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To cite this article: Linn J. Sandberg (2020): Too late for love? Sexuality and intimacy in heterosexual couples living with an Alzheimer's disease diagnosis, *Sexual and Relationship Therapy*, DOI: [10.1080/14681994.2020.1750587](https://doi.org/10.1080/14681994.2020.1750587)

To link to this article: <https://doi.org/10.1080/14681994.2020.1750587>



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Published online: 15 Apr 2020.



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# Too late for love? Sexuality and intimacy in heterosexual couples living with an Alzheimer's disease diagnosis

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## ABSTRACT

New sexual scripts on later life are emerging, discourses on “sexy oldies” challenge pervasive discourses on asexual old age. Still, sexuality among people with dementia, who are generally older, is rarely affirmed. Research on sexuality and dementia is, moreover, dominated by biomedical accounts that regard sexual and intimate behaviours as expressions of pathology. However, sexuality and intimacy could be significant aspects of later life, also when living with dementia. This qualitative study explores experiences of sexuality and intimacy among heterosexual couples where one partner was diagnosed with Alzheimer's disease. Interviews were conducted with seven couples, aged 55–87, and both the person with the dementia diagnosis and their partner participated. The findings point to a diversity of experiences, with differences between the older and younger couples. The older couples experienced changes more as a result of embodied ageing, and sexuality and intimacy were experienced as sources of pleasure, comfort and recognition. The younger couples understood changes more as caused by Alzheimer's disease and experienced a greater loss of intimacy and desire. The study shows how experiences of sexuality and intimacy when living with dementia are shaped by varying sexual scripts and expectations of health in different parts of the life course.

## ARTICLE HISTORY

Received 14 June 2019  
Accepted 1 March 2020

## KEYWORDS

Sexuality; intimacy; later life; ageing; dementia; Alzheimer's disease

## Introduction

“Inappropriate”, “improper”, “sexually ambiguous” and “hypersexual” are all terms that are used in scientific accounts and everyday discourses to classify and describe intimate sexual behaviours of people with dementia. These terms also reveal that it is often the troublesome aspects of sexuality and intimacy are brought to light (Benbow & Beeston, 2012). In recent years, research has shown that sexuality and intimacy are increasingly positioned as part of a healthy and successful ageing, with new sexual scripts on later life are emerging (Sandberg, 2015; Scherrer, 2009). Persons with dementia are, however, not included in these representations of the new “sexy oldies”

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(Gott, 2005). In medical scientific literature (Benbow & Beeston, 2012), media representations (Grigorovich, 2017) and care practice (Dupuis et al., 2012), the sexualities of people with dementia are commonly either overlooked or seen as problematic and burdening and associated with other assumed pathological and challenging behaviours in dementia. It is also notable that the perspectives of people with dementia are missing from these literatures (Roelofs et al., 2015).

Still, sexuality is often an important aspect of a person's subjectivity throughout their life course, including when living with illness and disability, and can often be part of overall health and well-being in later life (Syme, 2014). Although some studies suggest a decline in sexual activity, interest and sexual satisfaction for couples living with dementia (Nogueira et al., 2017; Simonelli et al., 2007; Tsatali & Tsolaki, 2014), research also shows that people in the early stages of dementia continue to regard themselves as sexual beings (Harris, 2009; Wright, 1993). Sexual intimacy may also be an important aspect of sustaining a couple relationship after the onset of dementia (Baikie, 2002; Davies et al., 2010). However, there is little research on how the sexual and intimate relationship is experienced by couples living with dementia, particularly qualitative studies that provide narrative resources on the topic from the perspective of people with dementia (for exceptions, see Bauer et al., 2013; Harris, 2009; Simpson et al., 2018; Wright, 1993).

Dementia is an umbrella term for cognitive illnesses that affect memory, thinking and behaviour, mainly among the older population. Fifty million people worldwide are estimated to live with dementia, and the most common form of which is Alzheimer's disease (WHO, 2019). Dementia greatly affects relationships in general and couple relationships in particular, where roles and responsibilities are often reversed. The non-ill partner often assumes responsibility for the increasingly dependent partner with dementia, and the relationship has to be renegotiated to adjust to the transitions and losses caused by dementia (Evans & Lee, 2014; Holdsworth & McCabe, 2018). These negotiations also involve the intimate sexual relationship; existing research has shown that the care burden of spouses negatively impacts their well-being and leads to a decrease in sexual desire and affection, particularly for women (Davies et al., 2010; Dourado et al., 2010; Harris et al., 2011; Simonelli et al., 2007; Wright, 1998). But there are also qualitative research that suggests that a committed relationship may contribute to couples' continued, or even increased, intimacy, touch and feelings of love and togetherness in the context of dementia (Baikie, 2002; Hayes et al., 2009; Shavit et al., 2017; Wright, 1998; Youell et al., 2016). The vast majority of research on couples living with dementia has focused on spousal care. However, as Youell and colleagues (2016, p. 5) point out, couple relationships in dementia are not solely about care, and thus need to be "located in a broader relational history", with a recognition that "intimacy and sexuality are key elements of those relational histories".

There is thus a need for qualitative research on sexuality and intimacy that explores the multi-faceted meaning-making of persons with dementia and their spouses, and how couples negotiate the intimate sexual relationship after a dementia diagnosis. The aim of this study was therefore to explore experiences of sexuality and intimacy among couples after an Alzheimer's disease diagnosis, among both diagnosed persons and their spouse. The following research questions are explored in the

article: How do couples experience sexuality and intimacy after an Alzheimer's disease diagnosis? Is Alzheimer's disease understood as causing distinct changes or challenges to couples' intimate sexual relationship, and if so, what are these changes or challenges associated with?

The article draws on the findings from a qualitative interview study with seven heterosexual married couples where one partner was diagnosed with Alzheimer's disease.

### **Sexual scripts and the life course: theoretical perspectives**

Is it ever too late for (making) love? This article draws on theoretical understandings of scripts and scripting, both of sexuality and the life course, to understand this question and the differences in experiences among couples in this study, including challenges that some couples report. Gagnon and Simon's influential sexual script theory (2005) has played a central role in understandings of sexuality as taking shape along societal and cultural expectations. Still, little work has explored how sexual scripts influence older people's experiences of sexuality (Muruthi et al., 2018). Pervasive ageist sexual scripts where sexuality is deemed inappropriate, dysfunctional or non-existent in later life influence how older people perceive themselves sexually and deter them from engaging in sexual activity (Traeen et al., 2019). However, ageist sexual scripts are also increasingly challenged by the "sexy oldie" who continues to be sexually active as part of successful ageing and emerges as a new available sexual script for older people (Gott, 2005; Sandberg, 2015; Štulhofer et al., 2018). Further, on an interpersonal level, people may negotiate sexual scripts in later life away from penetrative intercourse towards non-genital sexual practices and intimacy such as cuddling, as has been seen in several qualitative studies on sexuality among older couples (Sandberg, 2015; Ménard et al., 2015; Potts et al., 2006).

Notably, there are significant temporal aspects to sexual scripts. Sexual scripts postulate not only *what* should happen but also *when*, that is the timing and sequencing of sexual activities. This becomes most evident regarding the timing and temporal norms of orgasms, where women in particular are concerned with not taking "too long" while men are concerned with "not lasting 'long enough'" (Frith, 2015, p. 80). The temporality of sexual scripts also determines the timing of sexual activity in different parts of the life course. Within ageing studies, the theorising of "prescriptive timetables" of the life course has a long history (for an early discussion, see Neugarten et al., 1965), and in the last decade, a critique has also emerged of the heteronormative bias of life course perspectives (Brown, 2009). But just as sexuality studies rarely focus on sexual scripts in later-life sexuality, research that explores and theorizes the life course seldom discusses sexuality. I propose, however, that thinking of how sexual scripts coincide with life course scripts, including expectations of health and illness in the process of ageing, becomes useful for understanding the varying experiences of couples of different ages living with Alzheimer's disease. As this article's findings suggest, expectations of both health (including cognitive functioning) and sexual activity were different between older and younger couples. This can be understood in relation to timing. For example, sexual as well as memory changes

were considered as being “on time” for older couples and in accordance with their life course and sexual scripts, whereas for younger couples, sexual as well as memory changes were understood as being “premature” and thus at odds with sexual scripts and life course scripts on health and illness.

## **Methods and materials**

This article is based on a qualitative interview study that aimed to investigate the experiences of sexuality and intimacy when living with Alzheimer’s disease. Participants were seven heterosexual couples where one partner was diagnosed with Alzheimer’s disease (one participant’s diagnosis changed from Alzheimer’s disease to mild cognitive impairment after the interview). In studies on sexuality and intimate relationships and dementia, the perspectives of medical doctors, care-workers and spouses predominate and rarely include the perspectives of people with dementia. In exceptional cases where persons living with dementia are included, their experiences of sexuality and intimacy are sometimes understood as delusional, and thus not as valid and truthful accounts (e.g. Dourado et al., 2010). This is despite that the broader dementia studies literature has increasingly shown that people with dementia, despite communicative and memory impairments, want to have their voices heard in research (Hellström et al., 2007). Earlier research has shown that there are often evident discrepancies between the views of people with dementia and those of carers/partners/significant others (Harris, 2009; Nogueira et al., 2017). For this reason, and also if intimate relationships are indeed relational, both people with dementia and their partners were interviewed in this study.

### ***Inclusion and exclusion criteria***

Couples were recruited from memory clinics, support groups and a dementia day centre in different cities in Sweden. An invitation letter was distributed by staff or the project’s researchers. I, as the principal investigator of the study, also gave oral presentations on the project at these venues when possible. The inclusion criteria were: (1) the couples were willing and able to participate in interviews; (2) only one of the partners was diagnosed with Alzheimer’s disease and (3) participants were 55 years of age or older. Exclusion criteria included: (1) participants with other forms of dementia illnesses and (2) the partner without dementia was suffering from a major health condition or illness; one couple who was interested in participating was excluded because the partner without dementia had recently been diagnosed with cancer. Same-sex couples were included in the study, however none volunteered to participate despite targeted recruitment of this group. Overall, recruitment was challenging and took more than 12 months.

### ***Participant details***

Participants’ ages ranged from 55 to 87 years old; they were all white and born in the Nordic countries. Their occupational backgrounds varied, with both

**Table 1.** Information about participating couples.

Couples	Name <sup>a</sup> of participant with AD (gender, age)	Name <sup>a</sup> of partner (gender, age)	Time since AD-diagnosis	In an intimate/romantic relationship since
Couple 1	Anders (male, 57)	Anna (female, 55)	2.5 years	15 years
Couple 2	Bengt (male, 82)	Birgitta (female, 78)	3 years	55 years
Couple 3	Carl (male, 68)	Christina (female, 61)	2 months	40 years
Couple 4	Elisabeth (female, 79) Diagnosis later changed to mild memory impairment	Evert (male, 80)	6 months	40 years
Couple 5	Frida (female, 86)	Folke (male, 87)	4 years	66 years
Couple 6	Gunnar (male, 78)	Gudrun (female, 74)	3 years	52 years
Couple 7	Henning (male, 78)	Helena (female, 75)	7 years	54 years

<sup>a</sup>All names are pseudonyms.

working- and middle-class professions represented in the sample. Two participating couples were still working or on sick leave before the onset of dementia; all other couples were retired. All of the couples were living at home and had been married on average between 40 and 50 years at the time of the study (see Table 1).

The participants with Alzheimer's disease, five men and two women, had been diagnosed between two months and seven years prior to the interviews. All experienced mild to moderate problems in everyday life, including memory loss and difficulties with orientation and everyday activities, and one had a speech impediment. Some experienced living with a dementia illness as frustrating or frightening, while others argued that this was something one had to accept. Those more recently diagnosed expressed greater distress, whereas those who had been living with a diagnosis for some time voiced less concern. For example, 86-year-old Frida said that she was initially very distressed by the thought of becoming "a vegetable", and being dependent on care, but that she nowadays, understood that care dependency was an unavoidable aspect of old age.

Only people with a diagnosis of Alzheimer's disease were included in this study due to the differences in manifestations between different kinds of dementia. For example, frontotemporal dementia involves greater disinhibition and lower sexual drive than Alzheimer's disease, which may pose different problems in sexual and intimate relationships (Mendez & Shapira, 2013). However, rather than the "objective" aspects of Alzheimer's disease, this study explored the subjective meaning-making concerning living with the illness (cf. Hellström et al., 2007). For this reason, cognitive function or memory test scores (such as a Mini-Mental State Examination) were not collected; participants were instead asked to describe their everyday experiences of the illness. Hence, the interviewee Elisabeth, whose diagnosis changed from Alzheimer's disease to mild memory impairment in the course of the study was not excluded as it was Elisabeth's and her partner's subjective experiences of living with the diagnosis, not the objective symptoms, that were the focus of the analysis.

## **Interviews**

The person with Alzheimer's disease and their spouse were interviewed separately in order to allow them to freely express their experiences and discuss sensitive issues regarding their partner, including, for example, violence or extra-marital sexual experiences (Holdsworth & McCabe, 2018; Wright, 1993). The interviews were semi-structured and conducted by me, a female social scientist in her mid-30s with extensive experience of qualitative interviewing on sexuality in later life from previous research. The interviews were conducted in the participants' homes and lasted on average 75 min. The interview guide was structured loosely around the themes "Pre-diagnosis sexual and relationship biographies", "Understandings of sexuality and intimacy" and "Experiences of the sexual and intimate relationship after diagnosis". These themes were developed from reviews of literature, previous experiences from sexuality research and the clinical practice of one of the project members (a medical doctor and professor of geriatrics). Accordingly, participants were asked to talk about their relationship biographies (with their current partners in particular), including experiences of sexuality and intimacy before the dementia diagnosis. Interviewees were also asked about their experiences of living with Alzheimer's disease and how they experienced their relationships today, with particular focus on sexuality, intimacy, touch and desire, including how they understood these concepts. Since I was interested in if, and how, participants understood Alzheimer's disease to be relevant to their everyday lives and their relationships, rather than imposing Alzheimer's disease as the single major aspect that impacted, questions about Alzheimer's disease were asked late in the interviews if the interviewees had not introduced the topic themselves. However, because participants had been informed of the project's focus on Alzheimer's disease, it is likely that this may have influenced their responses. Interviews were both video- and audio-recorded to capture both verbal and non-verbal expressions, however this article focuses only on the analyses of the audio recordings. I transcribed all of the audio-recordings verbatim.

## **Analysis**

The data were analysed using a combination of thematic and narrative analysis to understand both how sexuality and intimacy were conceptualised thematically and how participants' narratives of their intimate sexual relationships were structured, both prior to and after the dementia diagnosis (Braun & Clarke, 2006; Riessman, 2008). Braun and Clarke's (2006) six-step thematic analysis process was followed: (1) Familiarising with the data through transcription and re-readings, (2) Generating initial codes, (3) Searching for themes, (4) Reviewing the themes, (5) Defining and naming the themes and (6) Producing the report. For this study, all interviews were analysed together as one data set. The material was coded for understandings and experiences of the sexual relationship (i.e. in the past and in the present) and perception of the relationship overall (i.e. in the past and in the present). Initial codes were generated as a mind-map where codes emerging from each interview were subsequently reviewed in the search for themes. Themes that emerged were then reviewed and revised through a process where interview excerpts containing aspects of the

themes were collected. A narrative analysis that “zoomed out” was also undertaken to explore how themes were related to overall life and relationship narratives in the interviews and identify turning points in the sexual and intimate relationship. The material was analysed using a constructivist approach, where participants were understood as performing their subjectivities through the interview narratives and by drawing on existing discursive repertoires (e.g. regarding sexuality, ageing, gender and dementia) in order to make sense of their everyday life experiences (Potter & Wetherell, 1987).

### **Ethics**

The study received ethical approval from a regional research ethics committee in Sweden. All participants were informed of the study aim and method. They were also notified that they could freely withdraw their participation. All provided both written and verbal informed consent to participate. Because some participants experienced memory difficulties and information processing problems due to Alzheimer’s disease, study information was written in a clear and accessible way and informed consent was sought on several occasions in accordance with the “process consent” model (Dewing, 2007). Of particular concern were the well-being and health of participants during interviews; if a participant showed signs of tiredness or distress, they were offered a break or asked if they wanted to continue at another time. One of the project team’s members (not the interviewer) was a trained therapist, and was available in case a participant needed support after the interview. All names and specific background details have been anonymised.

In accordance with a feminist research tradition, I want to underline that ethical considerations in this study went beyond issues of information and consent and involved reflections on whose voices were being heard (Lather, 1991). I have sought to include people with Alzheimer’s disease, recognising their voices as valid and important while also acknowledging the voices of their partners, whose perspectives sometimes differed. In relation to this, I have also sought to present the complex and sometimes contradictory experiences of dementia and intimate sexual relationships. All in all, I have tried to consider study participants’ simultaneous vulnerability and agency in the research process.

### **Findings**

The couples in the study differed regarding whether and how they were intimate and sexually active. Most of the older couples (in their late 70s and 80s) no longer had penile–vaginal intercourse, but several enjoyed touching, caressing and cuddling as ways of being intimate. Changes in their sexual relationships had often occurred before the onset of dementia and were attributed more to normal ageing than to Alzheimer’s disease. The two younger couples (in their late 50s and early 60s), in contrast, pointed to the onset of Alzheimer’s disease as a cause of the change to, and the breakdown in, their intimate sexual relationships.



### ***Embodied ageing and changing sexual scripts***

In contrast to earlier quantitative research that describes a decline in sexual intimacy and satisfaction after the onset of dementia (Dourado et al., 2010; Nogueira et al., 2017; Simonelli et al., 2007), older couples in this study did not mention that Alzheimer's disease caused a particular breakdown in their intimate sexual relationships. Instead, they related changes in their sexual relationship to ageing, and as something that had started before the onset of dementia. Both persons with dementia and their partners spoke of how "desire wanes as you age" and how your sexual function also changed as you got older. In particular, men's erectile function was discussed as something that changed with age: "The cock doesn't rise just like that [anymore]", as Henning, a male participant with dementia, expressed. Participants also discussed health and medical conditions, such as prostate or penile cancer and heart problems, as causing erectile problems for men, which brought about changes in their sexual relationships.

Only one couple in their 70s spoke of having penile–vaginal intercourse in the present. And when speaking about this, the male partner, Henning, added that "that might seem a bit strange, that someone who's seventy, eighty years old speaks [of still enjoying intercourse], suggesting that intercourse was something unexpected (or even undesirable, see Jones, 2002) at their age". Still, he made reference to how their mutual attraction to each other was important and as something that maintained his subjectivity.

Henning: Well, it's nice 'cause it's very important this intimacy; it becomes some kind of recognition.

Thus, among the older couples, changes in sexuality were attributed to embodied ageing and considered to be part of a normal life course, rather than as an effect of dementia.

### ***Same persons, comforting intimacies***

Even though Alzheimer's disease was perceived as affecting couples' everyday lives, in particular as the partner with dementia became more dependent on his/her partner and had to be helped with daily tasks, Alzheimer's disease was not considered to be abnormal but rather an expected part of growing old. For example, Birgitta, a retired nurse, underlined the importance of how one responds and interacts with persons with dementia. She stated: "To me, dementia isn't something strange" and despite challenges in everyday life "there is no difference in my relationship with Bengt [husband], he's the same person [as before] to me". Similarly, Helena, who regularly had penile–vaginal intercourse with her husband with Alzheimer's disease, said: "He forgets and repeats things, but I don't find him confused", suggesting that her husband was not strange or unfamiliar to her.

In line with existing qualitative research on later-life sexuality in general, the older couples underscored how other intimate sexual practices were more important (Ménard et al., 2015; Potts et al., 2006; Sandberg, 2015). This, for example, was expressed by the couple Frida and Folke, for whom lying together caressing each

other was just as enjoyable as penile–vaginal intercourse. Folke described in great detail how they lie together, piling up pillows to get close together, “feeling the warmth” of their bodies and how they were “getting the same kind of satisfaction from this as we did when we used to ‘hump’ in the past”. Notably, the increase in touching and the move away from penetrative sex was, according to Folke, was something they had developed already earlier in life due to his wife living with a disability for some periods of their midlife. Folke’s wife, Frida, who had been living with her dementia diagnosis for four years, concurred with her husband that bodily intimacy and being close were what were important to her. Living with Alzheimer’s disease, she said, sometimes made her grumpy or despairing and their bodily intimacy thus became a way of consoling her.

Frida: In my view, we’ve had a wonderful intimate life together. Today we can’t do it [intercourse] much. But then there’s being close, cuddling together and being able to be both happy and sad.

This experience of bodily intimacy as comfort and support mirrors that of Birgitta, who expressed that getting into bed and “spooning” her husband was a source of comfort throughout the years and also now when he had Alzheimer’s.

### ***“We’ve had a wonderful intimate life”***

Unlike other studies which have reported that erectile dysfunction and other sexual dysfunctions cause dissatisfaction for persons with dementia and their partners (Davies et al., 1998; Dourado et al., 2010), older couples in this study referred to touch and bodily intimacy as being pleasurable and enjoyable in their own right. Birgitta, for example, said that although there might sometimes be a sexual desire and a longing for penile–vaginal intercourse, this was “secondary” as she was “so incredibly fortunate” for what they had. Several participants shared this view, of being grateful for having a happy relationship that overshadowed any losses in a sexual relationship caused by ageing. Gunnar, living with Alzheimer’s disease, and experiencing erectile dysfunction, said that, although things were not working like they used to, they had “had good years too, so you have to be happy with that”. Gunnar also described that he used humour to deal with both his forgetfulness and his erectile dysfunction. For example, he sometimes pretended he had forgotten about his “impotence” and jokingly asked his wife, “Should we give it [intercourse] a try?” and then laughing together with her.

These findings echo the results of Harris’s study (2009, p. 71), where some participants stated that they had become less sexually active but more intimate in other ways, and that this was linked to an “appreciation of [the] smaller things in life” after the onset of Alzheimer’s disease. Moreover, the older participants referred more to the importance of a committed, positive relationship overall than to the role of sex, and sexuality was often made “too big a deal of”, as one participant phrased it.

Among the older couples, two spouses of men with dementia cited changes in their sexual relationships as partly related to Alzheimer’s disease. Helena, for example, discussed how, after the onset of dementia, her husband was more focused on himself and less attentive to her sexual needs and pleasuring her. Another example was

Gudrun's description of when she was on holiday with her husband; they had been lying naked together and that had evoked memories of past intimacies in the relationship. She said that it felt a bit sad that they could no longer talk about these past pleasures, highlighting how conversations about sex and intimacy can be another sphere of everyday life where couples may lose common ground (Nilsson, 2018). Overall, however, among the older couples, changes in their intimate relationship were rarely attributed to Alzheimer's disease but were understood as age-related, pre-illness changes that they had already experienced.

With the older couples, the narratives of the participants with dementia and those of their partners were very consistent; both mentioned having an overall positive relationship, both in the past and present, related changes to embodied ageing, and understood intimacy and touch as being more important today (see Harris, 2009). There was one notable exception among the older couples: 80-year-old Elisabeth, who was diagnosed with Alzheimer's disease just a few months prior to the interview and whose diagnosis later changed to mild cognitive impairment. Unlike the other older couples, Elisabeth talked about having a negative and destructive relationship with her husband that involved anger and psychological violence, both in the past and present. She and her husband had been alcoholics for many years, and although they were both sober at the time of the study they still fought constantly, which led to a relationship that was totally lacking in intimacy. Elisabeth said: "It's difficult to feel affection for a husband you're pissed off with". Still, although she was ill herself, she felt responsible for caring for her husband and this was what bound them together. Although Elisabeth's narrative was an exception in this study, it shows how experiences of the intimate sexual relationship when living with dementia are shaped by the overall quality of the relationship in the past and present, including that which relates to, for example, feelings of attachment and the presence of physical and psychological violence (Baikie, 2002; Harris et al., 2011).

### ***"She doesn't understand me"***

The two younger couples in this study described how they had been sexually active and intimate over the years. Despite periods of less sexual intimacy earlier in their relationships due to illnesses and relationship problems, they understood the dementia diagnosis as causing more profound changes. Both couples attested that their intimate sexual relationship was very important to their overall relationship and that the illness had caused a loss of sexual intimacy, which they experienced as damaging. While for the older couples, both participants were in agreement as to their relationship, for the younger couples, there were significant differences between the views of men with Alzheimer's disease and their wives.

Anders, diagnosed with Alzheimer's disease two years prior to the interview, and Carl, who received his diagnosis just a few months before the interview, both described a lack of sexual desire related to their current life situation. According to Anders, he lacked desire, was no longer attracted to his wife, and had stopped initiating sexual intimacy. His wife hugged him, he said, but he did not hug her as much as he was "kind of grumpy sometimes" and did not "like being here". Anders and

Anna had recently moved to a flat from living in a house in the countryside, partly because of Anders' illness. The "don't like being here" thus refers to Anders' discomfort with having to live in a small flat instead of his former house with a garden. Anders also noted that dementia affected their relationship as he felt he was losing his independence.

Anders: She does a lot of things for me, things I can do myself, and [I'm] kind of fed up with that.

He said that her interfering and depriving him of this independence also made him angry and frustrated. Anders's overall expression of life dissatisfaction, including how his life was both literally and figuratively restricted by his illness, could be interpreted as influencing his lack of sexual desire. However, the main reason that he gave himself for no longer being interested in sex was not illness-related but rather that he was not attracted to his wife.

Carl, diagnosed in his early 60s, described a very passionate, loving relationship before the onset of Alzheimer's disease. In recent years, they had had less penile-vaginal intercourse, but they had been intimate and sexual by cuddling and caressing. This intimacy stopped around the time of his diagnosis, and Carl described how Alzheimer's disease had caused considerable relationship conflict, which had affected his sexual desire.

Carl: I think a lot had to do with us being so angry with each other; we've been very angry like we've never been before in our lives. I felt that she didn't understand that I've got an illness that does this and that. And I got really angry, and she got really angry [...] and it was this aggression of course that destroyed the sexual desire.

From Carl's perspective, his anger and frustration were linked to a lack of confidence caused by Alzheimer's disease but also to his wife's inability to recognise the impact of dementia on his life.

Carl: She doesn't understand the difficulties I'm having and what they mean for me. [...] No, my wife has told me several times that "you're not the Carl I married" and there's a lot of truth in that. But I can't really do much if I'm not putting on an act. And that's the major problem: explaining to her why [...] I don't think my wife realises that I've got an illness that has changed me.

Carl argued that Alzheimer's disease made him different in the sense that dementia had disabling consequences. By using the words "if I'm not putting on an act", he referred to dementia as an integral part of who he now was. But he also perceived that the changes caused by the illness did not make him become a fundamentally different person. From Carl's perspective, the fact that his wife could not recognise this had resulted in conflicts which, in turn, had ended their intimacy.

Carl and, to some extent, Anders referred to Alzheimer's disease as having had consequences for their intimate relationships, and how, in particular, it affected their sexual desire and feelings of affection and closeness. Previous studies have shown that spouses experience increasing dissatisfaction with the intimate sexual relationship following a dementia diagnosis and that persons with dementia rarely initiate sexual intimacy as they did before (Davies et al., 2010; Hayes et al., 2009; Noguiera et al., 2017; Simonelli et al., 2007). Anders' and Carl's narratives offer further insight into

how these problems are experienced and made sense of by people with dementia. Their narratives on sexual desire are very much linked to having one's abilities and disabilities recognised, to conflicts and feelings of anger and frustration, as well as to an overall sense of dissatisfaction with one's situation. The barriers and problems that Carl voiced also mirror the results of Harris (2009), whose interviewees with dementia also expressed disappointment, both with changes in themselves and in how their partners responded to their illness, as well as a consequent loss of sexuality and intimacy.

It is notable, however, that both Anders and Carl talked about aiming/wanting to resume their sexual intimacy. Carl said that lately they had, after much fighting, held each other and fallen asleep together, which he saw as positive signs. Anders also expressed several times during the interviews that it was up to him to initiate intimacy because sexual desire "is something you need to work up".

### **The partner with Alzheimer's disease as strange(r) and childlike**

The wives of Anders and Carl, Anna and Christina, stated that Alzheimer's disease marked the point where the sexual intimacy stopped in their relationships. They both talked about intense passion, love and sexual intimacy as fundamental aspects of their pre-diagnosis relationships. For Christina, sexual contact was "number one in a marriage", and Anna recounted their sexual intimacy earlier in life: "When we were having sex, I looked into his eyes and felt that we saw each other's souls".

The onset of dementia had, they argued, caused their husbands to change and become different and more unrecognisable, and that this in turn affected their sexual relationships with them. Anna described how she viewed her husband as different because he could not reciprocate intellectually and have a long, full, conversation with her.

Anna: One of the things I fell for with Anders was his brain, his intellect. And suddenly there is another person in front of me who doesn't connect with me intellectually like before. [...] of course, it's different, cause it's not the same person.

Previous research has shown similar things to what Anna expressed. A significant change in relationships when living with Alzheimer's disease is the decreased ability of persons with dementia to reciprocate in intimate relationships due to communicative and memory impairments. In both the studies by Hayes et al. (2009) and Youell et al. (2016), in which partners of people with dementia were interviewed, participants discussed the loss of a shared everyday life and their partner's lack of the ability to partake in meaningful social interactions as significantly impacting on their overall experience of intimacy and sexuality. Similarly, in this study, Anna described how she not only missed intellectual exchanges with her husband but also how she viewed him as different because he did not reciprocate physically through touch, gaze and sexual initiation.

Anna: Who am I going to see now; it's the same Anders, yet not? It's the same physical body, the same eyes, but not the same gaze. And it's still not clear to me who Anders is today; I have a hard time knowing *where* he is.

Anna's quote shows the disjunction between her husband's body, which she regarded as the same, and his self, which she experienced as different and distant, mirroring a pervasive, negative discourse on dementia as a state where "the body remains but the person is lost" (Hillman & Latimer, 2017, p. 2). Anna wanted to reignite their sexual passion, but to do this, she needed to rediscover who her husband now was and what kind of couple they could become. Experiencing her husband as a kind of stranger made her uncertain about initiating sexual contact. Anna's narrative corresponds to the findings of Youell et al. (2016), where participants reported experiences of "absent presence" in their relationships and how this contributed to an ambivalent feeling of having sex simultaneously with a stranger and a husband (also Hayes et al., 2009).

Christina also talked of her husband as being the same but also different, but she was more convinced than Anna that her intimate sexual relationship with her husband had ended because she felt she had lost him as a husband. Unlike Anna, who was more focused on rediscovering and figuring out who her husband was turning into, Christina conceptualised the changes in her relationship with her husband more in terms of loss and grief: "I'm grieving the only man I've loved in my life. Constantly for 40 years". Sanders and Osterhaus (2013) similarly reported that a loss of sexual intimacy because of a dementia diagnosis may result in a particular form of sexual grief. However, for Christina, it was the experience of the loss of, and grief for, a husband with Alzheimer's disease that had caused her to reject physical intimacy.

Previous studies have also shown that partners of people with dementia start to experience the relationship more as a parent-child relationship and that this consequently impacts on sexual desire (Baikie, 2002; Davies et al., 2010; Hayes et al., 2009). The interviews with Anna and Christina point to similar experiences.

Christina: [H]e doesn't really feel like my husband anymore. He doesn't feel like my husband. More like a child. But not quite like that either.

[...]

Interviewer: And what are the consequences of feeling you no longer have a husband?

Christina: I reject him. [...] I reject him in every way. I physically reject him.

To Christina, perceiving her husband as being transformed into a child or a child-like person was largely linked to the fact that he no longer took responsibility for everyday tasks such as cleaning and shopping and that he was increasingly dependent on her. But because he no longer was seen as offering emotional support. Anna similarly expressed that she was "sexually absent at the moment", something that she linked to having to constantly care for her husband and take responsibility in their everyday life; cleaning, shopping and making all plans and decisions.

Anna: Suddenly I'm becoming Anders' parent. [...] So that's the thing, I am no longer a woman but a carer.

Just as Christina compared her husband to a child, Anna, in this quote, described herself as a parent/carer rather than a woman and a wife. In doing so, she suggests that being a sexual person depends on having a symmetrical adult relationship, and

that an illness such as Alzheimer's disease can disrupt this symmetry (Taylor, 2015). Christina also explicitly referred to her age, saying, "I'm too young" to be a carer, and compared herself to other (older) wives she saw at the memory clinic, "coddling" their husbands, who had dementia. She exclaimed: "I'm not like that".

Interestingly, Anna, in the above quote, also juxtaposes the role of the carer to that of being a woman, indicating that seeing herself as a gendered being was influenced by changes in their relationship. Earlier in the interview, she described how she used to feel as a very desirable woman in the company of her attractive husband, but that now, when taking on all the responsibility for their everyday life, she felt desexualised and consequently the degendered "mother of a baby".

Unlike the older spouse participants who did not see their partners as being different or changed by Alzheimer's disease, Anna and Christina reproduced the pervasive discourse of dementia as a loss of self and stated that their relationship was more like that of a parent-child rather than that between adult lovers who are equals (Davies et al., 2010; Hayes et al., 2009; Herskovits, 1995). This experience of having a different or "lost" husband fundamentally affected their desire for their partners, as well as their experiences of themselves as sexual (and gendered) beings.

## Discussion

This study aimed to explore experiences of sexuality and intimacy among couples where one partner was diagnosed with Alzheimer's disease. The findings show a diversity of experiences, with some couples experiencing great changes and challenges, while others did not. Of particular significance in the findings was the role of age and the life course position in participants' narratives, including the differences in the experiences of sexuality and intimacy between older and younger couples. The older couples understood changes in their intimate sexual relationships as consequences of embodied ageing and other health issues and attached less or no importance to Alzheimer's disease. All of the older couples, with one exception, expressed that sexuality and touch continued to be sources of comfort and recognition. The younger couples, in contrast, experienced dementia as clearly halting previously a passionate and intimate sexual relationship. However, younger persons with dementia and their partners also differed in how they perceived the impact of Alzheimer's disease. The younger persons with dementia reported a lack of sexual initiative and sexual desire, which they linked to overall life dissatisfaction and conflicts, the lack of understanding from their partner, as well as to experiencing increasing dependency. Their partners, in contrast, experienced Alzheimer's disease as radically changing their husbands and their relationships overall. Having to take on more responsibility, the lack of emotional support and reciprocity, as well as experiencing the relationship as more of a parent-child relationship led the partners to experience a loss of sexual desire (cf. Baiki, 2002; Davies et al., 2010; Hayes et al., 2009).

The younger and older partners also experienced Alzheimer's disease differently. For the former, it was an illness out of place, which they felt had turned their partners into strangers. For the latter, Alzheimer's disease was more often conceptualised as an expected part of ageing and part of a wider spectrum of later-life illnesses and

ailments. The older partners also viewed the persons with dementia as “still the same”. These different understandings, in turn, impacted how the intimate sexual relationship was experienced. For example, most older couples seemed to have an easier time moving between the role of a carer/assistant and that of an intimate partner (Taylor, 2015).

The differences in older and younger couples’ experiences can be understood as not only resulting from different sexual scripts in different parts of the life course, but also from how these sexual scripts intersected with life course scripts on health and illness. The older couples seemed to follow sexual scripts where sexuality was expected to decline and/or change as a result of embodied ageing. The older couples’ experiences, in several respects, corresponded to previous qualitative research on later-life sexuality among couples without dementia. This research has shown that older men and women often emphasise emotional intimacy and touch as significant to later-life sexuality (see e.g. Clarke, 2006; Hinchliff & Gott, 2004; Lodge & Umberson, 2012). While ageing embodiment was experienced as putting limits on some sexual practices, such as penile–vaginal intercourse, intimacy and touch were perceived as being important and pleasurable in their own right (Fileborn et al., 2017, Sandberg, 2015).

One reason that older couples did not attach great significance to Alzheimer’s disease and did not regard it as impacting their intimate sexual relationship could be a matter of timing; the older couples’ life course scripts were more aligned with changes in both health and sexual activity (compare Lodge & Umberson, 2012). Among the older participants, there seemed to be a symmetrical relationship between their life course position, dementia diagnosis, their ageing embodiment and their changing intimate sexual relationship. The older participants’ narratives in this study also echo findings from previous research that demonstrates that having a positive, happy, intimate relationship in the past may offer a way of negotiating intimate sexual changes experienced in the present (Baikie, 2002; Ménard et al., 2015, Sandberg, 2016).

The younger couples had experienced fewer age-related changes in their sexual relationships before the onset of Alzheimer’s disease. They also seemed to draw on different sexual scripts, where sexual activity during the most recent part of their life course, namely their early later life, was both expected and desirable. Also, a desirable relationship was associated with sexual intimacy more so for the younger couples than for the older ones, who, instead, mentioned other aspects as constituting happy coupledom. That sexual activity was expected can, for example, be seen in how Anders, diagnosed with Alzheimer’s disease, talked about how he “should” initiate sex more, almost as a duty, despite his lack of desire. In Anders’ case, this could be related not only to life course expectations, but also to gendered norms, where men are supposed to be the instigators of sex and that sexual desire is assumed to be a constant in men (Sandberg, 2016).

One reason that Alzheimer’s disease was perceived as a greater change and challenge for the younger couples’ intimate sexual relationships could be that a dementia illness disrupted their life course expectations to a greater extent. Alzheimer’s disease was perceived as occurring out of place and as a form of premature ageing. This was



reflected in how Christina and Anna drew on discourses of the person with dementia as strange/a stranger. But it was also seen in how Christina contrasted herself with other (older) women who care for their wheelchair-using husbands. She felt she was “not like them” and “too young” to be caring. In a similar vein, Anna talked about how her husband did not belong with the “oldies” at the adult day centre. That sexual scripts may vary over the life course was acknowledged by Anna, who spoke of how it was expected that a sexual relationship would be put on hold, for example around the time of childbirth, where caring for a child becomes more important. Being women in their 50s and 60s, however, was understood by both Anna and Christina as a time to be sexually active, and thus becoming the spouse of a husband with dementia represented a transformation into an (a)sexual carer instead of a sexual partner. It is plausible that the emergence of new sexual scripts on “sexy oldies” who continue to be healthy and sexually active as part of successful ageing, as well as more affirmative scripts on women’s sexuality in this generation, may have also influenced Anna’s and Christina’s expectations and experiences (Barrett & Hinchliff, 2017a).

In their systematic review of research on the impact of dementia on couple relationships, sexuality and intimacy, Holdsworth and McCabe (2018) argue that research so far has not discussed the impact of age on how the intimate sexual relationship is experienced when living with dementia. In previous studies, the participants’ ages varied quite significantly, with no mention of how these variations may impact results. Holdsworth and McCabe (2018) argue:

The needs of people may vary according to their stage of life. This is particularly evident in sexuality and sexual activity. (p. 16)

The findings of this study seem to support the above propositions: age and life course position appear to be of particular importance to couples’ meaning-making regarding sexuality and intimacy after an Alzheimer’s disease diagnosis. It is worth noting changes both in how sexuality and cognitive function in later life are viewed, where both the terms “senility” and “old age impotence” have in recent decades been substituted by medical discourses on “dementia” (or the more recent DSM-V classification: neurocognitive disorder) and “erectile dysfunction” (Ballenger, 2006; Katz, 2012; Lock, 2013; Marshall & Katz, 2002). These new terminologies on memory/cognitive and sexual functioning create a clearer divide between normal/healthy and abnormal/pathological sexual function and ageing. This may impact the everyday lives of couples who receive a dementia diagnosis, where successful ageing is increasingly centred around cognitive functioning as well as continued sexual activity through penile–vaginal intercourse. Still the consequences of age should not be overstated, with Anna and Anders, for example having been together considerably shorter than the other couples, which could also have impacted on how they coped with the illness.

Finally, age and life course position also intersect with gender. The younger female partners, Anna and Christina, experienced changes in sexuality and intimacy after the Alzheimer’s diagnosis as impacting their gendered subjectivity. Women carers in previous research have similarly expressed difficulties in combining their roles as wives and sexual partners with that of carers (Baikie, 2002; Davies et al., 2010; Hayes et al., 2009). Hayes et al. (2009), for example, highlight the significance of gender differences for

spouses' experiences of sexual intimacy when living with Alzheimer's disease. The women in their study cited a loss of emotional and social intimacy as leading to a decline in physical intimacy and that seeing their husbands as childlike decreased their sexual desire. The men, in contrast, were mostly concerned with knowing whether their female partners with dementia consented to sex, and they still regarded their partners as wives regardless of the changes. They also desired more sexual intimacy. This study partially supports these earlier findings, but also shows that changes in intimate sexual relationships as a result of dementia may influence the possibilities of performing gender. Experiencing oneself as a mother or carer becomes antithetical to that of a lover and wife and thus as a woman, which reduces women's feelings of sexual desire. If the sexual relationship is a significant social sphere where the performance of one's gendered self becomes possible, then a loss in sexual relationship may contribute to experiencing a loss or a disruption of a gendered self, not only for the partner with dementia but also for the partner without dementia (Sandberg, 2018).

### **Limitations**

The limitations of this study should be recognised. First of all, it has a small sample size, which is suited to qualitative research, but the discussion on the differences of younger and older couples should not be understood as absolute comparisons, and more research is needed that explores the significance of age and the life course. Moreover, the sample was limited in that it only includes heterosexual, white participants born in the Nordic countries, which may influence the experiences captured in this study. Finally, although the interviews were semi-structured and tailored to the diversity of narratives that participants wished to present, it is likely that "happier" couples with fewer major relational conflicts and experiences of abuse chose to partake (see Hellström et al., 2007).

Interviewing couples separately provided insights into both the similarities and differences in narratives between persons living with dementia and their partners. However, it is likely that some participants adapted their narratives as they knew that their partners would also be interviewed. During several interviews, participants' partners also waited outside the interview room and sometimes the partner even walked in. Power asymmetries, inequalities and violence in couple relationships thus need to be recognised and further explored in future research on couple relationships among people with dementia.

Furthermore, when individuals had been diagnosed varied considerably in this study, and the results of the study may also reflect these differences. For example, Carl (couple three) was diagnosed just a few months before the interview. At the time of the interview, Carl and his wife were going through a major adjustment and even a crisis. Their experiences may thus be understood as crisis reactions to a greater extent than some other couples who had received the diagnosis several years ago.

### **Conclusion**

This is one of the very few qualitative studies that explore the experiences of both persons with Alzheimer's disease and their partners to more fully understand the

congruent and divergent experiences of sexuality and intimacy among couples living with dementia. This study shows that sexuality and intimacy are important and desirable both to persons in early stages of Alzheimer's disease and their partners (see also Bauer et al., 2013; Harris, 2009), and are sources of pleasure, comfort and recognition. However, this study also shows that there are changes and challenges in sexuality and intimacy, particularly for younger couples. Thus, it appears that experiences of sexuality and intimacy in couples living with Alzheimer's disease should be considered in relation to life course positions and varying sexual scripts and "health scripts", including expectations regarding health and cognitive function in different parts of later life. There may be a particular need to discuss and support sexuality and intimacy among younger couples where one partner is in the early stages of dementia. However, generational changes in understanding regarding "normal" sexual activity, as well as dementia, may also influence couples' experiences.

An earlier quantitative study by Ballard et al. (1997) showed more dissatisfaction with the absence of a sexual relationship among younger couples living with dementia, which corresponds to the findings of this study. However, there is a need for more research in this area, both qualitative and quantitative, that further explores the role and significance of age and the life course. This study involved couples with one partner in the earlier stages of Alzheimer's disease. The findings may both reflect the relative independence of the partner with dementia and the early stages of adjustment to living with dementia. More research is needed on how the intimate sexual relationship develops over time, including the transition of moving into a dementia care home (Wright, 1998). As the illness progresses issues of consent of the ill spouse are also likely to be more prominent concerns for partners (Benbow & Beeston, 2012). Finally, the intersection of age and gender, which this study has discussed only to some extent, need to be further explored.

In contrast to biomedical approaches, where sexuality among people with dementia is primarily linked to cognitive functioning (see, e.g., Hartmans et al., 2014), this study underlines how sexuality and intimacy when living with dementia are linked to a broader psychosocial context, including expectations of changes in later-life sexuality, discourses on a loss of self in dementia, as well as the partner without dementia experiencing responsibility and the partner with Alzheimer's disease dependency. Moreover, although some couples living with dementia perceive sexuality and intimacy as challenging, the findings of this study demonstrate that the intimate sexual relationship also provides well-being and comfort to couples and even becomes a sphere for having one's subjectivity recognised. As such, these findings importantly challenge the pervasive discourses on sexuality in dementia as merely troublesome or pathological and allow for a more complex representation of sexuality beyond the focus on "inappropriate sexual behaviours".

## Acknowledgements

This project was developed in collaboration with Professor Jan Marcusson, whom the author would like to thank for his help with recruitment, advice and expertise on dementia illnesses. Thanks also to Professor Henrik Eriksson, Dr. Alisa Grigorovich, as well as colleagues at the Department for Gender Studies, Södertörn University and Centre for Dementia Studies,

Linköping University, for their comments and suggestions on earlier drafts of this article. The author would also like to sincerely thank the couples who participated in this study.

## Disclosure statement

No potential conflict of interest was reported by the author.

## Funding

This work was supported by the Swedish Research Council for Health, Working Life and Welfare (Forte) under Grant Dnr 2013-00275.

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