

Intimacy, Sexuality, and Early-Stage Dementia

The Changing Marital Relationship

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When one's marital partner receives a diagnosis of dementia, it has major ramifications for a couple. Such a diagnosis affects every aspect of marital life, including the most intimate areas. This qualitative study (1) focuses on the perspectives of married couples, caregivers, and their spouses in the early-stage dementia as they discuss their intimate relationships, both positive and negative aspects, (2) identifies how they cope with these changes to their marital relationship, and (3) develops evidenced-based recommendations for other couples in the early stages of dementia and for their healthcare providers.

Key words: Alzheimer's disease, intimacy, marital relationships, sexuality

We grow up with an understanding that your job and what you do is who you are. And if you can't do that... And I think sexuality is the same thing. What do we hear on television? All kinds of stuff, a good life, a good relationship, is two people sitting in matching bath tubs looking at the sun go down and being excited because their Viagra is kicking in. But that is not only who you are and what you are.

—60-year-old man with younger-onset dementia

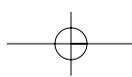
Dementia is a clinical syndrome and an all-encompassing term used to connote a loss of memory and other cognitive abilities. It is caused by a variety of conditions, Alzheimer's disease (AD) being the most common cause of dementia. Alzheimer's disease is a progressive irreversible dementia that is estimated to affect 5.2 million people currently in the United States and 11 million to 16 million by 2050, if prevention or effective treatment is not possible. The National Institutes of Health has labeled this disease a "looming national crisis." The prevalence of AD doubles every 5 years after the age of 65, and the US Census Bureau estimated that beginning in 2006 the baby boomer population started to

turn 60 at a rate of 330 persons every hour. In addition, the Alzheimer's Association estimates that there are 500 000 people in the United States younger than 65 years (younger onset) who also have AD or other types of dementia.¹⁻³ Thus, AD is a significant and mounting concern for older adults, their families, and the community.

When one's marital partner receives a diagnosis of dementia, it has major reverberating ramifications for a couple. Such a diagnosis affects every aspect of their marital lives, including the most intimate areas, for the well partner often moves from being a lover to becoming a caregiver, taking on more and more of the responsibility for her or his ill partner's daily care.⁴⁻⁷ Thus, AD can change the expression of intimacy and sexuality, yet this important part of the marital relationship, particularly in the very early stages of the disease, has not been well studied (H. Poole, PhD, unpublished data, 2003).⁸⁻¹⁰

What have most often been studied are problematic sexual behaviors of people with AD or sexuality issues in the later stage of the disease that arise in residential

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care.¹¹⁻¹⁶ One of the few major published empirical studies on AD and marriage^{17,18} includes only a limited section on affection and sexuality, but it does show that both caregivers and people with AD are willing to participate in the research. This is also the only study that includes the perspective of the diagnosed person; most studies simply provide the caregiver's perspective. Yet, intimacy and sexuality are an integral part of a couple's life and can be a major contributor to their quality of life.^{6,14,19} Indeed, when memory is gone, it is this intimacy that may provide an important bridge to the past.^{20,21} This proposed study seeks to add to this knowledge base and add a unique viewpoint by (1) focusing on the perspectives of married couples, caregivers, and their spouses in the early-stage dementia as they discuss their intimate relationships, both positive and negative aspects (their viewpoint has been given limited voice), (2) identifying how they cope with these changes to their marital relationship, and (3) developing evidenced-based recommendations for other couples in the early stages of dementia and for their healthcare providers as the couples negotiate this sensitive, yet vital part of marriage.

Sex most often refers to physical aspects, particularly the act of physical intercourse, yet sexuality has a much broader meaning that includes both social and psychological components. Indeed, one's sexuality is part of each person's identity.²² However, to fully understand the impact of a dementing disease on a couple's relationship, this study used an even broader framework that encompassed

sexuality but included much more, the concept of intimacy. As Taylor²³ writes in his personal essays on living with early-stage dementia, "Once I found that sex was not enough to create and maintain an intimate relationship, I began exploring additional components to create and maintain intimate relationships. There are levels within levels of intimacy."^(p169) Moss and Schwebel²⁴ proposed a formal definition of romantic intimacy, which provides a helpful conceptual framework from which it is easy to understand the people's narratives presented in the following text. They broke down the concept of intimacy into 5 components: (1) *commitment*, a desire to permanently remain with a partner; (2) *affect intimacy*, the emotional depth and closeness a couple shares; (3) *cognitive intimacy*, the shared thinking, information, values, and goals of the relationship; (4) *physical intimacy*, the shared physical attractiveness, encounters, proximity, and sexuality; and (5) *mutuality*, a mutual interaction and exchange, though partners may invest different levels of energy into maintaining intimacy. As you listen to the voices of the people in the "Findings" section, you will hear varying levels of these interrelated 5 components.

There has been a dearth of research in the area of intimacy, sexuality, and dementia for a number of reasons. First of all, sexuality is a very sensitive topic to study and to date there has been very few successful studies of the subject.²⁵⁻²⁸ Second, there are persistent prevailing cultural *agist* myths and stereotypes about sexuality and the elderly.^{21,22,29-31} Third, as a cohort, older adults do not openly talk about sexuality. As one of the male caregivers in this study admitted,

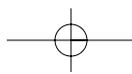
I wasn't happy about discussing this topic either. I'm sort of old school; whatever happens in your private sex life and marriage stays there. Of course, in the navy it was different when I was in the navy. But as far as husband and wife, it's a different situation. But we decided if we could help others....

Finally, for some people, there is still a stigma attached to a diagnosis of AD.^{32,33} However, given the predicted growing number of families whose lives will be touched by AD and other forms of dementia, it is imperative that this line of research be pursued.

METHODS

Design

A grounded theory approach was chosen to provide an in-depth understanding of the subjective experience of people with early-stage dementia and their caregivers around the topic of intimacy, primarily drawing on the work of



Glaser and Strauss³⁴ and Glaser.³⁵ As a qualitative phenomenologic methodology, grounded theory is particularly useful when there is limited knowledge about a phenomenon. This means that an inductive approach is used that begins with individual experiences and findings are grounded in this specific context.³⁴ Thus, in the context of the reported study, the words of the participants are used to explain the impact of dementia on the intimacy of their marital relationships.

Data collection

Background

The impetus for this research project originated with a social worker, who coordinated early-stage support groups for a local chapter of the Alzheimer's Association, and one of its national board members, who had also been involved in running support groups. They had seen from their groups a growing need to develop evidence-based recommendations for families and the diagnosed person on how to handle the changes caused by dementia in the area of marital intimacy and sexuality. The 2 leaders had noticed that if support group members were comfortable, they were willing to discuss these issues. These 2 leaders contacted the author to request her collaboration with the association and take responsibility for writing a grant proposal, and designing and conducting the study. Thus, the study was developed in full partnership with the Cleveland Area Chapter of the Alzheimer's Association and it was approved by the institutional review board of the researcher's university before data collection began.

In consultation with the association, given the sensitive nature of the topic, data were going to be originally collected through individual interviews with couples dealing with the early stages of dementia. However, after more discussions between the researcher and the Association, it was decided that a group format would be used. This topic originated in support groups, and by using a group format, themes and other valuable information might evolve from the group interactions, which could be missed through individual interviews. Thus, it was decided that the data would be collected through focus groups, using a purposive sample selected from couples who had attended early-stage support groups run by the association.

The sample criteria were as follows: (1) the person had to have received a diagnosis of early-stage dementia or mild cognitive impairment; (2) the participants had to be in a *long-term marriage* (defined as being married for at least 15 years); (3) both male and female caregivers and

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people with dementia would be represented; and (4) the participants had to have attended an early-stage support group. The social worker from the Association contacted the couples to inquire about their interest in participating in the study. At the time of the initial phone call, the reminder phone call, and before the focus groups started, the participants were again reminded of the purpose and topic of the group and the informed consent information was read to them. After initially agreeing to participate, only 1 couple decided not to participate.

It was decided that 8 focus groups would be conducted consisting of 3 to 5 people each. The groups were broken down by categories, that is, people with dementia and caregivers, and then further broken down by gender. Thus, for people with early-stage dementia, there would be 2 groups of women and 2 groups of men, and the same breakdown would occur for caregivers. A facilitator and an assistant led each focus group. All focus group leaders had experience with people with dementia and their families. In addition, they participated in a focus group training session, in which they also had a chance to discuss, review, and have input into the focus group questions. The focus groups were held in community buildings central to either the east or west side of the town and lasted for approximately 1.5 hours. All focus groups were audio taped with permission of the participants and later transcribed. Also, the assistant moderator took field notes during the focus group sessions, which were checked against the transcription for consistency. Debriefing took place by the group leaders after the sessions.

Sample

The total number of people participating in the study was 32; 16 caregivers and 16 people with early-stage dementia (Tables 1 and 2). All the participants were married, but 2 people with dementia came to the focus groups without

TABLE 1.

Characteristics of People With Early-Stage Dementia (N = 16)	
Characteristic	n (%)
Gender	
Male	7 (44)
Female	9 (56)
Age, y	
Mean	67.75
Range	56–77
Race/ethnicity	
White	14 (87)
African American	2 (13)
Pacific Islander	
Level of education	
High school	5 (31)
Some college	3 (19)
College	3 (19)
Graduate school	5 (31)
Occupation	
Blue collar	6 (38)
Office/sales/middle management	2 (12)
Professional/business executive	8 (50)
Diagnosis	
Alzheimer’s disease	9 (56)
Vascular dementia	4 (25)
Mild cognitive impairment	3 (18)
Number of years with diagnosis	
Mean	3.47
Range	5 mo–9 y
Number of years married to same partner	
Mean	39.13
Range	19–52
How long as member of support groups	
Mean, y	1.59
Range	5 mo–5 y

their spouses because 1 spouse was working and 1 was out of town. In addition, 2 caregivers came without their spouses because 1 of the spouses had recently died and 1 was recently placed in a long-term care facility. Thus, the average number of years married (for caregivers 41.81 years and for people with dementia 39.13 years) and the gender breakdown (for caregivers, 56% male, and for the people with dementia, 44% male) in Tables 1 and 2 does not match.

This was a younger sample of couples when compared with the age of the general dementia population. The average age of the individuals with dementia in the study

TABLE 2.

Characteristics of Caregivers (N = 16)	
Characteristic	n (%)
Gender	
Male	9 (56)
Female	7 (44)
Age, y	
Mean	62.19
Range	54–79
Race/ethnicity	
White	13 (81)
African American	2 (13)
Pacific Islander	1 (6)
Level of education	
High school	3 (19)
Some college	4 (25)
College	4 (25)
Graduate school	5 (31)
Occupation	
Blue collar	6 (38)
Office/sales/middle management	3 (18)
Professional/business executive	7 (44)
Number of years married to same partner	
Mean	41.81
Range	19–59
How long as member of support groups	
Mean, y	2.28
Range	4 mo–6 y

was 67.75 years (range = 56–77 years), and for the caregivers, the average age was 62.19 (range = 54–79 years). The younger age may be due to the sample criteria requiring a diagnosis of early-stage dementia or mild cognitive impairment and/or the specific topic of the study. It was a predominately white and well-educated sample, with 81% of caregivers and 69% of people with dementia having at least some college education. These demographics mirror the population that usually joins support groups, better educated, and white participants. The average number of years of support group attendance for the caregivers and the people with dementia was 2.28 and 1.59 years, respectively.

Focus group questions

The focus group questions were developed with input and feedback from the Alzheimer’s Association staff and volunteers, some of whom were caregivers. There were

9 questions that focused on the impact of dementia on the sexual/intimate relationships of the couples, changes that were occurring (positive and negative), how people coped, and recommendations to assist other couples and healthcare providers handle these concerns.

Data analysis

Using the analytical strategy suggested by Glaser and Strauss,³⁴ the transcripts were read to develop substantive codes for each focus group. This involved a 4-step process. First, each transcript was read in its entirety. Then, they were read a second time to develop codes that were grouped around the questions and/or the themes, which emerged from the discussions. To be considered a major theme or response, the code had to have appeared in 50% of the caregivers' group or 50% of the diagnosed persons' group. Third, a master list of themes and question responses from each focus group was developed to allow for easy cross-group examination. Finally, quotes that summarized these themes/responses were recorded on the master list.

Limitations

There are many limitations to this qualitative study. The sample was small, and the combined total of 32 participants certainly did not comprise a representative sample of people with early dementia and their caregivers. In addition, this sample was drawn from a unique population, that is, people who attend AD support groups. Such limited sample size and unique population constrain the generalizability of the findings. This study also used a cross-sectional method of data collection to examine a dynamic process, the impact of living dementia. However, qualitative research makes no claim to be representative of the population it is examining. The purpose of this methodology is to present a more in-depth, diverse, and complex picture of a phenomenon that has been previously reported and to identify possible variables that need to be tested and confirmed in larger representative studies. In addition, from the narratives comes a better understanding of the issues and complexities people with early-stage dementia and their caregivers face as they grapple with the impact of the disease on the most intimate aspects of their marital relationships.

FINDINGS

The analytical framework from which these data were examined revolved around 3 main areas: (1) changes in

couples' relationships, especially around the expression of intimacy as they deal with the early-stage dementia; (2) strategies that assist them in coping with the changes in the marital relationship; and (3) recommendations for other couples struggling with similar issues and for healthcare professionals, who provide assistance. These areas were analyzed from the perspectives of both caregivers and people with dementia, and when relevant, gender similarities and differences are highlighted. In this study, both men and women were equally willing to share their thoughts about their intimate relationships, going against some of the cohort and gender stereotypes of this older population.

Changes in the marital relationship

A diagnosis of dementia has a dramatic impact on a couple's relationship. The once established balance of roles and expectations in the relationship are forever changed. As one male caregiver in this study explained, "I'm walking a fine line and someone's erasing it right behind me. It's that tenuous at times. You don't know: should I do this or do I do this and, O, why didn't I do this?" The main focus of this study is the impact of a dementing illness on intimate relationships, but to fully understand what is happening in the lives of couples, it needs to be set within the larger context of the overall marital relationship. Thus, these first set of narratives from caregivers and people with dementia provide this context by voicing their concerns about role loss, dependency, changing social roles, role reversal, and trying to find a new balance in their relationship.

Role loss and dependency

In the focus groups, many people with dementia expressed concern about role loss and issues of dependency. The quotes in the subsequent text capture these thoughts. One woman with dementia stated,

Well. I think my husband has to work harder. He keeps well, track of everything that I'm supposed to be doing. You know, he had to take on responsibility of things that I might forget. *His day has become my day.*

A man with dementia in another focus group echoed similar ideas when he said,

She's [his wife] busy; she's got things to do. She'll get *ouchy* at times and I understand why. She's carrying the major load. The responsibilities used to be mine. The biggest things that I miss are the fact that I was able to.

Another man struggling with his growing dependency admitted, "Being dependent is the hardest thing for me to do, to be suddenly dependent."

Changing social roles and role reversal

As would be expected, some caregivers in the focus groups experienced the opposite effect from what was described. They had to acquire and learn new and additional roles in the marital relationship. Male caregivers particularly voiced these concerns, as evidenced by these quotes. "You reprogram and learn. You learn things that you never thought you'd have to, like makeup. Bathing.... How do you get your wife to take a shower?" Another husband stated,

And part of the change is also, it creeps in, in my mind that it's a little bit more of a father-daughter than it used to be. Probably because there are little things that I have to take care of that she would have taken care of before. Things that make you start to feel more like a father-daughter connectedness than 2 people on an equal level of operation.

Finding a new balance in the relationship

A key to continue enjoying the marital relationship for a number of couples in the focus groups was to try to find a new *flexible* balance. As one female caregiver confided, "We enjoy ourselves. We have really good times. It's not the life we had planned. 'Flexible Are Us' is what I say all of the time." A male caregiver expressed his views this way:

This has been a journey. So when she was first diagnosed, other than the brief short-term memory issue she was permanently herself. Our relationship was the same. It wasn't father-daughter. It was just that we knew something was coming upon us here. As time progressed, I probably had to assist her more. That's been a growing issue in our relationship. She's always been a very independent person, so she kind of resists that. But she knows she needs it. So we're fighting through how to love one another and respect one another, but, yet, there's some things I need to do to insure her safety and well-being. How do I become the spouse that is fair to the definition of spouse today that can still, I guess, provide that respect, but still take care of in a guarding way? That's difficult, in terms of knowing that fine line.

Changes related to intimacy and sexuality

From analysis of the data, 2 main notable themes emerged: (1) a typology of the changes and (2) recognition that some

positive changes could occur among the negative experiences. A typology of 2 overall types emerged, for both people with dementia and caregivers. There was the one type who felt that though there was less physical sexual intimacy, they had actually grown closer and more intimate on other levels. This is somewhat similar to the conceptual framework on intimacy of Moss and Schwebel²⁴ discussed in the introduction. This group talked about psychological intimacy, commitment, and other expressions of intimacy. They still found much satisfaction in their marital relationship. The second type had both limited feelings of intimacy and sexual satisfaction. They expressed a great deal of frustration, anger, and disappointment with the changing relationship.

Most of the time, the couples in the study were aware of each other's feelings and fell into the same type; however, there were a couple of cases in which the person with dementia and her or his spouse were at odds with each other, not in tune with how each other was feeling ($N = 3$). Three people with dementia believed that there were no changes, though their spouses did not agree. This incongruence might be due to the diagnosed individuals' lack of awareness, a symptom of dementia, or psychological denial. There were also 2 couples ($N = 4$) who believed that dementia had had no impact on their intimate relationship.

Also, some participants were cognizant of other positive changes that occurred in their marital relationship and within themselves. These changes included personal growth and reconfirming of their marital commitment.

Other healthcare issues

In addition, it is important to note that for some couples because of other healthcare issues, such as diabetes, heart conditions, or prostate problems, their level of sexual activity had already dropped, previous to the dementia diagnosis. Thus, dementia was not the cause, but it added to the change. This occurrence is best captured by the following 2 quotes. One husband caregiver of the first type in the typology admitted,

This is going to sound crazy, in a way, I am kind of thankful I have prostate problems, the urologist prescribed a couple of different medications and one of the side effects is that it causes me to lose some of that sexual drive. As this is [dementia] going along, I'm kind of thinking WHEW! [Let' some pressure off]. Maybe all of this'll kind of work out.

And, a female caregiver from the second type stated,

He is very interested in sex. But, because of his heart problems, he takes a lot of medicine for his heart

every day; his heart is very weak. It's not anywhere like it once was. He thinks about it, but he is just too tired. It's difficult.

Type 1: Less sexual but more intimacy (N = 12)

Both people with dementia and caregivers in this group voiced growing feelings of intimacy with their spouse, though the level of sexual intimacy had lessened. For them, this intimacy resulted in a closer level of relationship.

Perspectives of the person with dementia. One man described his growing relationship with his wife this way:

The closeness really extends to not only 1 thing. We are 2 people who were always close . . . each other's best friends. After the stroke, when I wasn't able to participate, I wasn't able to walk around. What she did; how she got through this, more than anything else helps me to recognize the importance of her and how close she is to me. Our closeness is intimacy. We go for walks, always hold hands; we talk. I say, "Let's go upstairs and I'll rub your back and you can rub mine."

A woman expressed her closeness to her husband this way: "I guess after everything's done and the dishes are put away and we sit together on the couch. And he will have his arm around me and we still talk. That is the very best, the most intimate time."

Perspectives of the caregiver. Three male caregivers expressed their growing feelings of intimacy with their wives in the following manner:

I would say in our situation it has tapered off a bit. Our relationship has been, oddly, more platonic but at a deeper level, too. I feel things about our relationship that have drawn me even closer to her, even though the physical has been decreasing a bit.

My wife has been suffering with a myriad of other health ailments that she's had for some time. She's faced quite a bit upon her. In terms of her sexuality, I would say it's probably less in terms of the physical now. The intimacy, the emotional intimacy, psychological intimacy, is stronger I feel. It has allowed me, perhaps to look deeper into myself, which is something men may have difficulty doing.

When you're a caretaker, the sexual intimacy that we had as husbands just isn't there any more. But we can still love them, REALLY love them, probably even more so that before.



For people with dementia, this loss of intimacy on multiple levels occurred for a number of reasons, such as the impact of the disease on their self-concept, anger and disappointment with themselves and their situation, and anger and disappointment at their spouse for their inability to handle the changes in them.

One female caregiver echoed a similar theme:

First of all, intimacy means so many different things. We have always been exceptionally close. We don't have any children, have always been each other's best friend, and just really shared so much with one another. On some levels, we are closer. Intimacy is [shown] in so many ways . . . just by sharing or talking.

Another wife described her feelings this way:

In some ways, it's made us closer in that now, I suppose, because it's now US AGAINST THE WORLD. When it comes down to it, you have children to support, you have friends, you have social workers, but when it comes down to it, it is the 2 of us. I think we both realize that. He kisses me every night, and I kiss him every morning, and we still love each other. Got good grandchildren and got good children. Our relationship is wonderful. I wouldn't trade it for anybody, and I still love him and he loves me. That means a lot. If you can't have sex, you can't have sex, though I know he feels frustrated.

Type 2: Limited intimacy on multiple levels (N = 13)

Perspectives of the person with dementia. For people with dementia, this loss of intimacy on multiple levels occurred for a number of reasons, such as the impact of the disease on their self-concept, anger and disappointment with themselves and their situation, and anger and disappointment at their spouse for their inability to handle the changes in them. The narratives in the following text capture some of the diagnosed individuals' frustration and disappointment.

One woman poignantly admitted:

I'm *not* who he married anymore. There's pieces of me missing. There are little pieces of me sort of breaking away... little chunks. If I was to see this little clay doll of myself, there's a piece there gone, and there's a piece here gone. My shoulder, my leg, my foot in my boot are gone, broken away. But it's the thought that we're trying to put the whole clay person together and it won't hold up. It's no longer a solid piece of clay. It's crumbling. I see so many changes this past month. I don't recognize who I am right now.

Another woman confided:

It's like the emotional part is just totally gone. It's hard, any intimacy. We used to go to the movies a lot, hold hands, and do those kinds of things. Little by little, everything that we had done as a couple is just gone. But, he still kisses me goodnight and tells me how much he loves me. But as far as any intimacy or anything like that, well... It's been quite an adjustment for me. He fills his days with meetings and bridge and everything else just to keep himself busy, and it's just not there. Never have deep personal conversations with my husband anymore. I just don't know how to hold on to that intimacy.

Another woman disclosed:

My husband cannot handle the situation; he left to spend the winter in Florida. My children stop in every day to see how I am doing. He does call once in awhile, probably my [daughter] told him to call. I'm not saying every day, it's not great communication, and I maybe was expecting more. I'm furious; I'm just furious. I had told my children that he can never come back home.

One man revealed simply that "she is not available any more. That's a fact." Another man expresses his disappointment this way: "She's busy all of the time. She's always doing something. She doesn't turn me away or anything like that. It's just maybe she thinks I'm not going to develop into anything, so why bother?"

And, another man stated,

I received the diagnosis of loss of memory from Alzheimer's. I became impotent about 4 weeks after that, after the diagnosis. Our sex life was pretty adequate, quite good. This eliminates that. I have not found any ease or [way to be] comfortable with this, any way not to be angry.

Perspectives of the caregiver. From some of the caregivers' perspectives in the focus groups, the disease has drastically

changed their marital situation. For some, role reversal has taken place, making them feel more like a caregiver (like a parent) than a lover. Also, with all the added responsibilities, by evening, many are so tired that expressions of intimacy are not a priority.

Three men voiced some of these thoughts as follows:

I was so busy getting things done, things I'd never done before. I was tired at the end of the day. Just trying to figure out a way to get her to go to bed, stay in bed, go to sleep, and stuff like that ... sex is the last thing I am thinking about.

The 2 things, the diagnosis and sexuality, seem so incongruous because when you've got Alzheimer's, there really isn't much sexuality. I can't remember when we had sex last. My wife has just forgotten it. And I really don't know what to do about it; it's just not there. It would be a 1-sided thing if I forced the issue. It's just part of our life that's not there any more. But again, there are so many things to occupy my time and my day that I don't need anything more.

She's been affectionate all along and may be now so. And I believe she would still like to have sex. She always enjoyed sex. And I feel some guilt about that because I just don't feel like it any more.

A female caregiver also echoed some of these concerns:

Our sexual life ended about a year after the diagnosis. Not because of Alzheimer's. I had cancer 16 years ago, and chemotherapy puts you right through the change of life. So I was no longer able to. He has diabetes; he was no longer able to either. So that kind of happened for us at the same time, [but the diagnosis exacerbated it]. It is definitely at that time he said, "I want to have sex even when I don't know you anymore." That was his first reaction to the diagnosis and that hurt my feelings. I really feel like I'm a caregiver taking care of a child a lot of times. The closeness is not there. He doesn't talk much. Yes, I'd say the intimacy is very low.

Thus, from the focus groups data, a typology emerged of 2 distinct groups, mirrored by both people with dementia and their caregivers. One group was able to develop deeper levels of intimacy, though sexual intimacy diminished. The other group couples were too devastated by the impact of the diagnosis on their marital relationship and had not found other means of expressing their love. This group was not well connected with each other and did not understand the depth of the others' feelings. Some of these couples had had close relationships previous to the diagnosis and others did not.

Positive changes in the marital relationship

Negative experiences from a diagnosis of dementia are often expressed and this also occurred in these focus groups. One women caregiver stated, "When I heard the diagnosis, I cried for about a year and a half." One man with AD declared, "Nothing positive has come or will ever come from this." However, also from this experience, some people were able to give voice to some positive changes that occurred. More of the male caregivers than the female caregivers could voice positive changes in their intimate relationships with their wives. They acknowledged a personal growth in themselves, gained an appreciation of smaller things in life, and recognized their commitment to care for their wives. Listen to the narratives of the husbands in the following.

Personal growth:

I think that because of all this it has perhaps forced or allowed me, to take a step back and sort of rediscover and redefine what this whole relationship means in terms of how we satisfy one another. Our sexual experiences are today, as I mentioned earlier, are not as frequent as they were. But the other kinds of things, I certainly have discovered, are so satisfying, at least psychologically, for me. Perhaps, to put it in a nutshell, I think I've grown somewhat. I've certainly grown somewhat. Now, would I have grown this rapidly had this not occurred? I doubt it. But I confess that I think I've grown. Why you have these types of experiences, sad though they may be, you find something that's positive something that's worth holding on to.

I just guess I learned that under the pressure of being the one that's got to do these things; I can do it [things never done before]. That was, on a personal level, that felt kind of good. It's great. I surprised myself.

Appreciation of smaller things:

I have leaned to relish everything we can do together. It's just a matter from taking all you can from life. But the good things don't have to be the silver lining. They don't have to be the big things. Not any more. Just give me a little bit of cream on the day.

Commitment:

You become not just a role player; you go back to these vows you took. How you were standing up and how they tell, from death do us part, united for better or for worse. I always felt that she would give

her heart and soul to do the same for me. It was never a question in my mind about what I had to do.

Whether we want to admit it or not, at least in my case, my wife did everything for me. I could say to her, "I've got a taste for ribs." And I come home and there are ribs on the table. Or I say, "I got to cut the grass before we go out." And I come home to grass that's been cut. She did that for 40 years, and for the last 6 or 7, it was my turn. It wasn't really all that difficult. It was difficult, but what I mean, it was a joy for me to take care of her

Perspectives of the person with dementia. Some people with dementia could also recognize that some positives had come from these changes in the relationship with their spouse, though for many, the negatives, especially the losses that were discussed earlier, overpowered the positives. Some of the positives that the individuals mentioned were a greater appreciation of their spouse and a better understanding of the depth of their relationship.

Appreciation of spouse:

I'm thankful for my husband. He's really great. He keeps track of all the things I have to do.

The thing is, I realize how much I depend on her, how much, how lucky I am. That's where I am.

I feel very fortunate to have a husband who cares about my feelings and not just his own.

Better understanding of the relationship:

One woman had written out a statement to share with her focus group:

I have come to realize in my experience, caring, loving, and sensitivity to ones spouse's feeling and concerns is more crucial to creating a successful marriage for us. It takes priority over the importance of sexual encounters with each other. Yet, sexual pleasure can enhance the closeness of the relationship as long as it can last, which might tend to be easier for the wife than the husband as they age. Often cuddling and holding and kissing can be a substitute somewhat. I feel very fulfilled with what we have because I have a positive good relationship that is close and caring. That's what comes first. It's nice when sex comes along with it, but it's not as common as it was before.

A man also voiced his growing awareness:

I think you take on a different view of the world around you. [You realize] there's too much time

wasted on playing games or on politics and that makes me crazy; it comes around to, it extends over to relationships. There's no point to that. My relationship with my wife now is relatively straightforward and you deal with the realities that you have, not things you lost. You can lament over it. You can think about it, maybe even be teased by it. But it's what left, what you have left is even more of a gift or more of a joy. So, I guess positive. Positive changes are how you look at the world. If you don't get caught up in the stuff that maybe before you would that would beat you down or that you'd be worried about. What you have, and what exists, what is now, is what's most important. You cherish what you have left. In that sense, there's the positive; the positive changes that have come from the memory loss. Not that I am saying that I'd be satisfied with that before, but it's not as bad as it could possibly be. Don't allow the "What ifs" or the "I wish it was" to influence you. What you're going to eat. Or what you have to have. That doesn't mean squat. You realize that now. I think the intimacy, the closeness of the relationship, probably even takes on more importance now because that IS here. And they can't take that away from you.

To summarize this first section on changes in the intimate aspects of the marital relationship, 2 groups emerged, both feeling the effects of the diagnosis of dementia on their levels of sexual intimacy. Few couples' relationships were untouched by a diagnosis of a dementing illness. One group, however, was able to develop other deeper levels of intimacy, which did not necessarily make up for the loss of sexual intimacy but provided a closeness often not developed before the diagnosis. The other group experienced both a diminishing sexual intimacy and intimacy on other levels. The diagnosis had a devastating impact on their relationship. Both caregivers and people with dementia fell into these 2 groups; both were for the most part insightful about what has happening to this aspect of their marital relationship. Not all but most couples' statements were congruent with their partner's reactions. In addition, in both groups, some people were able to express the expected negative experiences, as well as some positive ones, which had come from their struggle with dementia and on some levels brought personal satisfaction.

Strategies for coping with changes in the marital relationship

As heard from these narratives, a diagnosis of dementia has a tremendous impact on the balance of and satisfaction in

marital relationships, intimate and other aspects. A key question is how do couples cope and continue to find satisfaction with their marital life? Caregivers and people with dementia in the study identified some similar coping strategies, but they also spoke of some unique ones. There does appear to be some gender differences.

Perspectives of the caregiver

For many caregivers, the most often mentioned coping strategies were learning to become flexible, acceptance of their spouses' condition, a sense of humor, emotional support, family support, and their religious beliefs. There were no gender differences in these coping strategies. However, male caregivers also talked about their use of respite and physical exercising, not discussed by the women. Following are some of the narratives that explain these strategies:

Flexibility:

I get a mixture of things every day and I have learned to take it in my stride. I know it's not her; it's that monster [the disease].

Humor:

When you get through the day and you're both relatively intact. Then you sit down and you laugh. She laughs. Yes, where she has to put the glass down, pick the napkin up laugh. Cover her face in tears style, because we've always been a laughing family. So, for me, when I see that, it tells me that there's part of her that's still there, we're still there. So I relish that.

Acceptance:

You have to just step up to this and accept that this is what you have; this is your life, your spouse, it's what you've got to do. It is what it is. I wouldn't choose this, if I had my druthers. It's what you have to do. My wife would have done a much better job than I.

Emotional support:

The groups we go to, we've become good friends with everybody there. The honesty about having to talk about how angry you are, how *sad* you are. Maybe it's about how you deal with it. And guess what? *We don't always deal with it.* But, what are you going to do? There's been times when I've been so upset and I talk about it at the Association [support groups].

Family:

I have a daughter who is fantastic; I depend upon her, even though she lives in California. She wants to drop her whole life and come here. I'm trying to not allow her to do that.

Religion:

I pray all the time: before I go to bed and when I wake up. It helps, yes, it does. I put my faith in God.

Exercise:

I exercise daily. I realize I need to take care of myself.

Respite:

Sometimes you just think about you then. Sometimes you've just got to have a place, got to have some time for me. I got to get out and play golf once a week or something.

Perspectives of the person with dementia

Both genders used humor, acceptance, and support groups as coping strategies. However, as would be expected, women used an emotional release such as crying, whereas men created a separate place for themselves to get away and be alone.

Humor:

If I can keep humor in my life, then everything is fine.

Acceptance:

I'm having a problem with the word MEMORY LOSS. Everywhere we go and even online, I'm trying to find other women that have early onset. When I was diagnosed, I was able to say the word Alzheimer's. I have Alzheimer's. No one uses it, no one's using the word Alzheimer's; it's like the Big C-word; we couldn't say it.

Emotional support:

Thank God for support groups, without them I'd be gone.

Own space:

I've got a room all my own. It's a junky room but it's my own and I can close the door. Somebody comes to visit; they don't even know that room exists. But I know its there. It's a place where I can go.

Emotional release:

Mostly I cry on the inside. Periodically I tell him, I am having a meltdown. I have it; then I go on my way.

Both caregivers and people with the disease in this sample used coping strategies such as humor, acceptance of the reality of the situation, and support groups for emotional support. However, diagnosed individuals found solace in having a space of their own (men) and in the need for an emotional release (women). Both female and male caregivers relied strongly on other family members, especially their children for support, and religious beliefs. Male caregivers also relied on respite, time away, and the release of physical exercise. All these coping strategies assisted couples in dealing with the stresses in their marital relationship and thus still be able to maintain some marital intimacy and satisfaction.

Recommendations for other couples and healthcare professionals

From the focus group data, came recommendations for other couples struggling with similar issues dealing with intimacy and also recommendations for healthcare professionals, who provide assistance to the couples. The participants' recommendations for other couples dealing with early-stage dementia fell into 3 main areas: the need for emotional support; the importance of continually working on good marital communication; and the importance of being informed about dementia, its progression, and effects. These recommendations came from all the focus groups, people with dementia and their spouses, regardless of gender.

For other couples

Emotional support. Various types of emotional support were suggested from joining support groups (as might be expected from this sample) to seeking the help of a counselor.

One male caregiver stated:

I would tell them to seek help and input from others that also may be experiencing this same kind of thing. These types of groups are helpful. ... There's maybe no answer. But there are people who have experienced this before and who are experiencing this now. Even if you just come out of a meeting knowing that somebody tried this or that or something that you think is foolish. They tried it. You're not alone.

And, one female caregiver stated:

Seek help of counselor as a couple; see a therapist—my friends found out that he has Alzheimer's and I'm sitting crying. And she said, "Well at least you don't have it yourself." There are so many people who want to take away what you're feeling.

Another woman with dementia stated, "We need more groups like this where we can talk about this topic."

Good communication in the marriage. One man with dementia suggested, "The main thing is to try to understand the relationship. Togetherness is the main thing ... thinking, talking and having activities together. Togetherness [however it is expressed] means a whole lot."

A female caregiver echoed these thoughts when she recommended, "To be able to talk to each other. Keep the line of communication open."

Being informed about dementia. One female caregiver stated: "Read as much as you can on the topic of AD. Educate yourself." A man with dementia also recommended, "Always get a second opinion; and get a doctor who treats you both with dignity and listens to you."

For healthcare providers

Both caregivers and people with the disease talked about the important role doctors could play in helping couples deal with problems of intimacy. Doctors are often the first people couples talk to about their concerns with dementia, but only 1 couple mentioned that their doctors at all talked with them about the impact the diagnosis could have on the intimate aspects of their relationship. Most couples said doctors were too busy, did not think it was important or relevant to older adults, or were too uncomfortable themselves with the topic. However, the participants offered a number of creative and doable suggestions about how the healthcare profession could be of more assistance.

One female caregiver stated:

In a good relationship [patient-doctor], the doctor should be able to bring up the topic of sexuality with the couple. Asking questions like: How is your relationship? How is your sexual relationship? Do you want to talk about it? Is there anything I can do?

A man with dementia stated:

I'm thinking about my family doctor. He's concerned and that. But, I don't know. He doesn't have the time, for one thing. And so, he's unable to give you the time. Maybe the basics, maybe to hear you out, maybe able to confirm and to give at least a "heads-up," at least with the things that you're facing. So that when you run into it, it's not a negative or a positive. My doctor said, "Here's the Viagra." I just think that he, the professional, if he's a good professional, would look beyond just the physical things that you are going to have to deal with [sexuality].

One focus group of men with dementia talked about the need to develop a standardized list of questions regarding sexuality and dementia that people with the disease and/or their spouse can bring with them into a medical appointment to ask the doctor. Often because of the time constraints of the doctor and the difficulty of discussing the topic, couples neither initiate the conversation, as mentioned above, nor do the doctors. The men also suggested that they could role play asking the questions in a support group meeting so that they would not feel so uncomfortable.

You need some kind of a *crib sheet* going in that lets you tell the doctor "I'm sorry; there's nothing personal, I have a memory issue, and I need to have these questions answered." We have more rights than we use. It would be very helpful. You just feel that they're just so much smarter than you. When you've got dementia, you are always looking for a word that just doesn't come too easily. So, you can't talk like you used to. A sheet would be great. ... A sheet for our spouses too. It has to be short and succinct.

Once you develop this instrument, do a series within this organization of role playing situations. To get the Alzheimer's patient to sit, to go through it, play it out among pairs of Alzheimer's patients. One can play the doctor and the other the patient and they can switch. They can get comfortable asking these uncomfortable questions in a nonhostile environment. I don't mean that doctors are hostile, but time is their biggest asset and this is going to encroach on that.

Thus, given the opportunity, couples were able to suggest recommendations that would be helpful to other couples in their situation and could assist healthcare professionals in helping them. These recommendations were realistic and meaningful for this population.

DISCUSSION

What becomes clear from this study is that concerns about intimacy and sexuality in a marital relationship are not just the realm of young people. Older adults and, in this study, older adults with dementia and their spouses, when given the opportunity, were willing to discuss their concerns and experiences. A diagnosis of dementia impacts all aspects of the marital experience, including the most intimate ones. Studies have demonstrated that good marriages can have numerous positive health benefits and can increase quality of life and life satisfaction²¹; close feelings of intimacy with a marital partner are a component of this marital satisfaction. Thus, identifying ways to handle the changes that dementia creates on the most intimate aspects of the marital relationship is crucial.

From the focus group data, a typology emerged of 2 ways in which couples dealt with this impact of dementia. For both groups, the diagnosis had a detrimental affect on their level of sexual intimacy. However, one group was able to develop and draw on other levels of the relationship, becoming closer in the realms of psychologic and emotional intimacy. They also still had shared values. Although dementia can affect a cognitive connectiveness, it does not change the core being of individuals.^{7,32} The importance of these components of intimacy, psychologic intimacy, and shared values were central to the conceptual framework of romantic intimacy of Moss and Schwebel.²⁴ These couples also had a strong commitment to each other and were able to find other ways to express their physical intimacy, such as hugging, massaging, or intimate touching. The other group was more detrimentally affected by the diagnosis of dementia. It affected not only their physical intimacy but also all other intimate levels of relationship. The diagnosis of dementia caused the couples' relationship to become more distant on multiple levels.

No doubt, a strong marital relationship prior to the diagnosis makes it easier to develop other expressions of intimacy after the diagnosis; however, this was not true in all cases. For some couples, dementia drew them closer together but in different ways. A major difference that emerged from the data between the 2 groups was that in the first group, many of the couples developed the ability to establish or, in some cases, continue a meaningful honest level of communication with each other. They were able to express to each other in a nonthreatening, nonblaming manner their concerns, frustrations, disappointments, and desires around their intimacy. Some of this was expressed through verbal and some through nonverbal communication. These couples understood each other's needs and were committed to

one another. Although they might not be able to meet these needs for various reasons, such as other health issues, or diminishing feelings of physical attractiveness, they were able to establish new levels of intimacy in other aspects of their relationship. As Sherman observed,

In the early stages of dementia, when alteration in sexual behavior is a factor, some couples are able to renegotiate their patterns of arousal and intimacy. When new patterns can be established early in the course of dementia, they appear to be maintained for some time in the later stages.^{6(p91)}

Unfortunately, the other group was not able to renegotiate these new patterns. Their communication with each other was limited. They had difficulty adapting some of the positive coping strategies discussed, sometimes reverting to withdrawal. In addition, healthcare professionals did not see issues of marital intimacy as a priority or even within their medical domain; therefore, little effort and time, or a comfortable encouraging environment, was provided to discuss these issues. As Davies et al²⁰ mentioned, few healthcare professionals ask older adults, let alone people with dementia, about their sexual functioning.

Therefore, a major question with which this research leaves us is how to develop good or better communication skills to increase levels of intimacy. A communication model often used by sex therapists to deal with sexual behavioral problems is the PLISSIT model.³⁶ PLISSIT is an acronym standing for P (giving permission to discuss feelings and engage in sexual activity), LI (giving limited relevant information), SS (giving specific suggestions, behavioral or cognitive strategies), and IT (providing intensive psychotherapy). Kuhn¹⁴ and Davies et al²⁰ have discussed how this model might be applied to a dementia population. However, the idea of developing an open flow of communication between the spouse with dementia and the caregiver is not considered in this model. Matter of fact, the perspective of the person with dementia is never mentioned; it is not even a variable in the model.

CONCLUSION

This study adds to the knowledge base related to the marital intimacy of couples dealing with early-stage dementia in 3 ways: (1) it identifies a typology that distinguishes how couples respond to changes in their marital relationship around the expression of intimacy; (2) it pinpoints strategies that assist couples in coping with the changes in the marital relationship, positive coping strategies for both the caregiver and the spouse with dementia were

identified, such as flexibility, a sense of humor, acceptance, and the use of family and emotional support; and (3) it develops evidence-based recommendations for other couples struggling with similar issues and for healthcare professionals, who provide assistance; the focus group participants were clear about the need for good open communication between the couples, as well as with their healthcare providers.

Future research on this topic needs to consider these findings and develop a model of communication that assists couples improve their own communication patterns around intimacy and advocates for better communication patterns with their healthcare providers, for communication may be the *critical facilitator* that can increase levels of intimacy for couples dealing with early-stage dementia as they struggle to find a new balance and satisfying marital relationship, despite a diagnosis of dementia. In his personal essays on living with early-stage dementia, Taylor²³ implores researchers and healthcare professionals saying, "We need you to develop better communication models that change as the disease changes us and our family dynamics."

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