More Than Capacity: Alternatives for Sexual Decision Making for Individuals With Dementia

James M. Wilkins, MD, DPhil*1,2,3

1Department of Psychiatry, McLean Hospital, Belmont, Massachusetts. 2Department of Psychiatry, Massachusetts General Hospital, Boston, Massachusetts. 3Department of Psychiatry, Harvard Medical School, Boston, Massachusetts.

*Address correspondence to James M. Wilkins, MD, DPhil, McLean Hospital Adult Outpatient Clinic, 115 Mill Street, Belmont, MA 02478. E-mail: jwilkins1@partners.org

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Abstract

Sexual expression can be an important aspect of well being for older adults with dementia living in nursing homes. There is a tension in the nursing home, however, between ensuring autonomy of residents for sexual expression and protecting residents from harm. To alleviate this tension, nursing homes can conduct an assessment of residents’ capacity for sexual consent. This article argues that although such assessments can be useful in the initial evaluation of capacity, this is a somewhat flawed approach to sexual decision making and a finding of incapacity should not necessarily preclude sexual expression. In instances where residents are found to lack capacity but continue to express interest in sexual expression, a committee approach can be utilized where residents, the nursing home, and family members can convene to advocate for residents’ autonomy, dignity, and right to sexual expression while working to minimize harm. Such advocacy decisions can be based on substituted judgment, a best interest standard, or some combination of the two. Although committee decision making for sexual expression seems intrusive, it at least allows for continued discussion of the right to sexual freedom for residents in the face of significant counterbalancing forces.

Key Words: Autonomy, Ethics, Nursing homes, Person centered care

Sexuality in the Long-term Care Setting

Although myths may persist to the contrary, there is no age at which a person’s sexuality suddenly disappears (Gaile & Henderson, 2003). In fact, a significant number of older adults maintain a sustained interest in sexual activity throughout life even though the expression of that sexuality may shift as one ages from coital activities to noncoital activities, such as hand holding, kissing, physical embraces (e.g., hugging), flirting, and personal grooming (Benbow & Beeston, 2012; Hajjar & Kamel, 2003). In a recent survey of over 3,000 community-dwelling adults aged 57–85 years old, the majority of adults were found...
to be part of a spousal or intimate relationship, but the likelihood of sexual activity (i.e., vaginal intercourse, oral sex, masturbation) declined with age (73% of adults 57–64 years old to 26% of adults 75–85 years old) (Lindau et al., 2007). For the adults who were sexually active, however, the frequency of sexual activity was found to be similar to the frequency of activity in adults aged 18–59 years old (Lindau et al., 2007).

The sexual expression of older adults is complicated by a number of factors, one of which is the inevitable deterioration in health that one endures through the ageing process. For example, older men suffer from increasing difficulty with maintaining an erection, whereas older women suffer from difficulties with vaginal lubrication (Lindau et al., 2007). Other factors hindering the sexual expression of older adults are ageist stereotypes that older adults are asexual, that sexual activity is unimportant for their quality of life, and that it is abnormal for older adults to have an interest in sex (Allen, 2015; Higgins, Barker, & Begley, 2005; Subramani, Devasahayam, Wattis, & Curran, 2011). Older adults, however, regard sexuality as integral to their self-worth, social relationships, and mental health (Hajjar & Kamel, 2003). Indeed, intimacy and positive interpersonal relationships have been shown to not only reduce the risk of mood and behavioral disturbances and the risk of excess disability in older adults, but to also improve quality of life and prevent diseases like arthritis (Kuhn, 2002; Perkins, Ball, Kemp, & Hollingsworth, 2013; Rosen, Lachs, & Pillemer, 2010).

As adults are living longer with less of a dependence on the nuclear family, more older adults are moving into long-term care facilities (Gaile & Henderson, 2003). In the United States, it has been reported that 5% of adults over the age of 65 and 20% of adults over the age of 85 live in nursing homes (Hajjar & Kamel, 2003). The nursing home environment presents its own unique challenges to the sexual expression of older adults as a number of tensions between nursing home residents and the nursing home itself are played out. First, there is a tension between allowing residents to associate privately, including intimacy and sexual privacy, with whomever the resident chooses and the responsibility of the nursing home to protect its residents from foreseeable harm due to a sexual encounter (Casta-Kaufteil, 2004; Everett, 2007; Gaile & Henderson, 2003).

Second, there is a subtler tension between whether the resident lives in a staff member’s place of work or whether the staff member works in the resident’s home (Kuhn, 2002). If the latter is true, a resident’s personal needs including sexual intimacy will be made a priority, whereas if the former is true, the resident’s needs are more likely to be disregarded particularly if sexuality is deemed to be beyond the scope of care-giving (Benbow & Beeston, 2012; Jönnson & Harnett, 2015; Kuhn, 2002). The upshot is that sexual expression for older adults is generally more difficult in a nursing home environment than in a community setting as residents are more susceptible to invasions of privacy and ageist prejudices (Bouman, Arcelus, & Benbow, 2006).

Sexual expression in a nursing home becomes even more complicated for a resident with dementia. Although sexual interest may wane as the dementia process progresses, a diagnosis of dementia does not necessarily signal the end of sexuality (Davies, Zeiss, Shea, & Tinklenberg, 1998; Higgins et al., 2005). In fact, sexual intimacy may be an avenue to combat the loneliness and fear inherent to the dementia process and also a way for an individual to preserve some of his/her identity role in a family as things like financial decision making become more difficult (Davies et al., 1998; Kuhn, 2002). As cognitive abilities decline, however, sexual expression may become more challenging due to difficulties with emotional control, difficulties with sequencing sexual activity, and increased sexual demands (Davies et al., 2010; Subramani et al., 2011).

For residents with dementia in a nursing home environment, a crucial distinction to be made is what is appropriate and what is inappropriate sexual behavior. The crux of this distinction is that appropriate behaviors are those that should be encouraged to preserve residents’ autonomy whereas inappropriate behaviors are those that should be quelled to protect residents from harm. This subjective distinction is generally dictated by the mission of the nursing home and reinforced at the floor level by the care workers’ perspectives and values (Elias & Ryan, 2011; Subramani et al., 2011). Inappropriate sexual behaviors can be defined as behaviors that are unsafe, disruptive, and impair the care of the resident; in this context, these behaviors include sexually explicit language, sexual acts (touching, grabbing, exposing, masturbating in public), and implied sexual acts (reading sexually explicit material, requests for unnecessary care) (Black, Muralee, & Tampi, 2005; Subramani et al., 2011). Appropriate sexual behaviors, however, are more challenging to define, but one can assume that appropriate sexual contact implies consensual sexual contact.

The issue of consent to sexual activity for individuals with dementia has recently been in the news with the case of Donna Lou Rayhons. According to an article in the New York Times, Mrs. Rayhons had dementia and was living in a nursing home whereas her husband lived in the community, visiting her frequently (Belluck, 2015). They apparently had a loving relationship and Mrs. Rayhons was reportedly always happy to see her husband. There was concern from a daughter of Mrs. Rayhons from a previous...
marriage, however, that there was inappropriate sexual contact between the married couple. A doctor in the nursing home reportedly evaluated Mrs. Rayhons and felt that she did not have the ability to consent to any sexual activity, a determination that was communicated with Mr. Rayhons. Despite this recommendation, Mr. Rayhons reportedly had sexual relations with his wife, which ultimately led to charges against him of felonious sexual abuse.

This case highlights the complexities of sexual expression for individuals with dementia in a nursing home, particularly issues around capacity, consent, decision making, quality of life, sexual abuse, and intra-family dynamics. In this article, I will further discuss the assessment of capacity to consent to sexual activity for residents with dementia in a nursing home environment and alternative routes for evaluating consent if a resident is deemed incapable or the capacity evaluation is at least equivocal.

Assessment of Capacity to Consent to Sexual Activity for Residents With Dementia

For residents with dementia in a nursing home environment, sexual activity can elicit a number of ethical dilemmas for the residents, residents’ family members, and staff about what is appropriate behavior. For example, if a resident with dementia has a spouse in the community, is it appropriate for the resident to engage in a sexual relationship with someone whom the resident misidentifies as the spouse (Kuhn, 2002)? Should past values and beliefs of a resident enter into the equation of whether current sexual behavior is appropriate (Kuhn, 2002)? Although each of these topics could be covered in articles of their own, the main ethical questions I want to focus on in this article are is a resident with dementia capable of consenting to a sexual relationship freely and without coercion and what is the role of others (staff, family members) in deciding what kind of sexual relationships a resident with dementia can have (Kuhn, 2002)?

These ethical questions are tied to the tension described in Section 1 between ensuring a resident’s autonomy in pursuing a sexual relationship and protecting both the resident and other residents from physical and psychological harm due to sexual expression (Gaile & Henderson, 2003; Higgins et al., 2005). Consent is crucial in these interactions because by definition, sexual abuse occurs any time sexual activity is nonconsensual through physical, emotional, or some other kind of coercion (Teitelman & Copolillo, 2002). Indeed, elder sexual abuse is not only more likely to occur in a nursing home environment than in the community, but also diminished cognitive abilities (i.e., dementia in this context) increase the risk that a resident will be a perpetrator or a victim of sexual abuse (Dong, 2014; Rosen et al., 2010). A needlessly conservative approach to these dilemmas would be to outlaw all sexual activity for residents with a diagnosis of dementia. The upside would be a more rigorous protection of residents from harm (i.e., sexual abuse), but the downside would be a severe infringement upon a resident’s autonomy. Additionally, outright bans of sexual activity can create an “iatrogenic loneliness” (loneliness created by overly rigid nursing home policies that rob a resident of privacy and intimacy) as well as intense frustration and unhappiness for residents (Miles & Parker, 1999).

Thus, it seems that sexual expression for a resident with dementia is a healthy and worthwhile pursuit if the resident desires to be sexually active. To ensure reasonable safety for the resident and other residents in the nursing home, however, there needs to be a mechanism for assessing the capacity of a resident with dementia to consent to sexual activity. For the purposes of this article, capacity refers to the determination by a clinician or other professional whether an individual can perform a specific task, whereas competency refers to the legal determination in a court of law of whether the individual can perform a specific task (Moye & Marson, 2007). It is worth noting that a diagnosis of dementia is not pathognomonic for global incapacity, and that even if a resident is determined to be legally incompetent in regards to certain medical decisions, there still remains a significant amount of task-specific competency even with severe dementia (Haddad & Benbow, 1993a; Holm, 2001; Kuhn, 2002). Thus, capacity assessment for consent to sexual activity for an individual with dementia is unique to that individual and should be engaged on a case-by-case basis, particularly given that there are multiple stages of dementia and significant heterogeneity in symptoms between individuals (Kamel & Hajjar, 2004; Tarzia, Fetherstonhaugh, & Bauer, 2012).

Currently, there are no consensus guidelines for determining capacity to consent to sexual activity in general and for elderly populations in particular (Lyden, 2007; Metzger & Gillick, 2002). Moreover, the criteria used for establishing capacity for sexual consent can vary from jurisdiction to jurisdiction, capacity conclusions often differ between physician assessors, and there has been little empirical research studying capacity for consent in elder populations, further obfuscating the decision making process in these situations (Gaile & Henderson, 2003; Moye & Marson, 2007; White, 2010). What is interesting is that in this context, judgment about sexual intimacy has been “medicalized” such that medical staff members become the arbiters of an essentially personal choice in the same manner that medical staff members arbitrate consent for medical treatments (Miles & Parker, 1999). It is not clear, however, whether evaluation of capacity for sexual intimacy and for medical
treatments are equivalent and whether protocols used for one are transferable to the other. In fact, some have argued that deciding on whether to be sexually intimate is more akin to choosing an ice cream flavor for dessert than choosing a particular medical treatment (Casta-Kaufteil, 2004).

In practice, at least in nursing homes with a more permissive philosophy toward resident sexual expression, assessment of capacity for consent to sexual activity is pursued and usually involves a full history with a review of relevant records, physical examination, mental status examination, interviews with staff members who know the resident, and a formal assessment of capacity by a multi-disciplinary team (Haddad & Benbow, 1993b; Lyden, 2007). As mentioned previously, there is no consensus to the content of this formal assessment, but a number of authors have submitted useful models. For example, Lichtenberg and Strezepek focused on three areas for assessment: understanding of relationship (does the resident know who is initiating sexual contact, can the resident articulate what kind of intimacy with which he/she would be comfortable), ability to avoid exploitation (does the resident understand concepts of choice and voluntariness, is behavior consistent with past values and beliefs), and awareness of potential risks (is the resident aware of potential physical and emotional harm, can the resident take precaution against risk) (Gaile & Henderson, 2003; Lichtenberg & Strezepek, 1990; Teitelman & Copolillo, 2002). Some models have added the legal standards for assessing competency similar to the consent process for medical treatments, whereas other models focused specifically on evaluations of safe practices (Gaile & Henderson, 2003). Some have argued that a formal assessment of cognitive ability such as a mini-mental status exam (MMSE) should be part of the assessment, but it has been shown that the MMSE is not necessarily a good predictor for incapacity, at least for residents with dementia (White, 2010).

All together, there does seem to be significant overlap between the various models as well as significant overlap with models proposed for capacity assessment for sexual consent for individuals with developmental disabilities (Kuhn, 2002). Although there is no formal, validated consensus, at least six criteria should be addressed in any assessment of capacity for sexual consent: voluntariness (ability to decide without coercion, demonstrating preference), safety (reasonably protected from physical and emotional harm, recognition of dangerous situations), no exploitation (resident should not be taken advantage of, resident respects privacy of others), no physical or psychological abuse (does the partner understand and respect the resident’s signals to stop), ability to say “no” either verbally or nonverbally, and socially appropriate time and place (Table 1) (Gaile & Henderson, 2003; Kuhn, 2002). Ultimately, what is at stake here is that residents with dementia should not be held to a higher standard of consent than the general public (Kennedy & Niederbuhl, 2001). Additionally, if a resident with dementia is deemed capable, he/she has the same ethical and legal right to expose himself/herself to a reasonable level of harm as a community member without dementia, at least a level of foreseeable harm with which the nursing home is comfortable (Everett, 2007).

### Alternative Decision Making for a Resident Who is Deemed Incapable

Just as it is almost impossible to make a global decision about capacity (i.e., determining that a resident is universally capable), it is very difficult to make a definitive assessment about the capacity of a resident with dementia to consent to sexual activity (i.e., a concrete yes or no answer), even using the models described previously. Thus, a more nuanced approach has been proposed where a resident with dementia can be deemed capable of consenting to specific sexual acts but not to others and consenting to sexual contact with certain individuals but not with others (Lyden, 2007; Rosen et al., 2010). This approach implies a more fluid approach to capacity assessments in that more simple, lower risk acts will have a lower threshold for capacity versus more complicated, higher risk acts (Dong, 2014; Lindsay, 2010). In these situations, however, the burden of protecting residents from foreseeable harm falls on the nursing home staff, and the staff members are then responsible for supervising and ensuring that harm is reduced to a reasonable level (Everett, 2007; Lyden, 2007). If risk cannot be reduced to a reasonable level, then the nursing home has little option other than prohibiting such sexual activity (Everett, 2007).

The question still remains, however, about the path forward if a resident is deemed incapable of consenting to

<table>
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<th>Criterion</th>
<th>Examples</th>
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<tr>
<td>Voluntariness</td>
<td>Resident has ability to decide without coercion, resident demonstrates preference.</td>
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<tr>
<td>Safety</td>
<td>Resident is reasonably protected from physical and emotional harm, resident recognizes dangerous situations.</td>
</tr>
<tr>
<td>No exploitation</td>
<td>Resident is not taken advantage of, resident respects privacy of others.</td>
</tr>
<tr>
<td>No physical or psychological abuse</td>
<td>The partner understands and respects the resident’s signals to stop.</td>
</tr>
<tr>
<td>Ability to say “no”</td>
<td>Either verbally or nonverbally.</td>
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<tr>
<td>Social appropriateness</td>
<td>Time and place.</td>
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sexual activity or if the capacity assessment using a framework described previously is at least equivocal. From a liability risk standpoint, a nursing home will typically prohibit sexual activity in these situations, but this may be at the expense of a resident’s right to privacy, autonomy, and fulfillment of sexual needs (Lindsay, 2010). Further, there is debate about whether such a capacity assessment even applies to decisions about sexual activity and is sufficient to render one incapable of consenting to sexual activity (Lindsay, 2010). For instance, structured capacity assessments for consenting to medical (e.g., consenting to an operation), financial, or legal decisions are based on logic and reasoning whereas decisions about sexual activity are often based to some degree on irrationality with little attention paid to pros and cons or future implications of the decision (Lindsay, 2010; Tarzia et al., 2012).

Thus, capacity assessments can be a useful tool in the initial evaluation of residents for the ability to consent to sexual activity but these assessments should not necessarily drive the definitive ruling about whether a resident can engage in sexual activity. If a nursing home were to focus on a more person-centered approach to its resident by working to create an environment where sexual activity can be practiced safely, there seem to be other avenues available to augment capacity assessments to consent to sexual activity. Although the medical model of capacity assessments doesn’t necessarily fit with capacity assessments for sexual activity, there may be some useful parallels. For example, individuals deemed incapable of consenting to medical treatment decisions are often allowed to proceed with a treatment with the assistance of a substitute decision maker, raising the possibility of substitute decision making in capacity assessments for consent to sexual activity.

One worries, however, about substitute decision making regarding sexual activity in that there is a fine line between advocating for a resident’s interests and submitting that resident to possible exploitation through unwanted sexual attention and mistreatment due to a resident’s cognitive impairment (e.g., sexual activity with someone misidentified as a spouse) (Mahieu & Gastmans, 2012; Tarzia et al., 2012; White, 2010). Indeed, in some jurisdictions (e.g., England and Wales), consent to sexual relations cannot be made for someone who has been deemed to lack capacity to consent, thus prohibiting the option of a substitute decision maker (Benbow & Beeston, 2012). What is at stake here, however, is defining a mechanism to preserve as much as possible the right to autonomy, dignity, and fulfillment of sexual needs for residents who express interest, choice, and preference in sexual activity but do not necessarily meet the criteria for capacity using standardized assessments, which may be inherently incapable of capturing a resident’s capacity to consent to sexual activity as described previously.

Bringing other decision making entities to the table will allow for a more comprehensive evaluation of capacity to consent beyond the individualized assessment of the resident alone. In contrast to the more medicalized term of substituted decision makers, one can think of these entities as sexual decision making advocates for the resident. Typical options for such advocates include the resident’s family and the nursing home itself. It should be mentioned, however, that expanding the decision making for sexual activity beyond the resident alone complicates the overarching goal of respect for autonomy in that the resident is left open to infringements on privacy in a number of domains including physical privacy, privacy of association, and privacy of information (Mahieu & Gastmans, 2012).

In thinking about a committee approach to sexual decision making, one is really thinking about risk management in the setting of person-centered care. From a more paternalistic perspective, one can envision a scenario in which a resident expressing interest in sexual activity is found to lack capacity using structured capacity assessment, resulting in prevention of any sexual activity, removal of the door to the resident’s room, and disallowance of overnight visitors (Lindsay, 2010). In such a scenario, both the risk of harm to the resident and the risk of liability for the nursing home are minimized. From a more person-centered perspective, however, one can envision a similar scenario where a resident expressing interest in sexual activity is found to lack capacity using a structured assessment but a committee is mobilized to further interrogate the situation to look for any possible means to provide a safe environment for sexual activity (Tarzia et al., 2012). From this perspective, every attempt is made to prevent foreseeable and unreasonable harm but there is acknowledgement that decisions regarding sexuality carry inherent risk and that older residents with dementia should not necessarily be held to a higher standard of decision making than younger individuals (i.e., even younger individuals who are deemed “capable” occasionally make poor decisions) (Lindsay, 2010; Mahieu & Gastmans, 2012; Tarzia et al., 2012).

### Establishing an Approach for Sexual Decision Making Advocacy

When engaging other entities in sexual decision making for a resident, it is important to clarify potential advantages and biases up front (Table 2). For example, family is a reasonable choice for inclusion in committee decision making as the family ostensibly knows the resident best, but there is no assurance that the family will act in the resident’s best interests or that the family’s decisions will accurately reflect the resident’s preferences (Tenenbaum, 2009). Additionally, because sexual expression is such a value-laden and
Table 2. Advantages and Biases of Sexual Decision Making Advocates

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<th>Advocate</th>
<th>Advantage</th>
<th>Bias</th>
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<td>Family</td>
<td>Ostensibly knows the resident the best.</td>
<td>May struggle with conflict of interest regarding resident’s sexual expression (i.e., difficulty acknowledging older family member’s sexuality), no assurance decisions will accurately reflect resident’s preferences.</td>
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<tr>
<td>Nursing home</td>
<td>Obliged to provide for the resident’s autonomy and best interests.</td>
<td>Likely to favor family’s opinion due to fears of liability.</td>
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personal experience, the family might struggle with conflict of interest in challenging situations such as a married resident with dementia having a sexual relationship in a nursing home with someone other than his/her spouse (Metzger & Gillick, 2002).

The nursing home is also a reasonable choice for inclusion in committee decision making as the nursing home is obliged to provide for the resident’s autonomy and best interests (Tenenbaum, 2009). The nursing home is not free from conflict of interest, however, and might be more likely to favor the family’s opinion due to fears of liability (Tenenbaum, 2009). Indeed family members will most likely demand a role in the decision making process, regardless of whether there is any legal support for their involvement (Teitelman & Copolillo, 2002). Thus as no entity is likely to act unilaterally and no entity is without potential conflict of interest, the most balanced and balanced way forward is for the family and the nursing home to collaborate in sexual decision making for the resident in situations where the resident is deemed incapable to consent on his/her own (Everett, 2011).

Further, it is important to clarify the basis on which advocacy decisions should be made. There are generally two options available: substituted judgment and the best interest standard (Harvey, 2006). For substituted judgment, the bases for decision making are previous core values and religious and philosophical beliefs, which have in some cases been explicitly declared in an advanced directive (Tenenbaum, 2009). The upside of substituted judgment and advanced directives is that a resident’s decision making capacity and autonomy are preserved into the future (DeGrazia, 1999). One downside, however, is that a resident is then essentially locked in to certain conditions that may not coincide with the desires of the future self, new desires which the future self may have difficulty articulating due to the dementia process (Holm, 2001). It has also been argued that the psychological continuity that forms the basis for advanced directives is so severely compromised as dementia progresses that advanced directives and substituted judgment should not even apply in cases of advanced dementia (DeGrazia, 1999; Howe, 2011).

Thus as the dementia process progresses, a best interest standard may be the most appropriate decision making framework. In a best interest standard, the balance between benefit and harm is examined and an action is allowed if the potential benefits exceed the risks, at least the risks a nursing home is comfortable allowing (Everett, 2011). The best interest standard seems a reasonable alternative for residents with dementia because dementia is unique to the incapacitating illnesses in that there is a significant time between a determination of incapacity and death where pleasure can be experienced; indeed, sexual expression is one of the last sources of pleasure to deteriorate as the dementia progresses (Tenenbaum, 2009). In comparison to substituted judgment, which is focused on the past and precedent autonomy, the best interest standard is forward looking with a focus on the current autonomous wishes of the resident (Harvey, 2006; Tenenbaum, 2009). It is worth mentioning that a potential downside to the best interest standard is maintaining objectivity (Tenenbaum, 2009).

Whether the decision making advocate is the family, the nursing home, or both, it is near impossible for an objective decision to be made on the best interests of the resident without the imposition of the advocate’s values, philosophies, and desires (Tenenbaum, 2009).

Conclusions

Sexual expression is an important aspect of well being for older adults living in the community as well as residents with dementia living in a nursing home setting. For residents with dementia living in a nursing home, there is a tension between ensuring the autonomy of the resident for sexual expression and protecting the resident and other residents in the nursing home from physical and psychological harm. To alleviate this tension, nursing homes with a more permissive approach to sexual expression (e.g., those that do not ban sexual expression outright) will typically conduct a thorough assessment of the resident’s capacity for sexual consent. Although such assessments are useful in the initial evaluation of capacity, the arguments in this article suggest that this is a somewhat flawed approach to sexual decision making and that a finding of incapacity should not necessarily preclude the sexual expression of the resident.
In instances where the resident is found to lack capacity but continues to express interest in sexual expression, this article argues that a committee approach can be utilized where the resident, the nursing home itself, and family members convene in an effort to advocate for the resident’s autonomy, dignity, and the right to sexual expression while working to minimize harm. Such advocacy decisions can be based on substituted judgment, a best interest standard, or some combination of the two. Although committee decision making for sexual expression seems somewhat of a bizarre and frankly intrusive measure, it at least allows for continued discussion of the right to sexual freedom for a resident in the face of significant counterbalancing forces in the form of ageist stereotypes, liability concerns of the nursing home, and an overly medicalized approach to capacity assessments. Overall, the sexual expression of older adults with dementia is a complex process but should be encouraged and facilitated when appropriate by a well-trained nursing staff in a supportive nursing home environment.

References


