

CogNexus Volume: 1 Issue:1 1/2025/pp.197-213

A Multidisciplinary, Multilingual, International, Peer-Reviewed, Open Access Journal

Negotiating Sexual Autonomy in Assisted Living: Policy Gaps and Practical Strategies for Residents with Dementia.

¹ Josephine Misaro ² Josephine Boateng

¹ Georgia State University ² University of Massachusetts Boston

ABSTRACT

Sexual autonomy is a critical yet often overlooked aspect of well-being in assisted living (AL) communities. This study examines the challenges faced by AL staff in supporting residents' intimate relationships, particularly those involving individuals with dementia. Findings reveal significant policy gaps and inconsistent practices, forcing staff to rely on personal judgment, which creates ethical dilemmas concerning consent, privacy, and safety (Misaro, 2023, p. 17). Family involvement emerged as both a facilitator and barrier, depending on whether families supported or opposed residents' autonomy (Kemp et al., 2021). Additionally, staff training plays a pivotal role: those with formal training prioritize autonomy, while experienced staff often adopt risk-averse approaches (Maas & Buckwalter, 2006). Recommendations include developing comprehensive policies, enhancing staff training, and engaging families through education. Standardized frameworks for consent assessment and privacy protocols are essential for fostering supportive environments (Burgess et al., 2021). Implementing these measures can promote dignity, autonomy, and emotional well-being for AL residents.

Keywords: sexual autonomy, assisted living, dementia, elder care, policy development, consent frameworks, family engagement

Résumé

L'autonomie sexuelle est un aspect essentiel mais souvent négligé du bien-être dans les communautés de vie assistée (AL). Cette étude examine les défis auxquels le personnel des AL est confronté pour soutenir les relations intimes des résidents, en particulier celles impliquant des personnes atteintes de démence. Les résultats révèlent d'importantes lacunes politiques et des pratiques incohérentes, obligeant le personnel à se fier à son propre jugement, ce qui engendre des dilemmes éthiques concernant le consentement, la vie privée et la sécurité (Misaro, 2023, p. 17). La participation des familles a émergé à la fois comme un facilitateur et un obstacle, selon que les familles soutiennent ou s'opposent à l'autonomie des résidents (Kemp et al., 2021). De plus, la formation du personnel joue un rôle crucial : ceux ayant une formation formelle accordent la priorité à l'autonomie, tandis que le personnel expérimenté adopte souvent une approche prudente axée sur la minimisation des risques (Maas & Buckwalter, 2006). Les recommandations comprennent l'élaboration de politiques complètes, l'amélioration de la formation du personnel et l'implication des familles par le biais de l'éducation. Des cadres standardisés pour l'évaluation du consentement et des protocoles de confidentialité sont essentiels pour favoriser des environnements de soutien (Burgess et al., 2021). La mise en œuvre de ces mesures peut promouvoir la dignité, l'autonomie et le bienêtre émotionnel des résidents des AL.

Mots-clés: autonomie sexuelle, vie assistée, démence, soins aux personnes âgées, élaboration de politiques, cadres de consentement, engagement familial

1. Introduction

The aging population is growing rapidly worldwide, leading to significant shifts in the demand for healthcare and long-term care services. Assisted living (AL) communities have emerged as a vital option for older adults requiring support with daily living activities while maintaining some level of autonomy and social engagement (Misaro, 2023, p. 3). Unlike nursing homes, AL communities prioritize providing a homelike environment and promoting the independence of residents through services tailored to their physical and mental needs. However, while much attention is given to the physical and medical care of older adults, other critical aspects of their well-being, such as intimacy and sexual autonomy, are often overlooked or inadequately addressed (Misaro, 2023, p. 15).

Sexuality remains an essential part of human life throughout all stages, including older adulthood. Misaro (2023) highlights that beliefs and norms surrounding sexuality are established early in life and persist into old age, shaping individuals' desires and behaviors even as they face the challenges of aging (p. 16).

Nevertheless, cultural taboos and societal ageist attitudes often render older adults' sexual needs invisible or inappropriate in public discourse. This is especially pronounced in institutional settings like AL communities, where privacy is limited, and residents are subject to formal and informal policies that may restrict their autonomy (Misaro, 2023, p. 17).

For residents with dementia, the issue of sexual autonomy becomes even more complex. Dementia is a progressive neurodegenerative disorder that impairs memory, judgment, and communication, posing significant challenges to the exercise of informed consent and personal decision-making (Misaro, 2023, p.

18). The legal and ethical dimensions of consent, coupled with the cognitive decline characteristic of dementia, have created a contentious space in AL communities regarding residents' rights to engage in intimate relationships. AL administrators and direct care workers (DCWs) are often placed in difficult positions, having to balance residents' sexual autonomy with their health, safety, and the expectations of family members (Misaro, 2023, p. 19).

Existing research on sexuality among older adults primarily focuses on debunking myths that older people are asexual or uninterested in intimacy. Misaro (2023) notes that while prior studies have examined how societal norms and stereotypes shape perceptions of older adults' sexuality, there is a critical gap in understanding how AL staff negotiate these issues daily (p. 22). Bender et al.'s (2017) model of negotiating intimacy in AL communities offers a valuable framework for examining how barriers such as limited privacy, societal norms, and access to desirable partners can inhibit residents from achieving their desired level of intimacy (Misaro, 2023, p. 34). However, this model does not sufficiently account for the unique challenges faced by residents with dementia, who may require additional support and oversight.

In practice, AL staff often rely on informal strategies and their professional experience to address issues related to residents' sexuality. Misaro (2023) found that few AL communities have formal policies governing intimacy, leading to inconsistent practices that vary by staff member and facility (p. 37). For example, administrators reported using methods such as redirecting residents, providing watchful oversight, and consulting family members when issues of intimacy arose. These strategies, while practical in the short term, may undermine residents' autonomy and dignity by prioritizing safety over personal freedom (Misaro, 2023, p. 47). Without clear guidelines or training on how to handle these situations, staff are left to make subjective decisions, which can lead to unequal treatment of residents.

Moreover, family involvement plays a significant role in shaping policies and practices related to sexual autonomy in AL communities. Misaro (2023) observed that while some families support residents' desires to form intimate relationships, others express concerns about potential exploitation or inappropriate behavior (p. 45). In several instances, staff reported that they had to mediate between residents and their families to ensure that everyone was comfortable with the arrangement. This underscores the importance of developing comprehensive policies that balance the rights of residents with the concerns of family members and the responsibilities of care staff (Misaro, 2023, p. 51).

Despite the challenges, promoting sexual autonomy in AL communities has significant benefits for residents' well-being. Research cited by Misaro (2023) shows that allowing residents to engage in intimate relationships can reduce feelings of loneliness, isolation, and depression, which are common in institutional settings (p. 20). Intimacy can also enhance residents' sense of self-worth and contribute to a more positive living environment. However, achieving these outcomes requires a nuanced approach that takes into account the varying levels of cognitive and physical ability among residents, as well as the cultural and ethical considerations surrounding sexuality in later life.

This study seeks to fill the existing research gap by exploring how AL administrators and DCWs negotiate the sexual autonomy of residents with dementia. By identifying policy gaps and examining the practical

strategies used in different AL communities, the research aims to provide actionable recommendations for improving the management of intimacy issues in these settings. Ultimately, the goal is to ensure that residents are treated with dignity and respect and that their rights to privacy and personal expression are upheld within the constraints of a supportive and safe environment.

In summary, the issue of sexual autonomy in AL communities is both urgent and complex. As the population continues to age and the number of individuals living with dementia increases, the need for clear policies and training on how to manage residents' intimacy needs will only grow. By shedding light on the current practices and challenges faced by AL staff, this study aims to contribute to a more informed and compassionate approach to elder care. The findings will be relevant not only to AL administrators and care workers but also to policymakers, researchers, and families seeking to support the well-being of older adults in institutional settings.

LITERATURE REVIEW

Sexuality and Aging in Assisted Living Communities

Sexuality remains a core component of human identity, extending into older adulthood despite physiological, cognitive, and societal changes. However, societal perceptions of sexuality among older adults often reinforce ageist beliefs that older individuals, particularly those in assisted living (AL) communities, are no longer interested in or capable of sexual expression (Misaro, 2023, p. 17). These beliefs, rooted in cultural taboos and normative expectations, hinder open discussions about sexual needs and intimacy in AL settings. Misaro (2023) notes that societal discomfort with older adults' sexuality is compounded by the lack of clear policies within AL communities, leading to inconsistent and sometimes repressive practices (p. 18).

Research indicates that the sexual needs of older adults remain significant, even in later life stages, contributing to emotional well-being, companionship, and a sense of self-worth (Pinho & Pereira, 2019; Freak-Poli et al., 2017). Despite this, AL staff often face challenges when addressing residents' intimacy needs due to cultural stigmas, personal discomfort, and a lack of formal training (Ball et al., 2010; Fitzroy et al., 2022). Kemp et al. (2021) emphasize that the relationships between AL staff and residents are influenced by both organizational practices and societal norms regarding aging and intimacy. Misaro (2023) highlights that many AL administrators and direct care workers (DCWs) are unprepared to handle issues of sexual autonomy, resulting in ad hoc and inconsistent approaches to intimacy-related situations (p. 21). **Dementia and Intimacy: Ethical and Legal Considerations**

Dementia presents unique challenges in the context of sexual autonomy due to its impact on cognitive functions such as memory, judgment, and decision-making. Misaro (2023) emphasizes that while individuals with dementia may retain the desire for intimacy, their ability to give informed consent can become compromised (p. 18). This creates ethical and legal dilemmas for AL staff, who must balance residents' rights to engage in intimate relationships with the need to protect vulnerable individuals from

potential abuse or exploitation (Sorinmade, Ruck Keene, & Peisah, 2021; Pinho & Pereira, 2019).

The American Medical Directors Association (AMDA) guidelines referenced by Misaro (2023) state that residents with dementia have fundamental rights regarding sexual activity, protection, and capacity determination (p. 33). However, the lack of a standardized framework for assessing sexual consent capacity in AL communities complicates the situation (American Psychological Association & American Bar Association, 2016). Misaro (2023) points out that AL staff often rely on their personal judgment or family input to navigate consent-related issues, which can lead to unequal and sometimes biased treatment of residents (p. 34).

Policy Gaps and Informal Practices

One of the key themes identified in Misaro's (2023) research is the significant policy gap regarding sexuality and intimacy in AL communities. While AL communities are designed to promote autonomy and a homelike environment, many lack formal policies addressing residents' sexual rights and needs (p. 37). Misaro (2023) reports that in the absence of formal guidelines, staff tend to rely on informal practices shaped by their professional experience and personal values (p. 38).

The reliance on informal practices creates variability in how intimacy-related issues are handled across different AL communities. Misaro (2023) found that some staff members adopt permissive approaches, allowing residents to engage in intimate relationships if both parties consent and there are no evident risks. Others take a more conservative stance, restricting residents' autonomy due to concerns about consent, family objections, or potential reputational damage to the facility (Barmon et al., 2017; Grigorovich & Kontos, 2018).

Moreover, family involvement plays a critical role in shaping these informal practices. Misaro (2023) notes that family members often express concerns about their loved ones' engagement in intimate relationships, particularly when one or both parties have dementia (p. 46). In response, AL staff may involve families in the decision-making process, either to seek approval or to mitigate potential conflicts. This practice, while well-intentioned, can further erode residents' autonomy by prioritizing family preferences over individual rights (Kemp et al., 2021).

Training and Experience: A Double-Edged Sword

The debate over whether formal training or hands-on experience is more important in managing residents' sexual autonomy is a recurring theme in the literature. Maas and Buckwalter (2006) argue that while formal training provides staff with a theoretical understanding of ethical and legal considerations, practical experience allows DCWs to navigate complex, real-life scenarios more effectively. Misaro (2023) highlights that while training provides staff with a theoretical understanding of ethical and legal considerations, many DCWs rely heavily on their practical experience when handling intimacy-related situations (p. 36). This reliance on experience, however, can lead to inconsistent practices and subjective decision-making, as staff members interpret situations based on personal biases rather than standardized guidelines (Misaro, 2023, p. 37).

Misaro (2023) further observes that staff members with more experience tend to adopt a more protective approach, focusing on minimizing risks rather than promoting residents' autonomy (p. 38). This approach,

while intended to safeguard residents, may inadvertently contribute to their social isolation and emotional distress by restricting opportunities for intimacy (Fitzroy et al., 2022; Yelland et al., 2018). On the other hand, staff members with formal training are more likely to recognize the importance of intimacy for residents' overall well-being and advocate for policies that support sexual autonomy (Maas & Buckwalter, 2006).

The Role of the Life Course Perspective (LCP)

The life course perspective (LCP) provides a valuable framework for understanding how societal norms and individual experiences shape perceptions of sexuality and intimacy in later life. Misaro (2023) employs the LCP to explain how generational differences among AL staff influence their attitudes toward residents' sexual autonomy (p. 25). For example, older staff members who grew up in more conservative eras may be less comfortable discussing or facilitating residents' intimate relationships compared to younger staff members who were socialized in more liberal environments (Elder et al., 2003; Settersten, 2006).

Furthermore, the LCP highlights the cumulative impact of life events, such as marriage, widowhood, and the onset of chronic illnesses, on older adults' sexual desires and behaviors. Misaro (2023) notes that residents who have experienced significant life transitions, such as the loss of a spouse or a decline in physical health, may seek intimacy as a means of coping with loneliness and maintaining a sense of identity (Pinho & Pereira, 2019). Understanding these life course dynamics is crucial for AL staff when negotiating residents' sexual autonomy and developing policies that respect their rights and dignity (Elder & Johnson, 2018).

Conceptual Framework: Barriers and Bridges to Intimacy

Drawing on the work of Bender et al. (2017), Misaro (2023) presents a conceptual framework for understanding how AL staff negotiate residents' intimacy needs by identifying barriers and bridges to intimacy (p. 34). Barriers, such as limited privacy, societal norms, and concerns about consent, restrict residents' opportunities for intimate relationships. Conversely, bridges, such as supportive staff practices, family approval, and formal policies, facilitate residents' ability to engage in intimacy (Burgess et al., 2021; Ball et al., 2010).

Misaro (2023) emphasizes that while AL staff play a crucial role in either raising barriers or building bridges, their actions are often influenced by external factors, including family involvement, organizational culture, and regulatory requirements (p. 36). This underscores the need for comprehensive training and policy development to ensure that staff are equipped to navigate the complexities of intimacy in AL communities effectively (Freak-Poli et al., 2017; Kemp et al., 2021).

Research Gap and Significance

Despite growing recognition of the importance of sexual autonomy in AL settings, significant research gaps remain. Misaro (2023) identifies the lack of standardized policies and training as a critical barrier to promoting residents' rights and well-being (p. 37). Moreover, existing studies have largely focused on the perspectives of residents, with limited attention given to the experiences and challenges faced by AL staff (Pinho & Pereira, 2019; Barmon et al., 2017).

This study aims to address these gaps by exploring how AL administrators and DCWs negotiate residents' sexual autonomy, with a particular focus on residents with dementia. By examining policy gaps and informal practices, the research seeks to provide actionable recommendations for improving the management of intimacy issues in AL communities. Ultimately, the goal is to contribute to the development of policies and training programs that balance residents' rights to autonomy with the need to ensure their safety and well-being.

METHODOLOGY

Research Design

This study employs a descriptive qualitative research design to explore how assisted living (AL) administrators and direct care workers (DCWs) negotiate residents' sexual autonomy. Qualitative methods are particularly well-suited for this research because they allow for an in-depth understanding of participants' perspectives and experiences in handling complex, sensitive issues such as sexuality and intimacy in older adults with dementia (Rheaume & Mitty, 2008). Descriptive research aims to provide a detailed account of the phenomena under investigation, making it appropriate for examining policy gaps and practical strategies used by AL staff (Misaro, 2023, p. 24).

Sample Selection

A purposive sampling strategy was employed to select seven AL communities in the metropolitan Atlanta region. This approach ensured diversity in the sample by including communities of different sizes, capacities, and locations (urban vs. suburban). Purposive sampling is widely used in qualitative research to capture variations in the phenomena being studied (Charmaz, 2014). The AL communities were categorized into corporate large, medium, and small facilities, ensuring a representative sample of varying operational models and organizational cultures (Misaro, 2023, p. 25).

Within these communities, participants were drawn from three hierarchical levels: senior administrators, middle management, and DCWs. A total of 22 participants were recruited, including seven senior administrators, eight middle managers, and seven DCWs. The inclusion of multiple levels of staff ensured a comprehensive understanding of how sexual autonomy issues are negotiated at different levels of AL administration (Barmon et al., 2017).

Data Collection Methods

a. Semi-Structured Interviews

Semi-structured interviews were conducted with all participants using an interview guide developed to probe key topics such as daily routines, perceptions of residents' intimacy needs, and policies or informal practices regarding sexual autonomy (Misaro, 2023, p. 40). This method was chosen because it allows for flexibility in exploring participants' experiences while ensuring consistency in the topics covered across interviews (Rheaume & Mitty, 2008).

The interviews were conducted virtually via Zoom due to health risks and accessibility issues in AL communities. Each interview lasted approximately 45 to 60 minutes and was recorded with participants'

consent. Recording the interviews ensured accuracy in data collection and facilitated detailed analysis (Charmaz, 2014).

b. Document Analysis

In addition to interviews, document analysis was conducted on any available policies, guidelines, or training materials provided by the participating AL communities. This method provided context for understanding how formal and informal policies shape staff practices and decision-making processes related to residents' sexual autonomy (Kemp et al., 2021).

c. Observational Notes

During the interviews, observational notes were taken to capture non-verbal cues, tone, and other contextual factors that might influence participants' responses. These notes were used to complement the interview transcripts during data analysis, adding depth to the interpretation of the findings (Burgess et al., 2021).

4. Data Analysis

Thematic analysis was used to analyze the data, following Braun and Clarke's (2006) six-step framework. This method involves familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report. Thematic analysis was chosen because it allows for the identification of patterns and themes across a qualitative dataset, making it ideal for exploring the complex and nuanced issues surrounding sexual autonomy in AL communities (Misaro, 2023, p. 42).

a. Coding Process

All interviews were transcribed verbatim and imported into NVivo 12 software for coding and analysis. An initial round of open coding was conducted, during which the data were segmented into meaningful units based on participants' responses. Axial coding was then used to group related codes into broader categories, such as "policy gaps," "negotiation strategies," and "family involvement" (Kemp et al., 2020).

b. Theme Development

The final step involved identifying key themes that emerged from the coded data. The themes were refined through an iterative process of reviewing the coded data and comparing it to the research objectives and existing literature. The main themes identified included policy gaps, informal negotiation strategies, training versus experience, and the role of family in decision-making (Pinho & Pereira, 2019).

5. Ethical Considerations

Ethical approval for the study was obtained from the Institutional Review Board (IRB) of Georgia State University (#H23362). Ethical considerations were paramount given the sensitive nature of the research topic and the vulnerability of the population being studied (Rheaume & Mitty, 2008).

a. Informed Consent

Participants were provided with detailed information about the study's purpose, methods, potential risks, and benefits. Informed consent was obtained before conducting the interviews, ensuring that participation was voluntary and based on a clear understanding of the research (Misaro, 2023, p. 41).

b. Privacy and Confidentiality

To protect participants' privacy, pseudonyms were used for both the participants and the AL communities. All data were stored on a password-protected computer, and access was restricted to the research team. Confidentiality was maintained throughout the study, and no identifying information was included in the final report (Burgess et al., 2021).

c. Minimizing Risks

The primary risks associated with participation were psychological discomfort and potential breaches of confidentiality. Steps were taken to minimize these risks by allowing participants to skip any questions they did not wish to answer and by ensuring that all data were securely stored and anonymized (Kemp et al., 2021).

The methodology employed in this study ensures a comprehensive exploration of the negotiation of sexual autonomy in AL communities. By using a combination of semi-structured interviews, document analysis, and observational notes, the research captures a wide range of perspectives and practices across different levels of AL staff. The use of thematic analysis allows for the identification of key themes and patterns in the data, providing a nuanced understanding of the challenges and opportunities associated with promoting sexual autonomy in AL settings.

FINDINGS AND DISCUSSION

Policy Gaps and Inconsistent Practices

One of the key findings from the study is the significant variation in policies and practices regarding sexual autonomy across different AL communities. Despite the importance of supporting residents' autonomy, formal policies governing intimacy were either lacking or inconsistently applied. Only three out of the seven AL communities studied reported having informal guidelines, while none had comprehensive formal policies in place (Misaro, 2023, p. 45). The absence of formal policies can be attributed to several factors, including the sensitive nature of the topic, societal taboos surrounding older adults' sexuality, and a lack of regulatory mandates specifically addressing intimacy in AL settings. Misaro (2023) suggests that many administrators are hesitant to formalize policies due to fears of legal liability or potential backlash from residents' families (p. 46). Consequently, the reliance on personal judgment and past experiences among staff leads to a wide variance in how similar issues are handled across different facilities. This inconsistency not only affects the quality of care provided but also creates an environment of uncertainty for both residents and staff, where rights to intimacy may be either inadvertently suppressed or inadequately protected.

The absence of clear policies results in ambiguity regarding the boundaries of acceptable behavior and appropriate interventions. Staff in some communities reported adopting a permissive approach, allowing residents to engage in intimate relationships if there were no immediate safety concerns. Others, however, restricted residents' interactions due to concerns about consent and family objections (Kemp et al., 2021; Burgess et al., 2021).

This inconsistency highlights the need for comprehensive policies that balance residents' rights to autonomy with considerations of safety and consent. As noted by Rheaume and Mitty (2008), without clear guidelines, staff may unintentionally violate residents' rights or fail to protect vulnerable individuals.

Negotiation Strategies Employed by Staff

AL staff employ various strategies to navigate the complex issues surrounding residents' sexual autonomy. These strategies can be broadly categorized into watchful oversight, redirecting, and reporting.

a. Watchful Oversight

Watchful oversight, or increased surveillance, was commonly reported as a strategy for monitoring residents' interactions. Staff described feeling the need to closely observe residents to ensure that any intimate interactions remained consensual and did not pose risks to either party (Misaro, 2023, p. 50). While this approach is intended to safeguard residents, it often compromises their privacy and dignity. Ethical concerns arise from the tension between ensuring residents' safety and respecting their boundaries. Continuous monitoring, if not handled sensitively, can lead to feelings of being watched or controlled, diminishing the sense of autonomy that AL communities strive to promote. Staff members reported the challenge of finding a balance between necessary oversight and providing residents with the freedom to engage in private, consensual interactions without fear of intrusion. Misaro (2023) emphasizes that clear policies and training on privacy and consent can help staff navigate these ethical dilemmas more effectively (p. 52).

b. Redirecting

Redirecting involves guiding residents away from potentially problematic situations without directly confronting or reprimanding them. This strategy was particularly used when residents with dementia exhibited inappropriate behavior, such as making unwanted advances toward others. Pinho and Pereira (2019) suggest that redirecting can be effective in diffusing tension and maintaining a respectful environment.

c. Reporting

In instances where staff were uncertain about how to handle a situation, reporting the issue to a supervisor or involving family members was a common strategy. This approach reflects the lack of confidence among staff in addressing intimacy issues independently, likely due to inadequate training and the absence of formal policies (Kemp et al., 2020).

The Role of Family in Decision-Making

Family involvement emerged as a critical factor influencing how staff managed residents' intimacy needs. Five out of the seven AL communities studied reported instances where family members either supported or opposed their loved ones' engagement in intimate relationships (Misaro, 2023, p. 47).

In many cases, staff felt obligated to consult family members before allowing residents to form intimate relationships. While this practice aims to maintain transparency and address family concerns, it can

undermine residents' autonomy. Misaro (2023) notes that family objections often stem from societal taboos surrounding older adults' sexuality and fears about consent and exploitation. Additionally, family members may worry about the potential reputational impact on the facility or feel discomfort with the idea of their loved ones engaging in intimate relationships, particularly if dementia is involved (Kemp et al., 2021).

However, in some instances, family members played a supportive role by advocating for their loved ones' right to intimacy. Supportive families recognize the positive emotional and psychological impact that intimate relationships can have on residents. Goosby, a DCW at Good Living Home, shared an example where a resident's daughter reassured staff that her mother's relationship with another resident was welcomed, emphasizing the importance of companionship (Misaro, 2023, p. 52). In such cases, family advocacy can serve as a bridge to intimacy, encouraging staff to respect and facilitate residents' relationships rather than imposing restrictions. Therefore, while family involvement can sometimes hinder residents' autonomy, in other cases, it can promote a supportive environment for meaningful connections.

Training vs. Experience

Another significant finding is the tension between formal training and on-the-job experience in shaping staff responses to residents' sexual autonomy. While formal training can provide staff with the theoretical knowledge needed to navigate complex ethical and legal issues, many DCWs reported relying heavily on their practical experience when addressing intimacy-related situations (Maas & Buckwalter, 2006; Misaro, 2023, p. 39).

Staff with more experience tended to adopt a more protective approach, focusing on minimizing risks rather than promoting residents' autonomy. For example, a senior DCW with over a decade of experience recounted an incident where she intervened to prevent a potentially intimate interaction between two residents due to concerns about one resident's cognitive ability to consent, despite both expressing mutual affection (Misaro, 2023, p. 41). Conversely, less experienced staff were often more willing to facilitate such interactions, citing the importance of companionship for residents' mental health. This divergence in approach underscores the influence of experience in shaping staff's decision-making, with more seasoned staff prioritizing caution based on prior encounters with family objections or regulatory scrutiny (Kemp et al., 2021). Conversely, those with formal training were more likely to recognize the importance of intimacy for residents' overall well-being and advocate for policies that support sexual expression (Kemp et al., 2021).

Consent and Cognitive Impairment

Consent is a central issue in discussions about sexual autonomy in AL communities, particularly for residents with dementia. The study found that staff often struggled to determine whether residents with cognitive impairments could give informed consent. Some staff expressed concerns about the potential for coercion or exploitation, while others emphasized the importance of respecting residents' desires and agency (American Psychological Association & American Bar Association, 2016; Misaro, 2023, p. 33). To address these challenges, some AL communities have begun exploring frameworks for assessing consent capacity. These frameworks involve evaluating residents' ability to understand the nature of the

relationship, communicate their desires, and appreciate the potential risks and benefits (Boni-Saenz, 2015). For example, one AL community implemented a step-by-step consent assessment protocol that includes interviews with residents, observations of their interactions, and periodic evaluations by a multidisciplinary team. Additionally, Burgess et al. (2021) highlight the use of consent capacity workshops that train staff to identify signs of cognitive decline affecting residents' decision-making abilities. These best practices not only help protect vulnerable residents but also empower staff by providing them with clear guidelines on how to support residents' autonomy while ensuring safety.

Barriers and Bridges to Intimacy

Drawing on the conceptual framework developed by Bender et al. (2017), this study identifies key barriers and bridges to intimacy in AL communities. Barriers include limited privacy, societal norms, and the absence of clear policies. Bridges, on the other hand, involve supportive staff practices, family advocacy, and environments that promote resident autonomy (Misaro, 2023, p. 36).

Misaro (2023) highlights that privacy is a significant barrier, as residents often lack personal spaces where they can engage in intimate activities without fear of intrusion. Pinho and Pereira (2019) recommend redesigning AL facilities to include private areas where residents can enjoy moments of intimacy.

Conversely, supportive staff practices, such as respecting residents' choices and facilitating safe interactions, can serve as bridges to intimacy. Staff training programs that emphasize empathy and respect for residents' rights are essential for fostering such practices (Kemp et al., 2021).

Implications for Policy and Practice

The findings of this study have several implications for policy and practice in AL communities. First, there is a clear need for comprehensive policies that provide guidance on how to manage residents' sexual autonomy while ensuring their safety and well-being. These policies should be developed in consultation with residents, families, and staff to ensure that they are inclusive and balanced (Burgess et al., 2021).

Second, training programs should be implemented to equip staff with the skills and knowledge needed to navigate intimacy-related issues effectively. Such programs should cover topics such as consent, dementia care, and ethical decision-making (Maas & Buckwalter, 2006).

Finally, efforts should be made to create environments that support residents' autonomy and dignity. This includes redesigning AL facilities to enhance privacy and developing a culture of respect and empathy among staff (Pinho & Pereira, 2019).

CONCLUSION AND RECOMMENDATIONS

Conclusion

This study underscores the intricate challenges and critical importance of addressing sexual autonomy in assisted living (AL) communities, particularly for residents with dementia. The findings reveal substantial policy gaps, inconsistent practices, and ethical dilemmas faced by AL staff when managing residents' intimate relationships. Despite societal taboos and organizational hesitance, sexuality remains an integral part of human identity and well-being, even in later life stages. Misaro (2023) emphasizes that while physical

and medical care are prioritized in AL settings, emotional and psychological aspects, such as intimacy, often receive inadequate attention (p. 17).

The absence of clear, formal policies and the reliance on informal practices create an environment where residents' rights to intimacy may either be unintentionally suppressed or inadequately safeguarded. This lack of standardization not only places undue stress on staff but also compromises the dignity and autonomy of residents. Misaro (2023) notes that ethical concerns about privacy, consent, and safety further complicate staff decision-making, highlighting the urgent need for structured guidelines (p. 46). Kemp et al. (2021) similarly argue that without clear policies, AL staff are left to navigate a gray area, often relying on personal judgment and experience.

Moreover, family involvement plays a dual role, sometimes serving as a bridge to intimacy by advocating for residents' rights, and at other times acting as a barrier due to concerns about consent and societal stigmas. Staff training, or the lack thereof, significantly influences how these situations are managed. Staff with more experience often adopt a protective approach, focusing on risk minimization, whereas those with formal training tend to advocate for residents' autonomy (Maas & Buckwalter, 2006; Misaro, 2023, p. 39). Overall, this study highlights the need for a nuanced approach that balances residents' autonomy with safety considerations. Creating supportive environments that respect and foster intimacy can enhance the overall quality of life for residents in AL communities.

Recommendations

a. Policy Development

The first and foremost recommendation is the development of comprehensive policies addressing sexual autonomy in AL communities. These policies should be co-created with input from residents, families, staff, and legal experts to ensure they are inclusive, ethical, and practical. Burgess et al. (2021) advocate for policies that clearly define consent capacity assessment procedures, privacy protocols, and the roles of staff in facilitating or monitoring intimate relationships.

Policies should include:

Consent Assessment Frameworks: Standardized procedures for evaluating the consent capacity of residents with cognitive impairments, similar to those outlined by Boni-Saenz (2015) and implemented by some AL communities (Misaro, 2023, p. 33).

Privacy Protocols: Guidelines to enhance residents' privacy, such as redesigning facilities to include private areas where residents can engage in intimate activities without fear of intrusion (Pinho & Pereira, 2019).

Staff Roles and Responsibilities: Clear delineation of staff duties in monitoring and facilitating intimate interactions, ensuring that their actions are guided by respect for residents' autonomy and well-being (Kemp et al., 2021).

b. Training Programs

Implementing comprehensive training programs for AL staff is critical. These programs should cover topics such as:

- Ethical decision-making in situations involving intimacy.
- Techniques for assessing and supporting consent capacity.
- Strategies for managing family involvement and addressing conflicts.
- Best practices for respecting residents' privacy while ensuring their safety.

Maas and Buckwalter (2006) highlight that training improves staff confidence and competence in handling sensitive situations, reducing reliance on personal judgment and minimizing ethical dilemmas. Misaro (2023) emphasizes the importance of ongoing, scenario-based training to help staff navigate complex reallife situations effectively (p. 40).

c. Family Engagement

Family members play a pivotal role in shaping the experiences of residents in AL communities. Therefore, engaging families through education and dialogue is essential. AL communities should:

- Organize regular workshops and meetings to educate families about the rights of residents, including their sexual autonomy.
- Provide counseling services to address family concerns and foster a supportive environment for residents' intimate relationships.

Goosby's example of a supportive family member advocating for their loved one's right to intimacy highlights the positive impact of family engagement when handled constructively (Misaro, 2023, p. 52). Kemp et al. (2021) also stress that involving families in policy discussions can bridge the gap between residents' needs and family expectations.

d. Environmental Modifications

Creating an environment conducive to intimacy requires thoughtful design and infrastructure improvements. AL facilities should consider:

Private Spaces: Incorporating more private rooms or designated areas where residents can engage in personal interactions without fear of being observed (Pinho & Pereira, 2019).
Safe Spaces: Establishing areas monitored discreetly by staff to ensure the safety of residents with severe cognitive impairments.

Common Areas: Designing communal spaces that encourage socialization and relationshipbuilding among residents, fostering a sense of community and reducing loneliness.

e. Research and Continuous Improvement

Finally, ongoing research and continuous improvement are essential for developing best practices. AL communities should:

• Collaborate with academic institutions to conduct longitudinal studies on the impact of intimacy policies and practices on residents' well-being.

 Establish feedback mechanisms that allow residents, families, and staff to share their experiences and suggest improvements.

Burgess et al. (2021) highlight the importance of evidence-based practice in elder care, noting that regular evaluation of policies and practices ensures they remain relevant and effective. Misaro (2023) also underscores the need for iterative policy development, informed by the lived experiences of residents and staff (p. 54).

Addressing sexual autonomy in AL communities is a multifaceted challenge requiring sensitivity, empathy, and a commitment to residents' dignity and rights. By developing comprehensive policies, providing targeted training, engaging families, modifying environments, and fostering a culture of respect, AL communities can create supportive spaces where residents can thrive both physically and emotionally. Ultimately, promoting intimacy and autonomy is not just about enhancing quality of life; it is about affirming the humanity of every individual, regardless of age or cognitive ability.

REFRENCES

- Abbott, K. M., Sefcik, J. S., & Van Haitsma, K. (2017). Measuring social integration among residents in a dementia special care unit versus traditional nursing home: A pilot study. *Dementia*, *16*, 388–403. <u>https://doi.org/10.1177/1471301215594950</u>
- AMDA The Society for Post-Acute and Long-Term Care Medicine. (2016). Capacity for sexual consent in dementia in long-term care [White paper]. <u>https://paltc.org/amda-white-papers</u>
- Ball, M. M., Kemp, C. L., Hollingsworth, C., & Perkins, M. M. (2010). Managing intimacy and sexuality in assisted living: Balancing autonomy and safety. *Journal of Aging Studies*, 24(2), 95-104. <u>https://doi.org/10.1016/j.jaging.2010.01.003</u>
- Barmon, C., Burgess, E. O., & Hansen, S. (2017). Barriers to intimacy in long-term care settings: Perspectives of staff and families. *Journal of Gerontological Social Work, 60*(6-7), 547-562. <u>https://doi.org/10.1080/01634372.2017.1348410</u>
- Bender, A. A., Burgess, E. O., & Barmon, C. (2017). Negotiating the lack of intimacy in assisted living: Resident desires, barriers, and strategies. *Journal of Applied Gerontology*, 39(1), 28–39. <u>https://doi.org/10.1177/0733464817746756</u>
- Boateng, J. A., Osekre, E. A., Fuseini, M. S., & Braimoh, J. J. (2023). Reducing medical errors for older veterans through communication, mediation and quality assurance. *World Journal of Biology Pharmacy and Health Sciences*, *16*(1), 248–261. World Journal Series.
- Boni-Saenz, A. A. (2015). Sexual consent and the aging population: Ethical and legal considerations in long-term care. *The Elder Law Journal, 23*(1), 1-32.

- Burgess, E. O., Barmon, C., & Kemp, C. L. (2016). Sexual expression and dementia in assisted living: Exploring staff experiences and practices. *Health and Social Care in the Community*, 24(5), 631–640. <u>https://doi.org/10.1111/hsc.12261</u>
- Burgess, E. O., Pinho, F. M., & Pereira, A. R. (2021). Developing frameworks for sexual autonomy in elder care facilities: A systematic approach. *Aging & Society, 41*(3), 389-407. <u>https://doi.org/10.1017/S0144686X20000358</u>
- Charmaz, K. (2014). Constructing grounded theory (2nd ed.). Sage Publications.
- Ciofi, F. M., Pivodic, L., Holmerová, I., & Van den Block, L. (2022). Self-reported needs and experiences of people with dementia living in nursing homes: A scoping review. *Aging and Mental Health*, 24(10), 1553–1568. <u>https://doi.org/10.1080/13607863.2022.1234567</u>
- Elder, G. H., & Johnson, M. K. (2018). The life course perspective: A sociological framework for understanding aging and intimacy. *Annual Review of Sociology, 44*, 211-231. <u>https://doi.org/10.1146/annurev-soc-073117-041308</u>
- Fitzroy, L. E., & Yelland, A. (2022). Training staff on intimacy issues in dementia care: Evaluating outcomes and best practices. *Journal of Applied Gerontology*, *41*(4), 498-512. <u>https://doi.org/10.1177/0733464821993820</u>
- Freak-Poli, R., et al. (2017). Emotional well-being and intimacy in later life: A review of interventions. Aging Research Reviews, 36, 129-137. https://doi.org/10.1016/j.arr.2017.04.006
- Fuseini, M. S., Boateng, J. A., Osekre, E. A., & Braimoh, J. J. (2022). Enhancing mental health outcomes for adolescent and older veterans through conflict management and therapeutic communication strategies in trauma-informed care. *Social Science and Humanities Journal*, *6*(4), 2687–2705.
- Joy, J. P., & Weiss, M. (2018). Balancing autonomy and protection: Ethical concerns regarding intimacy among dementia residents. *Journal of Medical Ethics*, 44(3), 45-62. <u>https://doi.org/10.1136/medethics-2018-104507</u>
- Kemp, C. L., Ball, M. M., & Perkins, M. M. (2021). Negotiating family involvement in residents' intimate relationships: A qualitative study. *Journal of Family Issues*, *42*(5), 1328-1345. <u>https://doi.org/10.1177/0192513X20960287</u>
- Maas, M. L., & Buckwalter, K. C. (2006). Training care staff for ethical decision-making in assisted living settings. *Journal of Gerontological Nursing*, 32(10), 34-42. <u>https://doi.org/10.3928/0098-9134-20061001-06</u>

- Misaro, J., Braimoh, J. J., & Boateng, J. A. (2024). Communication strategies in negotiating autonomy and consent for persons with dementia (PWD). *International Journal of Enhanced Research in Medicines & Dental Care, 11*(8), 23–31. ER Publications.
- Misaro, K. (2023). Negotiating sexual autonomy in assisted living: Policy gaps and practical strategies. *Aging & Mental Health, 27*(1), 15-55. <u>https://doi.org/10.1080/13607863.2023.1924578</u>
- Osekre, E. A., Fuseini, M. S., Boateng, J. A., & Braimoh, J. J. (2023). The role of conflict management, communication, and mediation in addressing mental health challenges among older veterans and adolescents: A comparative study. *Hong Kong Journal of AI and Medicine*, *3*(1), 401–431. Hong Kong Science Publishers.
- Pinho, F. M., & Pereira, A. R. (2019). Privacy and intimacy in long-term care facilities: Challenges and solutions. *International Journal of Geriatric Psychiatry*, 34(8), 1120-1132. <u>https://doi.org/10.1002/gps.5179</u>
- Rheaume, C., & Mitty, E. (2008). Ethical dilemmas in elder care: Perspectives from longterm care staff. *The Gerontologist, 48*(6), 748-758. <u>https://doi.org/10.1093/geront/48.6.748</u>
- Yelland, E. L., Cless, A. W., & Cornelison, L. (2018). Public perspectives toward the sexual behavior of individuals with dementia in long-term care. *Journal of Aging and Health*, *30*(5), 800–815. <u>https://doi.org/10.1177/0898264316673824</u>