

Tilburg University

Care staff's sense-making of intimate and sexual expressions of people with dementia in Dutch nursing homes

Waterschoot, K.; Roelofs, T. S.; van Boekel, L. C.; Luijkx, K. G.

Published in:
Clinical Gerontologist

DOI:
[10.1080/07317115.2021.1928357](https://doi.org/10.1080/07317115.2021.1928357)

Publication date:
2021

Document Version
Publisher's PDF, also known as Version of record

[Link to publication in Tilburg University Research Portal](#)

Citation for published version (APA):
Waterschoot, K., Roelofs, T. S., van Boekel, L. C., & Luijkx, K. G. (2021). Care staff's sense-making of intimate and sexual expressions of people with dementia in Dutch nursing homes. *Clinical Gerontologist*.
<https://doi.org/10.1080/07317115.2021.1928357>

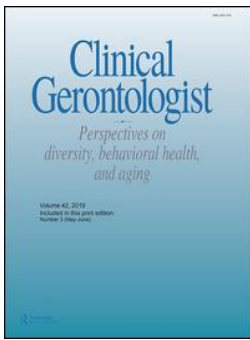
General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.



Care Staff's Sense-making of Intimate and Sexual Expressions of People with Dementia in Dutch Nursing Homes

Karien Waterschoot, Tineke S. M. Roelofs, Leonieke C. van Boekel & Katrien G. Luijckx

To cite this article: Karien Waterschoot, Tineke S. M. Roelofs, Leonieke C. van Boekel & Katrien G. Luijckx (2021): Care Staff's Sense-making of Intimate and Sexual Expressions of People with Dementia in Dutch Nursing Homes, *Clinical Gerontologist*, DOI: [10.1080/07317115.2021.1928357](https://doi.org/10.1080/07317115.2021.1928357)

To link to this article: <https://doi.org/10.1080/07317115.2021.1928357>



© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC.



Published online: 03 Jun 2021.



Submit your article to this journal [↗](#)



Article views: 213




View related articles [↗](#)



View Crossmark data [↗](#)

Care Staff's Sense-making of Intimate and Sexual Expressions of People with Dementia in Dutch Nursing Homes

Karien Waterschoot MSc^a, Tineke S. M. Roelofs PhD ^{a,b}, Leonieke C. van Boekel PhD^a, and Katrien G. Luijkx PhD^a

^aTranzo, Scientific Center for Care and Welfare, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands;

^bDepartment of Psychology, Schakelring Nursing Care Organization, Waalwijk, The Netherlands

ABSTRACT

Objectives: The Person-centered Care (PCC) philosophy emphasizes close care relationships to enable care professionals to recognize the needs of nursing home residents with dementia. This study explored how care professionals make sense of resident behavior with regard to intimacy and sexuality.

Methods: 26 nursing home care professionals (15 Nurses, 9 Health Care Professionals and 2 Managers) completed in-depth interviews that were subjected to an Interpretative Phenomenological Analysis (IPA).

Results: Three thematic layers were identified. 1. Care Professionals pursue a “true” understanding of intimate and sexual behavior that underpins a *resident's* expression. 2. When care professionals feel the need to protect themselves, they can reframe a specific *care relation* in order to continue care. 3. The *social context* around the resident, from family to professionals (i.e. peers), influences interpretation of behavior and, consequently, the provision of care.

Conclusions: Intimate and sexual expressions of residents can put care relations under pressure. Care relations that lack professional distance may compromise care professionals' judgments, impede their natural boundaries and decrease their well-being.

Clinical implications: Along with implementing PCC principles, organizations should empower staff to develop, discuss and include self-reflection skills and personal boundaries within their work.

KEYWORDS

Dementia; nursing home; nursing; intimacy; sexuality; qualitative research

Introduction

Intimacy and sexuality are lifelong elements of being human, being affected by interpersonal experiences (World Health Organization [WHO], 2006). When satisfactory, these experiences continue to influence quality of life positively (Syme, Cohn, Stoffregen, Kaempfe, & Schippers, 2019). Intimacy refers to feelings of closeness, connectedness and belongingness (Sternberg, 1997, p. 315) which are expressed in interpersonal interactions. One's sexuality encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction (WHO, 2006). Sexuality can be experienced in thought and behavior, solo or interpersonally. For people with dementia (PWD), intimacy as well as physical sexual activity becomes increasingly difficult due to multiple disabilities (Roelofs, Luijkx, & Embregts, 2019b; Tsatali, Tsolaki, Christodoulou, & Papaliagkas, 2011). As their condition progresses

it may become necessary to reside in a nursing home, which implies high dependency on care professionals in all aspects of their life, including the possibility to experience intimacy and sexuality (Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005). In addition to the dementia, residents experienced barriers for expression due to this dependency, such as lack of emotional support and privacy (Bauer et al., 2013; Roelofs, Luijkx, & Embregts, 2019a)

The care philosophy of Person-centered Care (PCC) is built around the needs of the individual resident and is contingent upon close care relationships (Fazio, Pace, Flinner, & Kallmyer, 2018; Koren, 2010). The care relationships should enable care professionals to recognize the needs that underpin a resident's expression, despite increasing cognitive impairments (Edvardsson, Winblad, & Sandman, 2008). Although a close relationship between care professional and PWD is

CONTACT Karien Waterschoot  K.Waterschoot@tilburguniversity.edu  Tranzo, Scientific Center for Care and Welfare, Tilburg School of Social and Behavioral Sciences, Tilburg University, Warandelaan 2, Tilburg 5037 AB, The Netherlands

© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

a fundamental element of PCC, an agreed upon balance between personal and professional closeness, including professional boundaries, is lacking in PCC literature (Edvardsson et al., 2008; Fazio et al., 2018; Koren, 2010). However, nursing literature on (therapeutic) care relations strongly emphasizes boundaries, and regards closeness as an element of professional intimacy (Blomberg & Sahlberg-Blom, 2007; Peternelj-Taylor & Yonge, 2003). Professional intimacy is defined as a component of the therapeutic nurse–patient relationship that fosters closeness, self-disclosure, reciprocity and trust through emotional and/or physical forms (Antonytheva, Oudshoorn, & Garnett, 2020). Care professionals can thus express (professional) intimacy toward residents and facilitate residents to, privately, experience intimacy and sexuality. Conversely, care professionals can also become the unwanted object of sexual advancement or even harassment (Villar, Fabà, Serrat, Celdrán, & Martínez, 2020).

A profound understanding of how care professionals make sense of intimate and sexual expressions of residents with dementia, within this close care relationship, is still lacking in literature. A systematic review on intimacy and sexuality of PWD in nursing homes, however, suggests that care professionals may interpret similar expressions differently (Roelofs, Luijkx, & Embregts, 2015). It is unknown whether the quality of the care relationship influences this interpretation. Moreover, research on the attitudes of care professionals provides a dual image; although a neutral and accepting attitude toward sexuality for PWD is reported in general (Di Napoli, Breland, & Allen, 2013; Roelofs, Luijkx, Cloin, & Embregts, 2019), feelings of discomfort (Roach, 2004) and ethical concerns (Archibald, 2002) were reported as well. For this reason, and to provide insight into the way this affects daily care, it is vital to explore the roots of care professionals' attitudes: their efforts to make sense of their experiences with regard to intimacy and sexuality.

This study aims to explore the experiences of care professionals with regard to the expressed intimate and sexual needs of nursing home residents with dementia. Moreover, we aim to understand how care professionals make sense of these

experiences and how this process influences the care relationship and so the provision of care.

Design and methods

Methodological approach

A qualitative research design was chosen, according to Interpretative Phenomenological Analysis (IPA). This method enabled a detailed exploration of how individuals make sense of the events and other people in their lives (Pietkiewicz & Smith, 2014). Moreover, the roots of this method in hermeneutic phenomenology make it possible to emphasize the role of personal involvement and context in the process of sense-making (Zimmermann, 2015). In this study, descriptions of resident cases received particular attention, since these entail both residents' behavior within the specific care relationship and the provision of care. IPA has been used before to explore experiences of care professionals (Brocki & Wearden, 2006).

Ethics

Tilburg University Psychology Ethics Committee approved the study [EC-2019.24].

Setting and participants

Within Dutch nursing homes which are almost exclusively governmentally funded, residents with moderate to severe dementia receive 24-hour care and guidance in specialized dementia nursing units (DNUs). These units are group homes housing six to twenty residents. Care is highly person-centered and provided through a multidisciplinary team structure. Licensed practical nurses (vocational degree) and registered nurses (bachelor degree) provide direct and daily care. Health Care Professionals (HCPs) (e.g. physicians, psychologists, occupational therapists, spiritual counselors, and by exception, a sexologist) provide treatment and advise nurses. A manager coordinates the team, and a specialist Geriatric Medical Doctor (MD) is responsible for the complete care process. Dutch nursing homes employ the Quality Framework from the Ministry of Health, Welfare and Sport

(VWS). This framework briefly mentions “the need for romance or sexual intimacy” (VWS, 2018). However, there are no policies or financial aid available for intimate and sexual care, and experts on sexuality within nursing homes are very scarce.

We chose a multi-perspective iterative sample design to give voice to all professionals whose sense-making influences care, however we predominantly targeted nurses since they have the most direct experiences with intimate and sexual behavior. In addition, context was taken into account by recruiting participants from 11 care organizations, and different DNU, across the Netherlands. Sampling continued until data saturation was reached.

Potential participants were first informed by liaisons of an academic collaborative center (Luijkx, Van Boekel, Janssen, Verbiest, & Stoop, 2020) about the nature and goal of the study. The first author approached the potential participants by e-mail to complete the consent procedure and schedule the interview. The participants ($n = 26$, see Table 1) were interviewed individually, except for two nurse pairs who preferred to participate in a double interview.

Data collection

In 2019, the first author conducted all 40–100 minutes in-depth interviews ($mean = 64$). Participants selected a location for the interview where they felt comfortable and could speak freely about sensitive topics (Smith, Flowers, & Larkin, 2009). Interviews were managed in a conversational style to encourage participants to elicit rich and detailed descriptions of their experiences (Pietkiewicz & Smith, 2014). A general topic list was composed, through a review of the literature (see Table 2). The interviews started with an open question asking what care professionals had experienced with regard to intimacy and sexuality. During the interview, the topics were introduced in a flexible manner to adapt to the narratives presented and areas of interest raised by participants. Participants were invited to describe resident cases from beginning to end in detail.

Data analysis

A stepwise qualitative analysis was performed (see Figure 1) conforming to the IPA guidelines (Smith

Table 1. Participant characteristics.

Profession (participant code)	Organization	Level of educational degree	Work experience (years)	Gender	Age (years)		
Nurse	N1	Nurse ¹	A	Vocational	16–20	F	> 60
	N2	Nurse ¹	A	Vocational	> 35	F	51–60
	N3	Nurse ²	B	Vocational	16–20	F	41–50
	N4	Nurse ²	B	Vocational	5–10	F	20–30
	N5	Nurse	B	Bachelor	> 35	F	51–60
	N6	Nurse	B	Vocational	16–20	F	31–40
	N7	Nurse	C	Vocational ^a	16–20	F	31–40
	N8	Nurse	C	Bachelor ^a	5–10	M	20–30
	N9	Nurse	C	Vocational	> 35	F	> 60
	N10	Nurse	D	Vocational ^a	5–10	F	20–30
	N11	Nurse	D	Vocational	> 35	F	51–60
	N12	Nurse	D	Vocational ^a	16–20	F	51–60
	N13	Nurse	D	Vocational	> 35	F	51–60
	N14	Nurse	E	Bachelor ^a	5–10	M	31–40
	N15	Nurse	F	Vocational	26–30	F	41–50
HCP	HCP1	Specialist Geriatric MD	E	Master	5–10	F	51–60
	HCP2	Physician	G	Master	< 5	F	20–30
	HCP3	Sexologist	A	Master	21–25	F	41–50
	HCP4	Sexologist	H	Master	26–30	F	51–60
	HCP5	Health Psychologist	C	Master	26–30	M	51–60
	HCP6	(Health ^a) Psychologist	I	Master	5–10	F	51–60
	HCP7	Psychologist	J	Master	< 5	F	20–30
	HCP8	Spiritual Counselor	K	Master	5–10	F	31–40
	HCP9	Occupational Therapist	E	Bachelor	21–25	F	41–50
Management	M1	Manager	G	Bachelor	31–35	F	51–60
	M2	Manager	F	Master	31–35	F	51–60

¹ 2 double interview

^a Current advanced educational level

Table 2. Topic list.

I. Experiences with expressed needs of residents	
Mutual	Spouses relations between residents
Singular	Falling in love with Co-resident care professional
Masturbation	Private public environment during care
	Directed erotic talk and behavior Spouse co-resident care professional
II. Context	
Characteristics of the care unit	Physical environment Work environment
Facilities for love, intimacy and sexuality	
III. Personal involvement	
Attitude	Knowledge
Education on intimacy and sexuality	

et al., 2009). First, the first author listened to the audiotapes to recall the context and emotional content of the interview and added these as notes to the verbatim transcripts in ATLAS.ti. Second, each transcript was analyzed successively through close line-by-line coding. In addition, 59 resident cases were identified and labeled throughout the data. We operationalized cases as descriptions of resident behavior, (care) responses, and their effect. We chose a double analysis to both have an overview of the entire dataset and to deepen (phenomenological) understanding through the cases, since these illuminated sense-making, and the consequences of this sense-making. Third, the first two authors identified recurrent themes across all data. Through an iterative process, both authors established patterns and superordinate themes among the data. Finally, in another iterative process, a corresponding narrative was constructed, and translations from Dutch to English were made.

Rigor

Sensitivity and reflexivity were prioritized throughout the process to honor the IPA's commitments to "giving voice" to and making sense of participants' experiences. The first two authors reflected systematically on their preconceptions and professional experiences (the second author is a nursing home Health Psychologist) with regard to their possible impact on the interpretation of the data (Smith et al., 2009). Transcripts of these reflections were discussed with, and contested by, the third and fourth authors (Krefting, 1991).

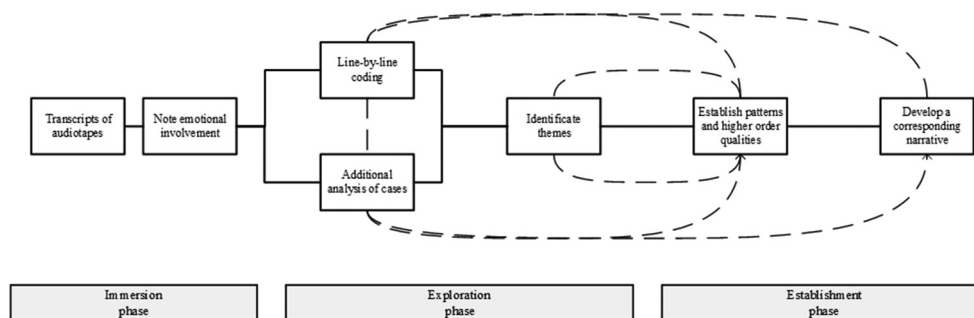
Results

Convergent themes and subthemes are presented in the following sections. They illuminate how care professionals made sense of their experiences within three interrelated constructs: resident, care relation and social context.

The resident: efforts to understand behavior through a personal lens

Love and sex are always personal

Participants perceived sexuality as a personal and private but also an intriguing matter. Whereas physical and emotional intimacy were considered part of daily practice, (accidental) encounters with sexual behavior impressed participants, which was noticeable through the vivid and explicitly detailed narratives, even of long past experiences. For example, N6 brought up that she and a colleague walked into two residents that were having oral sex in the hallway years ago; "that woman was 94 and was on

**Figure 1.** Analysis process.

her knees! . . . Well that shocks you tremendously; later we had a good laugh. However, when you experience it, you are just in shock."

Care professionals made sense of their experiences by means of a personal framework of values and beliefs with regard to love, intimacy and sexuality, and disease (dementia). Almost all shared how various values and beliefs influenced interpretation among colleagues. HCPs and managers particularly stressed these differences. Participants experienced that for colleagues and residents with a "conservative" cultural background or (sexual) upbringing (N10, N13, HCP7, M2) or (strong) religious conviction (N9, N14, HCP2, HCP3, HCP4, HCP6, HCP9, M1, M2), such as belongs to Reformed Protestantism, sexuality in general was surrounded with "taboos" (N14). However, when "true love" was at issue personal values and beliefs appeared to affect all sense-making. For example, N4 regarded herself as having highly progressive views of sexuality of residents, though when a resident told her that he had developed romantic feelings for his regular sex worker she struggled with this. She told him that he should try to avoid this, as she "was not his girlfriend, wife or whatever." However, when this sex worker intended to pay her respects after he died, she reframed their relation: "so actually it was still something . . . well, you can call it beautiful."

Underpinnings of resident expressions; attributions of cognitive functions and character

Care professionals took note of a wide range of intimate and sexually oriented expressions and often questioned their underlying causes and intentions. In different interviews, attempts to attribute meaning to these expressions were shown, and subsequently the way in which care was provided based on these attributions. N7, for example, described her teams' attempts to understand the needs of a resident with advanced dementia who continuously masturbated during hygienic care: "You just do not know. Because he could no longer speak either. So you had to do everything, everything was interpreted from his facial expression." Within the interviews, participants made two, partly overlapping, types of attributions to explain resident behavior. First, attributions were made with regard to the compromised neurocognitive abilities of the

resident. Nurses and HCPs often assumed that a distorted impulse control ("disinhibition"), limited understanding of surroundings, and limited insight into behavioral implications induced the behavior. Thus, N2 stated, "*we do experience sexual disinhibition. For people with frontotemporal dementia that happens quite often*". Second, various attributions regarding the character of the residents were portrayed, such as "a macho man" (N10) or "a perfect gentleman" (N14).

The "true" cause or intention of intimate and sexual behavior remained mostly ambiguous, especially because the required additional information stayed absent and residents' cognitive impairments increased over time. This ambiguity particularly concerned care professionals when the interests of more than one party were at stake and ethical issues arose, such as with co-residential relations. For co-residential relations, N15 explained "*it is always difficult when it concerns people with dementia. Where is the safety for both of them?*" HCP5 also felt that this "equality" in co-residential relations is often volatile. According to HCP6 however, the ambiguity of the (perceived) safety of residents has a counter side, as a single remark or expression of a resident can evoke suspicions of sexual abuse and soon "*lead a life of its own and then everyone has their own idea.*"

Composing a narrative to cope with ambiguity

Despite the unknown meaning of some expressions, care professionals needed to respond and provide care accordingly. Implicitly and explicitly, they manifested the construction of a coherent narrative: a narrative that most often (re-)confirmed their actions. An explicit example of narrating is the description of a female resident who experienced a phase where she masturbated daily. During this phase, the resident was convinced that she was still a student due to severe cognitive impairment. "*And what is typical for that age? A very high sexual need. So that proves that you [PWD] indeed go back in time*" (N12). However, it was for instance unclear whether this resident only frequently masturbated when she was a student. In general, different forms of attributions were used to compose a narrative that explained the residents' behavior.

First, uncommon or inappropriate sexual behavior was fully attributed to cognitive impairment

due to dementia. One of the sexologists (HCP4) expressed that almost all consultations she received were framed as sexual disinhibited behavior due to cognitive impairment, instead of as expressions of a healthy human need. The other sexologist (HCP3) confirmed that, although the inappropriate behavior can be a form of disinhibition, the explanation was used too quickly in her eyes: *“I suppose because it allows you to fully condone the behavior . . . and to focus immediately on a solution. Like how do we cope? . . . Yet, the resident’s needs remain overlooked, which is unfortunate.”*

Second, gender differences appeared to play a role in the interpretation of behavior. Male residents were overrepresented in descriptions of sexual needs and expressions, both solo and toward others. According to sexologist HCP3, a gender difference in masturbation style contributes to a reduced *“recognition among staff,”* as female residents generally masturbate *“much more subtly and covertly”* than males. Remarks of the two male nurses (N8, N14) on a variety of intimate and sexual expressions of female residents toward them also call into question the less sexualized image of female residents. N8 pointed out that, in his perception, female residents often express their feelings in a more *“concealed”* manner, for example by stroking or kissing him on the neck, in comparison to male residents who seemed to be more *“foul-mouthed or disinhibited in their behavior.”* Moreover, interpretations across cases showed that males were described more frequently as subjects, while females were often labeled as objects. This distinction also appeared for couples, and when female residents did explicitly express sexual desires, this behavior was mostly excused through other narratives, such as a depression or grief over a lost spouse.

Finally, perceptions of love, sexual intimacy and attractiveness were used to explain the behavior of residents and their partners. An explicit firm perception was the social principle of monogamous and “common” relationships. Co-residential relationships that, for example, had surprised an entire care team deviated from stereotypical norms, such as that of *“a female resident with beard growth”* and *“a 20 years younger pretty male resident”* (N5).

Care relationship: a balancing act of closeness and boundaries

Closeness: a prerequisite of good care

Participants portrayed the care relationship as intimate, physically as well as emotionally. Participants were profoundly driven to foster the emotional well-being of residents: *“Look at everyone’s wishes; just see the human being; everyone can just be. It doesn’t matter whether you are 80 and demented tremendously, you are simply important.”* (N13). Overall, nurses stressed the beneficial influence of emotionally driven intimate physical contact. M2 voiced intimacy most explicitly as a required aspect of caregiving: *“If you aim to take care of people with dementia you need to be able to deploy all your senses, especially touch . . . in fact, sometimes with [nurse] candidates, I briefly came very close and stroked them just to observe their reaction.”*

Even though intimacy is evidently perceived as “part of the job,” it appeared that the personal connection with a nurse and the interpretation of a resident’s behavior is reflected in the amount and type of intimacy that the resident received. Especially, a nurse’s interpretation of a residents’ touch – is it a pursuit for intimacy or a prelude for sexuality? – was shared to have an influence on the reciprocity of intimacy within the care relation. Additionally, remarks were made to the effect that female nurses tended to feel more easily *“threatened”* (M1, HCP3) by male than by female residents. A psychologist (HCP7) added that this interpretation can trigger a vicious circle. This happened with a new male resident who hugged female nurses a bit too firmly: *“I think there is a difference between men and women . . . I think nurses automatically take a little step backwards while he just needs that little step forward as far as intimacy is concerned, but, because they didn’t know him, they were a little bit more careful with him. Now that he has lived here longer, and they know him better, I think they unconsciously provide this intimacy now anyway.”*

Guarding paradox; (re)setting the boundary

Contrary to their efforts to provide intimacy, nurses felt that they needed to guard the physical and mental boundaries of multiple residents and

of themselves. This enduring balancing act appeared to require confidence and decisiveness, as voiced by an experienced nurse: *“your limits are set by yourself, not by the client”* (N1). Retaining these limits was an act that was mastered through experience according to several. In addition to personal experiences with inappropriate touching, and by exception, sexual aggression (N2, N4, N5, N6, N8, N12, N13, N15), nurses also described how they (tried to) remain in control in interpersonal situations which they described as (non-sexually) intimate, such as requests for firm hugs and friendly kisses. Moreover, the dependency of some residents makes facilitation of sexual expressions, such as masturbation, already fairly explicit. N6 shared that a male resident *“still has a great need. Well, who are we to find that weird or not to help in that sense?”* Though she repeats that she wants to *“grant”* him the opportunity, she also remarks that it is *“quite intimate”* and *“very explicit”* to do; *“to put him in bed, hand over a towel, open his trousers and say: ‘well, this is your moment’ and then select a pornographic movie for him.”* Additionally, several participants described that sperm needed to be cleaned up or wiped off a resident’s hands after masturbation, which was perceived as uncomfortable by several.

Reframed care relations; a new perspective to continue care

When nurses were not willing or able to overcome negative experiences within the context of a specific care relation, they could adjust their perspective on this relation. This changing perspective allowed them to cope and enabled them to continue the provision of care. Within the interviews, three strategies to handle negative experiences within imbalanced care relations were described.

First, a nurse could pull back from the care relation with the resident. N15 described an exemplary case of a male resident who persistently tried to masturbate in the shared living room. N15 mentioned that some colleagues had told her: *“In the morning right after hygienic care, I will touch him briefly. However, later on, it’s pure gloves on, changing incontinence material, getting him dressed and done.”* When this resident does not masturbate he still receives less close care than co-residents; *“But*

warmth, no that’s missing . . . So yeah, he’d have to find another way. Because he rarely gets it from us.”

Second, when a vicious cycle of pulling back and incidents occurred, a resident could be rejected fully by a care team, and relocation of the resident to a different DNU could become necessary. Relocation was only described in two situations in which caregivers felt that the well-being of co-residents was compromised (N9, N13).

Third and conversely, a nurse could also take an extra step forward to strengthen the care relationship. This was done, for example, by fully attributing the sexual behavior to the resident’s impaired cognition or by engaging in a process of self-reflection and reinterpretation of their own influence on the behavior of the resident. N6, for example, reflected on experiences with inappropriate touching during hygienic care: *“Of course, it may be that they don’t feel they’re doing anything wrong at all, to what extent it’s wrong, because that’s just how you pick it up, because we’re all people with feelings.”* Perceptions of their own influence could even extend to portraying themselves as being the cause of a resident’s behavior, such as because my *“shirt falls a bit forward”* (N10).

Distorted care relations were closely related to crossed personal boundaries of nurses. More than fixed norms, boundaries represented a feeling of being in control in nurses’ stories. When this feeling was compromised, the impact was significant. N5 described how she and a colleague cleaned feces from a resident’s anus and scrotum in a small sanitary cell. Hereupon he started to masturbate, but since he was *“staggering on his legs”* she felt there was *“no way out.”* *“I took a step back; the colleague was like: well go ahead. And ok, he was finished, so . . . and so I go, we put everything back on so, nothing to worry about, we continue. That night I had a nightmare about it. And phew, actually I was a bit traumatized.”* She approached her manager, who referred her to an EMDR-therapist. Most interestingly, participants addressed physical personal boundaries, but professional or emotional boundaries were scarcely mentioned. However, nurses especially could be very sympathetic to (victimized) residents. N9 related that the return of a male resident who was temporarily relocated due to his (sexual) fixation on a male co-resident made a deep

impression. She used an illustrative metaphor; *“Imagine that you had a neighbor who abused your child . . . he has served a sentence somewhere and he comes to live next to you without warning and he is with your daughter again the next day.”* She reflects: *“I don’t know if I could have vouched for myself.”* Sexologist HCP4 reflected most explicitly on a lack of awareness among nurses of the balance in professional distance and closeness. It worries her that nurses *“give goodnight kisses and tuck residents in” “intuitively,”* instead of as a conscious care act. She argues that when staff is close intuitively, *“many more boundaries are really being exceeded and that is not realized [by staff themselves]. So, I’m really into relationship building, but you have to realize that you are a professional either way.”*

Social context: integrating emotional involvement, team dynamics and structured care

Though experiences with intimacy and sexuality are common in DNUs, the topic was perceived as scarce in nursing training, general policies and guidelines. The interviews illustrated that the possibilities for residents to experience intimacy or sexuality in a positive fashion differed profoundly between DNUs, even those belonging to similar organizations. For example, some DNUs hired a specialized sex worker for a single resident, while couples could not experience sexuality privately. In other DNUs the opposite was the case.

Family matters

Participants described how family of residents often aimed to express their view of the wishes of their loved one prior to dementia. Romantic or sexually oriented behavior of their loved one provoked very different, though often emotional, responses. Participants described how most spouses were heartbroken, while some were at peace with the romantic relation of their partner and a co-resident. Disinhibited behavior, such as masturbating in public areas or sexual advances toward nurses, often caused the families embarrassment. All participants reported being empathic toward the struggles of family members, though nurses (the direct caregivers) seemed to be affected more by (emotional) requests of family members,

and occasionally by tensions between families. HCPs (the indirect caregivers), however, seemed to navigate more deliberately between the grief of the family and the feasibility of their requests.

Team dynamics

The impact of different perspectives and experiences within a team that works in care shifts was described frequently. These team dynamics influenced decision-making and, consequently, the way that care was provided. N15 acknowledged that when she started in a new DNU team; *“you’re just sensing: what is considered normal here and what not? . . . Like how far will you go?”* All participants stressed that a safe team climate in which sensitive topics can be discussed openly is necessary for well-functioning teams. Several participants added self-reflection skills as a pre-requisite. For example, N12 stated: *“For me, that’s the foundation of a team: openness and honesty . . . To be able to confess: I don’t find it comfortable; it actually scares me.”* On occasion, participants explicitly doubted the openness within teams; for example HCP2 stated: *“I only hear the loudest shouters, to put it rudely, those who say I’ll fix it myself. So actually, I’m not sure . . . it could be that the others are a bit overshadowed.”*

Although experiences with regard to intimacy and sexuality were considered complex, many small creative initiatives were described too, such as a spare room that was turned into a double “hotel” bedroom (N7), pornographic material that was downloaded for the shared library (N3) and work groups to develop policy and in-company education that were being set up (N15, HCP7, HCP8, M2). In addition, some participants described how their team learned how to facilitate the residents in a pro-active manner over time. N5 described this a *“win/win” situation*, for example, because hiring a specialized sex worker let a resident *“bloom”* (N9) and decreased a resident’s inappropriate touches toward staff as well (N3, N4, N5, N7, N8, HCP3, HCP4, M1).

Discussion

This study enhances conceptual understanding of how care professionals make sense of and respond to intimate and sexual behavior of people with

dementia in the context of nursing homes. In an attempt to show the proper response and provide “good” care, care professionals seem to pursue a “true” interpretation of the behavior of residents. In addition to care professionals’ individual framework of values and beliefs, attributions on resident characteristics influenced their interpretation, such as a resident’s (former) character, life conditions, current cognitive functioning and gender. However, the participants often felt great ambiguity, as they felt to lack insight into the “exact” current cognitive abilities and “real” former character of the resident. This seemed to decrease their confidence in coping with the behavior appropriately. The strain of this ambiguity in combination with the felt responsibility to protect their residents align with the findings of Edberg et al. (2008).

Interpretation of resident behavior occurs in a complex interplay of personal values and beliefs and social dynamics that shape the individual care relationship. A care professional thus does not employ one generic attitude toward all intimate and sexual expressions of residents. Research in this field has, however, emphasized that improved knowledge of residential needs could counter negative attitudes and consequently improve care (Bauer, McAuliffe, Nay, & Chenco, 2013; Haesler, Bauer, & Fetherstonhaugh, 2016; Villar, Celdrán, Fabà, & Serrat, 2017). Although improving knowledge seems valuable, these results suggest that solely improving knowledge will not be enough to resolve the ambiguity that care professionals experience, nor will it resolve ethical issues and balance these with the boundaries of the care professional (Archibald, 2002; Bolmsjö, Edberg, & Sandman, 2006; Edberg et al., 2008).

The PCC approach emphasizes care relations (Edvardsson et al., 2008). However, findings highlight that intimate and sexual expressions may put care relations under pressure and eventually may decrease the well-being of both parties. Boundaries – the natural counterpart of closeness in professional care relations – have been underexposed in PCC literature so far. This is remarkable considering how close care becomes both explicitly and implicitly in such a work setting. The findings reveal that a one-sided approach of seeking closeness and positive reassurance of personhood in PCC may compromise care professionals’

judgments, impede their natural boundaries, and consequently decrease their well-being.

The profound differences in opportunities for residents depending on the DNU were reflected in the group dynamics, and echoed the limited structural embedding of residential intimacy and sexuality in training, policies and guidelines, which has been reported previously from a U.S. perspective (Lester, Kohen, Stefanacci, & Feuerman, 2016; Syme, Lichtenberg, & Moye, 2016). Clear guidelines on what is expected of the nurse on a day-to-day basis, and the opportunity to discuss and include their own personal and professional boundaries in their work, are needed to keep them confident in their work and protect them from physical and emotional harm. These findings align with literature on care environments that lack acknowledgment of the personhood of care staff (Kadri et al., 2018), and their impact on burnout and retention problems (Nantsupawat et al., 2017). Hence, a holistic approach that includes interests of both parties is essential to reduce the barriers that residents experience with regard to intimacy and sexuality (Bauer et al., 2013; Mahieu & Gastmans, 2015).

Limitations

First, sample consists of care professionals who were willing and felt able to discuss and share (sensitive) experiences with regard to intimacy and sexuality. Second, the substantial sample limited opportunities for detailed elaborations of multi-faceted cases, and therefore individual experiences and considerations, in an idiographic manner. Third, on the respondent level, the interview approach is less sensitive to the influence of past professional or personal experiences and histories on current interpretations, and warrants further investigation. Further research is also required to investigate causes of individual differences in coping with (boundary-crossing) sexual expressions.

Clinical implications

- Organizations should foster Person-centered Care in a way that respects and stimulates nursing ethics, such as a professional sense of closeness between resident and care professional.

- Care professionals should receive education and on the job support to master strategies to cope with sexual behavior of residents.
- Self-reflection skills and the importance of personal boundaries should be taken into account to protect care professionals from harm.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the Ministerie van Volksgezondheid, Welzijn en Sport [640001011].

ORCID

Tineke S. M. Roelofs PhD  <http://orcid.org/0000-0002-3953-6000>

References

- Antonytheva, S., Oudshoorn, A., & Garnett, A. (2020). Professional intimacy in nursing practice: A concept analysis. *Nursing Forum*, 56(1), 151–159. doi:10.1111/nuf.12506
- Archibald, C. (2002). Sexuality and dementia in residential care—whose responsibility? *Sexual and Relationship Therapy*, 17(3), 301–309. doi:10.1080/14681990220149103
- Bauer, M., Fetherstonhaugh, D., Tarzia, L., Nay, R., Wellman, D., & Beattie, E. (2013). ‘I always look under the bed for a man’. Needs and barriers to the expression of sexuality in residential aged care: The views of residents with and without dementia. *Psychology & Sexuality*, 4(3), 296–309. doi:10.1080/19419899.2012.713869
- Bauer, M., McAuliffe, L., Nay, R., & Chenco, C. (2013). Sexuality in older adults: Effect of an education intervention on attitudes and beliefs of residential aged care staff. *Educational Gerontology*, 39(2), 82–91. doi:10.1080/03601277.2012.682953
- Blomberg, K., & Sahlberg-Blom, E. (2007). Closeness and distance: A way of handling difficult situations in daily care. *Journal of Clinical Nursing*, 16(2), 244–254. doi:10.1111/j.1365-2702.2005.01503.x
- Blomsjö, I. Å., Edberg, A.-K., & Sandman, L. (2006). Everyday ethical problems in dementia care: A teleological model. *Nursing Ethics*, 13(4), 340–359. doi:10.1191/0969733006ne890oa
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, 21(1), 87–108. doi:10.1080/14768320500230185
- Di Napoli, E. A., Breland, G. L., & Allen, R. S. (2013). Staff knowledge and perceptions of sexuality and dementia of older adults in nursing homes. *Journal of Aging and Health*, 25(7), 1087–1105. doi:10.1177/0898264313494802
- Edberg, A.-K., Bird, M., Richards, D. A., Woods, R., Keeley, P., & Davis-Quarrell, V. (2008). Strain in nursing care of people with dementia: Nurses’ experience in Australia, Sweden and United Kingdom. *Aging & Mental Health*, 12(2), 236–243. doi:10.1080/13607860701616374
- Edvardsson, D., Winblad, B., & Sandman, P.-O. (2008). Person-centred care of people with severe Alzheimer’s disease: Current status and ways forward. *The Lancet Neurology*, 7(4), 362–367. doi:10.1016/S1474-4422(08)70063-2
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist*, 58(suppl_1), S10–S19. doi:10.1093/geront/gnx122
- Haesler, E., Bauer, M., & Fetherstonhaugh, D. (2016). Sexuality, sexual health and older people: A systematic review of research on the knowledge and attitudes of health professionals. *Nurse Education Today*, 40, 57–71. doi:10.1016/j.nedt.2016.02.012
- Kadri, A., Rapaport, P., Livingston, G., Cooper, C., Robertson, S., & Higgs, P. (2018). Care workers, the unacknowledged persons in person-centred care: A secondary qualitative analysis of UK care home staff interviews. *PLoS One*, 13(7), e0200031. doi:10.1371/journal.pone.0200031
- Koren, M. J. (2010). Person-centered care for nursing home residents: The culture-change movement. *Health Affairs*, 29(2), 312–317. doi:10.1377/hlthaff.2009.0966
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*, 45(3), 214–222. doi:10.5014/ajot.45.3.214
- Lester, P. E., Kohen, I., Stefanacci, R. G., & Feuerman, M. (2016). Sex in nursing homes: A survey of nursing home policies governing resident sexual activity. *Journal of the American Medical Directors Association*, 17(1), 71–74. doi:10.1016/j.jamda.2015.08.013
- Luijckx, K., Van Boekel, L., Janssen, M., Verbiest, M., & Stoop, A. (2020). The academic collaborative center older adults: A description of co-creation between science, care practice and education with the aim to contribute to person-centered care for older adults. *International Journal of Environmental Research and Public Health*, 17(23), 9014. doi:10.3390/ijerph17239014
- Mahieu, L., & Gastmans, C. (2015). Older residents’ perspectives on aged sexuality in institutionalized elderly care: A systematic literature review. *International Journal of Nursing Studies*, 52(12), 1891–1905. doi:10.1016/j.ijnurstu.2015.07.007
- Nantsupawat, A., Kunaviktikul, W., Nantsupawat, R., Wichaikhum, O. A., Thienthong, H., & Poghosyan, L. (2017). Effects of nurse work environment on job dissatisfaction, burnout, intention to leave. *International Nursing Review*, 64(1), 91–98. doi:10.1111/inr.12342

- Peternelj-Taylor, C. A., & Yonge, O. (2003). Exploring boundaries in the nurse-client relationship: Professional roles and responsibilities. *Perspectives in Psychiatric Care*, 39(2), 55–66. doi:10.1111/j.1744-6163.2003.tb00677.x
- Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, 20(1), 7–14.
- Roach, S. M. (2004). Sexual behaviour of nursing home residents: Staff perceptions and responses. *Journal of Advanced Nursing*, 48(4), 371–379. doi:10.1111/j.1365-2648.2004.03206.x
- Roelofs, T. S. M., Luijkx, K. G., Cloin, M. C. M., & Embregts, P. J. C. M. (2019). The influence of organizational factors on the attitudes of residential care staff toward the sexuality of residents with dementia. *BMC Geriatrics*, 19(1), 8. doi:10.1186/s12877-018-1023-9
- Roelofs, T. S. M., Luijkx, K. G., & Embregts, P. J. C. M. (2015). Intimacy and sexuality of nursing home residents with dementia: A systematic review. *International Psychogeriatrics*, 27(3), 367. doi:10.1017/S1041610214002373
- Roelofs, T. S. M., Luijkx, K. G., & Embregts, P. J. C. M. (2019a). Love, intimacy and sexuality in residential dementia care: A client perspective. *Clinical Gerontologist*, 44(3), 288–298.
- Roelofs, T. S. M., Luijkx, K. G., & Embregts, P. J. C. M. (2019b). Love, intimacy and sexuality in residential dementia care: A spousal perspective. *Dementia*, 18(3), 936–950. doi:10.1177/1471301217697467
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage Publications Inc.
- Sternberg, R. J. (1997). Construct validation of a triangular love scale. *European Journal of Social Psychology*, 27(3), 313–335. doi:10.1002/(SICI)1099-0992(199705)27:3<313::AID-EJSP824>3.0.CO;2-4
- Syme, M. L., Cohn, T. J., Stoffregen, S., Kaempfe, H., & Schippers, D. (2019). “At my age ...”: Defining sexual wellness in mid-and later life. *The Journal of Sex Research*, 56(7), 832–842.
- Syme, M. L., Lichtenberg, P., & Moye, J. (2016). Recommendations for sexual expression management in long-term care: A qualitative needs assessment. *Journal of Advanced Nursing*, 72(10), 2457–2467. doi:10.1111/jan.13005
- Tsatali, M. S., Tsolaki, M. N., Christodoulou, T. P., & Papaliagkas, V. T. (2011). The complex nature of inappropriate sexual behaviors in patients with dementia: Can we put it into a frame? *Sexuality and Disability*, 29(2), 143–156. doi:10.1007/s11195-010-9187-z
- Villar, F., Celdrán, M., Fabà, J., & Serrat, R. (2017). Staff members’ perceived training needs regarding sexuality in residential aged care facilities. *Gerontology & Geriatrics Education*, 38(4), 443–452. doi:10.1080/02701960.2015.1127811
- Villar, F., Fabà, J., Serrat, R., Celdrán, M., & Martínez, T. (2020). Sexual harassment from older residents at long-term care facilities: Is it really part of the job? *International Psychogeriatrics*, 32(3), 325–333. doi:10.1017/S1041610219001431
- VWS. (2018). *Programma kwaliteit verpleeghuiszorg: Thuis in het verpleeghuis*. Retrieved from <https://www.rijksoverheid.nl/documenten/rapporten/2018/04/01/thuis-in-het-verpleeghuis>
- Ward, R., Vass, A. A., Aggarwal, N., Garfield, C., & Cybyk, B. (2005). A kiss is still a kiss? The construction of sexuality in dementia care. *Dementia*, 4(1), 49–72. doi:10.1177/1471301205049190
- World Health Organization. (2006). *Working definition of sexuality*. Retrieved from <https://www.who.int/teams/sexual-and-reproductive-health-and-research/key-areas-of-work/sexual-health/defining-sexual-health>
- Zimmermann, J. (2015). *Hermeneutics: A very short introduction*. Oxford: OUP.