

**Title**

A systematic review of observational studies of adult home care

**Authorship**

Monica Leverton<sup>1</sup>, Alexandra Burton<sup>1</sup>, Jessica Rees<sup>1</sup>, Penny Rapaport<sup>1</sup>, Jill Manthorpe<sup>2</sup>, Murna Downs<sup>3</sup>, Jules Beresford-Dent<sup>3</sup>, Claudia Cooper<sup>1</sup>

<sup>1</sup>University College London

<sup>2</sup>King's College London

<sup>3</sup>University of Bradford

\*Corresponding author: Monica Leverton, UCL Division of Psychiatry, 6<sup>th</sup> Floor Wing A, Maple House, 149-150 Tottenham Court Road, London UK W1T 7BN

**Acknowledgements/Funding**

This work was carried out within the UCL Alzheimer's Society Centre of Excellence for Independence at home, NIDUS (New Interventions in Dementia Study) programme (Alzheimer's Society Centre of Excellence grant 330).

## **Abstract**

The home care workforce is in high demand globally. Home care workers provide care for people at home, including practical and personal care, as well as other tasks such as medication management. We conducted a systematic review with the aims of understanding methods of observation that have been employed to study home care and to explore how these methods have enabled researchers to understand the quality of home care. We searched the literature using Pubmed and CINAHL databases in May 2018, with no limits applied to date of publication. We searched for MeSH terms of 'Home Care Services', 'Home Health Care', 'Home Nursing' and 'Observation\*'. Across 15 eligible studies, the types of observation methods employed were categorised as structured, guided and unstructured. The characteristics of these methods, such as the level of participation adopted by the observer, varied across the studies. Three themes were developed through a narrative synthesis of the included studies' findings: 'The impact of care delivery and organisational factors', 'Observing relationships and communications', and 'People and places behind closed doors'. We conclude that methods of observation are a fairly novel, yet rich and meaningful way of exploring home care practice. Researchers undertaking observations should consider elements such as the number of researchers observing and the potential for variations, how and when to record the observations, possible triangulation of data, the researcher's reflective stance as an observer, as well as ethical considerations.

Key words: home care, community, observation, ethnography, systematic review

### **What is known about this topic:**

- Home care is a substantial part of care and support services
- Research on home care has often relied on reports from surveys or retrospective accounts from interviews and focus groups
- Observation of home care work has the potential to inform understanding of the experiences of providing and receiving the service

### **What this paper adds:**

- Methods of observation can be a rich and meaningful way of exploring home care practice
- Observation of home care delivery brings practical and ethical challenges that should be considered in the design of research utilising this method
- Inter-rater reliability across observers in home care settings may be more complicated than in other health and care locations

## Background

Over 350,000 older people in England (The King's Fund, 2018) and more than one million older people in the United States (US) (Jones, Valverde, & Harris-Kojetin, 2012) use home care services. Employees providing direct care at home are variously described as home care workers, home health aides, home healthcare assistants, domiciliary carers, home carers, nursing assistants, as well as other terms (D'astous, Abrams, Vandrevalla, Samsi, & Manthorpe, 2017). In this review, we use the term home care worker throughout. The home care workforce is in increasingly high demand particularly among older people. In England, 72% of 1,811,000 new requests for care made to public services (local government) came from people aged 65 and above (NHS Digital, 2016). An estimated 60% of the home care workforce provides care to people with dementia (Carter, 2016).

Home care can encompass practical and personal care, domestic, emotional and social support to the client and sometimes their family. In England most home care workers are employed by commercial home care companies; half of whom are employed on zero hour contracts, with no minimum number of working hours (Griffiths et al., 2018); funded by a local authority if meeting eligibility and means-testing criteria, or they are paid by the client themselves. In contrast, in Sweden for example, social care is comprehensively covered by the state (Robertson, Gregory, & Jabbal, 2014) and over 200,000 elderly people receive home care support (The Swedish Institute, 2013).

The English home care sector is regulated by the Care Quality Commission (CQC) and is often under scrutiny. Clear organisational challenges include low fees from local authorities, low pay, minimal supervision and training, and high staff turnover. Some home care workers may experience a high psychological burden (Devlin & McIlpatrick, 2010). Internationally, home care workers have reported feeling inadequately trained and supported (Gleason & Coyle, 2016) and low job satisfaction resulting from low pay and poor job prospects (Chou, Fu, Kröger, & Ru-yan, 2011).

While the CQC assesses home care quality, there is less research in this field to inform quality and regulatory processes or home care management and commissioning, in contrast to care in residential and hospital settings. For this review, we defined good quality of care as care that was consistent and enabled the development of trusting relationships between the care providers and clients (Cabana & Jee, 2004; Denton, Brookman, Zeytinoglu, Plenderleith, & Barken, 2015; Olsson & Ingvad, 2001; Saultz & Lochner, 2005) and that promotes client independence and choice (Carter, 2016).

This review focuses on observational methods of evaluating the quality of home care. Observational methods are largely qualitative by design. While quantitative measures such as surveys are common in evaluating health and social care practices, qualitative methods enable a deeper and richer understanding of everyday phenomena (Johnson & Onwuegbuzie, 2004), providing the researcher with insight into the 'who, what and where' of experiences (Sandelowski, 2000). **Observational methods can also yield** quantitative findings such as length of time and frequencies of events observed. Therefore, these methods are well suited to conducting research on care in the home setting, delving into the meaning behind events (Briggs, Askham, Norman, & Redfern, 2003) and can reveal important insights into the context in which care is provided in the private domestic sphere. This review seeks to guide researchers planning future observational studies of home care.

Our review is part of a larger study of home care for people with dementia in England; although this review did not concentrate solely on home care for people living with dementia since many home care companies in England do not provide dementia-specific services (D'astous et al., 2017). As noted above, many terms are used for home care internationally and some indicate that nursing or clinical activities may be part of the service; in England, while home care contains some elements of health care, the service is described as social care reflecting the health and social care divide in legislation, sectors and funding.

Our review is, to the best of our knowledge, the first to synthesise findings from observational studies of home care.

Our research aims were:

- 1) To describe the methodologies that have been used to observe home care practices.
- 2) To explore how observation methods can inform researchers' understanding of the quality of care delivered.

## **Methods**

We systematically reviewed studies using observational methods to explore how home care workers delivered health or social care. We registered the review with PROSPERO (reference number: CRD42018097034).

### **Search strategy**

We systematically searched the literature to identify papers relevant to our research aims. On the 14<sup>th</sup> May 2018, Pubmed and CINAHL databases were searched (by ML) using the MeSH terms “Home Care Services” or “Home Health Care”, or “Home Nursing” and “Observation\*”. MeSH terms were used to incorporate the range of terms applied to home care workers. The search was limited to papers including only adult participants (specified at aged 19+ in Pubmed) and no limitations of language or date of publication were applied. The electronic search was augmented by a forward and backward search of included papers, and hand-searching relevant journals. We asked experts in the field for any relevant papers additional to those identified in our search.

### **Inclusion criteria and study selection**

We included studies that reported using a method of observation to study how care provided by home care workers was delivered and/or received. Studies where care was delivered by a family member, volunteer or health professional were therefore excluded. We also excluded protocol papers and conference abstracts. Studies were not required to explicitly comment on quality of care.

All titles and abstracts of papers identified in the search were screened against the eligibility criteria (by ML) and 10% of these were checked for inter-rater reliability (by AB). Full texts were read and judged potentially relevant (by ML) and again 10% of these were checked (by AB). Discrepancies were resolved by discussion.

### **Data extraction and quality assessment**

Data was extracted from papers that met the inclusion criteria (by ML). Table 1 presents the data collected.

We rated the quality of included papers (ML and JR) using the Qualitative Checklist Section A (Validity) from the Critical Appraisal Skills Programme (CASP) (Critical Appraisal Skills Programme, 2018). The checklist comprises 6 questions:

- 1) *Was there a clear statement of the aims of the research?*
- 2) *Was a qualitative methodology appropriate?*
- 3) *Was the research design appropriate to address the aims of the research?*
- 4) *Was the recruitment strategy appropriate to the aims of the research?*
- 5) *Was the data collected in a way that addressed the research issue?*

## 6) *Has the relationship between researcher and participants been adequately considered?*

We assigned one point per checklist item, so possible scores ranged from 0 to 6. Higher scores indicated higher quality. Discrepancies were discussed until shared agreement was reached. Studies were not excluded on the grounds of quality in line with standard practice for qualitative reviews (Campbell et al., 2012; Lawrence, Fossey, Ballard, Moniz-Cook, & Murray, 2012; Thomas & Harden, 2008). Quality scores are presented in Table 2.

### **Analytic methods**

We carried out a narrative synthesis to address our first research aim (see above). For our second research aim, we undertook a qualitative meta-synthesis, guided by the recommendations of Thomas and Harden (2008) and the guidelines of Braun and Clarke (2006). We open coded all text (including tables) describing the findings from observation methods. ML and CC developed an initial coding framework and agreed upon subsequent themes to respond to research aim 2, regarding how methods of observation have added to the researchers' understanding of quality of home care. We used the definition of good quality care described in our introduction. The initial coding framework was reviewed and discussed by PR and JM, and further revised by ML and CC in an iterative process.

## **Results**

### **Study characteristics and quality appraisal**

We included 15 papers (see Figure 1 for PRISMA flow diagram). The studies took place in Sweden ( $n = 4$ ), Denmark ( $n = 3$ ), Spain ( $n = 1$ ), Canada ( $n = 1$ ), UK ( $n = 2$ ), US ( $n = 1$ ), Zambia ( $n = 1$ ) and South Africa ( $n = 2$ ). They studied home care for: older people and people with dementia ( $n = 8$ ), people with chronic illnesses or disabilities ( $n = 3$ ), HIV/AIDS ( $n = 3$ ), and people receiving rehabilitative home care ( $n = 1$ ). See Table 1 for characteristics of included studies.

ML and JR agreed on most of their initial, independent quality ratings of papers (Cohen's Kappa = 0.70) and discussed all discrepancies to reach agreement for all ratings. Quality ratings ranged from 2-6, with 11/15 papers scoring 4 or more (Table 2).

Table 2. Quality appraisal of included studies using the CASP Qualitative Checklist, Section A – Validity.

Paper	Qualitative checklist criteria						Total score (out of 6)
	1	2	3	4	5	6	
Casado-Mejía and Ruiz-Arias (2016)	Y	Y	Y	Y	Y	Y	6
Cloutier, David, Prevost, and Teiger (1999)	Y	Y	Y	Y	Y	N	5
Nielsen and Jørgensen (2016)	Y	Y	Y	Y	Y	N	5
Rabiee and Glendinning (2011)	Y	Y	Y	Y	Y	N	5
Roberts, Philip, Currie, and Mort (2015)	Y	Y	Y	Y	Y	N	5
Swedberg, Chiriac, Tornkvist, and Hylander (2012)	Y	Y	Y	N	Y	Y	5
Tufte and Dahl (2016)	Y	Y	Y	Y	Y	N	5
Cataldo, Kielmann, Kielmann, Mburu, and Musheke (2015)	Y	Y	N	N	Y	Y	4
Czuba, Sommerich, and Lavender (2012)	Y	Y	Y	N	Y	N	4
Sundler, Eide, Dulmen, and Holmström (2016)	Y	Y	Y	N	Y	N	4
Swedberg, Chiriac, Tornkvist, and Hylander (2013)	Y	Y	Y	N	Y	N	4
Glasdam, Henriksen, Kjær, and Praestegaard (2013)	Y	Y	N	N	Y	N	3
Kalman and Andersson (2014)	Y	Y	Y	N	N	N	3
Uys (2003)	Y	Y	Y	N	N	N	3
Uys (2002)	Y	Y	N	N	N	N	2

## **Research Aim 1: To describe the methodologies that have been used to observe home care practices (Table 1)**

### Observation methods

The included studies used various terms to describe their observation methods. These were participant observations (Casado-Mejía & Ruiz-Arias, 2016; Kalman & Andersson, 2014; Rabiee & Glendinning, 2011; Tufte & Dahl, 2016), observations (Cloutier et al., 1999; Czuba et al., 2012) and field observations (Cataldo et al., 2015; Glasdam et al., 2013; Nielsen & Jørgensen, 2016; Roberts et al., 2015; Swedberg et al., 2012, 2013; Uys, 2002, 2003). The term ethnography was also used in one study (Cataldo et al., 2015).

We grouped the methods used into structured, guided and unstructured methods. Structured methods used time sampling procedures or structured observational tools (Czuba et al., 2012; Roberts et al., 2015). Tools used included the Two-Dimensional Interaction Scale (2DSIS) and a social and personal interaction observation schedule developed by the study authors. The 2DSIS (Wai & Bond, 2001) assessed social behaviours using four categories of interaction: 'active participate', 'active non-participate', 'passive participate', and 'passive non-participate'. Social behaviours of interest included participants' duration of speech, with and without eye contact, both when speaking and when spoken to. The social and personal interaction schedule recorded types of interactions that took place, such as 'humour' and 'reassurance touch', as well as whether these interactions were instigated by home care worker or client (Roberts et al., 2015).

Guided methods of observation employed a semi-structured plan to guide field work (Casado-Mejía & Ruiz-Arias, 2016; Cloutier et al., 1999; Glasdam et al., 2013; Kalman & Andersson, 2014; Swedberg et al., 2012, 2013; Uys, 2002, 2003). For example, in one study, researchers were guided to focus their observations on three key elements: 'the relationship between people', 'mutual satisfaction', and 'body position' (Casado-Mejía & Ruiz-Arias, 2016). Other studies' methods were unstructured, employing an inductive approach to observe how home care workers provided care in clients' homes (Cataldo et al., 2015; Nielsen & Jørgensen, 2016; Rabiee & Glendinning, 2011; Sundler et al., 2016; Tufte & Dahl, 2016).

### Observation procedures

*Ethical considerations:* Seven studies reported having obtained ethical approval from an appropriate ethics committee (Casado-Mejía & Ruiz-Arias, 2016; Cataldo et al., 2015; Kalman & Andersson, 2014; Roberts et al., 2015; Sundler et al., 2016; Swedberg et al., 2012, 2013). Two studies did not require ethical approval to carry out their observations (Glasdam et al., 2013; Nielsen & Jørgensen, 2016),



although the authors from one of these studies described following the principles of the Helsinki Declaration which outlines the codes of conduct for nursing research (Glasdam et al., 2013). Of the above studies, all but one paper (Roberts et al., 2015) discussed ensuring ethical rigour by securing confidentiality of all participants, including removing identifiable information such as name, location and job description from data collected and reported. Only one paper described ethical considerations made when observing the intimate care of people who are vulnerable or in poor health (Kalman & Andersson, 2014). These were checking for signs of distress, or objections made by the clients regarding the researcher's presence.

*Collecting the data:* In one study, home care workers wore devices to audio-record home visits (Sundler et al., 2016). In all other studies, researchers observed visits directly. While in most studies researchers sought to record events naturalistically, one study used the think-aloud technique, where the home care workers were asked to explain their activities as they performed them (Nielsen & Jørgensen, 2016).

*Number of researchers:* Where reported, the number of researchers observing ranged from one (in five studies) (Czuba et al., 2012; Glasdam et al., 2013; Nielsen & Jørgensen, 2016; Swedberg et al., 2012, 2013) to a team of researchers where either one (Kalman & Andersson, 2014) or two researchers (Casado-Mejía & Ruiz-Arias, 2016) were responsible for observing the same home care workers throughout.

*Researcher role:* Three papers described the researchers as taking some participatory role during the observations: engaging in brief conversations with the home care workers (Swedberg et al., 2012, 2013) or being 'active members' of the home care team (Casado-Mejía & Ruiz-Arias, 2016), though this was not explained further.

*Building rapport:* Three of the studies described a brief "getting to know" period before the observation period commenced (sometimes termed a familiarisation period). This involved the researcher engaging in 'small talk' with the home care worker (Swedberg et al., 2012, 2013), and gaining an understanding of home care workers' activities before observing them formally (Cataldo et al., 2015). None of the studies reported the researchers building rapport with clients before conducting the observations.

*Time spent observing:* (Reported in Table 1). Some studies pre-decided the number of observations, e.g. one single visit to each client participant (Uys, 2002, 2003). Others continued observations until they determined that saturation was reached, shortening the length of observations towards the end (Swedberg et al., 2012, 2013). Another study reported that the duration of the observations was

determined by the client's availability (Glasdam et al., 2013). Some researchers observed home care workers outside as well as inside the clients' home: within hospital settings and treatment clinics (Uys, 2003), physiotherapy appointments (Glasdam et al., 2013), meetings within their employer (Cataldo et al., 2015; Nielsen & Jørgensen, 2016), training events (Cataldo et al., 2015), as well as travelling with them between their visits (Nielsen & Jørgensen, 2016).

*Recording data:* Studies employing structured methods of observation, collected data during visits (Czuba et al., 2012; Roberts et al., 2015). In other studies, researchers made brief notes during observations, which they wrote up fully afterwards (Rabiee & Glendinning, 2011; Swedberg et al., 2012, 2013), or wrote all notes directly after observations (Kalman & Andersson, 2014; Uys, 2002, 2003). Sometimes, short unplanned interviews with home care workers, clients and family members during the observations were used to enrich field notes (Glasdam et al., 2013; Swedberg et al., 2012, 2013). In one study, notes were recorded using a laptop computer during visits, as this was considered less intrusive than the original method of hand-writing notes during the observation session (Glasdam et al., 2013). Only two studies explicitly stated that the researchers recorded their own reflective stance as an observer but did not report if this was done during or after the observations (Cataldo et al., 2015; Kalman & Andersson, 2014).

*Validating and triangulating findings:* One study included home care worker participants in the analysis of findings (Casado-Mejía & Ruiz-Arias, 2016). In another study, three independent raters conducted the initial coding of transcripts (Roberts et al., 2015). None of the other studies explicitly reported involving a rater other than the observer in the evaluation and analysis of field notes or observation data. Only two papers (from the same author) used a specific strategy to validate findings from observations. They evaluated the authenticity of the observations by judging against two criteria (Swedberg et al., 2012, 2013). These were the impact of the researcher's perspective (i.e. if the situation observed would occur regardless of the researcher's own perspective) and the researcher's presence (i.e. if the interactions between those observed would occur without their knowledge of being observed).

All but two studies (Kalman & Andersson, 2014; Sundler et al., 2016) triangulated observations with other sources of data. These included interviews (Cataldo et al., 2015; Cloutier et al., 1999; Glasdam et al., 2013; Nielsen & Jørgensen, 2016; Roberts et al., 2015; Uys, 2002), focus/discussion groups (Czuba et al., 2012; Tufte & Dahl, 2016) or both (Casado-Mejía & Ruiz-Arias, 2016; Rabiee & Glendinning, 2011; Swedberg et al., 2012, 2013). One paper reported audio-recording staff on-site with their employer and in staff meetings (Uys, 2003).

*Quantitative methods:* Four of the 15 papers reported quantitative results in addition to qualitative findings (Cloutier et al., 1999; Czuba et al., 2012; Uys, 2002, 2003). In two of these studies, these methods were used to quantify how much time home care workers were engaged in activities that were physically demanding during visits (Cloutier et al., 1999; Czuba et al., 2012). In two other papers, the frequency or timing of visits was analysed (Uys, 2002, 2003).

Table 1. Characteristics of observation methods employed by 15 included studies

Study and country	Care need population	Number of home care workers	Number of care recipients	Structure	Aims and objectives	Total Time spent observing	Triangulated data sources	Qualitative data analysis
Swedberg et al. (2012) (Sweden)	Chronic illness or disability	19	4	Guided	To understand the perspective of patients receiving 24-hour home care	78 hours over 17 visits	Interviews	Grounded theory
Swedberg et al. (2013) (Sweden)					To explore how home care workers manage home care			
Czuba et al. (2012) (US)	Chronic illness or disability	17	36	Structured	To explore risk factors for home care worker injury and test interventions for home care workers	54 hours over 611 observation samples	Focus groups	Frequency analyses
Casado-Mejía and Ruiz-Arias (2016) (Spain)	Older people and people with dementia	not reported	9	Guided	To explore immigrant care workers' relationships with care receivers and their family members	Spread over a 2 year period	Interviews; Discussion groups	Categories analysis
Cloutier et al. (1999) (Canada)	Older people and people with dementia	6	21	Guided	To identify and reduce risk and constraints for home care workers	30 hours over 22 visits in 5 days	Interviews	Descriptive
Nielsen and Jørgensen (2016) (Denmark)	Older people and people with dementia	16	not reported	Unstructured	To explore home care workers' engagement and role meaning	81 hours	Interviews	Thematic analysis
Sundler et al. (2016) (Sweden)	Older people and people with dementia	19	43	Unstructured	To explore communication challenges between home care workers and clients	100 audio recordings, mean=16 minutes	None	Hermeneutical phenomenological approach
Tufte and Dahl (2016) (Denmark)	Older people and people with dementia	8	69	Unstructured	To understand how home care workers manage their daily duties	Across almost 100 visits	Focus group interviews	Grounded theory and reflexive interpretation approach

Study and country	Care need population	Number of home care workers	Number of care recipients	Structure	Aims and objectives	Total Time spent observing	Triangulated data sources	Qualitative data analysis
Kalman and Andersson (2014) (Sweden)	Older people and people with dementia	7	23	Guided	To explore strategies used to deliver intimate care	Across 37 visits in 4 days	None	Inductive analytical approach
Glasdam et al. (2013) (Denmark)	Older people and people with dementia	2	1	Guided	To understand client involvement in home care	Across 8 days over 3 weeks	Interviews	Constructed analytical categories, guided by theoretical framework
Roberts et al. (2015) (UK)	Older people and people with dementia	4	6	Structured	To observe interactions between clients and workers, and what clients value in these interactions	1 visit per patient, duration 30 – 75 minutes	Interviews	not reported
Cataldo et al. (2015) (Zambia)	HIV/AIDS	48	31	Unstructured	To observe how the introduction of antiretroviral medication affected home care workers' role & client/family relationships	not reported	Interviews	not reported
Uys (2003) (South Africa)	HIV/AIDS	15	not reported	Guided	To assist in preparing home care workers and inform policy to address service provision limitations	not reported	Interviews; Recording onsite meetings; Questionnaires	Template analysis
Uys (2002) (South Africa)		16			To describe the practice of home care workers	25 visits	Interviews	Descriptive
Rabiee and Glendinning (2011) (UK)	Rehabilitation	not reported	not reported	Unstructured	To explore the practice of reablement services and what may influence effectiveness	26 visits	Interviews; Focus groups	Framework approach

**Research Aim 2: To explore how observation methods can inform researchers' understanding of the quality of care delivered.**

We identified three key themes that responded to our research question. These were: *The impact of the care delivery and organisational factors*, *Observing relationships and communications*, and *People and places behind closed doors*. The examples given in this review to support our themes were extracted from the included papers' field notes or observations.

***The impact of care delivery and organisational factors***

*The role of time*

Many of the observers reflected on how time availability affected or did not affect care. Sometimes, lack of time appeared to affect service quality as home care workers were observed to rush their work with clients:

“The client has finished his dialysis and suddenly remembers he had forgotten to fold swabs... [Home care worker] says he should have thought of that earlier... instead of talking. There is no time for folding swabs now; he has to take his shower’ (Glasdam et al., 2013) (page 5)

From this example, the researchers associated the time constraints of home care with the client's loss of freedom and lack of control in the care he received.

In other observations, good quality care seemed to be equated with care delivered without apparent time constraints:

‘The [home care workers] rarely checked their watches or mentioned how much time they had for the visit and instead took time to listen to the client in spite of tight schedules’ (Nielsen & Jørgensen, 2016) (page 4)

‘The [home care worker] performs the care tasks without visibly looking at the clock and without mentioning the time that is available or remaining (Tufté & Dahl, 2016) (page 7)

Tufté and Dahl (2016) commented that the home care worker “figuratively leaves time outside when entering the home” (page 7).

Sometimes, home care workers appeared to sacrifice personal time, especially where they were the care worker most accepted by the client. Some studies highlighted that for some clients, high quality care included having a good relationship with their care worker, and that delivering this might require allowing the client the option to select care workers with whom to spend more time. This was not however recompensed through additional pay, so took place in the care workers' own time:

'Often patients had favourites, typically among the experienced [home care workers], who were then willing to make personal sacrifices. ... Being a favourite could lead to disadvantages, such as diminished control over one's own working hours.' (Swedberg et al., 2013) (page 6)

'When one patient only wanted experienced staff to shower her, a novice [home care] assistant came in on her day off to learn the procedure.' (Swedberg et al., 2013) (page 5)

"... exerting effort to get to know the patients closely, spend extra time socialising and acting much as they would if the patients were their own family members' (Nielsen & Jørgensen, 2016) (page 4)

### Organisational context

The researchers observed how organisational systems affected the quality of care delivery, especially when they were experienced as unsupportive:

'The observations showed differences in the way the recording was done in different sites and between different workers within sites... In most cases what was recorded did not include the right information to enable the next worker to build on the progress being made by the service users' (Rabiee & Glendinning, 2011) (page 6)

Inconsistent recording of clients' notes was reported by the observer as inhibiting continuity of care.

Another example suggested that the home care worker required support in delivering home care, however supporting staff were unavailable:

'Calling [the office] when in need of help on a Friday evening, one [home care worker] experienced that nobody answered in spite of the fact that she had been told to use this number, even on evenings and weekends.' (Swedberg et al., 2013) (page 6)

Most studies observed home care workers visiting clients on their own, so the office staff would have been their only source of support, if help was needed.

### ***Observing relationships and communications***

Observers described how home care workers navigated often complex relationships, which were professional yet also sometimes intimate and close. Researchers were able to directly observe the home care workers' relationships between the client and sometimes their family, developing into close and trusting relationships:

'In almost all households visited, the [home care workers] were welcome friends, who talked, joked and became part of the family life' (Uys, 2002) (page 3)

'The caregiver is very affectionate but dignified, she is not submissive' (Casado-Mejía & Ruiz-Arias, 2016) (page 8)

Observations also often captured the role of home care workers in maintaining dignity and encouraging independence, which are considered important components of good quality care:

'[Client] is walking around in his underwear when the care workers enter his home. He has wet his underpants as he suffers from cystitis, and the care worker immediately tries to cover him up by pulling down his singlet' (Tufté & Dahl, 2016) (page 8)

'Usually, if the recipients were able to do some of the intimate washing themselves, the care worker assisted with the washcloth and then left the bathroom' (Kalman & Andersson, 2014) (page 9)

'After a while the [home care worker] wants [Client] to eat by herself, and after ensuring that she is managing she leaves. [Client] says very little, but calls the [home care worker] sweetie several times' (Tufté & Dahl, 2016) (page 8)

Researchers also observed the care strategies used by home care workers in challenging situations in context:

'Some clients pretend to have swallowed the tablets yet haven't; they keep the tablets under their tongue and wait for the caregiver to leave so that they can spit it out. It is for this reason that caregivers use a technique of interrogating the client immediately after taking their medication' (Cataldo et al., 2015) (page 6)

Furthermore, negative aspects of home care worker-client relationships (which may not be reported or described during an interview) relating to poorer quality care delivery and receipt were also captured by the observers:

'During one observation, the client lay completely naked in bed, with three persons in the room, while the [home care workers] kept talking to each other.' (Swedberg et al., 2012) (page 6)

'In one extreme case, even though a female care recipient had a rather big bathroom with space enough for two care workers to assist her, she was placed in the hall, naked and dressed there' (Kalman & Andersson, 2014) (page 10)



‘The TV is turned on at a very high volume. The [home care worker] manipulates the feeding tube with one hand and watches the TV at the same time. She changes TV-channel with the remote control using the other hand and keeps on watching’ (Swedberg et al., 2012) (page 6)

‘The lady [client] never called her [home care worker] by her name. She referred to her as “this” ’ (Casado-Mejía & Ruiz-Arias, 2016) (page 7)

Researchers observed non-verbal communications associated with care quality. These included expressions of care and empathy via touch, the familiarity between home care worker and client through mirrored behaviours, and expressions of relief and gratitude through non-verbal expressions:

‘ “Come here darling.” The [home care worker] touches the patient gently and turns her towards herself. The other [home care worker] continues with the washing procedure’ (Swedberg et al., 2012) (page 7)

‘The more intimate the body part involved in the performance of care, the more both parties avoided looking at that body part’ (Kalman & Andersson, 2014) (page 9)

‘As we drove into the yard... a middle-aged woman came running to us from the road. It was the mother of the client. ... As she reached us, she was crying with relief that we had arrived so timeously’ (Uys, 2003) (page 6)

Capturing the clients’ (or their family carers’) attitudes and/ or expressions resulting from their care seemed to illuminate perceived care quality.

### ***People and places behind closed doors***

#### Capturing all voices

Researchers were able to observe and capture the voices and experiences of care from clients who may have been too unwell or unable to take part in formal research interviews:

‘When we got there, the mother was just sitting in front of the house... with no energy to do anything except the most basic movements’ (Uys, 2002) (page 3)

‘For some older adults with chronic pain, opportunities to socialise... or leave the home and interact with others were very limited. For these individuals, the home visit provided personal contact that would otherwise be missing from their lives’ (Roberts et al., 2015) (page 7)

This observation alluded to some home care workers connecting the clients to the world outside their homes, particularly for clients living in rural areas where access to community facilities or networks may be limited by the need to travel over a distance or lack of transport.

### The home environment affects care delivery

Observations also captured how the home environment influenced care or care strategies, or raised health and safety concerns for the home care workers:

‘As the bathrooms and toilets were really narrow at times, and the care recipient was severely disabled, the use of toilet buckets [commodes] or the washing of intimate parts of the body might take place in the senior’s bedroom or sitting room’ (Kalman & Andersson, 2014) (page 7)

‘The bathroom was extremely narrow. She tried to cheer the man up by making small talk as she helped him to the small bathroom, and when crossing the threshold, an awkward pose was struck. “Now we have to do a dance”, the care worker said laughing, twisting the man on to the toilet’ (Kalman & Andersson, 2014) (page 8)

‘The wife tells that the client has not always been able to get a bath because of the design of the bathroom that meant bad physical working positions for the care staff’ (Glasdam et al., 2013) (page 7)

‘We observed care and assistance tasks requiring a high level of physical effort.... Washing in the bath is the most frequent activity’ (Cloutier et al., 1999) (page 4)

These examples demonstrate how the quality of care provided by the home care workers was hindered by the home environment. Sometimes, the requirements of the caring situation prompted changes to the client’s home environment to enable the home care workers to safely deliver care to the client:

‘The bath had to be refurnished if the client were to get a bath again’ (Glasdam et al., 2013) (page 7)

However, in some cases, adaptations to the home environment were not entirely welcomed by clients and their family members:

‘The client’s wife stands up against some of the iterations because any physical alteration in the home is a visible sign of their abnormal situation’ (Glasdam et al., 2013) (page 7)

‘“Everyone gets to decide except me”, one patient said when the [home care workers] decided where to place the furniture in her own apartment’ (Swedberg et al., 2012) (page 5)

## **Discussion**

This is the first review to explore how observational research can inform our understanding of the experiences and quality of care delivered by home care workers. While qualitative interviews and focus group methods have been used frequently to study home care (Barken, Denton, Plenderleith, Zeytinoglu, & Brookman, 2015; Lovelock & Martin, 2016; Yeh, Samsi, Vandrevalla, & Manthorpe, 2018), methods of observation have to date been used less widely. From the studies we reviewed, the researchers observed various home care practices that were in line with good quality care, defined as care that was consistent, and enabled the development of trusting relationships between the home care providers and recipients (Cabana & Jee, 2004; Denton et al., 2015; Olsson & Ingvad, 2001; Saultz & Lochner, 2005). These included care being delivered without apparent time constraints, the home care workers being seen as family or a close friend, and where care involved maintaining the client's dignity and encouraging their independence or involvement in tasks; such as during intimate care. On the other hand, rushed care, a lack of training and support for the home care workers, as well as the home environment, particularly the layout of the bathroom, were observed at times to inhibit the provision of good quality care. This sometimes limited the client's independence, autonomy and choice. There are clear benefits of directly observing and capturing the authentic, everyday interactions and relationships between home care workers, clients and possibly family members, beyond the scope of interview data.

Moreover, having a direct presence during the home care scenarios enabled researchers to observe interactions with people who might not be able to take part in research interviews, such as some people with dementia. In these cases, the observations also captured a picture of good quality care provision beyond direct care tasks. Home care workers were seen to "fill a gap" (Roberts et al., 2015) where some clients otherwise missed out on opportunities to socialise or engage with others. These findings highlight the value of observational methods to capture these moments, particularly where close relationships had been formed between client and home care worker. Observing the interaction between people in context, rather than capturing one perspective or story from an interview, enables the viewer to understand the complexities, challenges and tensions involved in delivering home care. These interactions may not normally be reported in interviews, or may be decontextualized, overlooked or avoided.

Delivery of good quality care in the home setting is often influenced by interactions between the home care worker, client and the physical environment. Observation methods enable these interactions to be recorded in context. In qualitative interviews, home care workers report their recollections and interpretation of how care is delivered and the associated challenges. The pressure of time for home care workers is not a new finding, however observational methods can explore how these pressures are absorbed or made explicit. Observing care directly can triangulate other

information. For example, problems to which a home care worker may have become habituated and thus ceased to notice, such as how the home environment is negotiated as a care setting and as a private home, may be more striking to an outside observer.

### **Implications**

We have highlighted methodological options that researchers may wish to consider when designing observational studies in this setting. Choice of method (that which we described: structured, guided and unstructured methods) should be appropriate to the study hypothesis. Structured observations are likely best suited when the research hypothesis concerns safety/risk or when quantifying frequencies (e.g. of care tasks performed by home care workers). Guided and unstructured methods may be better suited to more exploratory research, although limitations arise concerning inter-rater reliability when there are multiple researchers involved.

Although half of the reviewed studies discussed obtaining ethical approval to carry out observations in the home setting, the practicalities of observing the more private moments of home care with ethical rigour are not well reported. Intimate care is regularly provided as part of home care and observing such care raises potential ethical issues. These include considering how to balance the need for research to inform quality care initiatives and learn from current practice, whilst preserving the dignity of those participating, many of whom may be taking part with the consent of another person (e.g. family member), because they lack capacity to make a decision about participation. Researchers observing intimate care should reflect upon and adhere to ethical principles which promote dignity, avoid harm and distress. For example, they should pause or cease observations if the client becomes distressed by their presence, in addition to an ongoing process of negotiating and confirming consent (Hoeyer, Dahlager, & Lynøe, 2005; Savage, 2000). Ethical consideration and challenges should be clearly reported by researchers who have observed home care practice. Obtaining the views of lay advisors (through public and patient involvement) to research studies would be a further way to consider public opinions, especially those who have experience of home care or personal care receipt.

Most of the included studies did not specify the role of the researchers in the observed home care interactions. Gold (1958) described the roles that a researcher might take during participant observations as: the 'Complete participant', 'Participant-as-observer', 'Observer as participant' and the 'Complete observer'. Based on the reviewing authors' experiences of conducting participant observations in the home setting, the role of 'complete observer' may not always be feasible or practical. We have come to understand participant observation as a continuum of the researcher's level of involvement throughout the observation period. Some level of participation or engagement

with participants may be necessary to provide reassurance and gain trust, while finding a balance with maintaining the authenticity and validity of the observed care scenario.

In most of the studies reviewed, one researcher conducted all observations, and few studies validated their findings through seeking perspectives or data beyond the original observer. Observations are, by definition, from the point of view of the observer, but incorporating elements of participant validation or triangulating findings with other researchers, as well as with other sources of data collection, can evaluate and enhance external validity (Flick, 2004). Most studies did not explicitly report a familiarisation period prior to recording field notes. Burns (2000) suggests that observers refrain from note-taking for an initial period, to allow all involved to become used to having an observer present. The majority of studies also did not directly discuss the impact of the researcher's presence during the observations and in the data collected. The researcher's reflective stance is highlighted as key in the process of ethnographic research (Vindrola-Padros & Vindrola-Padros, 2018), considering how the observer's emotions and rationality may impact on their observations (Watts, 2011).

The majority of studies triangulated their findings from observations with other sources of data collection. Triangulation can increase validity and add depth and understanding to the overall findings (Mays & Pope, 2000). Observations were sometimes employed as a secondary source of data collection to support or expand on findings from interviews or focus groups.

### **Strengths and limitations of this review**

The home care sector is a rapidly growing workforce globally, yet research seeking to directly observe the nature of such work is limited. This review has highlighted that observations are a beneficial method of data collection to study care in the home environment, to obtain rich and meaningful data that other qualitative methods may overlook.

A limitation of this review relates to the degree to which the observation methods could be described; this was largely dependent on the richness of the methodological detail provided in the included papers. Furthermore, while the aim of this review focused on quality of care, the primary aim of the included papers varied and thus too the focus of the observations.

Moreover, many studies in this review triangulated observational and other research findings. Consequently, it was not always possible to distinguish which results were from the researchers' direct observations and which were drawn from other sources. Observational methods are seldom used in isolation and triangulating findings with other data sources adds to the richness and

authenticity of the overall findings. We did not include studies observing care delivered by people other than home care workers, such as volunteers and families, as our focus was on professional home care delivery. This was because we intend this review to inform a future intervention to improve home care delivery.

## **Conclusion**

Despite the richness of data captured across the included studies, methods of observation are rarely utilised to research health and social care practices, particularly within the home environment.

Carrying out observations of home care has the potential to enrich our understanding of how home care is delivered and received and allows reflection on the skills being deployed. Key methodological questions for researchers to consider are whether structured, guided or unstructured methods best fit their interests or hypothesis, the stance observers will take, how observations will be recorded, and how findings may be triangulated and validated.

## References

- Barken, R., Denton, M., Plenderleith, J., Zeytinoglu, I. U., & Brookman, C. (2015). Home care workers' skills in the context of task shifting: Complexities in care work. *Canadian Review of Sociology/Revue canadienne de sociologie*, 52(3), 289-309.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Briggs, K., Askham, J., Norman, I., & Redfern, S. (2003). Accomplishing care at home for people with dementia: using observational methodology. *Qualitative Health Research*, 13(2), 268-280.
- Burns, R. B. (2000). *Introduction to Research Methods, fourth edition*. London: Sage.
- Cabana, M. D., & Jee, S. H. (2004). Does continuity of care improve patient outcomes. *J Fam Pract*, 53(12), 974-980.
- Campbell, R., Pound, P., Morgan, M., Daker-White, G., Britten, N., Pill, R., . . . Donovan, J. (2012). Evaluating meta ethnography: systematic analysis and synthesis of qualitative research.
- Carter, D. (2016). *Fix Dementia Care: Homecare*. Alzheimer's Society, London.
- Casado-Mejía, R., & Ruiz-Arias, E. (2016). Factors influencing family care by immigrant women in Spain: a qualitative study. *Investigacion & Educacion en Enfermeria*, 34(3), 551-563. doi:10.17533/udea.iee.v34n3a15
- Cataldo, F., Kielmann, K., Kielmann, T., Mburu, G., & Musheke, M. (2015). 'Deep down in their heart, they wish they could be given some incentives': a qualitative study on the changing roles and relations of care among home-based caregivers in Zambia. *BMC Health Serv Res*, 15, 36. doi:10.1186/s12913-015-0685-7
- Chou, Y.-C., Fu, L.-y., Kröger, T., & Ru-yan, C. (2011). Job satisfaction and quality of life among home care workers: a comparison of home care workers who are and who are not informal carers. *International Psychogeriatrics*, 23(5), 814-825.
- Cloutier, E., David, H., Prevost, J., & Teiger, C. (1999). Importance of experience for older home care workers in facing up to the constraints of work. *Exp Aging Res*, 25(4), 405-410. doi:10.1080/036107399243878
- Critical Appraisal Skills Programme. (2018). CASP Qualitative Checklist. Retrieved from <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf>
- Czuba, L. R., Sommerich, C. M., & Lavender, S. A. (2012). Ergonomic and safety risk factors in home health care: Exploration and assessment of alternative interventions. *Work*, 42(3), 341-353. doi:10.3233/wor-2012-1433
- D'astous, V., Abrams, R., Vandrevalla, T., Samsi, K., & Manthorpe, J. (2017). Gaps in understanding the experiences of homecare workers providing care for people with dementia up to the end of life: a systematic review. *Dementia*, 18(3), 970-989.
- Denton, M., Brookman, C., Zeytinoglu, I., Plenderleith, J., & Barken, R. (2015). Task shifting in the provision of home and social care in Ontario, Canada: implications for quality of care. *Health Soc Care Community*, 23(5), 485-492.
- Devlin, M., & McIlpatrick, S. (2010). Providing palliative and end-of-life care in the community: the role of the home-care worker. *International journal of palliative nursing*, 16(4), 195-203.
- Flick, U. (2004). Triangulation in qualitative research. *A companion to qualitative research*, 3, 178-183.
- Glasdam, S., Henriksen, N., Kjær, L., & Praestegaard, J. (2013). Client involvement in home care practice: a relational sociological perspective. *Nursing Inquiry*, 20(4), 329-340. doi:10.1111/nin.12016
- Gleason, H. P., & Coyle, C. E. (2016). Mental and behavioral health conditions among older adults: implications for the home care workforce. *Aging & Mental Health*, 20(8), 848-855.
- Gold, R. L. (1958). Roles in sociological field observations. *Social Forces*, 36(3), 217-223.
- Griffiths, D., Fenton, W., Polzin, G., Price, R., Arkesden, J., & McCaffrey. (2018). The state of the adult social care sector and workforce in England. *Skills for Care, Leeds*.

- Hoeyer, K., Dahlager, L., & Lynøe, N. (2005). Conflicting notions of research ethics: The mutually challenging traditions of social scientists and medical researchers. *Social science & medicine*, 61(8), 1741-1749.
- Johnson, R. B., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational researcher*, 33(7), 14-26.
- Jones, A., Valverde, R., & Harris-Kojetin, L. D. (2012). *Characteristics and use of home health care by men and women aged 65 and over (No. 52)*: US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics.
- Kalman, H., & Andersson, K. (2014). Framing of intimate care in home care services. *European Journal of Social Work*, 17(3), 402-414.
- Lawrence, V., Fossey, J., Ballard, C., Moniz-Cook, E., & Murray, J. (2012). Improving quality of life for people with dementia in care homes: making psychosocial interventions work. *The British journal of psychiatry*, 201(5), 344-351.
- Lovelock, K., & Martin, G. (2016). Eldercare work, migrant care workers, affective care and subjective proximity. *Ethnicity & health*, 21(4), 379-396.
- Mays, N., & Pope, C. (2000). Assessing quality in qualitative research. *BMJ*, 320(7226), 50-52.
- NHS Digital. (2016). *Community care statistics, Social Services Activity, England – 2015-2016*. Retrieved from <https://digital.nhs.uk/data-and-information/publications/statistical/community-care-statistics-social-services-activity/community-care-statistics-social-services-activity-england-2015-16>
- Nielsen, M. S., & Jørgensen, F. (2016). Meaning creation and employee engagement in home health caregivers. *Scandinavian Journal of Caring Sciences*, 30(1), 57-64. doi:10.1111/scs.12221
- Olsson, E., & Ingvad, B. (2001). The emotional climate of care-giving in home-care services. *Health Soc Care Community*, 9(6), 454-463.
- Rabiee, P., & Glendinning, C. (2011). Organisation and delivery of home care re-ablement: what makes a difference? *Health Soc Care Community*, 19(5), 495-503. doi:10.1111/j.1365-2524.2011.01010.x
- Roberts, A., Philip, L., Currie, M., & Mort, A. (2015). Striking a balance between in-person care and the use of eHealth to support the older rural population with chronic pain. *Int J Qual Stud Health Well-being*, 10, 27536. doi:10.3402/qhw.v10.27536
- Robertson, R., Gregory, S., & Jabbal, J. (2014). The social care and health systems of nine countries *Commission on the Future of Health and Social Care in England: The King's Fund*.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in nursing & health*, 23(4), 334-340.
- Saultz, J. W., & Lochner, J. (2005). Interpersonal continuity of care and care outcomes: a critical review. *The Annals of Family Medicine*, 3(2), 159-166.
- Savage, J. (2000). Ethnography and health care. *BMJ*, 321(7273), 1400-1402. doi:10.1136/bmj.321.7273.1400
- Sundler, A. J., Eide, H., Dulmen, S., & Holmström, I. K. (2016). Communicative challenges in the home care of older persons - a qualitative exploration. *Journal of Advanced Nursing*, 72(10), 2435-2444. doi:10.1111/jan.12996
- Swedberg, L., Chiriac, E. H., Tornkvist, L., & Hylander, I. (2012). Patients in 24-hour home care striving for control and safety. *BMC Nursing*, 11(1), 9-20. doi:10.1186/1472-6955-11-9
- Swedberg, L., Chiriac, E. H., Tornkvist, L., & Hylander, I. (2013). From risky to safer home care: health care assistants striving to overcome a lack of training, supervision, and support. *Int J Qual Stud Health Well-being*, 8, 20758. doi:10.3402/qhw.v8i0.20758
- The King's Fund. (2018). *Home care in England: Views from commissioners and providers*. Retrieved from <https://www.kingsfund.org.uk/sites/default/files/2018-12/Home-care-in-England-report.pdf>
- The Swedish Institute. (2013). Facts about Sweden: elderly care. Retrieved from <https://sweden.se/society/elderly-care-in-sweden/>

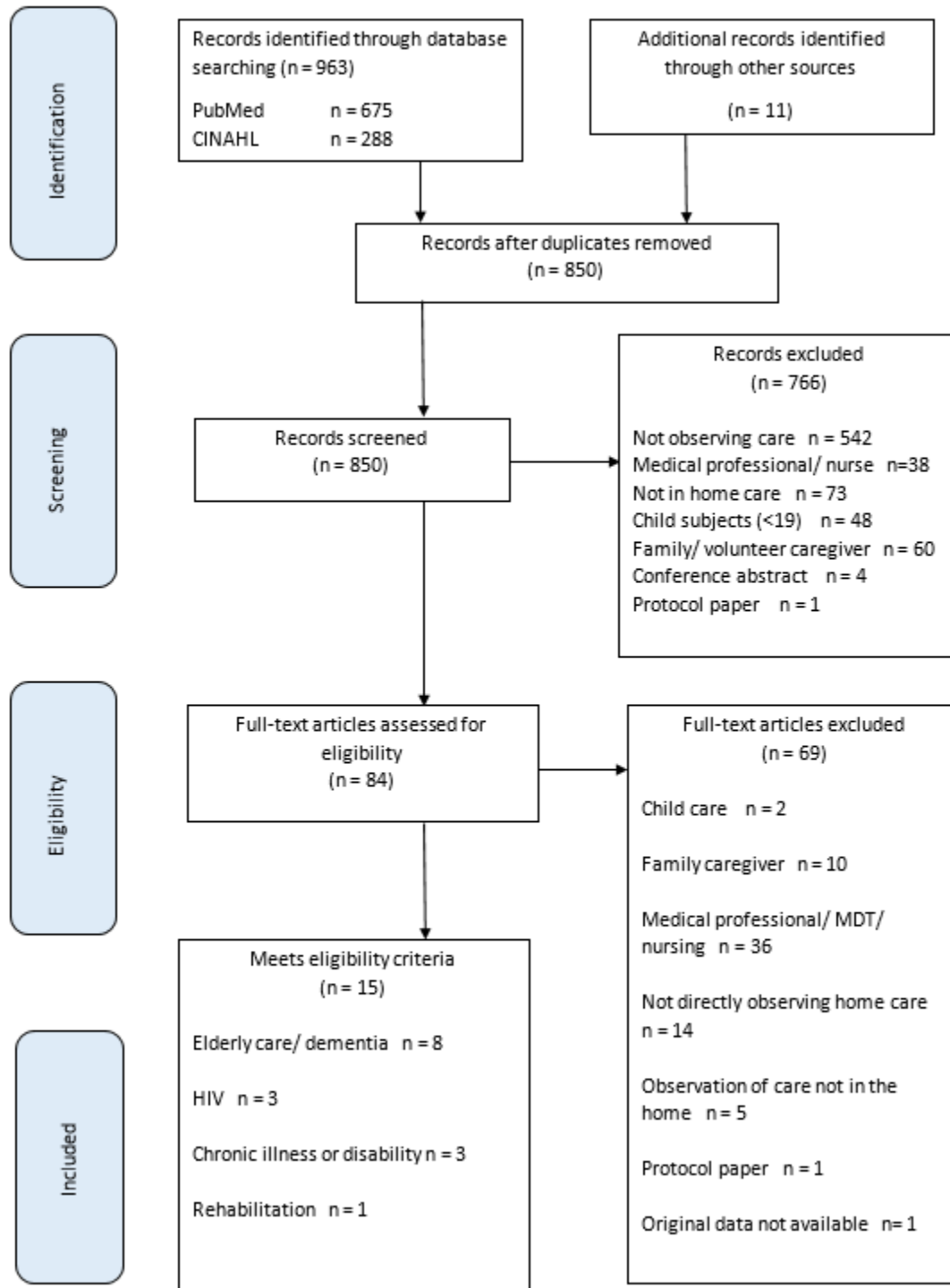


- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, 8(1), 45.
- Tufte, P., & Dahl, H. M. (2016). Navigating the field of temporally framed care in the Danish home care sector. *Sociol Health Illn*, 38(1), 109-122. doi:10.1111/1467-9566.12343
- Uys, L. R. (2002). The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *Journal of Clinical Nursing*, 11(1), 99-108. doi:10.1046/j.1365-2702.2002.00566.x
- Uys, L. R. (2003). Aspects of the care of people with HIV/AIDS in South Africa. *Public Health Nurs*, 20(4), 271-280.
- Vindrola-Padros, C., & Vindrola-Padros, B. (2018). Quick and dirty? A systematic review of the use of rapid ethnographies in healthcare organisation and delivery. *BMJ Qual Saf*, 27(4), 321-330.
- Wai, S. T., & Bond, A. J. (2001). Development and validation of the two-dimensional social interaction scale (2DSIS). *Psychiatry Research*, 103(2-3), 249-260.
- Watts, J. H. (2011). Ethical and practical challenges of participant observation in sensitive health research. *International journal of social research methodology*, 14(4), 301-312.
- Yeh, I. L., Samsi, K., Vandrevalla, T., & Manthorpe, J. (2018). Constituents of effective support for home care workers providing care to people with dementia at end of life. *International Journal of Geriatric Psychiatry*, ISSN (print) 0885-6230 (Epub Ahead of Print).

## Appendices

### 1) Figure 1

Figure 1. PRISMA flow diagram of systematic search



2) Figure titles

Figure 1: PRISMA flow diagram of systematic search

3) Table titles

Table 1: Characteristics of observation methods employed by the 15 included studies

Table 2: Quality appraisal of included studies using the CASP Qualitative Checklist, Section A – Validity.