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## Love, Intimacy and Sexuality in Residential Dementia Care: A Client Perspective

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### ABSTRACT

**Objectives:** Residential care facility (RCF) residents with dementia are highly dependent on care. This can influence their experience of intimacy and sexuality. The perspective of residents and their spouses with regard to love, intimacy, and sexuality were explored and analyzed.

**Methods:** The study was designed using the IPA methodology. Eight in-depth interviews were held with 12 participants: four couples and four individual residents with dementia.

**Results:** Varied stories were shared; however, dementia had a great impact on all of them. Love, intimacy, and being together were considered fundamentally important by both couples and individual participants, although profound dilemmas were encountered. While only one couple experienced physical sexuality within the RCF, other participants reported that love and being intimate were the most important aspects of their current relationship. Regarding the possibility of fulfilling their needs within the RCF, a secure feeling of privacy was considered to be important, but was absent at the time of the survey.

**Conclusions:** Although challenging to appropriately facilitate at RCFs, love, intimacy, and sexuality are still important aspects for residents with dementia and their spouses.

**Clinical implications:** This study addresses these dilemmas and adds to the normalization of love, intimacy, and sexuality within RCF settings; the findings will hopefully improve the wellbeing of residents with dementia and that of their spouses.

### KEYWORDS



Dementia; long-term care; couples

Residential care facility (RCF) residents with dementia are highly dependent on daily care and support provided by professional caregivers. Consequently the autonomy of residents is limited. This is also true for very private aspects of their lives, such as the expression and experience of love, intimacy, and sexuality. Attitudes and perspectives of formal caregivers are assumed to influence if and how these important aspects of life can still be expressed; for example, some consider sexual expression as prohibited problem behavior or abuse (Benbow & Beeston, 2012; Hajjar & Kamel, 2004; Villar, Celdran, Faba, & Serrat, 2014).

Simpson et al. (2017) appointed the negative myths and strong stereotypical thinking surrounding love, intimacy and sexuality of older people in general as “ageist erotophobia”, which restricts opportunities to the expression of sexuality (Simpson et al., 2017). However, the working definition of sexuality, described by the world health organization (WHO) is very clear on the lifelong importance of a wide spectrum of manifestations of intimacy and sexuality, including

thoughts, feelings and behavior, (World Health Organization, 2006). A growing number of studies demonstrate that the need for these life aspects is not confined to any age limit (Lindau et al., 2007; Taylor & Gosney, 2011; Weeks, 2002). Through a study by Drees et al. it was found that also RCF residents with dementia experience intimacy and sexuality as an important aspect of their quality of life (QoL; (Drees et al., 2006) and consequently cannot always be considered as inhibition, deviant- or problem behavior.

Research on the topic of love, intimacy and sexuality of RCF residents with dementia is scarce but different focal points were highlighted (Roelofs, Luijkx, & Embregts, 2015). First, observations of intimate and sexual behaviors have been reported. Although the prevalence of intimate and sexual behavior varied between the studies, a wide range of behaviors ranging from “greetings” to “sexual acts” was observed (Ehrenfeld, Bronner, Tabak, Alpert, & Bergman, 1999; Mayers, 1994; Ward, Vass, Aggarwal, Garfield, & Cybyk, 2005). Second,

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attitudes, perspectives, and (lack of) education of care staff have been investigated. Great concerns regarding how to cope with specific behaviors and caring responsibility versus autonomy of the residents with dementia were found (Di Napoli, Breland, & Allen, 2013; Mahieu et al., 2015). Moreover, the need for staff training and guidelines concerning resident intimacy and sexuality were stressed throughout the literature (Roelofs et al., 2015). Third, theoretical perspectives and ethical considerations have been described, which mainly include descriptions of dilemmas. (Bartlett, 2010; Everett, 2007; Kamel & Hajjar, 2004; Mahieu, Anckaet, & Gastmans, 2014). Studies constructing theoretical frameworks have focused more on the possibilities for expressing intimacy and sexuality within the RCF. Aspects as the need for privacy, which often lacks, and the right for autonomy are examples of highlighted themes from different ethical viewpoints (Everett, 2007; Mahieu & Gastmans, 2012; Rowntree & Zufferey, 2015). Although valuable, these studies did not directly include the client perspective. In a paper by Mahieu and Gastmans (2015) different studies on the perspectives of older residents with, but mostly without dementia were reviewed (Mahieu & Gastmans, 2015). Specifically, in the qualitative study by Bauer et al. (2013), RCF residents, both with and without dementia, were interviewed about the need for and barriers to expressions of their sexuality. In this study it is shown that intimacy was still an important aspect of peoples' lives, although their preferences and needs for expression of sexuality varied. Also different barriers to sexual expression were described, such as a lack of privacy. The severity of dementia and care needs of the residents varied greatly in this study, which probably affected the level of experienced autonomy and so the opportunities to experience intimacy and sexuality. Moreover, only single or widowed residents were included, which neglects the partner and broader relational aspects. These seem very important, as the (mostly) long-lasting relationships have been under pressure due to dementia process and care tasks when the partner with dementia was still community dwelling (MAHIEU 2017+ HARRIS)

Representing the client perspective in research is very important, because the topic of intimacy and

sexuality is strongly shaped by personal factors, such as gender, age and relational aspects (Bentrott & Margrett, 2011; Hajjar & Kamel, 2004). Moreover, the person-centered perspective is becoming increasingly important in clinical practice (Actiz, 2012a), which includes personalization of care and environment and shared decision making (Edvardsson, Winblad, & Sandman, 2008). Contributing to the Quality of Life (QoL) of residents has become a key objective for RCFs, in addition to ensuring safety and providing physical care (Actiz, 2012b; Elias & Ryan, 2011). To enable person-centered care, knowledge of the perspectives of the residents with dementia and their partners is of the utmost importance (Actiz, 2012b; Edvardsson et al., 2008). Therefore, the aim of this study was to explore and analyze the experiences of RCF residents with dementia and their partners relating to their love, intimacy, and sexuality.

## Methods

### *Methodological approach*

To gather explorative, in-depth information, a qualitative design was chosen, according to the method of interpretative phenomenological analysis (IPA; (Brocki & Wearden, 2006; Gibson, Timlin, Curran, & Wattis, 2004; Larkin & Thompson, 2012; Smith & Osborn, 2007). This design enables to conduct a detailed exploration of the way in which people make sense of their own personal worlds. The idiographical roots provide focus on the particular: in this study, residents with dementia and their experiences of love, intimacy and sexuality. The hermeneutic phenomenology enables both "giving voice" and the "making sense" of experiences, by reflecting on and offering an interpretation of the material (Larkin & Thompson, 2012; Smith & Osborn, 2007). With this approach, we aim to understand the wider picture in experiences, needs, and beliefs, regarding love, intimacy, and sexuality and the meaning these have in the lives of residents and their spouses based on their knowledge. This is in line with a scientific interpretation of the person-centered perspective that is increasingly important in clinical practice (Brocki & Wearden, 2006).

### Procedure and participants

Ethical approval was granted by the Tilburg University Psychology Ethics Committee (reg. nr. EC-2014.27) and approval of the executive boards of the three participating organizations was obtained (Figure 1).

Interviews were held with RCF residents with dementia and, if possible, with their partners (couples). Participants were recruited from specialized psychogeriatric units of three RCF organizations located in the south of the Netherlands, which all participated in the academic network of Tilburg University. In these units, highly intensive 24-hour nursing home care is provided. People living in these units generally have dementia in a moderate to severe stage, because living in the community is no longer possible. The participating partner could

be community-dwelling or living in any form of assisted living facility.

Because RCF residents with dementia are considered legally incapacitated in the Netherlands, (informed) consent is needed from an authorized representative before their enrollment in scientific research. The first enrollment in the study was therefore performed by a legally authorized representatives, who could be the (participating) partner, a child, or another relative of the resident. In some cases, a friend of the resident or legal professional carried out this role.

No exclusion took place based on age, sex, marital status, sexual orientation, or ethnic background. In addition, no prior exclusion was performed based on etiology or severity of dementia. However, residents and/or partners with severe communicative impairments, severe attention or

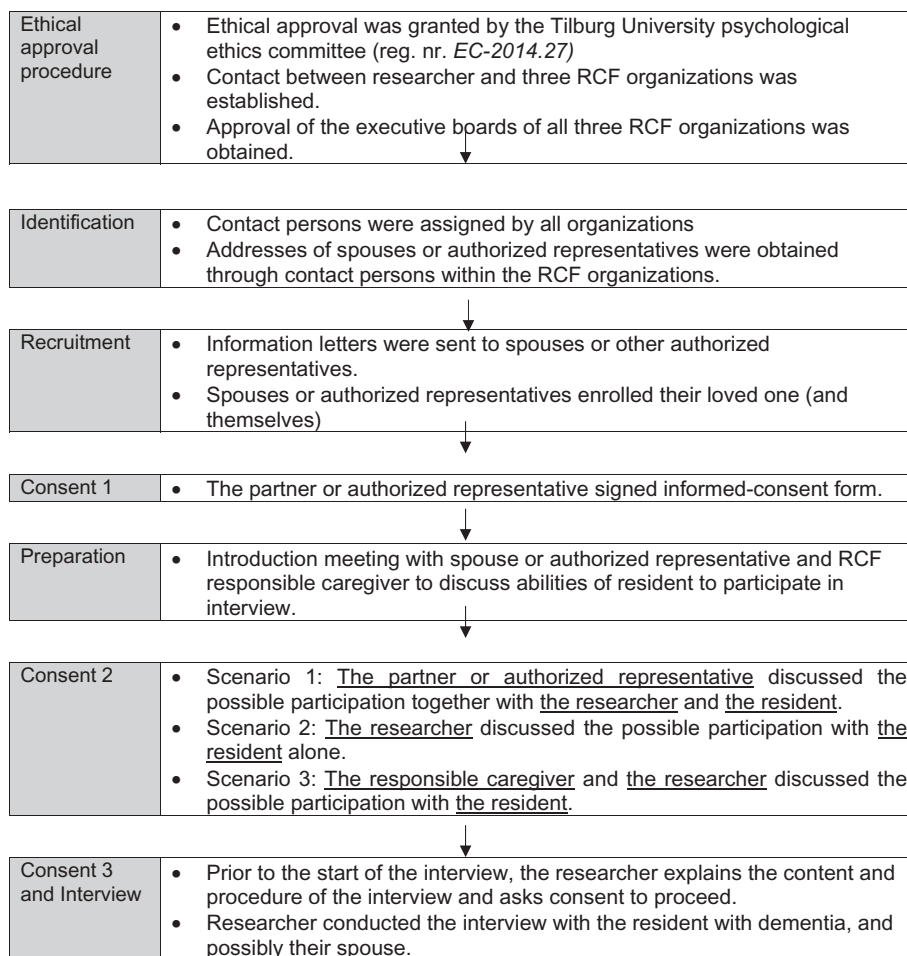


Figure 1. Recruitment process.

**Table 1.** Participant characteristics.

	Gender of resident with dementia	Years of marriage	Relationship status
<b>Couples</b>			
AB	M	17	Unmarried
CD	F	unknown	Married
EF	M	50	Married
FG	M/F	48	Married
<b>Individuals</b>			
A1	F	-	Widow
A2	M	-	Single
A3	M	-	Widower
A4	M	-	Widower

concentration difficulties, or frequently occurring behavioral difficulties were not included in the study. The ability of the resident to take part in an interview was discussed and estimated during the introduction meeting with the partner or other authorized representative (proxy) of the resident and the responsible caregiver (see Figure 1). The responsible caregiver was a member of the unit care staff who was the first contact point in care policy and procedures. During this study, no exclusion was performed based on information obtained during the introduction meeting. Also, during this meeting, the most appropriate way to introduce and explain the content and procedure of the study to the resident with dementia and the adequate consent procedure were discussed (see Figure 1). A more detailed description of the methodology has been published previously (Roelofs, Luijckx, & Embregts, 2017b)

A convenience sample of 12 people participated in the study; four individual residents and four couples (Table 1). Three couples were married; one couple, although together for a long time, were not married. In one of the couples, both partners lived with dementia and lived together in the RCF (couple FG). None of the residents who participated individually were in a relationship at the time of the interview; three were widowed and one had been single all his life. All participants were white and were heterosexual. In conclusion, eight interviews were held with nine people with dementia and three partners/spouses.

### Data collection and analysis

One researcher (TR) conducted the 30–60 minute duration interviews. A suitable location was discussed

and found during the introduction meeting (Roelofs et al., 2017b). In addition to working as a researcher, TR, works as a psychologist in one of the participating RCFs. She is experienced in communicating with people with dementia and their partners; however, she was neither clinically involved with nor responsible for any of the participating residents. The interviews were audio-recorded. Valuable non-verbally expressed information participants conveyed was also included in analyses as field notes in the transcription.

A semi-structured conversational style has been recommended when inquiring about information on sensitive topics (Barriball & While, 1994) and in conversation with residents with dementia (Tarzia, Bauer, Fetherstonhaugh, & Nay, 2013) in order to provide flexibility in the conversation. The topic list initially consisted of seven topics. During the process of data collection and analyzation, both the topics “romance” and “eroticism” faded into the background. The topic of “romance” overlapped strongly with the topic “love” and the same was true for “eroticism” and “sexuality”.

A stepwise qualitative analysis was performed, conforming to the IPA guidelines (Larkin & Thompson, 2012). Because we chose to include different cases, these were successively analyzed in depth. First, two researchers (TR, KL) independently performed line-by-line coding. In this coding process, the included field notes were also coded. Non-verbal expressions of emotions were identified as “memos”. Second, discussions between the two authors on coding resulted in one set of codes and the identified “memos” were included in this set. The possible meanings of the statements were discussed throughout this process. Third, one author (TR) gathered all the codes and identified the subthemes. Next, an iterative process began in which two authors (TR, KL) discussed the meanings of statements within codes and subthemes. This concluded in a final structure of

**Table 2.** Topic list.

Introduction
Friendship/companionship
Love
Romance
Intimacy
Eroticism
Sexuality



**Table 3.** Superordinate themes and subthemes.

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Intimacy and Sexuality: Alternative Fulfillment of Ongoing Needs
Barriers for expression of intimacy and sexuality
Privacy: more than shutting the door
Communicating about intimate needs; difficult and needed
Being together is most important; even in memory
Looking back
Missing of being together: physically and in memory
Love is everything: protection and intense loyalty
Protection
Loyalty

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superordinate- and subthemes (Table 2). Finally, in another iterative process, one author (TR, KL) composed a narrative where divergent and convergent patterns were defined. Discussion between the authors continued during the writing process.

## Results

Convergent themes are presented in the following sections (See Table 3 for an overview of the themes). First, the experiences with regard to intimacy and sexuality within the nursing home are discussed – Intimacy and sexuality: Alternative fulfillment of ongoing needs. Second, being together was found to be most important. Although sometimes difficult or impossible, the actual contact or memory of a loved one was still longed for and missed when absent. Third, love was put forward as a theme, but it was interpreted as so much more than simply love. It also included strong loyalty and feelings of protection.

### ***Intimacy and sexuality: alternative fulfillment of ongoing needs***

Only one of the couples (couple EF) shared they were still sexually active together within the RCF. Despite them being unique in this sample, issues that were brought forward by different participants, concerning the fulfillment of intimate and sexual needs, came together in their story, such as emotional barriers to expression of intimacy and sexuality and the difficult aspect of privacy.

### ***Barriers to expression of intimacy and sexuality***

Respondents said that they missed being sexually intimate and gave various reasons or barriers for why sexual activity was no longer possible. For

example, health issues which negatively influence the possibility to be sexually active were mentioned. Couple CD shared that they were not sexually active years before the admission, which was difficult for them. The male spouse of the couple explained this feeling: “Because I cannot be engaged with her as intensely anymore”. He further said that his impotence marked the beginning of their decreasing sexual activity. His wife, however, still felt the need for that sexual intimacy, especially in the first stages of the dementia process. The husband thought that, in those days, she probably forgot that he could not satisfy her needs. The female spouse of couple EF also experienced some physical problems (uterine prolapse); however, she and her husband found a way to be physically sexually active together without having intercourse.

Being older was also put forward as a reason for the absence of sexual activity; Couple AB seemed to find it difficult to elaborate on this subject in detail and the female spouse concluded with the statement: “We got older, right?” The single and widowed respondents (A2, A3, A4) described a total absence of sexual activity. Detailed reasons for this absence were not described, although one male resident (A2) also blamed his old age: “As a young boy, but not for now”

More practical barriers that were encountered within the RCF were also shared. For example, couple FG shared that they sleep in two single beds, which are put together in the same bedroom. The male spouse said that a double bed would not fit in their bedroom. They share two (RCF) rooms: one small bedroom, and a small living room.

### ***Privacy: more than shutting the door***

The female spouse of couple AB said that she thought it was possible for her to stay the night in the RCF with her partner. However, she never did. Moreover, she did not experience any inconvenience or lack of privacy when she and her partner wanted to be together in private. This was in contrast to the experience of couple EF, who were sexually active in the RCF. They did discuss the absence of a feeling of privacy. This absence of privacy persisted despite the “do not disturb” sign they used for the bedroom. The female spouse explained that it is still sometimes difficult for her and her husband to feel comfortable at the RCF, because “It is not exactly like home.” She,

for example, only feels comfortable taking her top off, but does not feel comfortable enough to take more clothes off. This demonstrates the importance and yet the difficulty of privacy in the RCF. Moreover, she did mention that she considered her participation in the study as a way to improve the possibilities for other couples. The male spouse of couple CD also said he felt reserved with regard to being intimate with his wife: “I want to hug her more, but that is difficult ... because of the visitors here”. Deriving from these examples, the level of privacy needed to feel safe to be intimate or be sexually active, seems to be more than just a closed door.

### ***Communicating about intimate needs; difficult but necessary***

Couples experience difficulty in communicating about the changes in their intimate and sexual lives with each other and care staff. Protection of the spouse with dementia seems to be a reason for the spouse not to communicate with them about their needs. The female spouse of couple AB said she did not want to confront her partner with dementia about the current absence of physical sexuality between them, so she kept her own needs to herself. Although she was the only one to make this statement openly, in two other couple interviews, this mechanism of “protection” was also noticeable. The male spouse of couple CD, for example, mentioned that he had found it very hard to talk about his feelings with his wife and, when sharing this, he lowered his voice and turned his face toward the interviewer. He did discuss difficulties regarding sexual activity (e.g., impotence and the ongoing sexual needs of his wife) with his geriatric physician when his wife was still living at home. As a response on the question whether he would appreciate to have a conversation with a health care professional (HCP) from the RCF on the current situation, he sighed: “You know, nothing can be done.”

The female spouse of couple AB shared that communicating with the caregivers is important in order to fulfill their privacy needs: “You just have to tell the caregivers you want to be alone and lock the door.” She, however, never did. The female spouse of couple EF discussed their needs with the care staff and they came up with a “do not

disturb” sign. Communication with caregivers or professionals seemed to be necessary, but difficult.

### ***Being together is the most important, even in memory***

Although not the direct aim of the study, throughout the interviews the concept of being together was found to be most important for our participants. This resonated through stories from the past and present, and included “being together” in memory. Also, the experiences of (physical) intimacy were partly explained through “being together”.

### ***Looking back***

The history of “being together” was an important part of the current experience. Some participants shared their intimate and sexual history comprehensively, and others made some small comments about it. However, all contributions can be characterized by figurative, metaphorical, or somewhat euphemistic language. A first example is a statement by couple FG, who did not share details about their sexual lives; the husband of this couple explained in this context that they “grew up together”. Ever since their marriage, they had lived together and never had children. His wife reminisced: “That was always a very good situation.” The male spouse of couple CD described their intimate life together in more detail: “In the old days, we could make love so well; then, it was instinctive.” His spouse with dementia explained that she had always been very happy with her husband and concluded that she must have been “a good wife” herself. Her husband complemented this by showing a photo book they had made of their 50-year anniversary celebration. He handed the book over and said: “We had a great life together.”

The single male participant (A2) with dementia recalled the period in which he was young and courted different girls. He never found a suitable girl to marry and he said that he was glad it turned out that way because married couples are “always fighting”. He made some further figurative statements about being intimate with different girls and the way he experienced that period:

Interviewer: “Did you experience love in your life?”

A2: “Well, just some fooling around.”

The past of long relationship histories were very important to all participants. The couples shared – all with smiles on their faces – the ways in which they met and how their love grew all those years ago; however, the widowers did not mention these stories of emerging love. They seemed to be still absorbed by the deaths of their spouses.

### ***Missing being together, physically and in memory***

Loss and missing a partner or missing a healthy partner was present throughout all interviews. The female spouse of couple AB shared that she misses her partner as a friend to come home to and to share her everyday stories with. She feels that she can still tell her everyday stories, but the fact that he does not remember these stories makes her sad. The desire to be together was expressed by all the couples. The couple in which both spouses (FG) live with dementia put it like this: “We just want to live our lives together and we don’t need other people’s interference.”

The participating widow (A1) initially forgot she was married previously. After a picture of her husband was shown to her, she remembered. She continued by spontaneously starting to sing a love song by a female Dutch popular singer with the title and opening line: “Those days were good when we were in love and still together.” Another widower (A3) stated that he missed his wife very much and he has to sleep alone since his wife died.

### ***Love is everything: protection and intense loyalty***

It became clear through the interviews that intimacy and sexuality are important aspects of the lifelong love participants feel. This love was still important for most participants as an underlying feeling of togetherness and definition of their relationship. For example, the couple who both had dementia (FG) argued that they do not experience friendship. Instead, they feel love for each other, as husband and wife: “We are really husband and wife.”

One single male resident (A2) shared that he had his eye on some of his female fellow residents. He

doubts, however, whether the other women would return his affection. The other two widowed residents both shared that they miss love. One (A3) defined it as “That you live happily together”; another (A4) stated more generally that “Love is everything”. He started crying when he talked about his wife dying (A4).

Some participants also shared that the feeling of love changed throughout the years due to the impairing process of dementia and admission to a RCF. Couple AB shared the experience of a changing feeling of love throughout time. They experienced a deeper feeling of love, in contrast with the love crush experienced at the beginning of their relationship. As the female spouse explained, “We just slipped into it, like he slipped into his disease.” She continued by explaining that the romance partly disappeared and they view each other more and more as friends instead of lovers.

### ***Protection***

Spouses showed feelings of protection both implicitly and explicitly as part of their love for each other. This was both touching and imaginable in the light of the long relationships they had. The spouse of couple CD tried to involve his wife with dementia by dividing his focus between her and the interviewer. He occasionally explained or reinterpreted things for his wife with dementia as a way to let her participate in the conversation like she used to. During the interview with couple FG, who both have dementia, it seemed that the wife had more orientation impairments than her husband. He sometimes corrected her directly and he also turned to the interviewer to correct his wife indirectly, trying not to confront her. At one point, they seemed to experience the RCF as a kind of hotel where they were staying temporarily: “We are here, more or less, on a sort of ... trip. We just have our own home and that is where we live together” (wife of couple FG). At another point, her husband seemed to remember their “real” situation more accurately: “No, we live here [RCF]” (husband of couple FG). The spouse of couple AB revealed explicitly having protective feelings toward her spouse: “I don’t want anything (negative) to happen to him.”

### ***Loyalty***

Participants showed great loyalty toward each other, despite the dementia and the admission.



Couple CD shared that they are still “very happy” with each other and they “put everything on the line for each other”. The male spouse stressed this reflection by saying: “We promised loyalty to each other and we persevere with that quite well”. They also revealed that to maintain their love together it is necessary to put in extra effort. He explained that having many conversations was important to them. This tends to be hard now, because his wife cannot converse at the same level as she used to.

Couple AB, with a female partner and a male resident, argued that they see each other as friends and even used a Dutch loving nickname for the word friend (“mate”) in reference to one another. The female spouse further affirmed that “he is the only one” for her, seeming to indicate that she does not feel the need to search for another (healthy) partner: “Other people say to me, you should get another partner and then I say, “I don’t need another partner! I already have a partner and that is enough for me.” Later, during the interview, she discussed this issue with her partner. He argued that getting a new partner is “rubbish”, whereas she further explained that she could imagine why people say that to her. In the other interviews with couples, getting involved with another partner was not brought up.

## Discussion

In this study, the experiences of RCF residents with dementia and their partners, with regard to love, intimacy, and sexuality, were explored. In general, love, intimacy, and sexuality were experienced as very important aspects of their lives and have been so for a long time. This seems coherent with previous findings of Droes et al. (2006), who found that these aspects are very important for QoL in individuals with dementia (Droes et al., 2006).

A mutual desire to be together, connectedness, love, and great loyalty characterized the found stories. However, being distanced at the same time because of the physical distance (living in the RCF or being widowed), and emotional distance, caused by the dementia process, came with a sense of sadness and missing an intimate connection by both residents with dementia and their partners. Most participants also tried – some in

vain – to play down the seriousness of their situation or share the way they currently cope with or resign themselves to it.

All participants shared missing being intimate with someone in their own way. Different physical (impotence) and nonphysical (being old in general) reasons were put forward to account for the absence of this intimate part of life. This can indicate that residents and their partners lack knowledge on the possibilities to be intimate or sexually active, despite physical limitations or their age (Taylor & Gosney, 2011). Moreover, participants also did not clearly define a distinction between intimacy and sexuality and contributions can also be characterized by figurative, metaphorical, or somewhat euphemistic language. This could implicate a different underlying construct, such as embarrassment derived from taboo on their own intimate lives.

Practical barriers that impeded the possibilities for the expression of intimacy and sexuality, such as a single bed, were described. Furthermore, while for most spouses communication with the professional caregivers and locking the door seemed to be sufficient to feel privacy to have a moment together, it turned out that much more privacy was needed with regard to physical intimacy or sexual activity, which complements prior findings (Bauer et al., 2013). Privacy was described to have different levels in this situation; the knowledge and feeling that the RCF situation is not home, despite the efforts of the professional caregivers, proved to impede the experience of physical sexuality freely.

Mostly partners underlined the role of loyalty and protection of their spouse with dementia, in their current relationships. This seems to cohere with the changing view on the relationship, more toward friendship, after the impairing dementia process began in one of the partners. This, however, was not the case in all couples and also seems to contradict with retaining the intimate and sexual life spouses and residents were used to. This contradiction was described previously from the perspective of the spouse alone (Mullin, Simpson, & Froggat, 2013; Roelofs, Luijkx, & Embregts, 2017a) and these mixed emotions can be considered to be personal dilemmas (Harris, 2009; Mahieu & Gastmans, 2012) However, the diverse stories voiced in this study, from both the

residents' and couples' perspective, prove that individual differences in the experience of this dilemma are great. This diversity emphasizes the importance of giving voice to both the residents and their partners in research and practice on this topic, as the dilemmas are strongly shaped by their own personal and relational histories. Moreover, it stresses the importance of extending the practice of person-centered care in which shared decision making can really take place.

### **Strengths and limitations**

This study was a first exploration of experiences of intimacy and sexuality of an exclusive sample of RCF residents with dementia and their partners. The aim was to give voice to the residents and their partners and to make sense of these experiences so their narrative knowledge can be added to the research field and also to the clinical practice of person-centered nursing home care. Because of the qualitative research method, the generalizability of the study is limited. Also the small and exclusively white, Dutch and hetero sexual sample size that was obtained, is a limitation to the generalizability. However, recruitment, consent and data collection was a challenge due to several reasons. Firstly, RCF residents with dementia are considered legally incapacitated and, therefore, an authorized representative had to enroll the residents to participate. This is an understandably difficult decision, considering the sensitivity of the topic at hand. However, the IPA guidelines, in which small samples sizes are proposed (Larkin & Thompson, 2012) enabled us to report new and valuable results. Secondly, only RCF residents with dementia who wanted to and could participate in an interview were included in the study. This could have caused bias, because only a small group of the total residential population was able and willing to participate. Furthermore, interviewing people with dementia on this subject was challenging. Although none of the conversations were stopped, the amount of valuable verbal information varied between the interviews. For this reason, non-verbal and more emotional information was also included in analyses.

The skills of the interviewer proved to be very important, because profound knowledge of

dementia and skills to guide a conversation were needed. In this study, an experienced psychologist in dementia care (BFR) performed the interviews. This also contributed to the analysis process as she could interpret the interviews first hand. The two other authors were researchers more based in the academic community, which helped to uplift the information from a practice point of view, to academic results. This contributes to the inclusion of the client perspective in research, as the person-centered care perspective does in clinical practice (Brocki & Wearden, 2006; Edvardsson et al., 2008)

Finally, in the interviews with couples, sometimes the spouse provided more information than the spouse with dementia. He or she also provided information to their spouse with dementia, so they could participate more in the conversation. The spouses also clarified statements of the residents with dementia, which were sometimes difficult to understand without context. This was of benefit to the results. The observations of conversations between the couples also gave even further insight into their current lives, relationship roles, and the way they mutually cope with the limitations of the spouse with dementia.

### **Clinical implications**

- Practical barriers, such as single beds, need to be resolved within the RCF, in a practical manner.
- Open conversations, in which residents and their spouses feel their dilemma and mixed emotions can be discussed, should be initiated and guided by care staff. Knowledge on old age intimacy and sexuality in general, and specifically the dilemmas found in this study, is crucial.

The different barriers that residents and their spouses experience form the base for the clinical implications. More research into the client perspective is needed to shape this body of knowledge further. A new, post-war generation will enter RCFs in the upcoming years, who are expected to differ in their needs to remain intimate and sexually active (Neeleman, 2012). Finally, for both current and future residents it is important that the normalization of the subjects of love, intimacy, and sexuality within the RCF takes place. This

seems inevitable as a first step in enhancing the possibilities for experiencing these important life aspects and further shape the person-centered care perspective in daily practice. This study shows that open communication on the subject, a feeling of “permission” to include the subject in care needs and care plans, as well as more practical measures – such as providing double beds and enhancing (the feeling of) privacy – are important.

## Disclosure statement

No potential conflict of interest was reported by the authors.

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## References

- Actiz. (2012a). *Deltaplan Ouderenzorg* (Actiz ed.). Bunnik, The Netherlands: Actiz.
- Actiz. (2012b). *Maatwerk is de oplossing om ouderenzorg betaalbaar te houden*. Retrieved from <http://www.actiz.nl/nieuwsberichten/website/nieuws/maatwerk-is-de-oplossing-om-ouderenzorg-betaalbaar-te-houden>
- Barriball, K. L., & While, A. (1994). Collecting data using a semi-structured interview: A discussion paper. *Journal of Advanced Nursing*, 19, 328–335. doi:10.1111/j.1365-2648.1994.tb01088.x
- Bartlett, P. (2010). Sex, dementia, capacity and care homes. *Liverpool Law Review*, 31, 137–154. doi:10.1007/s10991-010-9077-6
- 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), 269–309. doi:10.1080/19419899.2012.713869
- Benbow, S. M., & Beeston, D. (2012). Sexuality, aging, and dementia. *International Psychogeriatrics/IPA*, 24(7), 1026–1033. doi:10.1017/s1041610212000257
- Bentrott, M. D., & Margrett, J. A. (2011). Taking a person-centered approach to understanding sexual expression among long-term care residents: Theoretical perspectives and research challenges. *Ageing International*, 36, 401–417. doi:10.1007/s12126-011-9110-7
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21(1), 87–108. doi:10.1080/1476832500230185
- 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
- Droes, R. M., Boelens-van der Knoop, E. C. C., Bos, J., Meihuizen, L., Ettema, T. P., Gerritsen, D. L., ... Scholzel-Dorenbos, C. J. M. (2006). Quality of life in dementia perspective. An explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia*, 5(4), 534–558. doi:10.1177/1471301206069929
- Edvardsson, D., Winblad, B., & Sandman, P. (2008). Person-centered 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
- Ehrenfeld, M., Bronner, G., Tabak, N., Alpert, R., & Bergman, R. (1999). Sexuality among institutionalized elderly patients with dementia. *Nursing Ethics*, 6(2), 144–149. doi:10.1177/096973309900600207
- Elias, J., & Ryan, A. (2011). A review and commentary on the factors that influence expressions of sexuality by older people in care homes. *Journal of Clinical Nursing*, 20(11–12), 1668–1676. doi:10.1111/j.1365-2702.2010.03409.x
- Everett, B. (2007). Ethically managing sexual activity in long-term care. *Sexuality and Disability*, 25(1), 21–27. doi:10.1007/s11195-006-9027-3
- Gibson, G., Timlin, A., Curran, S., & Wattis, J. (2004). The scope for qualitative methods in research and clinical trials in dementia. *Age and Ageing*, 33(4), 422–426. doi:10.1093/ageing/afh136
- Hajjar, R. R., & Kamel, H. K. (2004). Sexuality in the nursing home, part 1: Attitudes and barriers to sexual expression. *Journal of American Medical Directors Association, Supplement*, s43–s47. doi:10.1097/01.JAM.0000061465.00838.57
- Harris, P. B. (2009). Intimacy, sexuality and early stage dementia. *Alzheimers’ Care Today*, 10(2), 63–77.
- Kamel, H. K., & Hajjar, R. R. (2004). Sexuality in the nursing home, part 2: Managing abnormal behavior-legal and ethical issues. *Journal of the American Medical Directors Association*, 5(2 Suppl), S48–S52. doi:10.1097/01.JAM.0000073961.02891.33
- Larkin, M., & Thompson, A. (2012). Interpretative phenomenological analysis. In A. Thompson & D. Harper (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 99–116). Oxford, UK: John Wiley.
- Lindau, S. T., Schumm, L. P., Laumann, E. O., Levinson, W., O’Muircheartaigh, C. A., & Waite, L. J. (2007). A study of sexuality and health among older adults in the United States. *The New England Journal of Medicine*, 357, 762–774. doi:10.1056/NEJMoa067423
- Mahieu, L., Anckaet, L., & Gastmans, C. (2014). Intimacy and sexuality in institutionalized dementia care: Clinical-ethical considerations. *Health Care Analysis*, 1–20. doi:10.1007/s10728-014-0287-2
- Mahieu, L., de Casterle, D., Acke, B., Vandermarliere, J., Van Elssen, H., Fieuws, K., & Gastmans, C. (2015).

- Nurses' knowledge and attitudes toward aged sexuality in Flemish nursing homes. *Nursing Ethics*, 6, 1–19. doi:10.1177/0969733015580813
- Mahieu, L., & Gastmans, C. (2012). Sexuality in institutionalized elderly persons: A systematic review of argument-based ethics literature. *International Psychogeriatrics*, 24(3), 346–357. doi:10.1017/S1041610211001542
- 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
- Mayers, K. S. (1994). Sexuality and the patient with dementia. *Sexuality and Disability*, 12(3), 213–219. doi:10.1007/bf02547908
- Mullin, J., Simpson, J., & Froggat, K. (2013). Experiences of spouses of people with dementia in long-term care. *Dementia*, 12(2), 177–191. doi:10.1177/1471301211418096
- Neeleman, A. (2012). Seksualiteit. In A. M. Pot, Y. Kuin, & M. Vink (Eds.), *Handboek Ouderenpsychologie* (pp. 236–252). Utrecht, The Netherlands: de Tijdstroom.
- 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), 367–384. doi:10.1017/S1041610214002373
- Roelofs, T. S. M., Luijkx, K. G., & Embregts, P. J. C. M. (2017a). Love, intimacy and sexuality in residential dementia care: A spousal perspective. *Dementia*. doi:10.1177/1471301217697467
- Roelofs, T. S. M., Luijkx, K. G., & Embregts, P. J. C. M. (2017b). A person-centered approach to study intimacy and sexuality in residential care facility (RCF) clients with dementia: Methodological considerations and a guide to study design. *NeuroRehabilitation*, IN PRESS, 41, 359–373. doi:10.3233/NRE-172205
- Rowntree, M. R., & Zufferey, C. (2015). Need or right: Sexual expression and intimacy in aged care. *Journal of Aging Studies*, 35, 20–25. doi:10.1016/j.jaging.2015.07.003
- Simpson, P., Horne, M., Brown, L. J. E., Brown Wilson, C., Dickinson, T., & Torkington, K. (2017). Old (er) care home residents and sexual/intimate citizenship. *Ageing & Society*, 37, 243–265. doi:10.1017/S0144686X15001105
- Smith, J. A., & Osborn, M. (2007). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 53–80). London, UK: Sage Publications Ltd.
- Tarzia, L., Bauer, M., Fetherstonhaugh, D., & Nay, R. (2013). Interviewing older people in residential aged care about sexuality: Difficulties and challenges. *Sexuality and Disability*, 31(4), 361–371. doi:10.1007/s11195-013-9297-5
- Taylor, A., & Gosney, M. A. (2011). Sexuality in older age: Essential considerations for healthcare professionals. *Age and Ageing*, 40, 538–543. doi:10.1093/ageing/afr049
- Villar, F., Celdran, M., Faba, J., & Serrat, R. (2014). Staff attitudes towards sexual relationships among institutionalized people with dementia: Does an extreme cautionary stance predominate? *International Psychogeriatrics*, 26(3), 403–412. doi:10.1017/S1041610213002342
- 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: The International Journal of Social Research and Practice*, 4(1), 49–72. doi:10.1177/1471301205049190
- Weeks, D. (2002). Sex for the mature adult: Health, self-esteem and countering ageist stereotypes. *Sexual and Relationship Therapy*, 17(3), 231–240. doi:10.1080/14681990220149031
- World Health Organization (Producer). (2006). *WHO working definition of sexuality*. Retrieved from [http://www.who.int/reproductivehealth/topics/sexual\\_health/sh\\_definitions/en/](http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/)