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Sexuality and Intimacy in Assisted Living: Residents' Perspectives and Experiences

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Abstract: The assisted living industry provides residential, medical, nutritional, functional, and social services for approximately 1 million older adults in the United States. Despite their holistic approach to person-centered care and their emphasis on a consumer-empowered, social environment, assisted living providers pay scant attention to clients' sexual needs. In this article, the authors discuss the realities of sex and intimacy in assisted living from the perspectives of residents, families, managers, and staff, exploring the discourse of sexuality, the impact of institutional structure and the role of oversight on sexual attitudes and behaviors, and the relationship of assisted living industry values to residents' sexual expression. Also presented are practical recommendations and policy implications for addressing the sexual and intimacy needs of current and future cohorts of assisted living residents. Data for this article were drawn from 3 National Institute on Aging–funded ethnographic studies conducted in 13 assisted living settings over 9 years.

Key words: long-term care; qualitative methodology; aging; ethnography; institutional oversight

The assisted living industry, a form of long-term care primarily marketed to older populations, currently provides residential, medical, nutritional, functional, and social services for approximately 1 million older adults in the United States (National Center for Assisted Living, 2008). Founders of the assisted living movement pioneered residences that paid deliberate attention to meeting consumers' physical and social needs, promoting the ideals of dignity and independence, providing a homelike environment, and encouraging long-term residency even as clients' needs increased, thus avoiding movement to a nursing home (Assisted Living Federation of America, 2007; Kane & Wilson, 1993; Mollica, 2001). Consistent with this underlying philosophy, assisted living emphasizes a person-centered and consumer-empowered environment and, as such, is often considered to be a social model of care—as opposed to the traditional medical model of nursing homes (Carder & Hernandez, 2004; Wilson, 1996).

Assisted living settings are unique in that they are not subject to the same federal rules and regulations that govern the operation of nursing homes in the United States. Although each state has a set of regulations specific to assisted living, these vary widely because no single, national policy defines what comprises assisted living. However, all assisted living regulations are hallmarked by ideals of privacy, autonomy, and quality of life (Assisted Living Workgroup, 2003; Mollica, 2001).

Despite a trend toward a holistic approach designed to meet residents' needs—and despite the documented benefits of sexual activity on physical and psychological well-being (Nye, 1999)—assisted living providers pay scant attention to clients' sexual needs. Furthermore, there is a dearth of research investigating resident experiences, practices, and expressions of sexuality and intimacy in assisted living. Yet, research (Mulligan & Palguta, 1991; Spector & Fremeth, 1996; White, 1982) has revealed that a majority of older adults, even for

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those residing in long-term care environments, maintain some level of sexual interest, albeit at decreased levels (Lindau et al., 2007). Future cohorts of older adults are expected to have even higher sustained interest in sex, as well as higher frequencies of participating in sexual acts, as generational acceptance and perception that sexuality is normal for elders increases (Hillman, 2008). Because assisted living continues to be a strong option for residential long-term care for growing numbers of older adults, it is critical to determine residents' expectations and experiences of sex and intimacy in this environment, as well as opportunities and barriers within the assisted living setting related to sexual expression, so that these settings can more effectively meet the needs of current and future residents.

Our purpose here is to contribute to an understanding of how sexuality and intimacy are experienced within the social models of care provided in assisted living communities. To accomplish this goal, we focused on residents' experiences regarding the meaning of sex and intimacy in assisted living settings. In this article, we examine the discourse of sexuality, the impact of institutional structure and the role of oversight on sexual attitudes and behaviors, and the relationship of assisted living values to sexual expression.

Literature Review

The importance of maintaining sexuality over the life course, as well as continued sexual desire and participation in sexual expression by older adults, has been well documented throughout the literature on sexuality (DeLemater & Moorman, 2007; Pangman & Seguire, 2000; Wojciechowski, 1998). However, evidence suggests that sexual desire is mediated not only by age but also by psychosocial factors, including partner availability, frequency of contact, and generational perceptions of the appropriateness of sexual activity in later life (DeLemater & Moorman; DeLemater & Sill, 2005; Trudel, Turgeon, & Piche, 2000), as well as biological factors, including the presence of chronic diseases and the medications used to treat them (Maurice, 1999; Schiavi, 1999; Schiavi, Stimmel, Mandeli, & Rayfield, 1993). For residents living in long-term care settings such as assisted living, these factors are likely to be highly relevant.

Assisted living serves a primarily female population: More than 76% of residents are older women (National Center for Assisted Living, 2006). Cultural factors dictate that, compared with older men, members of this group are less likely to report engaging in sexual activity (Lindau et al., 2007) and may be more likely to intentionally disregard their interest in sex, in order to cope with a loss of opportunities (Masters, Johnson, & Kolodny, 1994). Furthermore, a majority of the women in assisted living are widowed or single (National Center for Assisted Living), a situation that sharply limits partner availability for heterosexual women. For both women and men, interest in sex and sexual behaviors decreases with unavailability of partners (Wasow & Loeb, 1979); for men specifically, even when partners are available, behaviors and interest decrease if the partner does not have sexual desire (Schiavi, 1999).

Being widowed or single also may influence people's perception of partner availability, as well as their level of desire, because current cohorts of older adults have been shown to consider sexual behaviors and intimacy to be appropriate only within marriage (DeLemater & Moorman, 2007). Partner availability may be an even more critical issue for lesbian, gay, bisexual, and transgender (LGBT) assisted living residents, because long-term care settings notoriously ignore and often stigmatize the sexual needs of this group, resulting in residents' unwillingness to come out to staff and other residents (Cahill, South, & Spade, 2000).

Furthermore, the prevalence of chronic disease is high in assisted living; nearly 60% of residents have hypertension or cardiovascular disease, 32.5% have arthritis, and 14% have diabetes (Hyde, 2001). These conditions have been shown to be among the most debilitating with regard to impeding sexual interest and ability (Blake, Maisiak, Kaplan, Alarcon, & Brown, 1988; Schiavi et al., 1993). Additionally, medications used to treat these and other common conditions can decrease sexual drive, reduce sensitivity to stimulation, and result in other side effects detrimental to sexual experiences (Hillman, 2008).

Dementia is another condition present among assisted living residents. Although no nationally representative, systematic research has been conducted to estimate prevalence of dementia in assisted living, indirect estimates suggest that from 14% to 70% of assisted living residents have some level of cognitive impairment (Hendrie, 1998; Spillman & Black, 2006). One study of assisted living settings in Maryland (Rosenblatt et al., 2004) showed that 67.7% of residents had diagnosable dementia. It is important to note that consequences of dementia can be, at times, increased sexual expression, sexually inappropriate behavior, or sexual aggression (Alagiakrishnan et al., 2005; Kamel & Hajjar, 2004); however, even among those who do not show these effects of the disease, many long-term care residents with dementia retain the desire for and expression of sexuality (Kamel & Hajjar; Loue, 2005; Tabak & Shemesh-Kigli,

2006). Thus, even though dementia can complicate the understanding of sexuality and intimacy within the context of assisted living, it is possible to differentiate between healthy and unhealthy or wanted versus unwanted sexual behavior.

In addition to issues relating to gender, marital status, and health status, sexual interest and behavior may be influenced by the realities of living within a structured environment that provides oversight, rules, and monitoring. For example, studies (Eddy, 1986; Hajjar & Kamel, 2003; Luketich, 1991; Roach, 2004) have shown that nursing home staff attitudes toward older adults' sexuality (which are primarily negative) are barriers to residents' sexual expression. Such attitudes often lead staff and management to perceive any attempt at sexual expression as inappropriate, even by residents who have no cognitive impairment (Rheaume & Mitty, 2008). However, other research (Quinn-Krach & Van Hoozer, 1988; Walker & Harrington, 2002) has suggested that educating nursing home staff about sexuality and aging can elicit positive, supportive, and proactive attitudes that more effectively address the sexual health needs of residents to whom they provide care. Privacy is also a major barrier to sexual expression in long-term care settings. An unlocked-door policy, the presence of roommates, regular room checks by staff, and staff access to medical and health-related information have been shown to hinder residents' perceptions of privacy (Calkins & Cassella, 2007; Eckert, Carder, Morgan, Frankowski, & Roth, 2009; Morgan, 2009) and are suspected to significantly deter or prevent sexual activity or expression, as well (Bauer, 1999; Rheume & Mitty, 2008).

Collectively, these studies show that sociocultural and health biases may be present against older adults residing in long-term care who participate in sexual activity, even though current cultural attitudes are shifting to encourage individuals to remain sexuality active over the life course. The research presented also reinforces the potential impact that assisted living culture has on residents' sex lives. The present study explores how sexuality and sexual expression permeate the lives of assisted living residents, the staff and management working with them, and residents' family members.

Method

Participants

Qualitative data from three studies funded by the National Institute on Aging formed the basis for this analysis. *Transitions in Assisted Living* was a 5-year ethnographic study of entry into, through, and out of assisted living settings; *Quality in Assisted Living* focused on a mixed methods approach to determine elements of quality important to residents, staff, and family over 3 years; and the *Cultural Context of Residential Settings* is a 5-year ethnographic study of multi-residential housing types (including assisted living) that is investigating many topics, including social relations and the experience of stigma. The basic research design consisted of sequential ethnographies, lasting 6 to 18 months each, in 13 diverse assisted living facilities. The majority of residents across the settings were White middle-class females, with an average age of 80. Two homes of 100 residents each were predominantly African American and three had religious affiliations. Across the grants, one assisted living setting was rural, one urban, and the remainder suburban. Direct care staff were primarily White, African, and African American; few Hispanics were employed at these research sites.

Following the Collaborative Studies of Long Term Care typology of assisted living facilities, our ethnographies were conducted in small settings (i.e., those housing 15 or fewer residents), traditional settings (those built before 1987, often former nursing homes retrofitted for assisted living), and new-model assisted living settings—those built after 1987 specifically to address the goals of the assisted living movement (Zimmerman et al., 2001). All assisted living facilities included in our sample were located in the mid-Atlantic region of the United States, and were selected for size, profit status, level of care offered, assisted living type, religion, ethnicity, and affiliation (independent or corporate chain).

Data Collection

Using ethnographic methods, the research team studied daily life in these settings, exploring interactions among residents, their family members, direct care staff, and administrators. Ethnography involves research on individuals and groups within their own sociocultural or physical environments, the place where they live or work. Information is collected primarily through participant observation and in-depth interviewing. By immersing themselves in the setting, researchers are able to both observe and participate in daily activities (hence the term *participant observation*) and, thereby, come to understand the nature and meaning of interactions and ideas through the eyes of those who live and work in a specific place. Ethnographers visited the research sites at various periods of the day and evening over a 7-day week, going to lounges and suites, patios and smoking alcoves, lobbies and dining rooms—in other words, wherever people in a particular home gathered. Descriptive

and interpretive fieldnotes of one to 12 pages in length were written at the end of each field visit and circulated to the research team. In total, seven project ethnographers conducted research over 9 years.[1]

In ethnography, open-format in-depth interviews provide essential information from the perspective of the individuals in a study, including their daily lived experiences and the processes involved in formal and informal decision making (Charmaz, 2006). Reflexive interviews were conducted with a sample of the residents, families, staff, and directors in each setting using open-ended interview guides with questions directed toward the focus of the research—in this case, transitions within assisted living, residents' quality of life, or social relations within the setting. Numbers of interviews at each site varied, depending on the size of the setting, level of dementia in the resident population, and stipulations of the grant. However, over the course of the fieldwork, conversational interviews were also held with a larger proportion of people who live, visit, and work in each site. These data are embedded in fieldnotes.

The narrative data collected for the three grants were entered into Atlas.ti v5 (Muhr, 2008), a software program that facilitates qualitative data analysis by enabling researchers to catalogue and retrieve project transcripts, documents, notes, and specific quotations within them in order to apply various analytic strategies. For each of the three projects, initial analyses involved collaborative coding of each transcript and fieldnote by project personnel; codes were assigned to sections of every document based on a coding scheme inductively developed by each respective research team's thorough review and discussion of the data for its project.[2]

Analysis

It must be noted that the research studies on which this analysis is based were not designed specifically to collect data on sexuality and intimacy but rather, as previously stated, to explore transitions and quality of life within assisted living, and examine social relations among older adults in senior housing. However, the nature of ethnography lends itself to collecting a host of information not directly connected to the research questions. The amount of time spent at the field site interacting in the setting, as well as the flexibility inherent in using an interview guide (as opposed to a structured instrument), produced a volume of data tangential to the fundamental question. Data on sexuality and intimacy surfaced in fieldnotes, for example, when residents casually discussed sex or a staff member related her story of finding a couple being intimate in a public space. Interviews also produced such data. For example, in answering the question "What makes for a good life in assisted living?", a resident might answer "more men" or "sex." Executive directors, when asked in their interviews about residents' families, spoke, for example, of having to discuss parents' sexuality with their residents' children.

The *Transitions* and *Quality* grants yielded, respectively, 878 and 259 fieldnotes and interviews. The *Social Relations* grant, at the end of its 1st year, produced 196 documents. These fieldnotes and interview transcripts are stored centrally in a text base. To explore resident experiences, attitudes, and behaviors related to sexuality and intimacy, we used three analytical techniques to search these rich and numerous data. First, we identified narrative passages that had been coded, for example, as *culture, emotions, social contact,* and *friends* within the larger databases. From these data, we identified instances in which residents, staff, or family members discussed issues relevant to sexuality and intimacy within the assisted living settings. In the second strategy, we developed a list of key terms that were embedded within these passages to find additional data that had not been apparent in the first analysis. Key terms searched included *sex, boyfriend/girlfriend, romance, couple,* and *masturbate*. Finally, two other project ethnographers were interviewed to identify exemplary cases, passages, and fieldnotes encompassing any aspect of sexuality, sexual behaviors, intimacy, or sexual interest that we may have missed. Presented subsequently are thematic findings related to the experiences of sexuality and intimacy among residents within our sample of assisted living settings. All sites and participants are referred to by pseudonyms.

Findings

Our coding analysis, coupled with a search through Atlas.ti (Muhr, 2008), resulted in two categories of findings, the first pertaining directly to residents and the second to the relationships of assisted living settings to residents. The findings are suggestive, because the original research questions had distinct foci other than sexuality; they provide a baseline for future study. We have included exemplars from fieldnotes and interviews to illustrate each finding. Several exemplars illustrate more than one idea or theme, which we elaborate within the finding.

1 Frankowski and Clark have worked as collaborators, project ethnographers, or both on all three research grants.

2 For a more detailed explanation of these methods, see Eckert, Carder, Morgan, Frankowski, and Roth (2009).

Sexuality and Intimacy in Residents' Lived Experience

Sex happens. When asked directly, assisted living managers acknowledged that sex occurs in their assisted living settings. The director at one site commented, "It's a delicate situation but they still have sex, you know.... It's happened here quite often." Residents concur in conversations about the sex life of their neighbors; rumors and accounts of others' relationships document the nature and perception of sexual acts.

Although sexuality and intimate relationships of varying degrees and manifestations occur among couples, instances of solo masturbation also occur. At Huntington Inn, for example, one female resident asked her physician if he could recommend sex toys she could use for masturbation; he replied that he could not because he was not an expert in that area. Another resident in the same assisted living community had been found by staff on multiple occasions in what they called awkward positions after she had fallen asleep while masturbating.

Sexual expression varies from intimacy to intercourse. Sexuality and intimacy are manifested in various ways, including intercourse, but our findings overwhelmingly revealed that intimate touch, hand holding, and other less physically intense expressions were common. For example, Mr. Sidney and Ms. Perkins, an intimate couple who were acknowledged as such by the staff, were comfortable with and cared deeply for each other. They met for meals, attended activities together, supported each other through illnesses, and slept in each other's rooms when loneliness set in, he in his wheelchair and she in her recliner. In another assisted living community, Ms. Rosen said of a resident in whom she is romantically interested, "[He]...likes my hair. Keeps saying it's beautiful. He says when he touches my ponytail, he gets an orgasm."

In some cases, sex is assumed but intimacy is the reality. At Boxwood Gardens Assisted Living, for example, Ms. Francis was blatantly open about her relationship with a man she called her boyfriend: "People think we screw. I get my morning kiss and my nighttime kiss, and that's all."

Residents also discussed preferences. Dr. Catherine at the Chesapeake spoke of her friendships with two male residents, one who was a kindred spirit, as educated and intellectual as she was, and the other who sent flowers and talked of joint vacations and marriage, but was also domineering and verbally abusive. His speech was filled with sexual innuendoes, she said. With indignation, she asked the ethnographer, "Does he really think that I like it?"

Our data show that sexual expression in assisted living can be overt, noted, and subject to change: Residents have had sex in each others' rooms; a staff member recounted a couple's transition from acceptable public displays of intimacy (e.g., hand holding) to simulated pumping; a male resident preyed on women with dementia, to the chagrin of cognitively intact residents.

Interest in sex is resident dependent. Like Ms. Rosen, some residents have a continued interest in romantic relationships, and expressions of this desire were common in our data. For example, Mr. Howard at Greenbriar said, "I'm looking. I'd get a girlfriend if I made an effort." At the Franciscan Home, Opal "would like to go and get one (laughs) where you go to a movie or to a dance club...a companion." Yet others were very clear that they were not interested in pursuing romantic relationships. Mrs. Riley at the Chesapeake remarked, "I like men. I like to talk to them, but as far as that goes—that's it. My sex days are over." Tammy, the director of Huntington Inn, described one resident's response when asked to rate her sex life. The resident said, "I haven't had sex since 1974 and that's just fine with me, so I give it a 10."

Others are interested, but doubt they will find someone who suits them within their residence. For example, Mr. Braskey remarked, "I like women...[but] don't look for romance here at Wetherby Place...most of the ladies are very old—in their 80s, and I don't think they have an interest in relationships like that." About the men at Winter Hills, Ms. Audrey noted, "I don't even know one good-looking one." Opal stated her interest in finding a partner, but was not confident about her options: "I would like to have more boyfriends, but you don't get that many when you get 72—because a man 72 is going to go with a woman 45 or 50 anyway."

Sexual language is metaphoric. Residents referred to sexual activity in figurative language. (Methodologically, this tendency made for difficulty in searching the database.) For example, a couple in the midst of having their possessions packed and carted to Boxwood Gardens Assisted Living for a move they were resisting went into their bedroom to have, in their words, "a last tumble." (The last tumble marked the end of their lives as social activists in the community, not their sex lives.)

In an interview, a direct care aide spoke about how a female resident would talk to her about sexual issues because of her own gender and age: "You know, she's a woman like I'm a woman. I'm over 40 and so was she. They don't get deep with it, but they come up. They have those kinds of feelings and memories of things." The staff member said she feels that sexuality is something

residents deal with, although residents will remark, jokingly, "You know that's not allowed." This resident, the staff member noted, "said something they all say sometimes: 'Snow on the mountain, fire in the furnace—just because I'm old don't mean the other parts of me aren't hot'." Although a colorful exemplar, this narrative is about more than language: It speaks to a relationship of familiarity and openness developed between a staff member and a resident that allows such discourse, the recognition that residents think about sex and view themselves as sexual beings irrespective of age, and the belief (or rationale) that sexual behavior is not condoned within their assisted living community.

Sexuality and intimacy extend from autonomy to rape and victimization. Sex is often self-initiated, with residents forming amicable relationships and developing partnerships. In one example, a woman who was exercising in the hallway discovered a male resident watching her. Of this incident, the ethnographer wrote in her fieldnotes:

> She reported that she wanted to get him "all shook up," so she swiveled her hips just a little more. She was telling me this story with much humor and laughter. She now makes it a point to always "show off" for him.

Although sex in assisted living can be enjoyable, a physical release, and expected behavior, victimization also occurs. In one exemplar, a staff member assumed that marital rape was occurring in the relationship of a couple under her care. Her basis for this assessment was what she perceived as a controlling nature of the husband, as illustrated in part by his refusal to permit his wife to attend afternoon activities because he needed her, in his words, "to nap." By the wife's distressed look when she exited the apartment for dinner, this care aide believed that the wife has been forced to have sex. Such passive behavior has been noted in the data for wives in this older generation, a behavior alternatively attributed to dementia, fear, and generational spousal expectations.

One of the most egregious examples of victimization occurred at a suburban assisted living setting. Two women had complained to the executive director, both in writing and in person, as well as at Resident Council (a monthly meeting of residents with an administrator to air concerns and receive updates on happenings at the residence), that Wally was climbing into their beds; based on his actions, the women noted that "he must be sexually active." The directors and care aides ignored the women's complaints. Ms. Carson told the ethnographer, "When a man gets right into bed, sits down, and goes under the covers, it's sexual harassment and it has gone too far." She told the assisted living management that if it happened again, she would call the police. On Christmas Eve, "He [Wally] came in, started that stuff, and I called up the police. [The nurse] didn't like it [her calling]. He said, 'I can't keep an eye on him'."

When the police arrived, Ms. Carson knew that the officer who responded to the call did not take her seriously. The officer explained (rather condescendingly, she thought) that Wally has a psychological problem and suggested that she complain to the director—which she had already done on numerous occasions. The nurse and the police officer "were laughing; I let that be. After all, it was Christmas Eve." However, she continued, "It's no laughing matter. They suggested I lock my door. I don't want to."

Rather than supervise Wally, the management faulted Ms. Carson for complaining and publicly airing a grievance. In fact, she said, she felt victimized thrice: once by Wally, once by the nurse and the police officer, and once by the facility. Management expected Ms. Carson to take responsibility for keeping Wally out of her suite by locking her door. This expectation engendered a feeling of insecurity for Ms. Carson because, given her health problems, she wanted to know that she had quick access to staff (not all staff carried keys). Soon after this incident, Ms. Carson and the other woman who had complained were told that the assisted living residence had sufficient grounds to break their contracts and both were asked to vacate their suites. Wally remained to roam Boxwood Gardens.

Sexual orientation is rarely expressed. Sexual orientation of partners was rarely noted, although names gave some indication of gender preference. We found two discussions of gay or lesbian sex in our data. At an upscale assisted living community, the wife of a local prominent judge offered strong negative opinions about homosexuality to her dining companions one evening. A retired dentist from another table joined the group to explain and support LGBT perspectives.

In another setting, a female White resident reputedly took a decided interest in a female African American resident. A direct care staff person referred to this relationship as harassing. Implying lesbianism, another staff member corroborated sexual overtones by stating that this woman was "crazy about" a certain female staffer, openly voiced her preference for Black women, and described the head nurse as "pretty" and "her girlfriend." A third staff member intervened: "Everyone has this wrong. [This resident's] claim to liking Black women is her way of expressing a lack of prejudice against Black women." Her colleague responded that she was naive if

she truly believed this explanation to be true. The director of nursing reminded everyone that a resident's sexual preference was her own business but also stated that if the resident was truly harassing another, the situation needed to be addressed. No specific actions or policies materialized after this discussion.

Assisted Living Perspectives on Sex and Intimacy

Assisted living settings have minimal policies. At our research sites, we found that assisted living policies regarding sexuality tended to be informal. Assisted living directors instructed their staffs to leave quietly when they observed sexual activity in residents' apartments. In her interview, an executive director told us:

> They [care aides] do bedroom checks and they have to check every 2 hours. They are trained if they see them [residents] intimately together to just back off, but basically they are to report it. In case something happens, we'll be able to say this is exactly what happened that night….But every family member knows what's going on.

At several other homes, we heard the same. The typical guidelines regarding residents' sexual activity stipulated that care aides are expected to walk out of the room discreetly, family members are informed as a matter of course, and sometimes a meeting with the family (often excluding the resident) is called. Ethnographers reported that, in some instances, families gave permission for their relatives to engage in sex.

At another field site, the religiously affiliated St. Brigid's developed policies in line with a medical model, mandating that each resident must stay in a single bed so that optimum medical care could be offered as needed. One couple married more than 50 years had to abide by this policy, and their daughter noted that her parents missed "sleeping bum to bum."

Facility and family oversight competes with resident autonomy and privacy. The assisted living industry prides itself on fostering the values of choice, independence, autonomy, and privacy. However, we found instances of tension between residents' expression of their rights and facilities' responsibility to provide oversight. The execution of assisted living values sometimes conflicts with the everyday practicality of running a home, so it comes as no surprise that our data confirm a contradiction in the expression of these values in everyday experience. Whether sexual relationships are discouraged, promoted, or ignored is a decision forged by a resident's family along with assisted living management, often independent of the resident's choice. The following three examples focusing on family involvement are indicative of this decision-making structure.

After noting sexual behavior, the executive director of Laurel Ridge stated that "we always tell the family… so there won't be any gossip…or surprise," adding that some children "become very upset with their mom because Mom was never like this and it's embarrassing for them." One daughter visited during lunch, the director said,

> and she caught her mom and that person….It's where some family members just say "Mom, you came here like the Virgin Mary," and you have to respect that…and I try not to state my opinion so the family won't become offended with me in any way, shape, or form.

In protecting the privacy and autonomy of a resident, an assisted living setting risks alienating family members who might transfer their relative to another home, leaving the assisted living residence with a vacant suite and affecting its financial intake. This exemplar also reinforces the unease children feel in acknowledging the sexuality of their older relatives.

At Boxwood Gardens, two residents did everything together and were recognized as a couple for more than a year. The families knew the relationship existed, but when the man's children decided to move him to an assisted living community known for its clinical success with Parkinson's patients, they pulled their father out of the home without maintaining contact with his woman friend. The new residence did not permit telephones in the residents' rooms, and the only phone available was located at the nurses' station. To complicate matters, the man's woman friend was blind. A lay minister assigned to Boxwood Gardens took it upon himself to help the couple stay in touch by making arrangements for regular phone calls between them.

In the third example, a couple formed a relationship that was accepted by both the assisted living community and the families, as long as the individuals remained in separate apartments. When both individuals cognitively declined to the point where they had to move to the dementia unit, the director, knowing that the man was in financial difficulty and the unit more costly, and also recognizing the man and woman's status as a couple for several years, suggested they share a room. The woman's family agreed, but the man's son was concerned about appearances and refused permission for the cohabitation.

In these three examples, the opinions, actions, and decisions of family members overrode resident autonomy with regard to sexuality.

Facilities' responses to sex and intimacy are context related. Assisted living settings' responses to sex and intimacy are couched in the social context of the situation. If family members or powers of attorney want a behavior curtailed, directors and staff work toward that goal. If family members are supportive of relationships, then facilities respect them. If an assisted living setting is census-challenged—that is, unable to attract a sufficient number of residents to meet its bottom line—sexual behavior may be discouraged but the resident not asked to move. We have observed tolerance of flagrant sexual harassment and exploitation just to keep a bed filled. Direct care staff and other residents rarely have a voice in the matter. In the case of Laurel Ridge as an exemplar, one male resident had sexual relationships concurrently with several women with dementia. Other residents were appalled. The housing coordinator's response was to try and monitor the man's behavior, taxing the already overworked staff, who felt he should be told to leave.

Staff members are sometimes patronizing. One director was surprised at her own reaction to a situation:

> I'll never forget one night I was here, Millie was getting herself ready to go to bed in Mr. Rove's room—and being the mother I am, I said, "You go to your room and he stays in his room." And what right did I have to do this—I just took this stand—"you go to your room"; it sounded like I was talking to my children….He went to bed and…I walked her to her room. Didn't say a word to her the whole walk. It was the longest walk I ever took. I said, "Boy, do I have a lot of nerve"—I mean, aren't these two consenting adults?—but I just dismissed them like they were children.

We found that direct care staff often make subjective judgments. In one exemplar, when a heterosexual unmarried couple was found in bed, one aide said that she was not surprised because, she explained, Mr. Johnson is "silky smooth." Staff sometimes used stereotypes (e.g., "He's a ladies man") and pejorative language (e.g., "He was sneaking [not walking] into her room") to describe sexual activity, or laughed (e.g., at unsuitable-looking couples and mental images of elderly partners engaging in sex). Some staff were titillated by the sight of couples being intimate, whereas others were condescending, calling them cute. Our data show that unmarried couples in particular are singled out for attention and observation, rather than treated with normative acceptance.

Discussion

In canvassing our database, considering its size both in the number of documents and the years spent in the field, what initially most surprised us was the relatively limited data on sexuality and intimacy. Albeit the research questions formulated from the grants were specific to transitions, quality, and social relations in residential long-term care settings, the data collected in the more than 1,300 open-ended interviews and ethnographic fieldnotes resulted in a rich and varied database of material, irrespective of the original foci (e.g., spirituality). Thus, the resultant lack of abundant information on topics related to sex is remarkable.

We offer several reasons for this lack of sexuality-related information. One is generational. Most of the interviewees were residents in their 80s who may have been unwilling or disinclined to start—or even think of—such conversation, especially with younger ethnographers. Frailty and illness also might have been factors, as well as cultural assumptions about what people talk and do not talk about. This suggestion is consistent with literature that has described the impact of biological and psychosocial factors on attitudes and behaviors related to sex (DeLemater & Moorman, 2007; Hillman, 2008). We also considered the *researcher effect*[3]; however, because the ethnographers spent almost a year at each site and developed relationships in which much sensitive information was shared, such as where prohibited medications were hidden and which facility rules were broken, it is highly unlikely that the researcher effect was a factor.

Another factor, we posit, lies in the culture of assisted living settings. Staff view their clients as sexless and sexual behavior, when observed, is unwelcome. Residents are generally complacent and rarely take part in talk or action that could lead to their being ostracized or asked to leave the setting. For LGBT elders in our study, fear of retribution and discrimination may have made them reluctant to declare and discuss sexuality. This concern is well documented in LGBT literature, particularly among nursing home residents (Cahill, South, & Spade, 2000; MetLife Mature Market Institute, Lesbian and Gay Aging Issues Network of the American Society on Aging, & Zogby International, 2006).

In our research, we found that many administrators and staff were quick to patronize older residents or denigrate sex and intimacy. If an assisted living home assumes, on the whole, that residents lack or suppress active sex drives, then broaching the topic or creating guidelines or rules regarding sexuality is unnecessary;

3 The researcher effect can include such bias-producing factors as unconsciously transmitting expectations to participants or even influencing respondents' behavior simply by being present.

administrators deal with the issue only when confronted by specific incidences, such as two individuals groping each other in public. In tandem, our research has shown that residents' children are the main consumers of assisted living settings (Eckert, Carder, Morgan, Frankowski, & Roth, 2009) and that children prefer not to think of their parents as sexual beings; consequently, rather than risk alienating consumers, assisted living marketers and move-in coordinators prefer to avoid the topic.

Furthermore, although assisted living residences typically offer private rooms and take varying degrees of control of these areas, most of people's interactions occur in public spaces. This situation is related to the structure of life in assisted living, which is organized around mealtimes, medication administration, and activities, and so discourages residents from remaining in their room or suite; residents rarely report spending time with others in nonpublic areas (Eckert et al., 2009). As a result, researchers have difficulty gaining access to what is occurring behind closed doors and residents may not be able to engage in sexual behaviors in private.

Our findings are relevant to the domain of interest in current and potential future sexual expression and its relationship to partner availability. Gott and Hinchliff (2003) have found that older adults with a current sexual partner were more likely to express interest in and assign importance to sex, whereas those without partners did not consider sex to be an important aspect of their lives and believed they would not find another partner in the future. The researchers also reported that those who were widowed or had health problems assigned less importance to sex than people who were married and those who were healthy. Our results suggest, however, that the importance of and interest in sex persists among nonpartnered assisted living residents. This finding opens discussion for a potential strategy for assisted living providers, who could work with medical professionals and other relevant parties to provide residents access to products and services enhancing sexual wellness.

The two categories of nine findings speak to several issues revolving around the public nature of private behavior and the relationship between self-governance and institutional control. Assisted living is a soft institution—a subculture—providing care and meals to residents; after all, people move into assisted living because they have needs that no longer can be met at home (National Center for Assisted Living, 2006). Although assisted living settings espouse privacy, oversight makes this value more ideological than practical. Residents' care is noted in logs and reported to families, and observations of behavior are discussed at staff meetings. Many residents have difficulty adjusting to a shared environment, especially one that mandates nightly bedroom checks every 2 hours and whose staff enter apartments as they symbolically knock after opening doors. Almost every aspect of a resident's life is noted by someone and recorded, even if only mentally. Regarding sex and intimacy, this environment runs counter to the cultural prescription that sex is a private act between consenting adults. Almost nothing in assisted living is private or consensual.

In conjunction with the role of oversight, we found the frequent use of *elder-speak,* in which staff talk to residents patronizingly as if they are children, rather than with respect and deference to age (Bethea & Balazs, 1997). This stigmatizing act prevails both in assisted living and in society (Dobbs et al., 2008; Pasupathi & Lochenhoff, 2002), and our findings suggest that sexuality is yet another way in which elders are stigmatized. Residents' actions become the tidbits of passing conversation, often spoken in amused tones (especially when relating to sex and intimacy), again calling into question the value of privacy. Elder-speak is a powerful factor in reinforcing the notion that elders are child-like; in contemporary society, children are expected to refrain from engaging in sex.

The assisted living—and American—values of autonomy, independence, privacy, and choice also run counter to life in an institutional setting. The degree of choice and independence expressed in assisted living is directly related to the level of dementia and physical capability of each individual resident, as well as the policies enforced by management. Decisions regarding residents' sexual activity rest on evaluations by administrators in concert with families, thwarting the choices of the people they serve. The point at which a resident's sex life is curtailed varies with administrative policies. Noncompliance with these policies can possibly, if not probably, result in a resident's discharge by assisted living management.

In other research, we found that many issues in assisted living filter down to their impact on the bottom line (Eckert et al., 2009). Because management often perceives residents' children, not residents themselves, as the consumers of their service, residents' children are the ones who need to be mollified. Consumers' responsiveness to the negotiation of rules and development of policies support the assisted living residence's financial base, with the rights of residents and core values taking a back seat.

Last, we note that cognition is a moderating factor in sexual behavior in assisted living. Dementia is an issue

of major concern. Throughout the sites in our study, we found no consensus regarding what degree of dementia would result (or should result) in an individual's losing his or her right to make decisions related to sex. The issue lies in a mind-body dichotomy, privileging one over the other. When one care aide questioned a severely demented resident's participation in a sexual relationship ("This cannot be construed as consensual," she noted), her coworker responded that the woman in question "may not be fully aware, but she still can have feelings down there."

Conclusion

The rapid aging of the U.S. population, increases in life expectancy, and the growth of the senior housing industry are bound to result in dramatic changes in how assisted living settings view consumers (Federal Interagency Forum on Aging-Related Statistics, 2008; National Investment Center, 2007). Hyde and Golant (2008) have speculated that in their later years, baby boomers (those born 1946 through 1964) will be a demanding population requiring more humane environments from their providers. These demands, coupled with competition among providers and with home and family care, will effect changes in everyday life in assisted living, including attitudes toward sex and intimacy.

Future cohorts of older adults have been active participants in—or at least observers of—the sexualized culture of contemporary U.S. society and, as Hillman (2008) has noted, will be increasingly more sexually active in their elder years than previous generations. Adding to this trend are the scientific advances and changes in societal attitudes that make discussion of sex increasingly more open and that encourage sexual performance and intimate relationships across the life course.

The assisted living industry is at a crossroads where a new generation is beginning to consider a move into long-term care. Our research offers data to support policy initiatives needed to address issues pertinent to older adults currently in senior housing, as well as to the changing consumer populations of the future.

Fundamentally, the possibility and probability of sexual activity and demonstrations of intimacy need to be acknowledged—a task that is not as simple as it seems. Our research dovetails with findings from other studies indicating that there are a number of confounding issues. First, some discrepancy exists regarding who is the rightful client and the primary decision maker in assisted living. The philosophical underpinning of assisted living is that "residents have the right to make choices and receive services in a way that will promote the residents' dignity, autonomy, independence and quality of life" (Assisted Living Workgroup, 2003, p. 12). Yet our data show that assisted living management tend to regard residents' families as having power to override residents' choices. Although children do not like to discuss their parents' sexuality, because they are instrumental in finalizing the assisted living housing contract, they need to involve themselves in such a dialogue when initiated by the assisted living management. Practically speaking, decisions regarding sex can be formulated into care plans, which should be developed collaboratively by all stakeholders (i.e., residents, families, and administrators) to provide the written strategies assisted living settings will use to attend to residents' sexual needs.[4]

Another important issue is the extreme difficulty determining at what point in decline, if any, a resident should relinquish her status as rightful client. Is this relinquishment promulgated by a change in physical health or increased dementia? Discussion-based policies need to be formulated regarding individualized rights to sex and level of cognition, with assisted living providers primed to honor residents' choices if their actions are not harmful or unlawful. This point is becoming increasingly dramatic as the number of Alzheimer's patients rises. Estimates from 2009 indicate that 5.3 million Americans have Alzheimer's disease, with the number expected to reach 7.7 million in 2030 and up to 10% of cases occurring before age 65 (Alzheimer's Association, 2009).

We believe that the assisted living industry should rethink its core values. If the industry truly values autonomy and privacy, then these values need to be implemented, not skirted or ignored. Bedroom checks, unlocking doors without permission, and reporting residents' sex lives to relatives—the crux of facility oversight—need to be balanced with honoring values rather than compromising them. All of the executive directors we interviewed stated that residents currently moving into assisted living are more frail and in greater physical and mental decline than those in previous years. Perhaps two models of assisted living have a place—one medical, with heavy emphasis on facility and family oversight, a step before a nursing home admission, and the other social, oriented to resident autonomy and independence.

4 Care plans are assessment tools that assisted living providers use to coordinate and oversee residents' needs; these plans include specific information on how medical, functional, social, nutritional, and housekeeping needs will be managed within the assisted living facility. Depending on state regulations, care plans are updated every 3 to 6 months.

Furthermore, assisted living settings must carefully screen for ageism in their approach to the older adults they serve. Policies need to address direct care staff whose demeanor treats residents like children with their use of elder-speak and their authoritarian manner. This behavior is manifested in numerous ways in assisted living; pertinent here is the public status of residents' sexual and intimate relationships.

We also suggest implementing policies that work to inculcate in staff respect toward all diversity groups—for example, age, sexual orientation, religion, disability, and ethnicity. Such policies must be regulated and enforced, and care taken to prevent exploitation and victimization. The assisted living industry does not have federal oversight. Instead, states are responsible for defining assisted living and determining requisite services and characteristics of setting. This situation offers both challenges and opportunities, because the vast heterogeneity among assisted living settings prevents a single definition and approach to assisted living. This freedom for variation not only gives states flexibility to tailor regulations to fit the needs of the residents for whom they provide care (Hawes, 2001; Mollica, 2001) but also increases options for consumers.

In his seminal article, Parker (2004) emphasized that having sexual rights does not guarantee that those rights are exercised. Residents, families, and providers need to implement policies, both industry- and statewide, that not only address residents' needs and wants but also effect their inclusion regarding the care they receive. One of the respondents in our study, the daughter of an 80-year-old man, expressed her wish that the assisted living setting provide escort services for her father. She asked the administrator to find her father a companion with whom he could be physically intimate; based on the response, she felt that "they're not really helpful….I'm getting the feeling of a stonewall….I think the importance of just physically being held, and touching and feeling somebody would be very important." Although this provocative strategy may not be forthcoming in the near future, providers need to collaborate with consumers to ascertain how the sexual and intimacy needs of residents in assisted living would be best served.

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