and we would endorse the further promotion of relational research capacity building initiatives in future policy. We conclude by noting that sometimes timepoints emerge where there is the right environment, political climate and policies for there to be a paradigm shift. This is when

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research can have a key impact on driving change (Knapp, 2020). We argue that this is such a moment for care home research.

References

Andrews, N., Gabbay, J., Le-May, A., Miller, E., Petch, A., and O'Neill, M. (2020) 'Story, dialogue and caring about what matters to people: progress towards evidence enriched policy and practice', *Evidence and Policy,* Online, pp.1-22. doi: 10.1332/174426420X15825349063428

Banks, S. (2018) 'The social dynamics of devaluation in an aged care context' *Journal of Sociology*, Vol. 54 no. 2, pp. 167–177. Doi: 10.1177/1440783318766144

Barbarino, P., Goldhawk, D., Comas-Herrera, A., Rogers, L., Connaughton, P., Jones, M., Sivananthan, S., Weidner, W., Dawson, A., and Pattabiraman, M. (2020) 'The hidden casualties of COVID-19: revealing the emergency in care homes and the lessons learnt in day care' available at: https://www.alz.co.uk/content/adi-webinars-on-dementia-and-COVID-19 (accessed 5th June 2020).

Birt, A., Kramer, G., Logan, R., Mills, A., Macaskill, D. and Verissimo, L. (2020) 'Care during and beyond the COVID-19 crisis: people as partners in care' available at: https://integratedcarefoundation.org/events/building-integrated-care-as-the-cornerstone-of-our-new-reality#1590072317332-a7d0be75-d3bc (accessed 22nd May 2020).

Booth, R. (2020). 'Matt Hancock faces legal action from daughter of COVID-19 care home victim' available at https://www.theguardian.com/world/2020/jun/12/matt-hancock-faces-legal-action-from-daughter-of-covid-19-care-home-victim The Guardian, (accessed 12th June 2020).

British Geriatrics Society. (2020) 'COVID-19: Managing the COVID-19 pandemic in care homes for older people' available at: https://www.bgs.org.uk/sites/default/files/content/attachment/2020-04-14/BGS%20Managing%20the%20COVID-19%20pandemic%20in%20care%20homes%20V2.pdf (accessed 15th April 2020).

Burton, J., Goodman, C., and Quinn, T. (2020) 'The invisibility of the UK care home population- UK care homes and a minimum dataset' available at: https://ltcCOVID.org/2020/05/14/the-invisibility-of-the-uk-care-home-population-uk-care-homes-and-a-minimum-dataset/ (accessed 1st June 2020).

Comas-Herrera, A., Ashcroft, E. C. and Lorenz-Dant, K. (2020). *International examples of measures to prevent and manage COVID-19 outbreaks in resident care and nursing home settings.* Report in LTCCOVID.org, International Long-Term Care Policy Network, CPEC-LSE, available at https://ltccovid.org/2020/05/02/new-report-international-examples-of-measures-to-prevent-and-manage-covid-19-outbreaks-in-residential-care-and-nursing-home-settings/ (accessed 2nd May 2020).

Competitions and Markets Authority. (2017). *Care homes market study. Final report.* Competitions and Markets Authority, UK available at https://www.gov.uk/cma-cases/care-homes-market-study

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Davies, S. L., Goodman, C., Manthorpe, J., Smith, A., Carrick, N. and Iliffe, S. (2014) 'Enabling research in care homes: an evaluation of a national network of research ready care homes', *BMC Medical Research Methodology*, Vol.14, p.1-8. doi: 10.1186/1471-2288-14-47

Department of Health and Social Care. (2012). *Health and Social Care Act 2012*. Department of Health and Social Care, UK available at https://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

Department of Health and Social Care. (2014). *Care Act 2014.* Department of Health and Social Care, UK available at https://www.gov.uk/government/publications/care-act-statutory-guidance

Department of Health and Social Care. (2020) 'Coronavirus (COVID-19): admission and care of people in care homes. How to protect care home residents and staff during the coronavirus outbreak' available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878099/Admission_and_Care_of_Residents_during_COVID-19_Incident_in_a_Care_Home.pdf (accessed 15th April 2020).

Embregts, P., van Oorsouw, W., and Nijs, S. (2020) 'Impact of infection outbreak on long-term care staff: a rapid review on psychological well-being. *Journal of Long-Term Care,* Online, pp.70-79.

Fraser, N. (1998). "From redistribution to recognition? Dilemmas of justice in a "post-socialist" age". Willett, C (Ed.) *Theorizing multiculturalism: a guide to the current debate,* Wiley-Blackwell, Massachusetts America, pp. 19–49.

Goodman, C. (2020). Using research evidence to support the delivery of care in response to COVID-19 in care homes. [Personal communication].

Goodman, C., Baron, N.L., Machen, I., Stevenson, E., Evans, C., Davies, S.L., and Iliffe, S. (2011) 'Culture, consent, costs and care homes: enabling older people with dementia to participate in research', *Aging & Mental Health*, Vol.15 No. 4, pp. 475-481. doi: 10.1080/13607863.2010.543659

Goodman, C. and Davies, S. (2013) 'ENRICH: a new innovation to facilitate dementia research in care homes' *British Journal of Community Nursing*, vol.17, No. 6, p.277. doi: 10.12968/bjcn.2012.17.6.277

Gordon, A.L., Franklin, M., Bradshaw, L., Logan, P., Elliott, R. and Gladman, J. R. F. (2013) 'Health status of UK care home residents: a cohort study'. *Age & Ageing*, Vol.43, No.1, pp. 97-103. doi: 10.1093/ageing/aft077

Gradinger, F., Elston, J., Asthana, S., Martin, S., and Byng, R. (2019). Reflections on the researcher-in-residence model co-producing knowledge for action in an integrated care organisation: a mixed methods case study using an impact survey and field notes. *Evidence and Policy: A Journal of Research, Debate and Practice,* Vol. 15, No. 2, pp. 197-215. doi: 10.1332/174426419X15538508969850

Quality in Ageing and Older Adults

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Health and Social Care Board. (2013). *Transforming your care. Vision to action. A post consultation report*. HSCB Northern Ireland, UK available at http://www.transformingyourcare.hscni.net/wp-content/uploads/2013/03/Transforming-Your-Care-Vision-to-Action-Post-Consultation-Report.pdf

Honneth, A. (1996). *The Struggle for Recognition. The Moral Grammar of Social Conflicts.* Polity Press, Cambridge UK.

Houston, S. (2016). Empowering the Shamed Self: Recognition and Critical Social Work. *Journal of Social Work*, Vol.16, No. 1, pp. 3-21. doi: 10.1177/1468017314566789

Iliffe, S., Wright, P., Law, R., Rogerson, A., Cote, L., Manthorpe, J. and Khan, M. (2017) 'Enabling research in care homes', *Age & Ageing*, Vol.46, No.6, p.1017. doi: 10.1093/ageing/afx131

Ivory, M., Calveley, P., Gratton, K., and Phair, L. (2020) 'Effective, practical care and support of people living with dementia in care homes during and after Covid-19 pandemic' available at: https://www.ipevents.net/journal-of-dementia-care-webinars/effective-practical-care-and-support-of-people-living-with-dementia-in-care-homes-during-and-after-the-COVID-19-pandemic/ (webinar accessed 29th May 2020).

Jenkins, C., Smythe, A., Galant-Miecznikowska, M., Bentham, P., and Oyebode, J. (2016) 'Overcoming challenges of conducting research in nursing homes', *Nursing Older People,* vol.28, No.5, pp.16-23. doi: 10.7748/nop.28.5.16.s24

Johnstone, A.M. and Donaldson, A. I. C. (2019) 'Care home research: future challenges and opportunities', *Geriatrics*, Vol.4, No.2, online. doi: 10.3390/geriatrics4010002

Jonker, L., Fisher, S.J. and Dagnan, D. (2020) 'Patients admitted to more research-active hospitals have more confidence in staff and are better informed about their condition and medication: Results from a retrospective cross-sectional study', *Journal of Evaluation and Clinical Practice,* Vol.26, No.1, pp.203-208. doi: 10.1111/jep.13118

Knapp, M. (2020) 'You can't always get what you want. Can research help make big change in social care?' available at: https://socialcarefuture.blog/2020/06/12/you-cant-always-get-what-you-want-can-research-help-make-big-change-in-social-care/ (accessed 17th June 2020).

Lam, H. R., Chow, S., Taylor, K., Chow, R., Lam, H., Bonin, K., Rowbottom, L. and Herrmann, N. (2018) 'Challenges of conducting research in long-term care facilities: a systematic review', *BMC Geriatrics*, Vol.18, p.242. doi: 10.1186/s12877-018-0934-9

Laitinen, A. and Pirhonen, J. (2018) 'Ten forms of recognition and mis-recognition in long-term care for older people', *SATS Northern European Journal of Philosophy*, Online. doi: 10.1515/sats-2016-0017

MacKenzie, M., Conway, E., Hastings, A., Munro, M., and O'Donnell, C. (2013) 'Is 'candidacy' a useful concept for understanding journeys through public services? A critical interpretative literature synthesis', *Social Policy and Administration,* Vol.47, No.7, pp.806-825. doi: 10.1111/j.1467-9515.2012.00864.x

Quality in Ageing and Older Adults

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Mason, M. (2012). *Care home sweet home. Care homes of the future*. ILC-UK, UK available at https://ilcuk.org.uk/care-home-sweet-home-care-home-of-the-future/

Mattias, I. (2019) '"Recognition" The Stanford Encyclopaedia of Philosophy (Summer 2019 Edition), Edward N. Zalta (ed.)' available at: https://plato.stanford.edu/archives/sum2019/entries/recognition/ (accessed 30 September 2020).

McGilton, K. S., Escrig-Pinol, A., Gordon, A., Chu, C. H., Zúñiga, F., Sanchez, M. G., Boscart, V., Meyer, J., Corazzini, K. N., Jacinto, A. F., Spilsbury, K., Backman, A., Scales, K., Fagertun, A., Wu, B., Edvardsson, D., Lepore, M. J., Leung, A. Y. M., Siegel, E. O., Noguchi-Watanabe, M., Wang, J., and Bowers, B. (2020) 'Uncovering the devaluation of nursing home staff during COVID-19: are we fuelling the next health care crisis?' *Journal of the American Medical Directors Association*, Vol 21, No.7, pp. 962-965. Online. doi: 10.1016/j.jamda.2020.06.010

McLaughlin H. (2012). *Understanding social work research- second edition.* SAGE Publications, UK.

Older Peoples Commissioner for Wales. (2020). *Care home voices. A snapshot of life in care homes in Wales during COVID-19.* Welsh Government, UK.

Older Peoples Commissioner for Wales. (2014). *A place to call home? A review into the quality of life and care of older people living in care homes in Wales.* Welsh Government, UK available at http://www.olderpeoplewales.com/Libraries/Uploads/A_Place_to_Call_Home_-_A_Review_into_the_Quality_of_Life_and_Care_of_Older_People_living_in_Care_Homes_in_Wales.sflb.ashx

Oliver, D. (2015) 'Enhancing health care in care homes: integration in practice' available at: https://www.kingsfund.org.uk/blog/2015/05/enhancing-health-care-care-homes-integration-practice (accessed 15th June 2020).

Orme, J. and Powell, J. (2007) 'Building research capacity in social work: process and issues', *British Journal of Social Work,* Vol.38, No. 5, pp.988-1008. doi: 10.1093/bjsw/bcm122

Pereyra, R., Tsao, M. A., Jauregui, R., Byles, J., Gillis, M., Holmerová, I., Halimi, D., Greengross, S., Abma, T., and Kalula, S. (2020) 'A caring world- response to the impact of the coronavirus on long-term care', available at: https://ilcuk.org.uk/an-ilc-ga-webinar-a-caring-world/ (accessed 22nd June 2020).

Schwehr, B. (2020) 'CASCAID on hospital discharge, DNAR and human rights in COVID-19' available at: https://www.youtube.com/watch?v=qtvfJPacqh8&utm_source=newsletter&utm_medium=email&utm_campaign=what_are_the_legal_issues_related_to_the_deaths_in_care_homes_live_q_a_tonight_7pm_weds_6_may_free_from_cascaidrs_belinda_schwehr&utm_term=2020-05-12 (accessed 12th May 2020).

Quality in Ageing and Older Adults

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60

Scottish Government. (2019) *'Social care support: an investment in Scotland's people society and economy. Programme framework. A partnership programme to support local reform of adult social care'*, Scottish Government, UK available at https://www.gov.scot/publications/social-care-support-investment-scotlands-people-society-economy-programme-framework-partnership-programme-support-local-reform-adult-social-care/pages/3/

Scottish Government. (2016) *'Health and social care delivery plan'*, Scottish Government, UK

Shepherd, V. (2020). An under-represented and underserved population in trials: methodological, structural and systemic barriers to the inclusion of adults lacking capacity to consent. *Trials*, Vol, 21, p. 445. doi: 10.1186/S13063-020-04406-y

Shepherd, V., Nuttall, J., Hood, K., and Butler, C.C. (2015) 'Setting up a clinical trial in care homes: challenges encountered and recommendations for future research practice', *BMC Research Notes,* Vol.8, p.306. doi: 10.1186/s13104-015-1276-8

Simpson, C. R., Beever, D., Challen, K., de Angelis, D., Fragaszy, E., Goodacre, S., Hayward, A., Lim, W. S., Rubin, G. J., Semple, M. G., Knight, M., and NIHR hibernated influenza studies collaborative group. (2019) 'The UK's pandemic influenza research portfolio: a model for future research on emerging infections', *The Lancet Infectious Diseases*, Vol, 19, No.8. pp. e295-e300. doi: 10.1016/S1473-3099(18)30786-2

Smith, N., Towers, A-M., Collins, G., Palmer, S., Allan, S. and Beecham, J. (2019) 'Encouraging managers of care homes for older adults to participate in research', *Quality in Ageing & Older Adults*, Vol.20, No.3, pp.120-129. doi: 10.1108/QAOA-04-2019-0017

Taylor, C. (1992). *'The Need for Recognition' The Ethics of Authenticity*. Harvard University Press, Cambridge UK.

The Health Foundation. (2020) 'Care Homes have seen the biggest increase in deaths since the start of the outbreak. COVID-19 chart series' available at: https://www.health.org.uk/news-and-comment/charts-and-infographics/deaths-from-any-cause-in-care-homes-have-increased (accessed 12th May 2020).

Trigg, L. (2018) *'Improving the quality of residential care for older people: a study of government approaches in England and Australia'*, Doctor of Philosophy Thesis, London School of Economics, UK.

Welsh Government. (2015). *Well-being and future generations (Wales) act 2015*. The Stationary Office Limited, UK available at https://gov.wales/well-being-future-generations-wales-act-2015-guidance

Welsh Government. (2014). *Social services and well-being (Wales) act 2014*. The Stationery Office Limited, UK available at https://gov.wales/sites/default/files/publications/2019-05/social-services-and-well-being-wales-act-2014-the-essentials.pdf

Quality in Ageing and Older Adults