

Relational Care, Dementia, and Communication Challenges in Long-Term Care: A Meta-Ethnography

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Article

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Résumé

Peu d'études examinent les soins en tant que processus relationnel dans les soins de longue durée. Un nombre encore plus restreint d'études décrivent la participation des résidents atteints de démence. Dans cet article, l'objectif était de présenter le développement des connaissances dans ce domaine au moyen d'une méta-ethnographie. Notre processus de recherche a permis de recenser six articles admissibles, qui documentent qualitativement les interactions entre les résidents et le personnel pendant les activités de soins dans un centre d'hébergement, et incluent des participants avec démence. Les quatre phases de soins de Tronto ont été utilisées pour identifier des pratiques de soins relationnels dans les articles sélectionnés. Cinq concepts transposables sont ressortis de ces six études : (1) faire avec ou faire pour, (2) la réactivité du personnel, (3) le rôle du résident, (4) la communication inclusive, et (5) le temps. Dans notre nouvelle configuration de soins relationnels, nous associons ces concepts pour délimiter un « espace interactif » dans lequel l'action des résidents et l'initiative du personnel ont une visibilité équivalente.

Abstract

Few studies examine care as a relational process in long-term care, and still fewer describe the participation of residents with dementia. In this article, our objective was to understand the development of knowledge in this area by means of a meta-ethnography. Our search and selection process resulted in six eligible articles. Each documents a qualitative study of resident–staff interactions during care activities in a residential care setting, and includes participants with dementia. Tronto's 4 Phases of Care were used to guide the identification of relational care practices within the articles selected. We identified five translatable concepts across the six studies: (1) doing with versus doing for, (2) staff responsiveness, (3) resident agency, (4) inclusive communication, and (5) time. In our new configuration of relational care, we combine these concepts to delineate an “interactive space” in which the agency of residents and initiative of staff are equally visible.

Introduction

For those who are cognitively and physically frail, long-term care provides a place of collective living; for staff, it represents a place of work. Relationships between these two groups are, understandably, complex. The professionalization of care, the burden of care discourse, and the frailty of many residents all contribute to an uneasy power differential between those in need of care and those who are qualified to provide it (Barnes, 2006; Tronto, 1993). With disproportionate attention focused on caregiving, care is often assumed to be unidirectional, with those in receipt of care positioned as “passive and unable to contribute” (Brannelly, 2016, p. 309). Such relational inequalities are all the more pronounced for residents who experience communication difficulties. Ward, Vass, Aggarwal, Garfield, and Cybyk's (2008) ethnographic study found that a quarter of all long-term care staff–resident interactions lasted no longer than 5 seconds and that the great majority happened in silence. Under these circumstances, the response from the person cared for frequently goes unheard and unheeded (Kitwood, 1997). Yet care interactions involving two or more people are inherently relational. Indeed, Brown Wilson's (2013) ethnographic research suggests that older adults residing in long-term care do contribute to the process of care. Their influence will be minimal, however, unless these contributions are recognized and valued.

The invisibility of relational care in long-term care is an ongoing theme in scholarly writing (Armstrong & Braedley, 2013; Armstrong & Lowndes, 2018; Brown Wilson, 2013; Diamond,

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1992). Diamond's (1992) landmark institutional ethnography, *Making Grey Gold*, reveals how the formal charting of caretaking tasks in nursing home care disregards their relational context. Armstrong (2013) argues, similarly, that relational care remains invisible because it is under-valued. It is also under-explored in research. In 2009, Brown Wilson and Davies (2009) drew attention to the fact that there are a scarcity of studies examining relationships in long-term care. Ten years on, it would appear that little progress has been made. A majority of studies focus on caregivers and care receivers as separate groups. Few are designed to examine interactions between these two groups (Macdonald & Mears, 2018). Indeed, as Tolhurst, Weicht, and Kingston (2017) observed, there is a tendency, even in dyadic studies, to bypass conversational interaction and present findings as stand-alone individual-level data.

If relational care is, indeed, both under-valued and under-explored, then finding ways to make it more visible would seem important (Brown Wilson, 2013). A synthesis of qualitative studies examining everyday care interactions between long-term care staff and residents who are living with dementia will help clarify the development of knowledge in this area and potentially contribute to its visibility. In this review, therefore, our objectives were two-fold: (1) to establish what is known about relational care in this context, and (2) to synthesize *what is known about what works* into a new configuration of relational care knowledge.

A Working Definition of Relational Care

We have chosen to define *relational care* as a bidirectional process, one in which the agency of both people – those who give and those who receive care – is recognized (Tronto, 1993). This conceptualization of relational care is informed by two theorists from different disciplines: nursing and political science. Brown Wilson, a nursing scholar, is one of few researchers to focus on how relationships develop in the everyday care context of long-term care. In *Caring for older people: A shared approach* (Brown Wilson, 2013), she identified “care that involves us all” (p. 130) as both a concept and an outcome that can be measured in the assessment of a relationship-centred approach to care. The route by which this outcome is achieved begins with valuing the contributions made by everyone – residents, families and staff – in the caring relationship. By contrast, Tronto's (1993) ethic of care was developed at the intersections of care ethics, feminist theory, and political theory, and has been used to discuss care in diverse academic disciplines, including dementia studies (Brannelly, 2006, 2016). Arguably Tronto's most significant contribution to the field has been to reinstate care receiving as an essential phase of the care process. In *Moral boundaries: A political argument for an ethic of care*, Tronto (1993) set out a 4 Phase Process of Care, with each phase aligned to a moral quality, as follows: (1) Attentiveness – caring about, (2) Responsibility – caring for, (3) Competence – care giving, and (4) Responsiveness – care receiving. Once care is given (Phase 3), Tronto argued, there will be a response from the person receiving care. Observing their response and establishing whether the care given was adequate requires the moral quality of *responsiveness* (Phase 4).

The interfacing ideas of Brown Wilson and Tronto offer a lens through which to make the relational nature of care more visible and the voices of those who receive care more audible. Both were instrumental in our delineation of inclusion criteria for this review.

Methods

Meta-Ethnography

We chose meta-ethnography as our review methodology. Meta-ethnography is a method of synthesizing qualitative research, first described by Noblit and Hare (1988), and now widely used in health care, to develop theoretical understanding of complex phenomena (France et al., 2019).

Noblit and Hare (1988) describe the process of meta-ethnography as “a series of phases that overlap and repeat as the synthesis proceeds” (p. 26). These phases include: getting started, deciding what is relevant to the initial interest, reading the studies, determining how the studies are related, translating the studies into one another, synthesizing translations, and expressing the synthesis. Rather than being a sequence of phases, however, meta-ethnography entails a dynamic and continuous process of comparison and interpretation, during which qualitative studies are *translated into* and, therefore, made sense of in terms of one another. In this way, insights are combined to offer a more complete understanding of the phenomenon in question (Noblit & Hare, 1988). In their evaluation of meta-ethnography, Campbell et al. (2011) found the method effective in “establishing what is known and what remains unknown or hidden about a topic at a given point in time” (p. 119). In light of a perceived under-representation of relational care in long-term care research and practice, meta-ethnography was deemed an appropriate methodology.

As Noblit and Hare (1988) point out, “all syntheses begin with some interest on the part of the synthesizer” (p. 40). Our review team brought a variety of perspectives to the task. These were informed by professional backgrounds in social work, nursing, creative arts therapy, sociology, and rehabilitation sciences, along with research interests in communication, knowledge translation and narrative, and arts-based approaches to explore illness, disability, and end of life. Our shared interest was in researching relational care.

Following, we discuss our methodology under two broad headings: Search and Selection and Translation and Synthesis.

Search and Selection

A comprehensive search strategy was developed through team discussion and was conducted by first author and a Faculty of Health Sciences librarian. Search term categories aligned with our review topic as follows: context (long-term care), population (elderly), and phenomenon of interest (relational care), defined as “a bi-directional process of care”. We learned, through trial and error, that replacing the term “dementia” with “elderly” in the context of “long-term care” produced more promising results, without excluding the target population. In addition, we included the term “personhood”, because Kitwood's (1997) use of this term has framed the dementia experience as relational (Brooker, 2004). The search strategy was developed in MEDLINE[®] (Ovid) using a combination of subject headings and keywords. It was then adapted for the following databases: Cumulative Index of Nursing and Allied Health (CINAHL), PsycInfo and Embase, using their respective subject headings. See Appendix 1 for the MEDLINE search strategy. Our search was conducted on October 17, 2019, yielding 3,652 results. These were entered in Covidence, a systematic review management system, where duplicates were removed. The first author then screened the remaining articles, initially by title and abstract, whereupon a further 3,012 articles were removed, and then by full text. On close reading, a further 136 articles were excluded. A citation search was performed for each of the

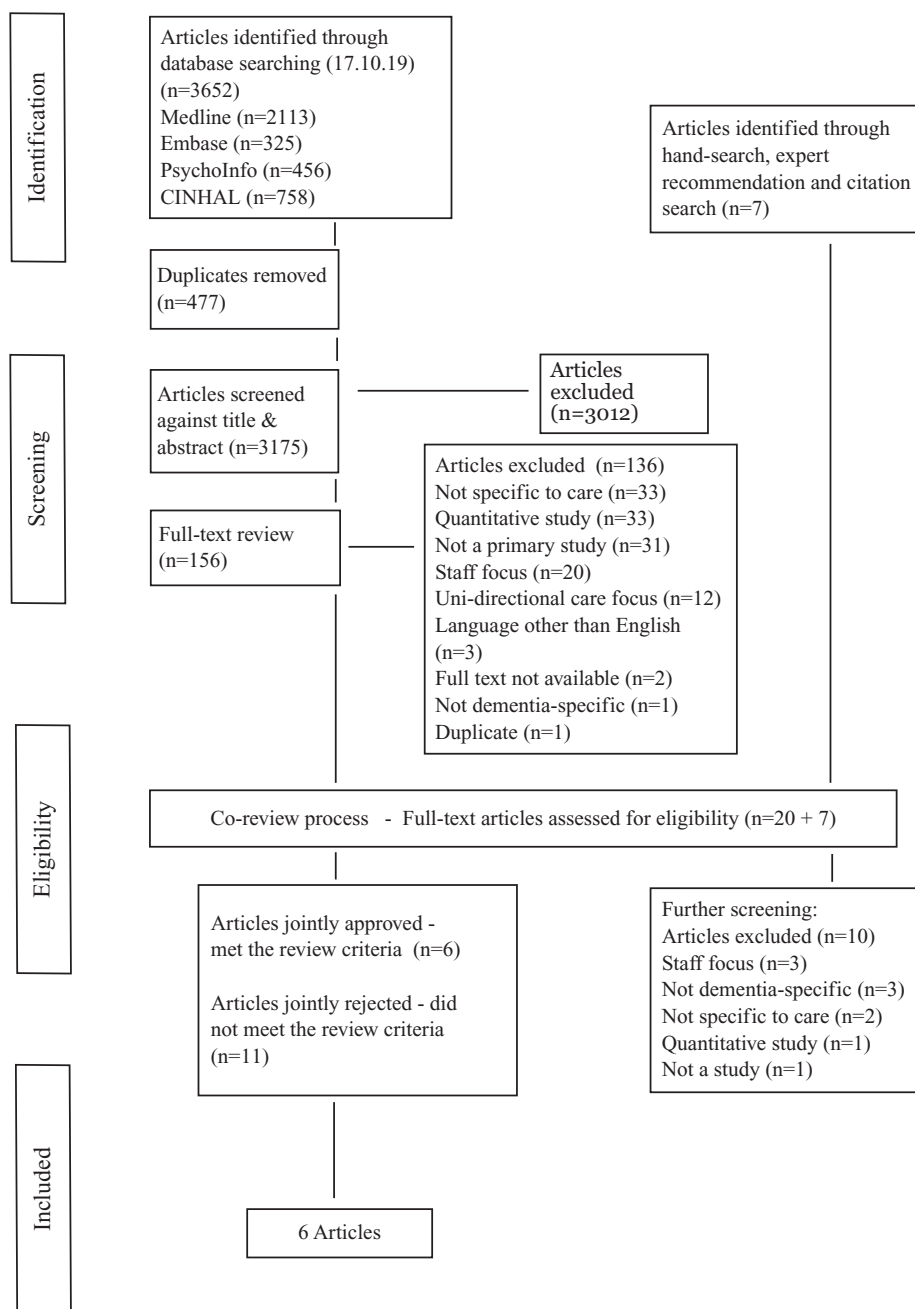


Figure 1. PRISMA flow diagram.
The PRISMA flow diagram details our review's search and selection process.

remaining 20 articles, which resulted in an additional seven articles. Figure 1 shows a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram that provides an overview of the selection process and grounds for exclusion.

Selection Criteria

The second phase of our selection process involved close reading of the remaining 27 articles by the first and fifth authors, who met to discuss each article's eligibility for inclusion. To prepare for these meetings, both reviewers independently filled out a customized full-text review table that served as a checklist for our selection criteria. These required that all eligible articles (1) document a

qualitative study, (2) be set in a residential care facility, and (3) involve participants living with dementia. Although an actual diagnosis of dementia was not essential, evidence of impaired cognitive and communicative abilities was, and this criterion required validation through the inclusion of data such as quotations and field note entries. In addition, eligible studies needed to include: (1) a focus on resident-staff interactions during everyday care activities, and (2) data corresponding to our definition of relational care, in which the resident participants were visible and/or audible. By default, this necessitated data collection methods designed to accommodate both verbal and non-verbal communication.

Noblit and Hare's (1988) approach to meta-ethnographical synthesis does not include a formal process of quality appraisal.

Rather, they recommend that studies be judged in terms of their relevance and contribution to the topic of interest; and that their worth be “determined in the process of achieving a synthesis” (p. 16). Because the concept of relational care was rarely named as such, we relied on Tronto’s (1993) 4 Phase Process of Care to guide our identification of relational care practices. At times, this brought to light inconsistencies between first order constructs (raw data such as participant quotations and field note observations) and second order constructs (the researchers’ interpretations of these) (Britten et al., 2002). The question of how researchers interpret what they see was particularly relevant when first order constructs included field note descriptions of non-verbal communication; or when a response from the person receiving care was missing, although the author reported the interaction to have been positive. Detailed discussions of this nature led to greater precision in the delineation of our selection criteria. They also helped to define *worth* in terms of the quality criteria Tracy (2010) has proposed for qualitative research. To justify inclusion, an article needed to demonstrate (1) “rigour” in terms of providing “sufficient data to support significant claims”; (2) “credibility” in terms of “thick description, concrete detail, explication of tacit (non-textual) knowledge and showing rather than telling”; and (3) “meaningful coherence” in terms of achieving “their stated purpose” and accomplishing “what they espouse to be about” (p. 840). A further 11 articles were excluded at this stage. See Table 1 for a complete list of our inclusion criteria.

The co-review process resulted in 6 of the 27 articles being retained for synthesis. See Table 2 for an overview of the included articles. Our reasons for excluding articles at this stage included: (1) the voice (verbal and non-verbal) of the person receiving care was thinly represented (Criterion #5); (2) descriptions of the care process stopped short at Phase 3 of Tronto’s 4 Phase Process of Care; that is, links between the care given, the care receiver’s response, and staff responsiveness were missing (Criterion #6); (3) a disparity existed between first and second order constructs; that is, the data provided did not sufficiently substantiate the authors’ interpretations (Criterion #7).

Translation and Synthesis

Noblit and Hare (1988) employ the concept of *translation* to describe an iterative process of constant comparison during which concepts from one study are *translated into* and, therefore, understood in terms of the others, and vice versa. This process began during the focused discussions of our selection phase, when conceptual similarities among the studies were noted. These similarities included some recurring attributes of relational care practice as well as factors that seemed to foster its development. To complete this process, the first author re-read the six included articles to identify key descriptors for each commonality (Doyle, 2003). The first and fifth authors then independently searched across the articles for the same or equivalent descriptors. For example, in three of the articles, a distinction is made between interactions that include and interactions that exclude those receiving care (A1, A3, A6). In Clarke and Davey’s article (A1, 2004), this idea is expressed in terms of staff who “*did for* the residents in their care rather than allowing them to make their own decisions” (p. 23). The same idea and wording appear in Watson’s article (A6, 2019): “staff tried to *do things for* residents which they could still do themselves” (p. 555). The opposite process of *doing with* was also a term used to describe a bidirectional process of care in two of the articles (A2, A5). In this way, the concept of *doing with versus doing for* was eventually

Table 1. Inclusion criteria

Inclusion criteria	Description
#1	Peer-reviewed journal publication
#2	English language
#3	Long-term care or similar facility
#4	Residents in long-term care living with a dementia/ experiencing communication difficulties
#5	(a) The agency of participants with dementia is recognized, in spite of communication challenges, in descriptions of the care process, and (b) participants with dementia are included in the first person, either directly through their voice or through observation of their responses (verbal & non-verbal) to care. (c) Exception: although the focus is caregiving, the author/s show “a commitment to ethical and empowering research methods that enabled the voice of people with dementia to be heard” (Brannelly, 2006, p. 201).
#6	Evidence of a connection between staff “responsiveness”, or lack thereof, and the responses of persons living with dementia during everyday care routines; i.e., care as a bidirectional process.
#7	To justify inclusion, an article must demonstrate (a) “rigour” in terms of providing “sufficient data to support significant claims”, (b) “credibility” in terms of “thick description, concrete detail, explication of tacit (non-textual) knowledge and showing rather than telling”, and (c) “meaningful coherence” in terms of achieving “their stated purpose” and accomplishing “what they espouse to be about” (Tracy, 2010, p. 840).

translated across all six articles. Through discussion, four further conceptual categories were agreed on, and a similar translation process was performed for each. To synthesize the translations, the first author drafted an overarching model that brought together the key findings into a *line of argument* synthesis (Noblit & Hare, 1988) or new “storyline” (Noblit, 2016, p. 4). The model and accompanying narrative were then discussed with all of the review authors, and a number of modifications were made.

Results

The studies included in a meta-ethnography will relate to one another in different ways, and this will determine the type of synthesis. *Reciprocal translation* is undertaken when studies are about similar things; when studies are dissimilar or refute one another *refutational translation* is recommended (Noblit & Hare, 1988). Our finely tuned inclusion criteria necessitated that all of the eligible articles share a number of common characteristics (see Table 1). As such, reciprocal translation proved a good fit. Our translation process resulted in five common, conceptual categories: *doing with versus doing for*, *staff responsiveness*, *resident agency*, *inclusive communication*, and *time*. Following, we discuss how each conceptual category aligns with each of the included articles.

The ways in which researchers interpret and write about what they see will be shaped by particular discourses about the topic under study (Noblit, 2016). Altogether, the articles span 15 years of dementia studies (2004–2019), during which time scientific and cultural understandings of dementia have evolved considerably (Bartlett & O’Connor, 2010). Conceptual differences arising from

Table 2. Overview of included articles

Authors	Title	Country	Research Quest/Objective	Methodology	Participants	Care Context	Summary of Findings
Clarke & Davey (2004) (A1)	Communication and decision making among residents with dementia	Australia	How do the communication characteristics of staff influence the personal care decision making of residents with dementia?	Not specified	Resident (“with a diagnosis of dementia”) and caregiver dyads	Morning care	Caregiver communication can undermine or enhance the capacity of residents to participate in personal care decisions.
Dran (2008) (A2)	A new look at episodes of mistaken identity: Opportunities for preserving personhood	United States	Offshoot of a larger study investigating the use of biographical information in residential care	Not specified	Caregivers (“of persons with dementia”)	Everyday care interactions	Episodes of mistaken identity, during which a caregiver is mistaken for a person from a resident’s past, provide opportunities to validate a resident’s experience of the world and preserve their personhood.
Hammar et al. (2011) (A3)	Communicating through caregiver singing during morning care situations in dementia care	Sweden	To describe verbal and non-verbal communication during care situations with and without caregiver singing	Not specified	Resident (“diagnosed with dementia” – severe) and caregiver dyads	Morning care	Caregiver singing for or together with residents can enhance communication and cooperation during morning care activities.
Doyle & Rubinstein (2014) (A4)	Person-centred dementia care and the cultural matrix of othering	United States	To examine how person-centred care is defined, shaped, and practiced by staff members within a dementia care setting	Ethnographic	Resident (with moderate to severe dementia) and caregiver dyads	Interactions occurring in the public space	“Othering” practices (categorizing people as less than human) work against person-centred care to distance residents from their caregivers.
Corwin (2018) (A5)	Overcoming elderspeak: A qualitative study of three alternatives	United States	Which modes of communication do caregivers who avoid elderspeak employ when engaging in lexically and grammatically complex interaction with communicatively impaired older adults?	Ethnographic	Resident (“with impaired communicative ability”) and caregiver dyads	Pastoral care and foot massage	Blessings, jokes, and narratives offer communicative exchange patterns that allow for rich interaction between a resident and their caregiver without the risk of communicative breakdown.
Watson (2019) (A6)	Developing the senses framework to support relationship-centred care for people with advanced dementia until the end of life in care homes	United Kingdom	What is the role of embodied and inter-embodied selfhood in ensuring that people with advanced dementia remain active agents in their relationships until the end of life?	Ethnographic with an appreciative intent	Residents and caregivers	Hands-on body work	“People with advanced dementia are not passively receiving care, but actively involved in the care-giving/care-receiving interaction” (p. 554).

shifts in the interpretive context were noticeable across the articles and will also be discussed.

Doing with versus Doing for

The concept of *doing with versus doing for* was chosen to represent the overall process of relational care; whereas *staff responsiveness* and *resident agency* represent constituent parts. Although we discuss each of these concepts separately, they are closely inter-related. In Table 3¹, we summarize the translation process for each category and the inter-relationships between them. Each vertical column shows how the three concepts interconnect within the unique storyline of each article, whereas reading across the rows allows for comparisons to be made across all six articles (Erasmus, 2014).

Doing for is associated with a caregiver's under-estimation of a resident's capacity to participate in the care activities (A1, A3, A6). This places the resident in a "passive position" (A3, Hammar et al., 2011, p. 163) and can lead to a uni-directional or task-focused approach to care (A1, A3). The tendency to exclude a resident from participating in care activities is attributed variously to a lack of caregiver knowledge and skills in capacity assessment (A1), a task-focused care culture (A1, A3) and the influence of dominant discourses, such as the biomedical focus on progressive functional decline (A4), or *social death* (A6).

By contrast, *doing with* implies that care activities are inclusive and that both people in the relationship are somehow working together. Two articles (A2, A5) focus exclusively on naturally occurring inclusive care practices. As such, the theme of *doing with* is implicit in the first order constructs, which include detailed "communicative exchange patterns" (A5, Corwin, 2018, p. 729). Elsewhere, this type of care interaction is variously described as participatory (A1, A2, A3, A5), cooperative (A3), and collaborative (A2). In Dran's article (A2, 2008), for example, the author describes a process during which staff worked with a resident "to complete the meaning of a situation or a story" (p. 644). Dran describes this quality of interaction as "a collaborative effort" (p. 642) and is careful to highlight the agency of both people: the resident, who initiated the episode, and the staff member, who went along with and did not try to correct "the resident's perception" (p. 646). However, *doing with* is also characterized as enabling in two of the articles (A1, A6). Indeed, in the case of severe dementia, Watson (A6, 2019) describes the caregiving/care-receiving relationship as "asymmetrical", because it requires staff to take the initiative (p. 559). This more nuanced understanding of *doing with* would seem to fit with Doyle and Rubinstein's (A4, 2014) vision of "a greater equality and empathy contained within the care relationship" (p. 958). In the context of communication challenges, this involves, as Brannelly (2016) has argued, creating space for people with dementia to make their own decisions (A1), preserve their sense of self (A2), try things for themselves (A4), participate in conversations (A5), and do the things they can still do (A6). Therefore, *doing with* requires a certain aptitude on the part of staff, which we have named *staff responsiveness*.

¹A note about language: To preserve each article's singularity, we adhere as far as possible to the authors' own choice of language (Doyle, 2003). In each of the articles, terms used to describe the two participant groups varied, however, so to provide some uniformity we have chosen to use the shorthand terms "resident" and "staff" throughout. These categories define each group's affiliation with long-term care, which provides both a home for residents and a place of employment for staff.

Staff Responsiveness

We chose *staff responsiveness* as an umbrella term to cover a number of relational care skills mentioned in the articles. As discussed, *doing with* involves creating space for residents to participate in care activities; however, in a dementia care context, it also involves an ability to recognize when a resident is able to make their own decisions and do things for themselves (A1, A6). Capacity assessment, as Clarke and Davey (A1, 2004) advise, is a skill that can be developed through education and training. It can also be acquired through "personal exploration" (p. 22) or, as Watson (A6, 2019) suggests, through "doing and experiencing" (p. 554) in the course of care work. There are two main skills that would seem to facilitate this learning. The first skill can be summarized as "being open" (A6, Watson, 2019, p. 556), and is variously described in the articles as "genuine interest in and engagement with the resident" (A1, Clarke & Davey, 2004, p22), a caregiver taking their cue from a resident (A2 Dran, 2008, p. 643), inviting communication (A3, Hammar et al., 2011, p. 163), and "paying attention and expecting a response" (A6, Watson, 2019, p. 556).

The second skill connects with the theme of visibility and can be summarized as *noticing* or *awareness*. In two of the articles, for example, *doing with* is seen to occur when a resident and their abilities are more visible to staff (A3, A6). Hammar, Emami, Engström, & Götell (A3, 2011) observed that during caregiver singing situations, as staff became more intensely aware of residents, they communicated differently: they "expressed a willingness to co-operate" (p. 166) and more often left space for residents to "try to do things themselves before helping" (p. 165). Similarly, Watson (A6, 2019) contrasts staff who enable residents to "do the things they can still do" (p. 559) with those who "fall into the habit of seeing residents as passive" (p. 555). In summary, both skills place an emphasis on *doing with* and, therefore, work against attitudes more often associated with *doing for*, such as under-estimating, ignoring, or overriding resident contributions to care (A1, A3, A4, A6).

Resident Agency

In line with our inclusion criteria, *resident agency* is recognized and visible in the first order constructs of all six articles and, during the translation process, we chose this term to encompass the different levels of agency represented. In four of the articles, when care interactions fell under the *doing with* category, resident agency was described as *engagement* or *participation*. This active response was captured in the data both verbally and non-verbally through descriptions of body movements, singing, laughing, eye contact and touch (A1, A3, A5, A6). Indeed, in five of the articles (A1, A3, A4, A5, A6) we see how embodied expression was used by the resident participants to compensate for verbal communication difficulties.

Resident responses during interactions that fell under the category of *doing for* were also represented. However, authors in just two of the articles recognized non-verbal communication in such circumstances as attempts to express care needs (A4) or as responses to care (A6). In large part, this disparity can be explained historically. As scientific and cultural understandings of dementia have evolved, researcher engagement with the significance of non-verbal communication has increased (Bartlett & O'Connor, 2010). Hammar et al. (A3, 2011), for example, adopt a biomedical frame to organize their data in terms of problematic behaviours thought to be symptomatic of the disease process: "compliant", "resistant and

Table 3. Reciprocal translation of key concepts

Key concepts	Clarke & Davey (2004) (A1)	Dran (2008) (A2)	Hammar et al. (2011) (A3)	Doyle & Rubinstein (2014) (A4)	Corwin (2018) (A5)	Watson (2019) (A6)
Relational care as “doing with” (vs. “doing for”)	Staff enable residents to make their own decisions (p. 20).	Staff work with the resident “to complete the meaning of a situation or a story” (p. 644).	Residents try things for themselves, staff provide assistance when needed (p. 164).	“A greater equality and empathy contained within the care relationships” (p. 958)	Residents participate in “rich communicative interaction” with minimal risk of “communicative failure or breakdown” (p. 724).	Staff enable residents “to do the things they can still do” (p. 559)
Staff responsiveness	“Genuine interest in and engagement with the resident” (p. 22) vs. adhering to procedures (“task focused”) (p. 23).	“Going along with”/not correcting “the resident’s perception” (p. 646) vs. ignoring/dismissing episodes of mistaken identity as “a sign of impairment” (p. 641).	Staff invite residents “to join their communication attempts” (p. 164) vs. staff exclude residents from communication.	Person-centred care vs. staff relying on biomedical dementia discourse “to (a) interpret the residents’ behaviours and (b) infer the extent of their lost behaviours” (p. 957)	“Communicative exchange patterns” that do not require “a specific response” (p. 728) vs. elderspeak	“Being open” to the person, “paying attention and expecting a response” (p. 556) vs. staff viewing residents as “passive recipients” of care (p. 546)
Resident agency	“Increased engagement”.. “in the communication process” (p. 21)	The resident’s former identity and past accomplishments are integrated into the present care context (p. 645).	Active participation in verbal communication by singing, humming, or whistling; non-verbal participation in getting dressed through body movements (p. 165)	A resident’s repeated attempts to express their care needs, despite being ignored	A joke can be answered with “a nod, a smile or shared laughter” (p. 727). The “narrative genre is flexible enough to accommodate a wide range of responses” (p. 728).	Actions such as “spitting food out” or turning away signal that the resident is “actively involved in the care-giving/ care-receiving interaction” (p. 554).

aggressive”, “confused”, and “disruptive”. In contrast, the later articles reflect a significant shift towards understanding behaviours as responsive and, therefore, as meaningful communicative action (Dupuis, Wiersma, & Loisele, 2012; Gilmour & Brannelly, 2010). In Doyle and Rubinstein’s (A4, 2014) detailed field note account, for example, Raúl’s repeated and frustrated attempts to express his care needs – by “pulling at his pants and ... saying that he needed to get in “the room” (p. 957) – are extremely visible, despite staff oblivion. Similarly, Corwin (A5, 2018) draws attention to the interactive sounds and expressions that signify a resident’s engagement in conversation irrespective of staff comprehension. Lastly, in Watson’s article (A6, 2019) resident responses to care, such as spitting out food or not making eye contact, are legitimized as small acts of “embodied agency” that indicate a resident’s active involvement in the caregiving/care-receiving interaction (p. 554).

Inclusive Communication

Although spoken instruction is, by and large, the dominant mode of staff interaction reported, authors in three of the articles discuss alternative approaches to communication that include a creative dimension or art form. Dran’s (A2, 2008) article reveals how biographical knowledge can be “seamlessly integrated” into the present context of care through spontaneous role play (p. 645), thereby providing an experience of acceptance and belonging for the resident (p. 646). Hammar et al. (A3, 2011) highlight the potential for singing to enhance communication during morning care. They note, for example, that residents “were more active in both getting dressed and communicating” and that verbal instructions or requests became unnecessary (p. 166). Similarly, Corwin (A5) reveals how the sharing of jokes and narratives creates opportunities for residents to engage in meaningful interaction without the risk of communicative breakdown. In each of these examples, the arts are seen to facilitate a more democratic relationship that cuts across the usual staff–resident power differential. Hammar et al. (A3, 2011) suggest, for example, that singing together enabled staff to see residents as “whole human beings” (p. 166). Doyle and Rubinstein (A4, 2014) suggest similarly that opportunities for staff to learn about the “narratives and perceived realities” of residents might offer an antidote to othering practices (p. 961). This, they caution, would necessitate more time for care activities.

Time

One of the oft-cited obstacles to relational care in long-term care is lack of time. Without discounting the significant time pressures under which front-line staff operate, in this review time does not appear to be a significant variable. Clarke and Davey (A1, 2004) explain that their observation methods were designed “to fit in” with the long-term care routine, during which the staff they observed were allocated a prescribed number of residents. Similarly, Hammar et al. (A3) recorded morning care situations, with and without caregiver singing, that lasted the same amount of time. Corwin’s article (A5, 2018) discusses “naturally occurring interaction” that occurred during care activities, such as foot massage, that lasted an average of 15 minutes (p. 725). Watson (A6) found, similarly, that body work provided opportunities for staff to connect with residents one-to-one and that staff had little time to spend with residents beyond body work. Lastly, Dran repeated a number of times that episodes of mistaken identity

were brief, unrehearsed, and seamlessly integrated into the task at hand. How staff perceived and used the available time *did* seem to vary however. For example, Clarke and Davey (A1, 2004) report that for some staff, an “obsession with time” became a barrier to inclusive care. Their delivery of information was seen to be rushed, and residents were not always given sufficient time to respond. By contrast, during *doing with* situations, staff were seen to approach time differently. They appeared to have a “cheery and personal demeanour” and to encourage recall (p. 17). Hammar et al. (A3) found, likewise, that staff and residents operated at different paces and that some staff did not wait for a response after posing a question or interrupted the resident as they attempted to participate. By contrast, when staff sang for or together with residents, the pacing of care activities seemed to be more accommodating.

Summary of Findings

We chose the term *doing with* to represent care practices in which both parties are actively engaged in the care activities, albeit in different ways. In the context of communication challenges, we learned that this requires *leaving space* for residents to participate. Space in which they can, for example, make their own decisions, try things for themselves, do the things they can still do, interact socially, and preserve their sense of self. Therefore, during care termed as *doing with*, the person receiving care and their contributions to care are distinctly more visible. We also learned that leaving, or indeed, creating space for residents to participate during care activities does not necessarily require more time, but does involve a number of skills. These skills are obtained through specialized training but equally, they are obtained through experience acquired in the course of care work. They include: (1) an openness to the resident during the care activities, (2) an ability to recognize when a resident is able to make their own decisions and to do things for themselves, and (3) a sensitivity to non-verbal communication as a means towards more inclusive communication. Sensitivity to non-verbal communication would seem key in re-centering residents during care activities. Furthermore, it became apparent that as researchers engage with the meaning of non-verbal communication, resident contributions to care become more visible and residents themselves are brought “to the fore as key players in the caring relationship” (A6, Watson, 2019, p. 552).

Synthesizing the Translations

In this section of our synthesis, we integrate these findings into a visual model (see Figure 2). Because our objectives are to understand the process of relational care and contribute to its visibility, the model is designed to spotlight the different components of *doing with* interactions that were seen to contribute to more inclusive, relational care practices in the six reviewed articles. The overlapping circles designate the staff–resident relationship. The dotted circle characterizes *staff responsiveness* as a circular process, and the bidirectional arrows indicate how first-hand experience feeds into experiential knowledge and vice versa. The three boxes – inclusive communication, education, and experiential knowledge – along with the broader institution-wide culture, represent contextual factors that can positively impact the interactive space. The interactive space is discussed in more detail in the next section.

A CARING WITH INSTITUTION-WIDE CULTURE

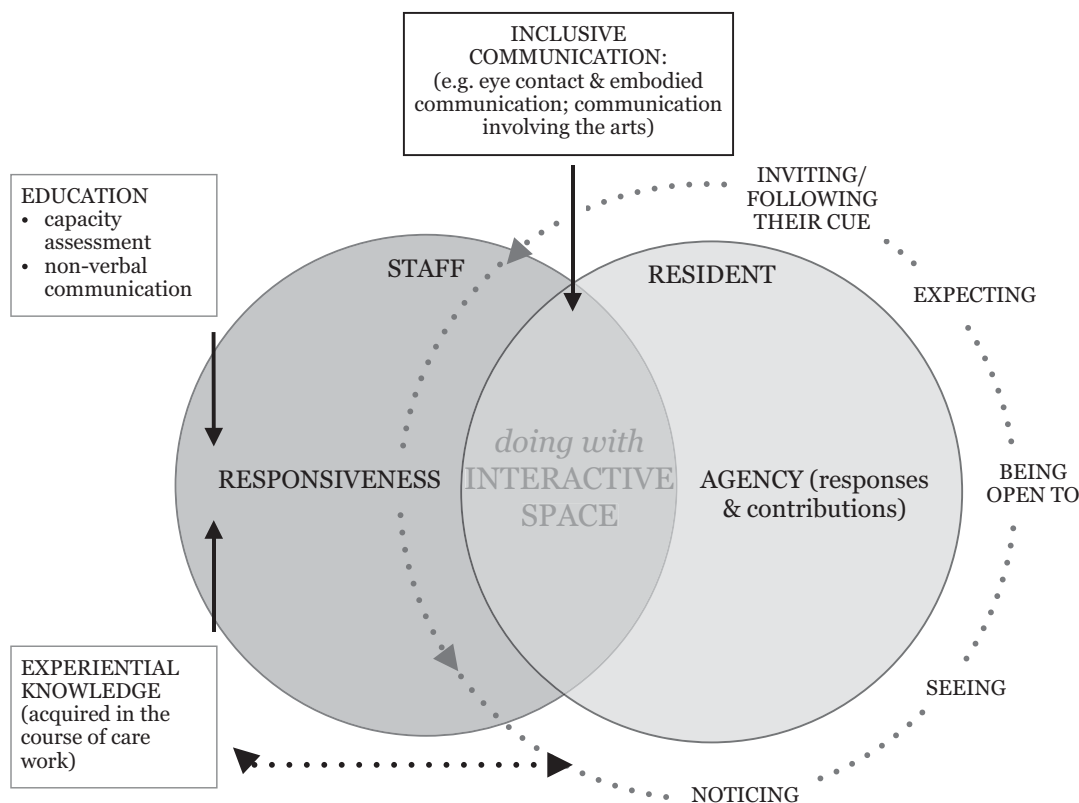


Figure 2. New configuration of relational care.

The new configuration model shows different components of doing with interactions seen to contribute to relational care practices.

Discussion

Brannelly (2016) argues from an ethics of care standpoint that “it is the responsibility of society to create the space and place for people with dementia to contribute” (p. 311). As highlighted in our summary, a *doing with* approach to dementia care involves *leaving or creating space* for residents to participate during care activities. In our model, we have delineated and defined this space as the *interactive space*. It is both literal, because it involves a physical encounter, and conceptual, because it requires a particular orientation. As such, the *interactive space* exists as a potential space. It can be filled by *doing with* but, equally, it can be closed by *doing for*. In the discussion that follows, we tease out and expand on the different dimensions of a *doing with* orientation. We begin by explaining what we mean by “inclusive communication”.

Inclusive Communication

There is general consensus that people receiving care should be involved in the process, whatever the level of their impairment (Clare & Cox, 2003). Furthermore, from a human rights perspective, Clare and Cox (2003) point out, those who communicate differently should be allowed to communicate on equal terms and from their own perspective (p. 935). As this review illustrates, however, in a dementia care context inclusion is difficult to achieve and there is clearly a need to “to identify the kinds of interactions” that allow for more equal communication during care activities (Webb, 2017, p. 1105).

Full awareness of residents as contributing partners during care interactions has developed over time, as our understanding of dementia has evolved (Bartlett & O’Connor, 2010). Engaging with the significance of non-verbal communication has been critical in this evolution (Hubbard, Cook, Tester, & Downs, 2002; Kontos, 2004) and, as the findings from this synthesis reveal, a sensitivity to alternative forms of expression is certainly a stepping stone towards more inclusive communication. Yet the question remains, when verbal communication is the more dominant mode, how equal or inclusive can the interaction be? Three of the six articles in this review feature alternative modes of communication, including role play, singing, and narrative. In each, the resident participants seemed more able to participate on their own terms and, as Corwin (A5) phrased it, without risk of communicative breakdown. Furthermore, a creative approach to communication during care activities appeared to foster a more equal exchange that cut across the usual staff–resident power differential. That the arts are a great leveller was demonstrated in a study by Kontos, Miller, Mitchell, and Stirling-Twist (2017) exploring reciprocal engagement between elder clowns and residents with dementia in a long-term care setting. The study findings revealed a capacity in residents, often with severe symptoms of dementia, to reciprocate and, equally, “to initiate affective, creative, and playful” interactions (p. 60). These authors drew attention to residents’ “creative and imaginary capabilities”, which, they argued, are rarely supported in dementia care (p. 60). The incorporation of an alternative expressive mode would seem both to support resident participation and allow for more equal communication. In our model, we group

together communication through the arts with other non-verbal modes of communication under the broad umbrella of inclusive communication. Our findings suggest that these kinds of interactions engender opportunities for residents with communication difficulties to participate on more equal terms.

A *Worthwhile Activity*

In a care culture more often focused on efficiency than on “residents’ need for slowness” (Armstrong & Lowndes, 2018, p. 63), it is easy to see why *doing* for a resident during care activities is, by and large, the default approach. During *doing with* situations, however, staff were seen to approach time differently. In Hammar et al.’s article (A3), for example, when staff sang for or together with residents, the pacing of care activities seemed to be more accommodating. Overall, we learned that allowing space for residents to participate during care activities does not necessarily require more time. It does require us to think differently about how we value that time, however, and, as Tronto (2015) has written, “that means first noticing it as time we’re spending doing worthwhile activities” (p. 29). Tronto’s (1993) 4 Phase Process of Care redefines care as a relational activity that plays a role in mediating relationships (Tronto, 2015). This, as our findings indicate, involves relational skills such as being open to the person receiving care, inviting their participation and following their cue, expecting their response, and noticing their contribution. In summary, then, a *doing with* orientation during care activities would seem to depend on a more inclusive approach to communication, a different understanding of time, and, perhaps, also, a different way of thinking and talking about care.

A “Caring with” Institution-Wide Culture

The professionalization of care in long-term care has led to a top-down organization of care work in which “experts arrange processes of care for less-skilled care workers to carry out” (Tronto, 2015, p. 165). This situation, as Clare and Cox (2003) point out is not the best foundation for promoting inclusion; or, indeed, for recognizing *soft skills*, of the kind just mentioned, that are used by staff to build and maintain relationships (Armstrong, 2013). Aside from Doyle and Rubinstein (A4), the authors included in this review do not address the broader long-term care context in which their studies took place. The focus of our review is similarly narrow. Although we were guided by a definition of relational care based on Tronto’s (1993) 4 Phases of Care framework, our topic was limited to resident–staff interactions. In failing to provide a more complete picture of institutional care, there is a risk that those who provide care will be blamed for decisions made by those who oversee care (Tronto, 2015). However, the majority of articles included in this review bring to light relational care practices in which the agency of residents and the initiative of staff are equally visible. Furthermore, authors in three of the articles infer that the observed staff responsiveness was acquired through experience gained in the course of care work. This finding concurs with research by Scales, Bailey, Middleton, and Schneider (2017) that highlights the creative, often unrecognized, care work performed by frontline staff in hospital-based dementia wards. These authors recommend that more is done to recognize, support, and develop “the creative capacity of this workforce and their potential role in collectively producing change” (p. 240).

In later work, Tronto (2013) added a fifth phase to the 4 Phases of Care framework: Solidarity – *caring with*, which is intended to

situate care within a broader social context. A *caring with* institution-wide culture is one in which differing contributions to the caring relationship are recognized, and conversations about care include all those directly involved (Brown Wilson, 2013; Tronto, 2015). The later articles included in this synthesis indicate a new trend towards acknowledging the experiential knowledge and skills of front-line staff in long-term care. Overall, our findings suggest that as researchers shift their focus to what *is* working during care interactions, relational care becomes more visible.

Implications for Research and Practice

Each of the studies reviewed in our synthesis succeeds in making relational care more visible. Although detailed discussion of the methods employed for this purpose is beyond the scope of this article, their collective contribution to research and practice is worth mentioning in three regards. By employing data collection methods that capture both verbal and non-verbal communication, these researchers underline the importance of visual data in monitoring inclusiveness during care activities. Furthermore, by designating gestures and non-verbal sounds as measures of engagement and participation, they create a more democratic research environment for people with communication difficulties. This is particularly significant for long-term care residents, who are under-represented in research (Luff, Laybourne, Ferreira, & Meyer, 2015). Lastly, by drawing attention to relational care practices already in operation, they give this work “the attention it deserves” and make these skills more available to others (Driessen, 2017, p. 127). Through their efforts, we have been able to shine a light on relational care practices already in operation and wish to encourage further research in this area. In this regard, each of the articles offers valuable methodological guidelines.

Strengths and Limitations

During the search and selection process for this meta-ethnography, we identified only six articles that met our selection criteria. This is in part the result of a general scarcity of research examining relational care. It is also the result of our purposeful selection of studies during the co-review process. Our finely tuned eligibility criteria ensured that each of the included articles attained credibility in terms of “thick description”, “concrete detail”, and “explication of tacit (nontextual) knowledge” (Tracy, 2010, p. 840). In turn, this led to an in-depth synthesis. Although the review findings were certainly robust enough to provide a fresh configuration of relational care (France et al., 2019), some aspects require substantiation, and there are gaps that need filling. For example, friends and family, whose contribution to care in long-term care is considerable and especially valued by residents (Milte et al., 2016), were excluded. A more representative interpretation of relational care would need to account for the triadic nature of many care interactions (Tuijt et al., 2020). The focus of this meta-ethnography was also limited to the interactive process – the giving and receiving – of care, rather than the quality of care provided. Nonetheless, although the configuration is far from complete, it does provide “a new interpretive context” for relational care (Noblit & Hare, 1988) and future reviews on this topic.

Lastly, our selection criteria excluded a significant body of book-length nursing home ethnographies (Vesperi, 1995). These typically combine micro-analysis of everyday care interactions with a broader, macro-analysis of the organizational context, and may

help to explain both how and why relational care is so often overlooked.

Conclusions

To date, there have been few studies that examine care as a bidirectional process in long-term care, and still fewer that describe the participation of residents who are experiencing communication difficulties. In this article, our objective was to understand the development of knowledge in this area by means of a meta-ethnography. The review findings suggest that a relational, or *doing with*, approach to care is being practiced in residential care settings, albeit sporadically. To underscore collective understandings arising from our synthesis, we provide a new configuration of relational care that brings together what is known about what works. As such, we hope to have joined forces with these researchers in making relational care more visible. As Campbell et al. (2011) have pointed out, however, meta-ethnographies can help to reveal both what is known and what is not known about a given topic. In this regard, further research is needed to gauge more fully the differing contributions of staff, residents, and family to this joint endeavour of relational care.

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