Balancing Sexual Expression and Risk of Harm in Elderly Persons with Dementia

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Assessing decision-making capacity in older individuals with dementia, now known as major neurocognitive disorder (MND), is a complex and challenging endeavor. There is a dearth of literature that touches on the sensitive and controversial topic of sexuality in institutionalized settings, despite the rapid increase in the global population of older individuals. In this article, we assert that evaluations of sexual expression in institutionalized older individuals with MND is essential, as there are concerns specific to risks and benefits of sexual expression in elderly persons with MND that should be considered. Jurisdictions differ in the interpretation of capacity to consent to sexual activity, and there are also discrepancies in policies regarding assessment of sexual activity in residents in long-term care facilities. In addition, there is controversy within the literature regarding how to assess capacity to consent to sexual activity in elderly persons with MND. We discuss some of the proposed methods and consider ways that the evaluee's life narrative can help explore the various prongs of capacity.

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The World Health Organization (WHO) 2015 report on Ageing and Health stated that the global population of people aged 60 years and older will more than double, from 900 million in 2015 to ~2 billion in 2050.[1] The current worldwide prevalence of all types of major neurocognitive disorder (MND) is 47.5 million and is projected to increase to 75.6 million in 2030 and to 135.5 million in 2050.[2] Many people in this fast-growing segment of the U.S. population came of age during the sexual revolution of the 1960s, and as young adults in their 20s and early 30s many reconfigured their identities in terms of sexual expression and freedom.[3] The "Hippie" counter culture slogan was "make love not war."[4] Medical advances such as sildenafil have also made sexual activity feasible for more elderly individuals. Living together in long-term care (LTC) facilities has created bountiful social opportunities to meet others and lead to the possible development of sexual encounters.

A poignant real-life example that captures the essence of sexuality in elderly persons with MND is that of Supreme Court Justice Sandra Day O'Connor, whose husband had Alzheimer's dementia. He fell in love with another woman in his assisted-living facility. Justice O'Connor was happy for him; she even visited with the new couple while they held hands on the porch swing. She described a sense of relief overtaking her as her husband of 55 years was filled with happiness, even when he no longer recognized his wife.[5] However, not all situations will resolve as harmoniously as they did for Justice O'Conner and her husband. Although autonomy regarding sexual intimacy for institutionalized elderly persons with MND extends itself to the right to privacy, this behavior is often open to scrutiny for institutionalized elderly persons, and it can be inhibited by environmental constraints, staff, and family.[6] Causes of such scrutiny include staff discomfort and negative familial attitudes toward sexual behaviors by elderly family members, especially if they have MND.[7] It has been the experience of these authors that many family and staff view sexual expression as something older people should no longer be inter-

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ested in at their advanced stage. Some of the family dynamics that add an additional layer of complexity to an already controversial subject include multiple marriages and blended families with step children. Furthermore, an adult child is faced with a difficult decision when their parent makes a sexual choice that goes against the adult child's wishes. Given our litigious society, long term care facilities may also be concerned about legal action or the loss of revenue if family members were to remove their aging relatives if sexual expression was permitted. Family members are often informed of the resident's sexual activities as a matter of policy, generally *de facto*, and this communication, without attendant education, is frequently independent of the residents' choice.[8] Given all the factors described above, it is quite foreseeable that, in the future, clinical and forensic psychiatrists can expect to be asked to address the sensitive and controversial topic of capacity to consent to sexual activity in this aging population with MND.

Topics Specific to Sexual Expression in Elderly with MND

Before embarking on a discussion of capacity to consent to sexual activity, we will briefly review some of the topics related to sexual activity in elder adults with MND, specifically pertaining to benefits and risks. Besides being a basic human right and having the potential for significant emotional benefits, sexual activity appears to be associated with some physical health benefits in the elderly. While no causal conclusions can be drawn, it is notable that some studies have seen associations between sexual activity and weight loss, reduced risk of heart disease and stroke, pain relief, improved mood, and a bolstered immune system.[9]

There are also risks associated with sexual activity in elders, just as with any population, although, in elderly individuals with MND, there are additional considerations to take into account. No discussion of sexual intimacy in the elderly population is complete without acknowledging the potential for vulnerable individuals to be victims of abuse. Rates of abuse may be higher for older people living in institutions than in the community. Given the rapid increase in aging populations globally, the number of those subjected to elder abuse is predicted to increase.[10] Surprising data from WHO state that only 1 in 24 cases of elder abuse is reported, in part because older individuals are often afraid to report cases of abuse to family, friends, or the authorities.[10]

Signs of elder sexual abuse include weight loss, bruises, broken bones, and increased confusion.[11,12] However, evaluation of these signs of sexual abuse in elderly individuals with MND can be challenging. Bruises may be attributed to the aging process rather than to an assault, and a common explanation of genital bruising or bleeding might be a "botched catheterization" or "rough perineal care" (Ref. 13, p 114). Reported behavioral markers of sexual abuse can be a sudden behavioral change, such as withdrawing to a fetal position, or repeatedly refusing personal care.[14] In one study that examined behavioral markers of elderly victims of sexual abuse, the victim displayed only fear or strong ambivalent feelings toward the suspected offender in about 50 percent of cases. As one might expect, patients with MND were less likely to self report instances of abuse than were those without MND.[14]

Sexually transmitted disease is another risk in the elderly population, and in particular in those with MND, who may be less able to report symptoms. There are unique challenges in elderly persons that prove to be a barrier for prevention of STD transmission: older persons are less likely to discuss their sexual habits with their doctor, and providers may not routinely take a sexual history in older persons because of their own discomfort or personal bias.[15] Additional challenges for sexually transmitted disease (STD) prevention in elderly persons is that, when pregnancy is not a concern, couples may be less likely to use a condom and to practice other forms of safe sex. Regarding HIV in particular, the Centers for Disease Control (CDC) reports that in 2013, people aged 55 and older accounted for 26 percent of the estimated 1.2 million people living with diagnosed or undiagnosed HIV infection in the United States. Although people aged 50 and older have the same HIV risk factors as younger people, they may be less aware of their HIV risk factors and tend to be diagnosed with HIV infection later in the course of the disease.[15]

Policies to Address Sexual Capacity in Long-Term Care Facilities

It is helpful for the consulting forensic psychiatrist to know what policies, if any, an LTC facility has when asked to perform an evaluation for a resident's

competency to consent to sexual intimacy. It is also useful to know if such policies include discussions with family members.

The American Psychological Association and the American Bar Association created a handbook[16] discussing evaluations of capacity for sexual consent. In this publication, they recommend that LTC facilities have policies and procedures regarding sexual relations that are consistent with state statutes, if any. Some LTC facilities have a policy to address sexual activity in their residents, but such policies are not universal among all facilities. Failure to examine these possibilities may increase the potential for curtailing the rights of the elderly with MND, as well as for exposure to civil litigation and even criminal charges, all problems potentially involving consultation and opinions by forensic psychiatrists.

As an example, criminal charges resulted in the case of Henry Rayhons, a nine-term Iowa Congressman charged with third degree felony sexual abuse when he was accused of having sex with his wife in a nursing home.[17] It was noted she had severe MND. They were both widowed when they met in a church choir and subsequently had a reportedly loving marital relationship. Even though Mrs. Rayhons was experiencing severe MND, staff at her nursing home noted she "was always pleased to see Henry."[17] Because of Mrs. Rayhons' level of cognitive impairment, the facility's doctor determined that she did not have the capacity to consent to sexual activity, although she would allegedly initiate sexual activity with her husband. Mr. Rayhons' stepdaughter was concerned about this contact between her mother and stepfather. She successfully petitioned for guardianship of her mother, but her petition did not specify sexual activity. She subsequently pressed charges after she learned that Mr. Rayhons continued to have sexual activity with her mother after she specifically limited her mother's contact with him. Mr. Rayhons was eventually acquitted of all charges, but decided to not run for another term.[18] It is not known whether this LTC facility had a policy in place to evaluate sexual capacity, but it appears that in this case, a family physician initialed a one-page document listing restrictions for Mrs. Rayhons which included a question as to whether she was able to consent to "any sexual activity," on which the physician wrote "no." Allegedly the care plan and the decision were based on faring poorly on a standardized cognitive test: the Brief Interview for Mental Status, which tests recognition, temporal orientation, and recall (cited in Ref. 19).

The example of Mrs. Rayhons' capacity assessment stands in contrast with the assessment process at the Hebrew Home at Riverdale (The Home) in New York. The Home pioneered a sexual rights policy that applies to all older adults who receive services from or reside at The Home.[20] It highlights the importance of emotional and physical intimacy in the lives of older adults. The Home has a policy for evaluating consent to sexual activity in which key aspects in The Home's interpretation of consent include "ability to express a choice, ability to appreciate sexual activity, and the personal quality of life choices in the here and now" (Ref. 21, p 13). The Home assesses ability to express a choice by asking the person's wishes about relationships and observing clues when the person is nonverbal, such as facial expressions, body language, and mood before and after sexual contact. The Home's staff assesses the ability to appreciate sexual activity by asking the person what it means to have sex, what it means to the partner, and how the person or the partner would stop the activity if desired or necessary. The Home's staff assesses the personal quality of life choices in the here and now by asking the person, "Was and is intimacy important in your life? What are your social and companionship needs? What brings happiness or fulfillment to your day?" (Ref. 22, p 2). In instances with cognitively impaired residents, an interdisciplinary care team makes clinical determinations weighing benefits and risks associated with the resident's sexual expression. The differences in the two examples highlight the discrepancies seen in long-term care facilities in response to questions regarding sexual capacity.

Defining Sexual Capacity

As in all legal matters, forensic psychiatrists should be aware of the applicable rulings and statutes in the jurisdictions in which they are consulting on matters regarding sexual capacity in elderly individuals with MND. Jurisdictions differ in their definition of capacity to consent to sexual activity. Some states have case law addressing capacity to consent to sexual activity in an individual with intellectual disability. For example, New Jersey takes a position that a person only need understand the physical nature of sexual intercourse and engage voluntarily (*State v. Olivio*).[23] States such as North Dakota have determined that in addition to these factors, knowledge of the practical

consequences, such as sexually transmitted diseases and pregnancy, is also a requirement (*North Dakota v. Mosbrucker*).[24] Other states, such as New York, use yet a more extensive definition of capacity, requiring that a person must understand not only the medical consequences, but also the moral and social consequences to be capable of consenting to sexual activity (*People v. Easley*).[25]

Some jurisdictions fall silent on how to interpret capacity to consent to sexual activity. In addition, it is unknown whether courts would view capacity to consent to sexual activity in individuals with MND differently from capacity to consent to sexual activity among individuals with intellectual disability, as the examples above from case law do not involve individuals with MND. What is generally agreed upon is that the approach to assessing sexual capacity needs to be flexible and account for the varying levels of risk in different situations, as one might for various medical procedures or for different levels of criminal charges. A person might be capable of consenting to some intimate acts such as kissing but not sexual penetration, or capable of consenting to contact with certain individuals but not with others.[26,27] Among writers who have discussed specific prongs of capacity assessments in elderly persons with MND, commonly endorsed criteria for assessment are knowledge of relevant information, understanding and reasoning, and voluntariness of the consent.[6,21,26] However, there is no broad consensus on which factors in each of these prongs is the most relevant.

Take for example, the criterion of knowledge. One commonly cited paper by Lichtenberg and Strzepek[6] advocates assessing the knowledge prong of capacity by considering the awareness of the relationship. In assessing the person's awareness and knowledge of the relationship they recommend evaluating whether the person is cognizant of the other's identity and intent and "whether the person can state which level of intimacy they would be comfortable with" (Ref. 6, p 119). Tarzia *et al.*[28] argued that this definition of knowledge or awareness erroneously places the burden to prove capacity on the evaluee rather than putting the onus on others to prove incapacity. In addition, they argue that asking individuals to define their comfort with various levels of intimacy poses an exceedingly high standard. They point out that many people without MND, who presumably have capacity, have been in a situation where they found it difficult to predict what level of intimacy they would be comfortable with before engaging in such behavior. The recommendations of how to assess knowledge, as proposed by Tarzia et al., differs from that of Lichtenburg and Strzepek by arguing that only accurate recognition of the other person in the sexual dyad is required. They state, "the only justification for interfering in a sexual relationship between two people who appear to be happy, we suggest, is if one or both residents are not aware of the identity of the other person and believes the person to be someone else (spouse/partner)" (Ref. 28, p 612).

The criteria for assessing rationality and understanding are similarly variable. One of the consequences of sexual activity, pregnancy, is not applicable in the elderly population with MND. The understanding of pregnancy as an outcome of sexual intercourse is, however, common in case law in some of the states mentioned above. Stavis and Walker-Hirsch[29] have recommended assessing understanding of safe sex practices and STDs when assessing for capacity for sexual consent in individuals with intellectual disabilities. The risk of STDs is certainly a theoretical possibility for any sexually active person, regardless of circumstances, and, ideally, the individual would be able to accomplish this risk–benefit calculation.

However, others have argued that LTC staff could take practical measures to reduce risks for institutionalized residents, such as lowering beds to prevent falls, or providing condoms to prevent transmission of STDs.[26,28]

Besides the physical risks of sexual activity, another factor occasionally mentioned in literature on assessments is the factor that has been described as emotional risk. For example, Lichtenberg and Strzepek recommend evaluating whether the person "realizes that the relationship may be time limited" and asks "can the patient describe how they will react when the relationship ends?" (Ref. 6, p 119) The Society for PostAcute and Long-Term Care Medicine issued a white paper in 2016 that stated, "Emotional involvement, fear of abandonment and loneliness may increase an individual's vulnerability to exploitation by a potential partner. Evaluation of capacity for consent should take these factors into consideration" (Ref. 21, p 6). On the other hand, it could be argued that this risk of emotional vulnerability is no different from risks that people without MND face and that taking this into consideration in a capacity argument would deprive the evaluee of

some degree of dignity inherent in being able to take risks.[28]

The American Psychological Association and the American Bar Association created a handbook discussing various assessments of older adults with diminished capacity. On sexual capacity, they too list knowledge, understanding, and voluntariness as three critical factors and then provide their interpretation of the criteria.[16] The interpretation includes, but is not limited to, a basic knowledge of sexual activities in question, potential risks such as STDs, how to prevent them, the responsibilities of parenthood, illegal sexual activities, how to determine whether sexual activities are not desired by the partner, and appropriate times and places for sexual activity. The handbook also recommends including the abilities to appreciate the consequences of various courses of action, express a choice based on rational logical consideration of relevant knowledge (including the personal benefits and risks of sexual activity), and assess whether the anticipated behavior is consistent with the individual's values and preferences.[16]

Commentary

Absent an applicable legal standard, most authors have used the three prongs of knowledge, understanding and voluntariness, but what exactly each of these prongs entails regarding sexual capacity in the cognitively impaired elderly patient is controversial. Lindsay[30] pointed out that in the same fashion in which one chooses whom to marry or to vote for, sexual activity is a form of expression that does not necessarily unfold in a structured manner, after logically weighing risks and benefits. Decisions to engage in sexual activity are neither medical nor legal, and they are so intertwined with an individual's values, culture, and life history, that one could argue that capacity assessment for sexual activity is not warranted, given it is a personal choice and means of self-expression. When legal precedent is not clear, an argument can be made that examining the evaluee's values could assist the forensic evaluator to determine which factors within each prong should be explored. However, within the three generally recognized principals, the evaluator may find some guidance in where to focus efforts and where to comment on how MND may or may not affect those factors.

We will use two hypothetical examples to illustrate how this may unfold. A woman living in a jurisdiction with no legal precedent for defining sexual capacity is admitted to a long-term care facility with a diagnosis of MND. Staff notice that there are several men in the facility who have demonstrated an interest in developing a sexual relationship with her, and she likewise appears to be interested in engaging with all of them. She does not appear to mistake any of them for someone else, but often she cannot identify some of them by name. She cannot state explicitly what level of sexuality she would be open to in each relationship, but she has made it clear to staff that she knows how to stop encounters when she loses interest. She and all of her potential partners are free of STDs. She states that she is willing to use condoms, but it is not clear whether she uses those provided. No evidence of coercion or undue influence was noted in any of her relationships. Examination of her life narrative shows a woman described by loved ones as a "strong willed feminist who knows what she wants and isn't afraid to get it." She was known for telling stories about growing up during the "free love" movement and was noted as having had a "high sexual appetite" before her diagnosis of MND. She was known to have had multiple self-described "casual" sexual encounters throughout her life and highly valued her freedom of sexual expression.

Another woman who lives in a jurisdiction with no legal precedent for defining sexual capacity develops MND and is admitted to a long-term care facility where she meets a man, falls in love, and wants to engage in sexual activity with him. She could accurately identify him by his name, knew he was not her husband, could explicitly list the exact sexual activity she was interested in enacting. She knew that both were free of STDs, and she understood the potential theoretical risk of contracting a STD in the future. No evidence of coercion or undue influence were noted in their relationship. She was aware that her husband was saddened and hurt when the relationship with the other man developed and was able to state that her husband would be even further saddened by the development of a sexually intimate relationship between her and the other man. Examination of her life narrative shows a conservative religious woman who valued fidelity and piousness, from all accounts had a loving relationship with her husband of 30 years, was active in her church, and was extremely conscious of how her friends and family viewed her up until the development of her MND.

In the first example, the evaluator would be likely to take note that the woman may have deficits in the knowledge prong and possibly the understanding prong. However, the degree to which these would interfere with her capacity for sexual encounters is debatable. The fact that she does not always recognize the men in her relationships by their names would be concerning to some, but on the other hand, it could be argued that she is aware that there is a relationship with each of these individuals and that, based on her previously held values, this is the more important facet of knowledge in her case.

In the second example, the evaluator might ultimately find that the woman's disease process was causing disinhibition, personality changes, and affecting her decision-making in such a way that was starkly at odds with her previously long-held values and preferences. In other words, if not for her disease process, this new relationship would not be forming. The evaluator might alternatively find that the woman's disease process was actually unrelated to the change in her life choices, and that this time in her life represented a chance for her to explore ideas and gain experiences that she had been fearful to express her desire for up until this time. In this scenario, taking into account the woman's historical background may assist the evaluator in identifying various avenues that need further exploration, such as further probing her understanding of the potential impact of her relationships with loved ones. In both examples, even if the evaluator ultimately chooses to refrain from directly opining on the binary question of "capacity to consent or not," the forensic evaluator will still be of assistance by educating the court on what impact, if any, the disease process may have on the various factors at play within the three prongs of the capacity assessment.

Conclusion

The topic of sexuality in elders with MND is undoubtedly a controversial and sensitive one. Personal biases in staff of long-term care facilities, patients' families, and forensic psychiatrists can influence the responses to the sexual needs and desires of elderly individuals with MND. When clinicians or forensic psychiatrists assess the needs of elderly patients, the potential benefits of sexual intimacy in patients with MND should not be underestimated. At the same time, some patients with MND may be vulnerable: emotionally, cognitively, and physically. It is essential to remain cognizant of the risks presented when questions of capacity for sexual intimacy arise. Clinicians who treat geriatric patients should consider having a discussion with patients about their views on their sexuality and their wishes before or at the start of the development of MND. Helping to increase awareness of the needs and benefits of sexual expression in the elderly with MND among multidisciplinary providers, nursing home staff, and family members may ultimately benefit the patient, as increasing understanding may help optimize safe opportunities for sexual expression, while also helping identify when someone does not have capacity to consent. Long-term care facilities can start developing policies to address sexual capacities of their residents, some of which can include preemptively assessing capacity for sexual activity at or before admission and then on a periodic basis thereafter or as needed if staff notes signs of interest or development of a relationship. Forensic psychiatrists may be asked in increasing numbers to comment on cases involving matters of capacity for sexual activity.

Jurisdictions differ when defining what capacity for sexual activity entails. Some states have adopted a stance that only voluntariness and a basic understanding of the physical nature of sexual intercourse is required. Other states have used a standard that requires the additional understanding of the practical consequences of sex, such as unwanted pregnancy and STDs. Yet others states have defined capacity to mean that a person must also understand, not just the medical consequences of sexual intercourse, but also the moral and social implications of their sexual behaviors. Finally, not all jurisdictions have a legal precedent as of yet to define capacity for sexual activity, and thus the term is left ambiguous. Commonly, endorsed criteria in the literature uses a medical ethics viewpoint, including knowledge, understanding, and voluntariness. We recommend that assessors who are asked to evaluate these three prongs also consider taking a narrative-based approach by considering the evaluee's life story and values before MND to determine how to examine knowledge, understanding, and voluntariness. These three concepts, particularly those of knowledge and understanding, may be defined differently under individual circumstances. Assessment of knowledge encompasses a basic recognition of the other person, of the relationship, and of the sexual activity in question. Understanding includes the meaning of the po-

tential risks of engagement and how the sexual behavior affects other relationships in the person's life. Voluntariness entails an assessment, not only of willingness in the here and now, but also capability to resist or stop the activity if there is a change of heart. In using this approach, the basic capacity assessment is used as the framework of the overall evaluation, but within each of the prongs, the assessor would use the patient's life narrative and values to highlight what aspects of each prong are most relevant in each case and how the patient's MND might affect each.

This area of competency and viable approaches to such an assessment have been overlooked, although an increasing awareness of this complex problem is evident. Questions regarding sexual capacity are certainly already being raised in long-term care facilities across the country and are likely to occur even more frequently as the aging population grows. Infringements upon privacy or instances of elder abuse are likely to occur when the discussion of capacity has been avoided. Psychiatrists may be in a unique position to provide insights into how a person's impairments from MND might affect the three prongs of capacity. It is our hope that such efforts will help spur discussions and debate and generate practical guidelines for those who are on the front lines of forensic psychiatry.

There are several ways to address the gap in the understanding of sexual decision-making capacity in those with MND. We believe surveys of multidisciplinary staff, family members, and patients in a residential setting should be formulated to gather information about sexual activity in institutionalized elderly persons. We propose that this identified gap can be addressed by qualitative prospective research. We recommend that surveys be developed that would assess the following:

What are the sexual choices of a resident, regardless of the capacity to make those choices?

How could the exploration of these choices be accomplished by asking the residents whether they understand risks and benefits of making those choices, similar to the assessment of any other capacity for decision-making?

What is the clinician's perspective of sexual decision-making capacity?

The surveys that address these three interdependent areas could guide the forensic community. The results can be used to address institutional policy. As previously described, there are wide variations in policy; however, it is difficult to formulate clear policy without first achieving scientific consensus of what is acceptable.

There are not enough data regarding public and professional opinions about sexual activity in institutionalized elderly persons in general. The development of future policies will serve as a tool for the forensic psychiatrist in the complex evaluation of capacity for sexual activity in patients with MND and when and how to identify sexual abuse in vulnerable patients. Furthermore, guidelines for this assessment may ultimately provide a balance of autonomy, beneficence, nonmaleficence, and safety for sexual activity in patients with MND who reside in an institutionalized setting.

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