

## **The Impact of Caregiving: Older Women's Experiences of Sexuality and Intimacy**

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# The Impact of Caregiving: Older Women's Experiences of Sexuality and Intimacy

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## Abstract

Using an adapted phenomenological approach, the current study explores older women's stories about the ways in which providing care to their spouse or partner has affected their sexual and intimate lives. Findings suggest that older women's sexual identities and experiences of sexuality are marked by both ageist constructions of "older woman as asexual" and loss of self associated with taking on the role of caregiver. Findings also suggest that women resist these constructions of self through the development of other forms of intimacy in their lives. Suggestions for increasing opportunities to address women's realities in service provision are highlighted.

## Keywords

caregiving, aging, sexuality, women, identity

## Introduction

The emotional, social, and financial consequences of providing care to a spouse or partner with chronic care needs have been well documented. These impacts are heightened for women spouses who tend to carry out some of the heaviest forms of caregiving with little respite (Brazil, Thabane, Foster, & Bédard, 2008; Keating, 1999; Lee, 1999; Montgomery, Borgatta, & Borgatta, 2000; Strang, 2001). While a knowledge base of women's experiences with caregiving has emerged over the past two decades, relatively few studies explore how women's intimate and sexual lives are affected by their caregiving status. Failure to examine the impact of spousal caregiving on women's sexuality and intimacy is striking, given that positive experiences of sexuality and intimacy have been associated with adult health and well-being and that maintaining sexual intimacy in later life

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is associated with healthy aging (Woloski-Wruble, Oliel, Leefsma, & Hochner-Celnikier, 2010). The current study aims to fill this important gap in the literature by exploring women's stories of providing care to their spouse or partner and how these experiences have affected their sexual and intimate lives. This study understands spousal caregiving as the unpaid, informal care provided by a spouse or partner to an older adult living at home. Spousal caregiving can involve both emotional and instrumental assistance with a range of daily living activities. Sexuality and intimacy are broadly defined in this study to include sexual acts as well as cognition (e.g., knowledge, thoughts, identity), emotion (e.g., emotional closeness, affection, prolonged eye contact), and touch (e.g., holding hands, dancing) in the context of these relationships (DeLamater & Hyde, 2004).

### **The Unique Nature of Women's Caring for a Spouse and or Partner**

While much of the caregiving literature focuses on experiences of *family* caregivers, feminist writings have recognized the gendered nature of caregiving (Brazil et al., 2008; Strang, 2001), and have identified the different roles, responsibilities, and involvement women caregivers face when compared to other family members (Lee, 1999). For example, women spousal caregivers have been found to provide between 40 and 60 hr of care per week, approximately double that of other familial caregivers (Keating, 1999). Further, women spouses are the least likely of all family "carers" to seek and use formal services, and receive less informal support (Barusch & Spaid, 1996; Dwyer & Conrad, 1992); perceiving their caregiving functions as an extension of their role as wives and partners (Montgomery, Rowe, & Kosloski, 2007).

Perhaps as a consequence of these caregiving demands, women spouses are more likely than other familial caregivers to experience increased strain and health impacts for their caregiving roles (Armstrong & Armstrong, 2001; Fast & Keating, 2000). Distress, depression, anxiety, chronic illness, loss of income, poverty, and isolation have all been found to be prevalent among women spousal caregivers (Armstrong & Kits, 2004; Bookwala & Schulz, 2000; Cheung & Hocking, 2004; Harris, Adams, Zubatsky, & White, 2011; Pinquart & Sorensen, 2006).

In addition to experiencing more negative caregiving consequences, women spouses report fewer caregiving rewards than other familial caregivers. For example, women spouses are less likely to report increased resilience, greater patience, and stronger relationships than adults, children, or male spouses (Netto, Goh Yen Ni, & Yap Lin Kiat, 2009; Raschick & Ingersol-Dayton, 2004; Rozario, Morrow-Howell, & Hinterlong, 2004). Intimacy appears to play a role in women spouses' positive caregiving experiences as women who are able to maintain companionship, friendship, and physical and emotional closeness within their relationships appear to experience more rewards than those who do not (Harris et al., 2011). Yet, despite preliminary evidence that intimacy between women spouses and their partners may positively impact their caregiving experiences, intimacy is rarely defined or examined (Hubley, Hemingway, & Michalos, 2003).

A handful of researchers have looked at how Alzheimer's disease affects the intimacy between spouses in the context of caregiving (Boylstein & Hayes, 2011; Davies et al., 2010; Harris et al., 2011). Findings from this work suggest that caregivers struggle with the ethics of engaging in intimate acts with their partners who occasionally get confused and do not recognize them and that women spouses are reticent to continue an intimate relationship with a person who they perceive as completely different than the one they knew (Davies et al., 2010; Harris et al., 2011). Findings also highlight that these concerns about intimacy are rarely discussed with health and social care providers (Gilbert, Ussher, & Hawkins, 2009). Quite possibly the absence of empirical literature and practice approaches examining intimacy and caregiving may, in part, be due to stereotypes associated with aging, where older adults, especially women, are seen as asexual (Allen, Petro, & Phillips, 2009; Deacon, Minichiello, & Plummer, 2006).

Given that satisfaction with sexuality and intimacy in later years has been found to contribute to the health, well-being, and quality of life of older adults (Katz & Marshall, 2003; Weeks, 2002), it seems timely and important to understand more fully how caring for a spouse with chronic health problems impacts sexuality and intimacy within the context of the relationship and how this in turn shapes the caregiving experience for women spouses (Weeks, 2002). To this end, the current study aims to explore how older women caring for a spouse at home experience and understand their identities as women, wives, partners, caregivers, and sexual beings. The study asks how the caregiver role and its associated risks to health and well-being affect the sexual and intimate relationships of women spousal caregivers.

## Method

We used an adapted phenomenological approach in order to understand the meaning older women caregivers attribute to their experience of sexuality and intimacy (Creswell, 1998; Moustakas, 1994; Tesch, 1990). Phenomenology is a qualitative methodological approach designed to render explicit the essential meanings attributed to the lived experiences of a particular phenomenon and engages with the subjective experience as a means of both data collection and analysis (Bogdan & Biklen, 1982). A phenomenological approach focuses on understanding how people experience a situated phenomenon, such as is the case of the impact of caregiving on the experience of sexuality and intimacy, through conversation between researcher and research participant. Questions are broad and give room for the participant to tell the story of their experience. An emphasis in both data collection and analysis is placed upon how meaning is made of the lived experience. While phenomenological approaches tend toward unstructured interviewing techniques, recent phenomenological accounts have also used semistructured interviewing techniques to focus participants on particular aspects (themes) of a phenomenon (Beharry & Crozier, 2008; Haj-Yahia & Cohen, 2009). Moustakas (1994, p. 116) affirms that the interview guide can “facilitate the obtaining of rich, vital, substantive descriptions of the co-researcher’s [participant] experience of the phenomenon.” Themes identified in our study included those related to the lived experience of caregivers, the meaning they attributed to sexuality and intimacy, and issues regarding service provision to address these issues (i.e., the place of discussions of sexuality and intimacy in the caregiver–service provider encounter).

Our recruitment strategy focussed on identifying older caregiving women spouses who were willing to talk about how the lived experience of caregiving has affected their experience of sexuality and intimacy. Community residing women aged 60 or older, caring for an ill spouse in the home, were included in the study. The sample was diversified in terms of age, length of caregiving role, and living situation in order to reflect some of the diversity of the population. Sample size in the current study was limited (six individuals) as is consistent with a phenomenological approach.

In addition to interviewing older women providing care to spouses or partners, we undertook several key informant interviews with service providers to enhance our analysis. These interviews were undertaken once we had developed preliminary ideas that emerged from older women’s stories. Key informant interviews provided perspective on the emerging themes in order to both confirm and explain what women were telling us. This was particularly important in developing an understanding of women’s stories regarding the lack of opportunity to discuss issues of sexuality and intimacy with care providers and to their discomfort in engaging in these conversations. In the current article, the service provider interviews are analyzed for the sole purposes of complementing the voices of women who live the experience of caregiving, bringing an important dimension of depth and clarity to the theme of encounters with health and social services. Key informant interviews included service providers who, within their organizations, work directly with older adult caregivers. Findings related to service provider perspectives on their own work with caregivers are not included in the current analysis and will be used for a future article.

Caregiver participants were recruited through several health care organizations serving seniors with a loss of autonomy living in the community and their caregivers. The setting for recruitment was selected based on the significant population of older adults in the health care setting's geographic territory. We engaged many managers and service providers in our outreach and recruitment process through study information flyers, attending organizational team meetings, one on one contact, and e-mail. We also positioned the research coordinator within the agency for several days per week over a period of months. Despite these recruitment efforts, we had several significant delays in locating interview participants. The time period for recruitment was extended considerably to allow for prolonged engagement in the field in order to build linkages with key informants for the purposes of outreach and recruitment. Given the silence around discussions about sexuality and intimacy between service providers and their clients, key informants told us it was difficult for them to identify potential participants. It was suggested by key informants that an extended outreach design was necessary to help locate women willing to discuss sexuality and intimacy. This included the development of information flyers and presentations at drop-in programs where we felt we may come into contact with potential participants.

In total, six women were interviewed. These participants were aged between 60 and 80, and all were providing care to their male spouse in the home. All of those who participated in the study were Anglophone and heterosexual. Five of the six participants were married (all were in long-term marriages over 25 years) and one woman lived with her boyfriend of 7 years, considered a common law marriage.

Following phenomenological methodological principles developed by Moustakas (1994), our study included several semistructured theme areas in order to both allow individuals to tell their own stories of their lived experiences of sexuality and intimacy while at the same time ensuring such themes as experiences of the body, relationship to self and others, and access to care were covered through the interview. The interviews lasted approximately 1½ hours and were conducted in a secure, confidential location of the participants' choice, either in their home or at the community organization through which the person had been recruited. The interviews were audio taped with the consent of the participants and transcribed in full. All information regarding participants' identities was removed from transcripts to ensure confidentiality. Ethical procedures were followed according to ethics protocol guidelines. All participants were given pseudonyms in the presentation of the current findings to ensure anonymity.

The first part of the interview was open ended and prompted participants to tell their story and describe their role as a caregiver, the health situation of their spouse and the resulting changes to their spousal relationship. Depending upon the way in which participants framed and told their stories, several other subquestions were asked in order to allow the participant to elaborate on key areas that included the impact of caregiving on the self and the body (health, aptitudes, self-perception, body image, view of life, romantic and sexual life, identity, etc.); social life (relationship with their spouse or partner, social life, activities); experiences related to the intersection of caregiving and sexuality; experiences associated with stigma; and experiences accessing health and social services. The participants' stories were rich and complex and pointed to the multiple challenges of the impact of caregiving on women's sexual and intimate lives.

Data analysis followed a phenomenological approach (Tesch, 1990) in which interviews were transcribed and then analyzed first as separate units to uncover statements in which participants described their experience. Each interview was analyzed thoroughly and meaning units were noted in the margins of text, these units were then organized into theme areas relevant to participants. It is important to note that not all participants shared in the meaning attributed to a particular lived experience or phenomenon but rather, units of meaning were collected into themes that converged among participants, while also noting points of divergence. This enabled us to locate points of shared meanings while also staying true to the multiple ways in which sexuality was experienced by participants

with diverse social locations and realities (e.g., by age of partner's diagnosis, dynamics of relationship prior to the onset of partner's illness, living arrangement of couple, presence of support). Data were then interpreted using a descriptive method centered on a specific level (the specifics of a person's experience) and the identification of a fundamental structure (a general description centered on themes across multiple people's experiences), in order to develop themes related to living the intersection of caregiving and sexuality among women. Saturation of the data was reached taking into account the initial objective of highlighting the essence of the lived experience. Key informant interviews were subsequently considered to provide additional opportunities to deepen analysis on the caregiver-service provider encounter.

Authenticity and trustworthiness principles of analysis were respected by implementing different methods throughout the research process (Creswell & Miller, 2000). These included prolonged engagement in the field (the coinvestigators and research coordinator have all been involved in research on caregiving and/or sexuality and aging for many years), peer debriefing, and member checking, primarily through the presentation of preliminary results with key informant service providers and other practitioners working with this population.

## Findings

Interviews were rich, diverse, and complex. Women caregivers spoke of the impact of caregiving on the experience of sexuality and intimacy, including their experience of their body and the aging process, their sense of self and identity, their relationships with others, and their ability to negotiate health care and social service systems. Service providers interviewed as key informants confirmed the impact of caregiving on all areas of women's lives, including the sexual and intimate relationship with the care-receiving spouse and spoke of the numerous personal, social, and cultural barriers for both caregivers and service providers in addressing this topic. While we cannot present all their stories here, we will focus upon key issues that formed the essence of experiences across participants' stories.

### *Shifting Identities*

Several subtle shifts of women's identities were noted. This included the primary shift from "woman" to "caregiver." Most often, women interviewed in our study described their current identities only in terms of their primary role as caregivers. Women talked about the process of taking on the identity of caregiver which, over time, overshadowed other parts of self, including their sexuality and sexual expression. Women's narratives spoke to the reality of how the role of caregiver required women to take on the primary identity of the "good wife," expressed as having to let go of one's own needs in favor of the other. As one participant said:

Him being sick and me being a caregiver have taken over. I know it's not supposed to for me, I try to do other things, but that's sort of the overwhelming part of our identities. So it's hard to work ourselves out of it and go back to some sort of you know who we were. So in that sense that makes it very hard. I'm not always "caregiving" but I'm always alert. It's just encroaching on everything so it's very hard to re-establish that other kind of thing you know. I am aware of it but it doesn't make it that much easier. (Sidney, Caregiver).

Another participant stated: "I'm from the old school, I was taught that my husband comes first in my life, that I have to look after him, so on and so forth" (Estelle, Caregiver).

The intersecting identity of both "older" and "caregiver" invariably excluded women's expression of sexuality. For example, some participants described themselves as having felt "desirable" or

“sexually confident” in their precaregiver, younger lives, feelings that were repressed or negated once a shift was made from spouse to caregiver. For these women, parts of their identities were disrupted by the act of embodying the role of caregiver and by the aging process. Both disruptions, caregiving and aging, worked together to undermine women’s experience of self-actualization as separate from their role as caregiver, making it challenging to see themselves as sexual or desirable. The intersecting realities of caregiving and aging became internalized as negative self-imagery or self-talk. For example, one caregiver did not see herself as desirable enough to continue to have a sexual life with her husband after she had aged. She said: “who would want a fat old broad like me at 72 years old, even just thinking about it, I don’t think I would have enough nerve” (Estelle, Caregiver).

Many women interviewed could identify the *moment in time* when they experienced a shift in their identities from spouses to caregivers. For some, this realization occurred when they had to take on new roles and responsibilities previously identified as the “man’s role” as a consequence of their partner’s illness such as managing finances. For other women, it became evident when their caregiving status was named by others. As one participant stated, “I always thought I just provided the normal wifely activities one does for ones partner and I recently found out that some of these are considered under the heading of caregiving” (Dorothy, Caregiver).

Taking on the caregiver role meant ascribing the role of care receiver to spouses thus reflecting the reality that women’s own identity shifts were entwined with shifts in how they identified their partners. This change was particularly apparent when women took on responsibilities for their partner’s hygiene. One health professional explained that taking care of hygiene needs can change the caregiver’s relationship to her partners’ body:

They start to imagine in their mind they are caring, the way they get through that is they blank their mind and think that they are caring for a child. They think of it as something they used to do for their children. So when you start moving into that mental space of considering your partner someone who needs to be wiped when they go to the bathroom the whole sexuality thing from what I hear is well “how could I possibly imagine sleeping with him anymore when I’m wiping his behind”. It’s not pleasant. (Tara, Service Provider)

In another example, a caregiver whose husband is cognitively declined spoke of a loss of attraction toward him. She said:

It doesn’t look appealing when he stays undressed, so now that he wets all the time what he’s been doing is keeping his t-shirt on, his underwear t-shirt and taking the bottom off and walking around the house like this, talk about making yourself appealing. (Rose, Caregiver)

Another caregiver described how caring for her husband’s hygiene was unpleasant:

He a few years ago had a problem with his stomach and we would be out and if he had to go to the bathroom and didn’t make it we would rush home and I would clean him and clean the bathroom and everything else. My daughter is a nurse in Florida, and when she heard I was doing these things she was really very annoyed. She says he’s not a baby and he can clean up for himself. But, it was more of a chore for him to do it himself, such a mess, it was a lot easier for me, and I was his wife and in sickness and in health and it had to be done. Let me tell you it was not pleasant. (Estelle, Caregiver)

In the caregiver–care receiver dynamic keeping a partner “as comfortable as possible” (Francine, Caregiver) and “making it through another day without killing him” (Francine, Caregiver) was deemed more important than considering how to maintain intimacy in one’s relationship. As one participant stated;

Oh my god, of all the things that are happening to us, and I know that sex is supposed to be very important . . . but I think it's one of those things that most, from what I see and I guess in our lives, it's sort of fringe. You know everything else is so bad for R . . . when you are dealing with that, like ok so you don't have sex. (Sidney, Caregiver)

When asked about her current sexual and intimate life with her partner, one caregiver described that what she needs help with the most right now is her own psychological issues resulting from the intensity of her caregiving situation. She said: "You see it's just how to deal with the struggles I have now. Intimacy wouldn't enter into the picture at this point" (Rose, Caregiver). Health providers echoed this sentiment, saying that sexuality and intimacy get "pushed to the side" (Ruth, Service Provider), and go "down the list of priorities" (Tara, Service Provider).

With respect to sexual intercourse, all of the women we spoke to stated that they were no longer sexually active with their partners. When asked about their current sexual lives, caregivers responded by stating: "there is nothing to tell you" (Francine, Caregiver), "nothing to talk about" (Estelle, Caregiver). While some caregivers suggested that this level of intimacy was absent from their relationships prior to the onset of their caregiving role, others felt it was a result of the cognitive or physical decline of their partners. Caregivers who discussed physical decline suggested that their partners were no longer able to "perform." As one caregiver stated: "he was on three injections a day, morning, afternoon, and supertime, and he just couldn't perform. He tried once in awhile, but he couldn't. So we just let it go" (Estelle, Caregiver).

Another caregiver, whose husband could not get an erection, felt it was his reaction that led to the dissipation of sexual relations in their relationship. She stated:

There was a particular change I noticed in his performance, I'm trying to find the right words, I don't talk about this with anyone . . . he was always a gentle and sweet lover, and a very considerate lover. And then I found when he wasn't able to perform his initial reaction was blaming me for it . . . he blamed me that my vagina had dried up, which wasn't true . . . he had gone flaccid when trying to penetrate and he said that it was my fault. There is nothing I could do about him being flaccid. You know, ain't my department. Except that I would tell him, I could verbalize that he had a problem but he denied it, he said it wasn't him. Of course it discouraged me very much from wanting to help him in any way. (Dorothy, Caregiver)

Most caregivers insisted that it had been so long since they were sexually active that they were no longer bothered by the absence of sexual relations. Others felt that their sexual lives had never been a priority:

I don't think it's such a, it's funny when I think about it, I do think back and think about it and I don't think it was all that. I don't think I had much of a need for, to be sexual. You know I didn't miss it as much as some people might. (Sidney, Caregiver)

One caregiver and her partner met later in life and have never had a sexual relationship, she explained:

I'm going to be 77 and really it's pretty dry down there (laughter), really I have to say 100% it does not bother me at all. I don't think I could tolerate it, like leave me alone already. I'm still getting flashes you think I need him crawling all over me? No no he's 225 pounds, I can't, he's too heavy, that's out of the question really. (Bonnie, Caregiver)

Some women did share stories of the regret they experienced at the loss of this aspect of their identities, lives, and relationships. For example, a few caregivers spoke to us about trying to maintain a sexual relationship despite their partner's declining health only to be faced with rejection,



which ultimately led to a feeling of “giving up.” One woman spoke to us about her attempts to be intimate and affectionate with her partner. Unfortunately, since being rejected by him, she has stopped attempting to touch him. “I tried at the beginning like holding hands and touching like we did before but he was like ‘get away from me’. After two or three times of that . . . after a while you get the hint” (Francine, Caregiver). Another woman stated: “[I tried to] get him to use a vibrator, and he wouldn’t, he just wouldn’t” (Estelle, Caregiver). She went on to describe her disappointment that this part of their relationship had ended. She said; “He had the best of it because let me tell you something, when you enjoy sex you become very good at it, and let me tell you something, I was damn good at it, I really was. What a waste, all my talents” (Estelle, Caregiver).

In summary, most spouses in this study could describe a moment in time when they became aware of a shift in their multiple identities directly connected to the shift in their role from spouse to that of caregiver. This resulted in a corresponding shift from sexual to asexual or unattractive. The ever-present new identity as caregiver made it difficult for them to even contemplate intimacy because they began to see themselves as only “carers” and their partners as care receivers. Women stated that their primary function was to provide care and comfort rather than share sexuality. Women had several ways of coping with this reality. Some stated that sexuality was irrelevant, either in the context of their relationships over the life course or because of the current caregiver–care receiver dynamic. Still, other women who expressed loss regarding their sexual lives quickly reverted to statements of irrelevance. These latter comments reflected women’s sense of a lack of control over current circumstances. Overall, sexuality and intimacy receded as a possibility for women who participated in our study. It is important to consider that some women may have used the language of “irrelevance” (i.e., stating that “it doesn’t matter”) as a coping mechanism to enable them to continue with their caregiving role.

### *Women’s Agency Expressed Through Intimacy*

As a matter of necessity, women demonstrated agency in the ways in which they redefined their sexual identities in the context of caregiving. Women’s agency can be understood as an individual sense of being able to function autonomously, and “should also incorporate an analysis of the ways that limited political agency (due to race, sexuality, class, and gender oppression) circumscribe women’s lives and . . . responses to these limitations” (Pollack, 2000, p. 83). In the context of this study, women’s political agency is also limited by ageist social conditions, their status as caregivers, and the associated gendered social expectations.

Although women stated that there was currently no sexual activity between themselves and their partners, they did identify a myriad of ways in which sexuality and intimacy continued to be expressed, either on their own or in the form of affection between themselves and others, including their spouses. For example, one woman discussed sexuality with her friend:

I only mentioned it (sex with my husband) once to my friend . . . and I said ‘you know what? there is nothing to talk about’ . . . she was the one who said ‘well do you masturbate?’ And I said ‘yah!’. And she said well good . . . Good, good, good. (Francine, Caregiver)

Women told us about the varied ways in which they maintained a sense of intimacy in their current lives. This referred to intimacy shared with their partners as well as identifying other sources of intimacy in their lives, which helped to satisfy their need for closeness. Women’s memories also served them well in times of distress to remind them of the intimacy they had once shared with spouses. These memories helped to bring a sense of closeness with their spouses despite the shift in identity from spouse to caregiver.

For example, some women told us that when couples had had an affectionate relationship in the past, this part of their dynamic remained in some form after illness. Participants talked about showing kindness to their spouse, expressing feelings of compassion, sympathy, and cherishing the emotional part of the relationship. Others spoke of continued reciprocity in their relationships, which challenged the rigid binary of caregiver and care receiver. Affection in the form of holding hands, hugging, and doing nice things for each other came up when caregivers talked about the ways that intimacy was currently shown in their relationships. “The cuddling was sufficient for me, the hugging, going out for dinner that was more important to me, and to him” (Bonnie, Caregiver).

One caregiver spoke about how her husband brought her tea in the evening to show affection, and she would buy him things that he needed, like T-shirts, which made him happy. Another caregiver described how even though her husband cannot move very much and preferred to be lying down, they still managed to hold hands, try to kiss, and touch each other. She explained what this meant to her:

We try to, you know, we try to kiss and hug but R. sits here and I have to bend down and he’s always liked breasts so we try to sort of do something but um it’s not really, it’s playful. I mean it’s not what you would call overtly sexual. It’s nice. I like it, it means we are both in a good mood but that’s why I like it . . . it’s not that I like it that he’s kissing my breasts, I like it because it means we are both okay enough that we can manage it. It’s a sign of something; it isn’t the feeling in and of itself. (Sidney, Caregiver)

Caregivers gained some comfort recalling sexual activities of the past. As one caregiver said, “I’m 72 now, I was about in my 50’s so I was young and the feelings, how do I put it, the feeling doesn’t bother me as much as it used to. Yet I still think of sexual intercourse and enjoying it” (Estelle, Caregiver). Another caregiver explained: “The intimacy part is long in the past. It’s just nice to remember because that’s how come we have two kids and stuff” (Francine, Caregiver).

However, not all participants had an affectionate relationship with their partners. In these circumstances, women sought out others with whom they could share affection. For one caregiver, she explained that since her spouse was unfaithful many years ago, she emotionally disconnected herself from him. Although she continued to feel compassion for him she talked about being grateful that she had children and that they have provided an outlet for her affection.

I was very happy when I had my kids and I could show my affection to my children. Because I have a need to hug and to be affectionate, I mean this is my inner nature. When he let me know that showing affection was phony and that you are just putting it on you don’t really mean it, once that was communicated to me I curtailed showing affection to my husband. But there were other people I could show affection to so that was okay. (Dorothy, Caregiver)

In summary, caregivers adapted to the changes resulting from their own and their spouses’ shifts in identity by developing new ways of expressing intimacy in order to create situations in which some of their needs could continue to be met. This demonstrates considerable agency in contrast to the overarching narrative of “older caregiving woman as asexual.”

### *Talking to Others About Sexuality and Intimacy*

We spoke at length with women about who they talked to about sexuality in the context of caregiving. Women told us that they rarely talked to their spouse about sexual concerns and when they did, it invariably was a negative experience. Women expressed the uselessness of engaging in conversations with spouses considering the dynamics of their partner’s illness and their role as caregiver. For

example, caregivers whose spouses had become aggressive or angry as part of their illness, feared a negative reaction if they were to bring up sexuality or intimacy, so they avoided the topic. One caregiver spoke to us about the time she brought up the topic of sexuality with her husband:

Not well . . . he was unpleasant, you know like 'you ugly cow, like uh how can I' he said 'I can't even go to the bathroom by myself why are you bugging me with this other stuff, all you think about is you.' So uh you know I thought ok that's it. (Francine, Caregiver)

Another caregiver used to discuss these topics with her partner when he first became ill, but has since chosen not to do this anymore:

There was no point talking to my husband about it, because like I say. It wasn't his fault, he got diabetes and all the rest, and um it's just your sex life comes to an end. (Estelle, Caregiver)

Finally, some caregivers felt that because of their partner's cognitive decline, a conversation about sexuality and intimacy would not be possible.

Caregivers stated that they rarely brought up intimacy or sexuality with friends or family. For example, when speaking about her friendship circle, this participant stated:

None of my friends have ever spoken about . . . We've said things about not having sex . . . another friend doesn't talk about it. No one talks about it. One friend talked about it at some point and I sort of mentioned something. But it isn't something that any of us talked about, our actual sex lives. (Sidney, Caregiver)

Conversations about sexuality in general were rare. When they did occur, caregivers felt that "it didn't do any good talking about it really" (Estelle, Caregiver), because "even if it would have helped, I couldn't do anything. It was a 'fait accompli', let me put it that way" (Estelle, Caregiver).

Caregivers told us that they would not talk about sexuality and intimacy with their service providers for a number of reasons. As stated above, some caregivers felt that there was nothing to discuss or that they were resigned to the way things were in their relationships. Caregivers expressed that service providers rarely brought up sexuality and intimacy and seemed to be uncomfortable in doing so, "I think for a lot of health care professionals they are uncomfortable" (Sidney, Caregiver), and "No one asks" (Sidney, Caregiver). For example:

He [my doctor] says things like 'down there' referring to vaginas, my family doctor, he is sort of my age and it's awkward for him I guess . . . given that you can see that he doesn't ask too much about our sex lives . . . and even actually, surprisingly I love my therapist, she hasn't really asked, maybe a long time ago but not recently, I guess she knows. (Sidney, Caregiver)

Very few caregivers we interviewed had talked to a health care professional about sexuality and intimacy in the context of caregiving. Some expressed that the issue came up only within the context of erectile problems related to illness.

Service providers we interviewed reaffirmed the almost total silence that exists around sexuality and intimacy in the health care encounter, confirming both the assumption of irrelevance and the discomfort of service providers in discussing sexuality with their older women clients. One service provider gave an example of one of the ways that the topic of sexuality is avoided, referencing the standardized tool used in caregiver assessments;

I mean the area of sexuality has always been a part of the evaluation, the global evaluation that is done in the home care setting but it's usually one of the areas that is consistently left blank, because people just don't approach that issue. (Shannon, Service Provider)

Service providers described some of the assumptions that are made about older women caregivers, such as "I think it's this assumption that with everything else going on in their lives that sexuality just kind of gets thrown on the back burner . . . I know that's not always true, but that's often the assumption" (Tony, Service Provider).

In summary, considering participant's narratives of sexuality as "irrelevant" and service provider's assumptions and discomforts, it is not surprising that sexuality is a topic absent in the caregiver and health care service provider encounter.

## Discussion and Conclusion

Our findings reveal several emergent themes related to the ways in which caregiving impacts the expression of sexuality and intimacy among women spousal caregivers. First, our study confirms the work of previous research which has emphasized how the caregiving role becomes all encompassing for older women, taking over other aspects of selfhood for women engaged in this type of care to their spouses (Brazil et al., 2008; Cheung & Hocking, 2004; Keating, 1999; Lee, 1999; Montgomery et al., 2000; Strang, 2001). Previous research on caregiver identity has explored caregivers' work and social lives (Arksey & Glendinning, 2008; Bainbridge, Cregan, & Kulik, 2006; Druxbury, Higgins, & Schroeder, 2009). Our findings contribute to this scholarship by adding findings related to women caregivers' sexual identity. The data confirm that sexual identity, like other aspects of caregiver identity previously researched, becomes subsumed with the weight of the tasks of caregiving. This leaves women little room to express their sexual selves within their relationships. For most women, their sexual identity is "put away," overshadowed by the demands of providing care. For some, women have tried to maintain a sexual life with their partners to no avail, either as a result of the shift in their perception of their partner as "care receiver" or because their partner has rejected their efforts to do so. Unfortunately, social expectations regarding older women as "asexual" or "undesirable" feed into women's perceptions of themselves, rendering the requirement to "give up" on their sexual lives once becoming caregivers. Women cope with their changed identities and realities by conceptualizing sexuality as "irrelevant" to their current lived experience. We are left to wonder about whether or not sexuality and intimacy are actually irrelevant to older women caring for their partners or if this is what women must tell themselves so that they can continue providing care under circumstances in which selfhood is denied. In some situations, the intersection of ageism in the form of "older women as asexual" (DeLamater & Sill, 2005) and denial of selfhood related to caregiving work together to limit older women caregivers' sense of possibility as sexual beings.

Still, women find ways to counter this experience in their daily lives. Women told us about how acts of intimacy experienced alone, with their partners, or with others with whom they share affection, provide opportunities to experience some forms of sexuality and intimacy within or despite their caregiving roles and responsibilities. It is important for these acts to be noted and visible, as they challenge our assumptions about older women as asexual beings. These findings add to the caregiving and sexuality literature by making us more aware of what older women caregivers need, and what they are already doing for themselves. Acknowledging the ways in which older women caregivers continue to experience sexuality and intimacy shows us that sexual expression is a continuum to be honored and supported, particularly within health and social care services designed to address the needs of caregivers. Recognizing the expression of sexuality and intimacy as part of an older women's health agenda is a necessary strategy to respond to older women caregivers' needs and realities.

Most women maintained that sexuality and intimacy are irrelevant to the point that they would not discuss these subjects with friends, family, or service providers. This is exacerbated by situations of silence and invisibility regarding sexuality and intimacy in the health care encounter originating with service providers themselves, who by omission, either reinforce that sexuality is indeed irrelevant to older women caregivers or that they themselves are too uncomfortable to bring these issues up with women (Bouman, Arcelus, & Benbow, 2006; Grant & Ragsdale, 2008). Women's hesitancy to discuss sexuality and intimacy with anyone, including friends, family, partners, and service providers, caused us to wonder about who women talk to about their feelings, and if they talk to anyone. We must go beyond women's expressed language of "irrelevance" to unearth feelings about their sexual and intimate identities that they may be deeming to be in conflict with their caregiving role and/or social norms of aging. In order to uncover what women are experiencing if/when they lose their identities as sexual beings to the identity of caregiver, we need to increase opportunities for women to discuss these issues in an environment that acknowledges the impact that the caregiving role can have on caregiver's sexual and intimate lives. Service providers can facilitate these discussions by bringing up the topic of sexuality and intimacy at the point of diagnosis and throughout the caregiving trajectory. Caregiver support groups can put sexuality and intimacy on the agenda, and work can be done with couples to address both partners' feelings about the impact that the caregiver/care receiver dynamic may be having on their sexual and intimate lives and identities.

This study reminds us that we must continually challenge the current constructions of caregiving and ageism, which result in older women being forced to embody the intersecting meta-narratives of "caregiver" and "old" to the detriment of all other aspects of selfhood. This is reinforced in society and in institutional systems, which require older women to provide the vast majority of care to their spouses. Because of this women have no space to claim themselves as multifaceted and as embodying multiple identities. We must continue to find ways to acknowledge, and make space for, the parts of women's identities that are denied or ignored, such as is often the lived experience among older women caregivers. In this way, we can contribute to women's agency and selfhood throughout their lives.

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