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POST-ACUTE AND LONG-TERM CARE MEDICAL ASSOCIATION

CAPACITY FOR SEXUAL CONSENT IN DEMENTIA IN LONG-TERM CARE

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Introduction

The purpose of this White Paper is to provide a context for approaching the challenge of evaluating the capacity for consent for sexual activity by persons with dementia residing in long term care (LTC) facilities. This area of LTC practice is still poorly understood and inadequately researched. A 2013 survey found that only 26% of 91 Kansas nursing homes had a policy on sexuality.[1] Also in 2013, a survey of 175 PALTmed medical directors found that only 13% said their facilities provide staff training addressing sexual behavior in the facility.[23] Only 23% were certain their facility had a policy on intimacy and sexual behavior. Only 20% said their facility had a policy addressing capacity for sexual consent. The most helpful resources preferred by respondents would be a staff training manual (71%), samples of documents and forms related to sexual consent capacity and sexual behavior (63%), creation of specific policies regarding sexual behavior (57%), multimedia educational resources (56%), and online continuing education offerings (52%).

Consensus around standard of care on this issue is limited at best. There are limitations in knowing how to determine sexual consent capacity in dementia. In addition, there is irreducible ethical diversity within our society, particularly in the area of sexual values. Given the lack of a widely accepted standard to identify capacity for sexual consent, this paper is primarily descriptive of a current overview of the topic. The conclusions reached are necessarily modest, but intended to motivate further progress.

This paper begins with a brief statement of the contrasting but complementary rights at play in this dilemma. These rights point to the need for clarity on what constitutes capacity for sexual consent in dementia. Second, the perspective of the American Psychological Association and American Bar Association is reviewed from their joint work on a monograph devoted to formal assessment of older adults with diminished capacity, including capacity for sexual consent. The third section reviews the research literature on perspectives of other disciplines involved more directly in the care of older adults with dementia and sexual expression. Fourth, the literature on family perspectives is sampled. Fifth, examples of proposals for LTC policy formation are examined. Sixth, three sample cases are discussed, followed by concluding remarks.

The focus of this paper is on ethical, clinical and administrative aspects of this issue. Legal standards vary from state to state and should be consulted for particular LTC settings before policies are enacted.

1. ETHICAL RIGHTS: SEXUAL ACTIVITY, PROTECTION, AND DETERMINATION OF CAPACITY

In matters of sexual behavior by LTC residents with dementia, three fundamental rights are in focus. First, in America, all persons who have reached the age of consent (varying by state from 16-18 years) have the right to consensual sexual activity, and are presumed to have the capacity to consent, absent evidence to the contrary.[2] Thus, as an implication of respect for persons, resident autonomy, and privacy, LTC residents have a right to appropriate accommodation for consensual sexual relationships.

Second, all persons have the right to not have unconsented-to sexual aggression directed at them. If one assumes a definition of sexual abuse that includes nonconsensual physical contact of a sexual nature, not necessarily involving intercourse, most sexual abuse of older adults probably occurs in nursing homes and involves resident-to-resident sexual aggression (RRSA).[3, 24-28] LTC facilities have been found liable as third parties in cases involving RRSA leading to abuse, and are expected to take steps to mitigate the risk of unwanted RRSA that may lead to abuse.[29]

Given the significant prevalence of dementia in the LTC population, the importance of a process to determine capacity for sexual consent of an older adult with dementia in LTC is clear. These realities point to a third right, the right to an authentic process by which LTC professionals evaluate capacity for consent by individuals with dementia in LTC engaging in sexual activity.

For the purposes of this paper, capacity for decision-making will be considered a clinical determination. The term "competency" has historically been used to refer to a legal determination by a court of global functioning in making personal decisions across a wide range of domains. "Capacity" can refer to specific functions; thus, a clinician may determine an individual has the capacity to perform simple daily activities such as selection of menu items, but lacks the capacity to consent to a major medical procedure. Capacity thresholds for varying degrees of intimacy activities likewise may vary.[2]

2. FORMAL ASSESSMENT OF OLDER ADULTS WITH DIMINISHED CAPACITY FOR CONSENT

The American Bar Association (ABA) and the American Psychological Association (APA) have co-published a resource for psychologists entitled "Assessment of Older Adults with Diminished Capacity."[2] This perspective provides an overview of a formal approach to capacity evaluation. The following is a synopsis of excerpts from this resource on the general issue of consent, and sexual consent particularly.

2.1 General Considerations Concerning Evaluation of Capacity to Consent (ABA/APA)

Capacity may be defined as an individual's physical or mental ability relative to a specific task, e.g., executing a will, consenting to medical treatment, or sexual consent. Unless they have been adjudicated as lacking capacity, all individuals are presumed to have capacity for personal decisions, and with it the right to make what others may consider bad decisions. Neither advanced age nor the presence of cognitive impairment in themselves are sufficient to declare incapacity to decide or to consent.

What formerly was referred to as competency is now more commonly referred to as legal capacity. This should be distinguished from clinical capacity, which is a determination by a clinician as to the presence or absence of an individual's capacity to make a decision or consent to a specific activity. Incapacity is a legal status determined by a court that an individual lacks sufficient ability to make personal or financial decisions for her or himself.

There is no single test for determining capacity to consent. The ABA/APA Handbook posits a complex framework for approaching capacity determinations, depicted as a balancing scale encompassing several categories of evidence. The foundation of the scale is the legal standard for the particular function. The balancing point is clinical judgment, which weighs the several factors which are part of the assessment.

On one side of the balance are more standardized, objective, or structured measures. These include:

1) **functional assessment** of the capacity in question (for some functions, such as medical consent, there are structured assessment instruments (e.g., the Aid to Capacity Evaluation), whereas for others, such as sexual consent, there are no validated instruments);

2) **diagnoses** which may affect a capacity (e.g., Alzheimer's, Parkinsonism);

3) **cognitive underpinnings** of cognitive, emotional, and everyday functioning; and ,

4) the presence of **psychiatric or emotional factors** such as depression, anxiety or disinhibition.

On the other side of the balance are more subjective or hypothetical factors, including

1) **values** and preferences of the individual;

2) the **risk** of harm in the activity for which capacity is being assessed, and,

3) **possible interventions** which may enhance capacity.

Current decisions which are consistent with longstanding values may indicate capacity. However, it is recognized that values may change over time without indicating a loss of

capacity. Clinicians must be aware of an individual's values and base a capacity determination on the individual's values, not on the clinician's values.

This conceptual framework considers multiple aspects of the situation involving a person with diminished capacity to determine if sufficient capacity exists for the task in question. It should be noted that the APA/ABA Handbook does not emphasize the role of formal tests for capacity over and above an analysis of the broader perspective. "One difference between capacity assessment and most neuropsychological assessment is this focus on functioning, and the inclusion of some method to assess the specific capacity in question using direct assessment." (ABA/APA, p.26).

The concept of undue influence is also part of capacity assessment. Undue influence is a legal term used to refer to the intentional use of social influence, deception and manipulation by one person to exert control over the decisions of another person. Power and role are sometimes used to exploit the trust, dependency or fear of the individual who is the object of undue influence. The presence of undue influence does not equate to incapacity, but it may hinder or negate the ability of the victim to exercise their capacity for a voluntary choice, free from coercion or manipulation.

2.2 Sexual Consent Capacity Assessment (ABA/APA Handbook) – A Summary

"Sexual behavior between long-term care residents is a complicated issue that can create a tension between the desire of staff and family members to protect potentially vulnerable residents, and the desire of residents to meet their sexual needs and assert their rights to sexual relations. Long-term care staff are particularly concerned with the diminished capacity of residents to consent to sexual relations." (ABA/APA, p. 63). Thus, determination of sexual consent capacity is crucial.

To use the conceptual framework described above, sexual consent capacity is based first on the legal standard. There is no universal set of criteria for sexual consent. The most commonly endorsed criteria are: **1) knowledge** of relevant information, including risks and benefits; **2) understanding or reasoning** which is consistent with individual values; and **3) voluntariness** of the consent, free from undue influence or coercion.

A functional assessment of capacity for sexual consent would be framed by these three criteria. Does the individual **know** the nature of the sexual activity in which they are engaging? Does he or she know the risks of sexually transmitted diseases? Does the individual know how to tell if the partner desires the activity? Does she or he know

appropriate times and places for particular sexual activities, and with whom they are engaging in the activity? Does the individual **have the capacity for the reasoning process** inherent to sexual consent, including an understanding of sexual options, consequences of sexual choices, and consistency with the individual's values and preferences? And is the sexual choice being made in a manner that is free from undue influence or coercion, i.e., is it a **voluntary** choice?

While the ABA/APA Handbook does not explore diagnoses in detail, certain **diagnostic considerations** which could have an effect on sexual consent capacity might include dementia, though its presence by itself is not necessarily indicative of incapacity. The disinhibition of impulses common in certain dementias may be associated with inappropriate sexual behavior (ISB). The presence of frontotemporal dementia or the use of dopaminergic medication in Parkinson's disease may be associated with hypersexuality and ISB and may complicate the determination of capacity for consensual sexual activity.

The **cognitive underpinnings** affecting sexual consent capacity are not well-studied, but a variety of cognitive domains are likely essential to sexual consent, in order for it to meet the criteria of knowledge, capacity and voluntariness. Attention, semantic memory, historical memory, auditory and confrontation naming, and executive function all may play a role in adequate processing of sexual consent choices.

Psychiatric and emotional factors such as depression and anxiety may impact sexual consent capacity. 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.

Personal values of the resident must be taken into consideration as well. As alluded to above, ethical values surrounding sexuality are diverse, with social, cultural and religious variables. The sexual rights of each resident should be treated equally, and with respect for their personal sexual values, regardless of what those values are, and regardless of the clinician's values, when evaluating capacity for consent.

Risks vary for the differing levels of sexual activities. Thus there may be a lower threshold for consent for engaging in handholding or kissing compared with sexual intercourse. For residents with diminished capacity, in addition to the physical risks of injury or sexually transmitted diseases, there may be risks of exploitation, psychological abuse, and social rejection by staff, other residents, or even by family members of one's sexual partner.

The ABA/APA Handbook suggests the possibility of some **steps to enhance capacity for sexual consent**. These include sexual education materials, memory aids to assist the resident, and problem solving skills to help avoid or escape inappropriate or coercive situations.

In the model proposed by the ABA/APA Handbook, the clinical judgment of sexual consent capacity is based on the complex set of the several factors listed above. It need not result in a binary judgment. Varying levels of sexual intimacy and risk may be permissible along the continuum from handholding to intercourse, depending on the knowledge, understanding, and voluntariness of each person involved. "Ultimately one must be convinced that the resident is capable of acting with capacity in the moment. The more functional the assessment, the more confident one is likely to be with the final judgment." (ABA/APA, p. 66).

Among the steps in making such an assessment listed by ABA/APA are: review of resident records and obtaining sexual history, including any inappropriate or coerced activities, and history of cognitive disorders that may impair cognitive function or alter sexual activity. In addition, discussions with staff, and family when relevant, may be helpful in assessing capacity. Finally, a formal assessment of the resident's cognition and function is performed.

The ABA/APA cites the following suggested questions framed by Lichtenberg for consideration when performing an assessment of sexual consent capacity (ABA/APA, p.67).[30]

1. Patient's awareness of the relationship:
    a. Is the patient aware of who is initiating sexual contact?
    b. Does the patient believe that the other person is a spouse and, thus, acquiesces out of a delusional belief, or [is he/she] cognizant of the other's identity and intent?
    c. Can the patient state what level of sexual intimacy [he/she] would be comfortable with?
2. Patient's ability to avoid exploitation:
    a. Is the behavior consistent with formerly held beliefs/values?
    b. Does the patient have the capacity to say no to uninvited sexual contact?
3. Patient's awareness of potential risks:

a. Does the patient realize that this relationship may be time limited (placement on unit is temporary)?

b. Can the patient describe how [he/she] will react when the relationship ends?

The ABA/APA Handbook mentions that Lichtenberg emphasizes assessment of the ability to refuse sexual advances as important a consideration as assessing the capacity to consent.

A final perspective on formally defining capacity for sexual activity is provided by Lyden. He identifies the primary areas of evaluation as knowledge, rationality, and voluntariness. ***Knowledge*** includes the specific activity at issue; the presence of a choice to engage or reject the activity; the illegality and risks of certain sexual behaviors, including sexually transmitted diseases; social and legal constraints; and (for younger subjects) the implications and responsibilities of pregnancy. ***Rationality*** includes the ability to critically weigh pros and cons of an anticipated activity. It is dependent upon level of intelligence. Criteria for rationality include orientation to person, place, time and activity; ability to accurately report events and to differentiate truth from lies; ability to describe the process of deciding to engage in sexual activity and when mutual agreement has been reached with another; and ability to perceive verbal and nonverbal signals of another's feelings. ***Voluntariness*** requires that a person must be able to protect themselves against unwanted intrusions, abuse and exploitation.[4]

3. PERSPECTIVES OF OTHER DISCIPLINES WORKING IN LONG TERM CARE

The ABA/APA Handbook is useful in that it comes from disciplines which may become involved when the dilemma of determining capacity for sexual consent has reached an impasse, and formal consultation is called in. This approach is more formally structured than what may be seen in day-to-day clinical care. However, there are also insights from professionals working directly with older adults in LTC found in the research literature which support many of the principles of consent capacity determination found in the ABA/APA handbook. Some of these insights add further depth to the understanding of this complex issue, while some findings suggest need for more education on this topic as well.

3.1 A Nursing Staff Perspective on Sexual Consent in Dementia

A survey of 100 Alabama nursing home care staff with an average time worked at their respective facilities of 4.2 years found the following beliefs representative of the overall group concerning decision-making capacity for sexual activity among nursing home residents:

a) the resident should have a neuropsychological assessment to evaluate their current cognitive function;

b) the resident should be aware of who is initiating contact;

c) the resident's behaviors should be consistent with former beliefs;

d) the resident should be able to state the level of sexual intimacy they would be comfortable with;

e) the resident must realize the relationship may be time-limited;

f) the resident needs to think about how they would react if the relationship ends;

g) the resident should not engage in sexual activity if they (mistakenly) believe the other person is their spouse;

h) staff should ask resident permission to discuss sexuality.[5]

3.2 Administrator/Social Worker Perspectives on Sexual Consent in Dementia

A survey of administrators or social workers from 91 Kansas nursing homes found a division of opinions about sexual activity by residents with dementia. Some believed they should never engage in sexual behavior and instead be redirected. One respondent felt that if a resident has dementia, they "cannot enter the act and be able to predict the consequences, voluntarily participate, or assess the risks and/or benefits of the act." A few respondents believed dementia would not preclude a resident from forming intimate relationships, and that they would try to persuade families to accept these relationships. Nearly all felt that families must be notified, as with other significant changes of condition.[1] While the author acknowledges these findings are likely not generalizable outside the region, these results suggest a need for more education of LTC leadership on the issue of sexuality in dementia.

3.3 Medical Director Perspective on Sexual Consent in Dementia

In commenting on a case of sexual interaction between two residents in a facility with mild to moderate dementia, Levenson states that the medical director "should ensure that decision-making capacity is determined appropriately." This may include recognizing partial decision-making capacity and capacity specific to the extent of the behavior. Acknowledging that criteria for sexual consent capacity in dementia are not well-defined, he states that the presence of partial decision-making capacity may imply the need for evaluating each new situation as it arises. In addition, he identified depression as a relevant factor which may affect decision-making ability, but its mere presence should not by itself lead to a conclusion that the resident lacks capacity for the decision at hand.[6,7]

The cases he discussed described processes of consent determination which included ethics committee consultation, which recommended psychiatric assessment of consent capacity for sexual activity. Of note, the psychiatric evaluation of one resident with mild to moderate vascular dementia found that although there were some memory problems, judgment was intact for her to want this significant source of pleasure in her life. Another aspect of the facility response was to recommend a family meeting to educate them about decision-specific competency and reassure them that the resident's safety and dignity would be an ongoing priority.[6]

3.4 Ombudsmen Perspectives on Sexual Consent and Response to Areas of Conflict

The long-term care ombudsmen program was mandated in all states in 1978. Ombudsmen serve as advocates for residents in nursing homes, assisted living facilities, and other senior care residential settings. They address conflicts and complaints that may arise.

Cornelison and Doll conducted 31 interviews with ombudsmen in 6 states. Twenty-nine of 31 had been involved in handling a case related to resident sexual expression. The concerns which often motivated intervention by the ombudsmen clustered around 5 major areas: risk to resident safety or that of others; risk associated with dementia; limited knowledge on the part of staff, residents or families; lack of privacy; and conflict of values.[8] The first two impact specifically on the process of ensuring consent for sexual activity.

Risks included concerns for physical safety of the resident or others. The cases cited involved falling off a bed, causing injury during sexual activity; protection from STD when one resident has HIV and will not inform the other; and threat to another person's rights caused by the sexual activity. Financial abuse and exploitation were of concern in a situation where a resident made a "dating" acquaintance on the Internet, and then the individuals came to the nursing home and turned out to have criminal and substance abuse backgrounds. The ombudsmen expressed concern for the safety of other residents as well as the resident involved. The concern over these collateral risks of sexual activity in older adults raise concern over how well the residents understand the inherent risks, a recognition of which is essential to authentic consent.[8]

The risks specific to dementia were seen as inherent in the heightened conflicts between freedoms, rights and protection as dementia develops. Marital relationships may be a source of conflict. Ombudsmen may provide support and education for the spouse as well as the resident as intimacy patterns change or if a resident develops another sexual relationship in the facility. Ombudsmen recognize the spouse may have the right as a primary decision maker to remove the resident from the facility. In order to assess consent capacity specifically, "medical history and records, personal interviews, involvement of other medical professionals and psychiatrists, and substitute decision makers such as family members or medical powers of attorney were all used to assess capacity. An ombudsman's goal is to consider the situation from the resident's perspective and advocate for their best interests. This is difficult to achieve when the issue of consent is ambiguous."[8]

3.5 Summary of Interdisciplinary Perspectives on Sexual Consent in Dementia

This survey of perspectives from a variety of disciplines on sexual consent in dementia found in the literature is limited at best and is not meant to represent the overall perspectives of each discipline. However, it provides a multidisciplinary foundation for further work toward defining what is authentic consent for sexual activity in dementia and understanding our limitations in assessing this capacity.

There are common themes which run through these accounts which can be used to develop a fuller understanding of considerations to be addressed when faced with sexual consent determination in dementia. Diminished cognition alone does not necessarily imply diminished capacity for sexual consent. Capacity for sexual consent in dementia should be viewed along a continuum of intimacy activities, from nonsexual

touching to sexual intercourse. Higher degrees of intimacy and risk may require a higher threshold of capacity for consent. Vulnerabilities of individual residents and potential sources of coercion should be identified when assessing capacity for consent. Observations of staff and family members may be useful in capacity assessment, but these should be balanced with respect for the resident's right to privacy and authentic choice in sexual relationships. Resident knowledge of certain basic information about sexual activity and one's sexual partner is viewed by many as inherent to consent, as well as knowledge of the risks and temporary nature of sexual relationships in LTC. The consistency of a resident's sexual choices with her life values should be considered, while acknowledging the right to change one's values over time. Ombudsmen, ethics committees, and psychiatric consultation are additional resources for more complex and challenging cases.

4. PERSPECTIVES OF FAMILY MEMBERS ON SEXUAL CONSENT IN DEMENTIA

If the literature concerning professional perspectives on sexual consent in dementia is limited, the literature on family perspectives is nearly nonexistent. However, some recent research sheds some important light on this aspect of the topic. LTC facilities and medical directors work with families regularly on practically all other aspects of resident care. Thus it is important to understand how family members see the issue of capacity for sexual consent in dementia involving their loved ones.

There are inherent tensions in the role of the family in sexual consent determinations for older adults with dementia residing in LTC facilities. On the one hand, there is a perception that families may have attitudes that inhibit the right of the older adult to engage in sexual activity in the facility. On the other hand, when an older adult has diminished decisional capacity, a determination must be made if that capacity is sufficient to engage in sexual activity. To make that assessment, the input of family members may be sought. When sexual consent capacity is lost, family members or proxy decision makers must be made aware of sexual interactions of the resident. Surrounding this tension, there are concerns about the risk of litigation if family members are not informed and then later discover the sexual activity of a resident with diminished or absent consent capacity.[9, 10]

Little has been published on family members' views of sexual activity of persons with dementia in facilities. A recent study in Australia reviewed the scant literature and

presented an interview study of family members. Previous studies found that spouses were less tolerant than staff of residents masturbating, involvement in sexual relationships, and viewing sexual materials.[31] Family members may perceive staff tolerance of sexual behavior as exposing the resident to unnecessary risk.[32] Anecdotal reports indicate some spouses are supportive, others react with jealousy.[33] However, empirical studies are lacking. The attitudes of adult children are also poorly understood, with little research focusing on situations involving dementia.[9]

4.1 Bauer et al. Family Perspective – "We need to know what's going on"

Bauer et al recruited 7 family members of institutionalized persons with dementia. Recruitment was difficult because of low interest, possibly from the uncomfortable nature of the topic. Five were women, two who were wives of a resident, two with a mother who was a resident, and one whose father was a resident. The two men were the husband of a resident and the same-sex partner of a resident. The participants were questioned in recorded interviews about their attitudes toward sexual activity by older adults with dementia living in a LTC facility. They were also questioned about a fictional scenario in which the husband of a woman with dementia in a facility, who had maintained a loving marriage for 60 years, discovered his wife having sexual foreplay in her bed with another demented resident. The staff had intentionally kept the relationship a secret from the husband.[9]

Responses by the participants were clustered around three key themes as described by the researchers. These response themes were 1) "residents can go so far . . . but not all the way!"; 2) "It's difficult for the staff to cope"; and, 3) "We need to know what's going on."

1. The participants were supportive of sexual expressions if that made the resident happy or improved quality of life. For two wives this even extended to accepting the formation of a relationship between their husband and someone else in the facility. Some respondents felt that sexual behaviors should be limited to activities such as handholding and kissing, while intercourse should be avoided. The reason stated for this view was that dementia would preclude the resident from understanding intercourse or its potential consequences. Others felt that with adequate supervision, potential harms could be mitigated.

2. The participants realized the difficulties facing staff members in managing sexual expression by residents with dementia. Lack of training and lack of time were cited as barriers perceived by the family members. Family members sympathized with the dilemmas faced by staff, as well as the legal risks facing staff if they fail to intervene and litigation ensues.

3. "Family members were adamant that no matter what happened in regards to the sexual expression of residents with dementia, they wanted to be kept informed." Consider the actual statements of the family members:

    - "I think it's important for the family as well as the person with dementia to understand everything that's going on, because that affects them when you go to visit them. If something like that's happened [a relationship] and someone's drawn them away, the person you're visiting will be totally different and you'll be wondering, 'Ok what's wrong? What have I done?'" (Woman whose father with dementia is in a facility)

The following comments were in response to the fictional scenario, in which the family members' consensus was that the staff was wrong not to inform the husband of the sexual behavior by his wife:

- "I do believe that legally with a woman with dementia [her husband] is her guardian. And therefore, yes, he must be advised of what's going on, and yes, he has the right to decide for her." (a woman whose mother with dementia is in a facility)
- "It's ridiculous to try to keep the family member out of the circle. It's very, very painful for a family member . . . to come and find their spouse walking hand in hand with someone, and when sitting down for a family talk together to find that this [new] partner has sat down as well." (a man whose wife with dementia , now deceased, had lived in a facility within the past 4 years)
- "I would be concerned too to find out a situation like that. And I would react as he [the husband] did – Why the hell is this going on? What sort of place is this?" (a man whose same-sex partner with dementia is in a facility)[9]

These comments raise the issue of the balance between respecting the resident's right to privacy with the need of the family to be informed. It is at the heart of the consent

dilemma that faces LTC facility staff. If a resident has sexual consent capacity, they have a right to privacy and appropriate accommodation of their sexual choices that supersedes the right of the family to be informed about their sexual expression. On the other hand, if the resident lacks sexual consent capacity, it would seem obvious that the right to adequate protection from unconsented-to sexual activity would entail positive action by the facility, including enlistment of the appropriate decision-maker (usually a family member) in the event sexual behavior involving or directed at the resident occurs.

This study is important because, while it was small in size, it accessed the perspectives of people who had actually gone through the process of following a loved one with dementia through institutionalization in LTC. Their comments touch on various aspects of consent determination, especially concerning whether, how, and when family members should be informed and consulted.

4.2 Divergent Family Perspectives and the Risk of Litigation over Alleged Nonconsensual Sexual Acts

Not all families are receptive to finding out about sexual activity of a loved one. These concerns were highlighted in a case reported in the media involving a 78 year old man and an 87 year old woman, both with dementia. The woman mistook the man for her husband. The facility staff believed the sexual activity between the two was consensual. The woman's son, who was her power of attorney, was notified, but not her husband. The state was not notified. Eventually, regulatory penalties and the firing of the administrator and DON occurred after the state became aware of the situation. Litigation claiming the woman had been raped followed once the husband became aware of the situation, and was eventually settled with undisclosed terms. Media reports hypothesize that this case portends more dilemmas concerning sexual issues for the LTC industry, given the approaching boomer generation and its freer attitudes toward sexuality. [10, 11]

Contrast the case cited above with the situation of Justice Sandra Day O'Connor. After she placed her husband with dementia in a nursing home, he developed a romantic relationship with a woman in the facility. Justice O'Connor gave permission for this to continue, happy that her husband seemed content.[12, 13]

These cases highlight the divergent attitudes one will encounter among families of those with dementia who exhibit sexual behaviors in the LTC setting. They illustrate the importance of dealing with each case individually and not assuming a singular approach to family members in consent determination.

5. EXAMPLES OF POLICY PROPOSALS FOR LTC FACILITIES RE: SEXUAL CONSENT IN DEMENTIA

Two examples of attempts to develop and implement policies on sexual consent in dementia are addressed below. Both carry forward several of the insights already mentioned above, while having various nuances. These are put forth not necessarily as templates for all settings, but as useful starting points for any facility considering developing a policy.

5.1 From Hamilton, Ontario: Intimacy, Sexuality and Sexual Behavior in Dementia – How to Develop Practice Guidelines and Policy for Long Term Care Facilities.

Available at http://www.piecescanada.com/pdf/Resources%20-%20sexuality.pdf. Accessed 11/18/15.[14]

A group of Long Term Care professionals from the Hamilton, Ontario region developed this resource. Other members of the working group included a government health official, police officer and psychiatric social worker.

In addition to affirming the sexual rights of older adults with cognitive impairment, this resource is notable for the purposes of this paper for the following:

- It emphasizes the importance of an interdisciplinary team in developing a policy;
- It suggests the inclusion of family members on the team;
- It recommends developing working definitions which distinguish between sexual behaviors to be interpreted as normal, those that require assessment, and those that are of concern because of risk;
- It states, “the facility needs to develop working definitions of consent related to sexual behaviors and relationships,” and then provides the same list of questions

framed by Lichtenberg in the ABA/APA handbook (page 5 of this paper above) as a helpful suggestion;

- It challenges the idea that a specific mental status score can be used as a cutoff for determining sexual consent capacity;
- It emphasizes the importance of observation of behaviors and the involvement of family or power of attorney decision makers in team meetings and decision-making;
- It mentions that if there is a specific cultural or religious affiliation of the facility, the policy needs to reflect those inherent values;
- It promotes education of staff and new families to the facility policy;
- It recommends policy review and revision every two years.

5.2 Policies and Procedures Concerning Sexual Expression at The Hebrew Home at Riverdale Available at www.hebrewhome.org.[15]

The Hebrew Home has had a sexual expression policy for more than 20 years, with revisions as recently as 2013. Two resources within their policy which should be reviewed by facilities seeking to develop a policy are described below.

1) **ABUSE or INTIMACY: Older Adult Sexuality**. This is a simple 4-question algorithm to distinguish when assessing sexual behaviors, much like the third bullet point in the Ontario guidelines above. See Appendix A of this paper.

2) **Assessing Consent to Sexual Activity in Older Adults**: this resource is a series of questions and considerations when making a consent assessment, categorized into the ability to express choices and consent, the ability to appreciate sexual activity, and personal quality of life choices in the here and now. See Appendix B.

In addition to these practical resources, the following aspects of the Hebrew Home policy are relevant to the discussion of consent capacity determination in dementia:

- Consent may be demonstrated by words and/or affirmative actions;

- A resident who has intact decision-making ability but is non-verbal may require an assessment by the Home's consent tool listed above (see Appendix B);
- A resident who has Alzheimer's disease or dementia does require an assessment with the consent tool;
- The consent assessment tool, conducted by the clinical staff, is used to confirm that consent was and continues to be given, and to insure the safety of those involved;
- All residents are entitled to their personal beliefs, choices and practices in matters of sexuality, and staff should set aside their personal biases to maintain objectivity in upholding residents' sexual rights and choices;
- Residents' sexual rights do not extend to acts which are non-consensual, acts with minors, acts where there is a possibility of transmission of an STD, or acts that impact negatively on the resident community as a whole through public display (found in Preamble A of Hebrew Home policy);
- "In instances where conditions expressed in Preamble A are not fulfilled, including those involving cognitively impaired residents, the relevant Interdisciplinary Care Team (ICT) will make clinical determinations weighing the relative benefits or potential harm associated with the resident's(s') sexual expression. Involvement of a family member or legal representative may be indicated only in instances where the involved resident(s) is cognitively impaired. In such cases, it is the facility's responsibility to uphold the choices and rights of cognitively impaired residents, and to work with families and/or legal representatives if their suggested course of action is discrepant."
- The Home's policy is linked to its mission, which respects the centrality of intimacy and privacy.

5.3 Comments on Sample Policies for Determination of Sexual Consent in Dementia

The two policies reviewed above carry forward many of the principles identified by various professional perspectives cited earlier in this paper. Both policies aim to

respect and protect rights of sexual expression of older adults with cognitive impairment. Both stress the importance of differentiating appropriate from inappropriate or illegal sexual behavior. Both acknowledge the importance of assessing capacity for sexual consent when cognitive impairment is present. Both employ tools to assess capacity which involve a series of questions for the staff member(s) performing the assessment to address as a structure for that task. And both mention the importance of linking a policy on sexual expression in the facility to the cultural setting or mission of the facility.

There is some contrast between the two proposals in regards to the series of questions suggested. The questions suggested by Lichtenberg referred to in the Ontario policy are more formal and directed to the examiner who is to make a judgment in response to the question. The questions in the Hebrew Home policy are directed to the resident, are worded in a more personal and conversational manner, and are thus eliciting subjective responses on which to base a determination of consent (and consent capacity). Lichtenberg's list includes a specific question as to whether there is confusion or delusion as to the identity of the sexual partner, whereas the Hebrew Home list does not. Some of this difference in emphasis may be that the Hebrew Home list of questions is focusing on consent determination, whereas Lichtenberg's questions focus more on consent *capacity* determination.

The point of these observations is not to favor one list over the other, but to stimulate further thought and discussion as to the relative merits of specific aspects of similar but differing approaches to the process of sexual consent determination in dementia. It may be that a facility seeking to develop a policy would examine these two lists of questions and select a mix of questions from the two lists, and/or perhaps develop questions of their own for their particular setting.

A second area of difference in emphasis is the relative degree of family involvement envisioned in the two policies. The Ontario perspective seems to solicit a greater degree of family involvement, whereas the Hebrew Home focuses more on protecting the sexual rights of the cognitively impaired resident. Again, this may be more a matter of relative emphasis pertinent to the needs of the particular setting.

The matter of family involvement in decisions regarding sexual activity by cognitively impaired residents is likely to continue to be a source of challenge in individual cases. More studies like those by Bauer described above are needed to more fully understand family perspectives. It is possible that the arena of sexual consent determination could become a territorial battleground between families and facilities, much like cases involving end of life determination of medical futility a couple of decades ago. Facilities may find it more helpful to focus on ways in which as much of the decision making

process can be shared with families, while still seeking to safeguard what level of resident autonomy remains as sexual decisional capacity is waning.

Clearly more research in these areas of limited knowledge and resultant controversy would be helpful. For now, however, this paper will conclude with three case examples – one in which consent is clearly not established, one in which it seems quite clear, and a third in which matters are uncertain.

CASE 1

Tom is an 85 year old widowed LTC resident with advanced Parkinson's disease, Lewy-body dementia, hypertension, orthostatic hypotension, and recurrent falls. He still ambulates occasionally with a walker and supervision. He takes carbidopa-levodopa 5 times a day and lisinopril-HCTZ. He is sitting in his wheelchair just outside his room. With one hand he is masturbating, and with the other he leaning forward, smiling, reaching across the hall toward his neighbor, Gerri. A family member of a third resident down the hall observes this and reports to the nurse at the desk.

Gerri is a 95 year old widow with CHF, atrial fibrillation, vascular dementia, peripheral vascular disease, spinal stenosis, Type 2 diabetes mellitus, hypothyroidism, and legal blindness from macular degeneration. She is immobile, spending most of the day in a reclining chair. She still communicates verbally with friends and family, though she often mixes up their names. She still talks fondly about many things she and her late husband did together. Today Gerri is facing down the hall with Tom three feet away to her right. She is flapping her blouse up and down with both hands, exposing both breasts.

Tom has occasionally attempted to fondle the breasts of staff members during care. Because of persistence in this behavior and conflict with staff related to this, he was moved up from the floor below 2 months ago. Tom and Gerri have never been known to socialize together before this incident. How should the staff respond?

A) Place both residents in their respective rooms and contact adult protective services to report resident-to-resident sexual aggression and possible sexual abuse.

B) Contact the families to educate them about the sexual rights of residents and advocate for a plan for Tom and Gerri to spend time privately in one another's room.

C) Request a neuropsychological consultation on both residents to assess capacity for sexual consent.

D) Move both residents to their respective rooms to perform a nursing assessment on each to identify and address their needs, inform the attending physician(s), and monitor their needs more closely.

ANSWER: D.

Inappropriate Sexual Behavior (ISB) may be defined as "a verbal or physical act of an explicit, or perceived, sexual nature, which is unacceptable within the social context in which it is carried out;"[16] "any vigorous sexual drive after the onset of dementia that interferes with normal activities of living or is pursued at inconvenient times and with unwilling partners."[34, 17] Public display of normally private sexual activity and unwanted sexual aggression qualify as ISB. ISB due to disinhibition can occur in a variety of neurodegenerative processes. In advanced Parkinson's disease, psychosis occurs in 20-40% of patients, and may include paranoid delusions of spousal infidelity.[18,35] Dopaminergic medications may also lead to hypersexuality which may overwhelm a partner with sexual pressure.[18,36] One survey of staff from 300 nursing homes found that 17-25% of residents had unpleasant experiences from the hypersexual behavior of other residents, requiring staff intervention in 20-30% of incidents.[37]

Staff should intervene immediately before unwanted touching occurs. A proper nursing assessment should be done immediately on both residents, as there are both safety and dignity issues. Gerri may have been feeling hot from too much clothing. She likely was unaware of Tom's presence or behavior. Tom needs privacy when he masturbates, redirection when done in public, and perhaps a review of his dopaminergic therapy and fall risk factor assessment and mitigation.

CASE 2

POST-ACUTE AND LONG-TERM CARE MEDICAL ASSOCIATION

Robert, a 76 year old widower for 5 years, was recently moved into the nursing facility by his family for long term care due to increasing forgetfulness, safety concerns, and his refusal to accept caregiving help at home. Despite his mild to moderate dementia, he remains physically healthy, outgoing and quick to make new friends. Within a few weeks, he and Sally, a 78 year old resident with moderate dementia, have developed a friendship. They usually dine together in a corner of the open dining area. Sally's husband of 50 years, Bill, passed away 6 months ago on hospice in the same facility from lung cancer. Prior to Robert's arrival, Sally would often ask the nurses where Bill was. Since she developed the relationship with Robert, she no longer asks about Bill. She refers to Robert by name on occasion, and the two are often seen holding hands in the sitting area. Both families are aware of the relationship and are supportive, as long as the nurses monitor the relationship to ensure that it remains consensual. The assessment of nursing and social work is that both Robert and Sally are aware of the nature of their relationship and are happy with pursuing greater degrees of intimacy, including sleeping together. This happens once or twice a week. In an assessment done by a staff nurse and social worker, there are no signs of abuse or inappropriate behavior within the relationship.

Which of the following are true about sexuality in dementia?

A) Persons with dementia have lost the capacity for consensual sexual relationships.

B) Although the prevalence of sexual activity decreases with age, a significant percentage of people remain sexually active into their later years

C) Capacity for consent for sexual activity is best assessed using a standardized mental status score such as the MOCA.

D) Capacity for consent for sexual activity includes aspects of knowledge, understanding and voluntariness.

E) B and D

ANSWER: E.

In a national probability sample of 3005 U.S. adults age 57 to 85 living in the community in 2007, Lindau found that the prevalence of sexual activity declined with age. Sexual activity was defined as "any mutually voluntary activity with another person that involves sexual contact, whether or not intercourse or orgasm occurs," and "sexually active" referred to those respondents who had sex with at least one partner in the previous 12 months. The rate of sexual activity fell from 73% for ages 57-64, to 53% for ages 65-74, to 26% for ages 75-85. In all age groups, women were less likely than men to report

sexual activity. In ages 75-85, 38.5% of men reported sexual activity, while only 16.7% of women were reportedly active.[19] In 2013, Lochlain cited a global study finding that 53% of men and 21% of women age 70-80 had been sexually active in the preceding 12 months, and another study finding that of those over 70 who were sexually inactive, 52% of women and 38% of men reported "no partner" as the main reason.[20,38,39] In a U.K. survey of 40 spouses of persons with mild to moderate dementia, 22.5% reported continuing sexual activity, all of whom were satisfied with the relationship.[21]

There is no standardized test for sexual consent capacity. Sexual consent capacity is a complicated function involving knowledge, understanding, and freedom from coercion. Sexual consent capacity determination should evaluate various aspects of these domains in a functional manner appropriate to the level of intimate behavior involved. A variety of questions may be helpful in determining if capacity is present (see Appendices A, B, C).

CASE 3

The same couple in Case 2 above, Robert and Sally, have been together for 7 months. Sally's dementia seems to be worsening, with some agitation in the form of yelling out at the staff over trivial matters. She seems more anxious and occasionally cries. Her family is concerned when she begins to refer to Robert as Bill on several occasions. They are questioning if the relationship is truly consensual and request that the nursing staff intervene to keep the social interactions between Robert and Sally out in the open area.

Robert remains very social and engaging of others, in addition to displaying his fondness for Sally. He tells other residents that he and Sally are planning to marry. When his children hear of his intentions, they are enthusiastic and supportive. Sally's children are concerned over her apparent diminishing capacity for consent and the sizable estate they believe may be at risk.

What are some options for addressing the issue of Sally's capacity for consent?

A) Obtain formal neuropsychological or psychiatric consultation to establish Sally's capacity for sexual consent

B) Ethics committee consultation

C) Consult the local ombudsman

D) Repeat the assessment done by the staff to establish Sally's capacity for sexual consent

E) All of the above

ANSWER: E

As cognitive function declines over time, sexual consent capacity will need to be reevaluated periodically. Sally is displaying the possibility of a diminishing capacity for consent in at least two of the three primary domains of knowledge, understanding and voluntariness. First, her mistaking of Robert for Bill, her deceased husband, indicates a deficit in her knowledge of a key aspect of the sexual relationship. Second, the increased agitation and emotional lability may simply be a manifestation of progression of dementia, but it could be due to other factors such as depression or emotional distress from fear of loss of relationship if she rejects Robert's offer of marriage.

The element of voluntariness is in question in this case. Coercion, whether intentional or not, may be present. Coercion of a vulnerable older adult can involve social, financial, sexual, and other forms of pressure. A cognitively impaired older adult may be more prone to manipulation through fear of abandonment, rejection, loss of care, or emotional attachment due to mistaken identity. A process of authentic consent determination would seek to identify if coercive factors are at work in a situation and seek to mitigate such influences.

A variety of perspectives can be brought to bear on the above situation. Formal psychological or psychiatric consultation may provide more in-depth assessment and/or diagnosis of Sally's capacity, affective state, and presence of coercion. Ethics committees can help clarify key questions without necessarily making a final decision. An ombudsman provides an outside perspective with the rights of the resident as her/his top priority. A repeat assessment by the staff members who know Sally well may uncover her secret fears, if any, if those staff members have won her trust over time.

CONCLUSION

The right to engage in intimate sexual activity is a basic right for all older adults, including those with cognitive impairment. Capacity for sexual consent must be assessed in some manner for those with cognitive impairment in order to provide protection for them from non-consensual sexual aggression.

At present there is no uniform standard for determination of sexual consent capacity in dementia. Formal approaches attempt to look at the multiple domains of function underlying knowledge, understanding and voluntariness of an individual choice. Professional perspectives generally support these criteria. Degrees of capacity required vary for increasing levels of intimate behavior, from simple touch to penetrative intercourse. Sexual consent capacity may wane over time, thus requiring serial assessments if consent capacity is deemed present in a cognitively impaired older adult.

While there is not a validated formal instrument of assessment for determining sexual consent capacity, the list of questions by Lichtenberg and the questions included in the Hebrew Home policy provide a practical starting point for those facilities developing a policy on this issue. It may be helpful to include a variety of questions, perhaps designing questions unique to the needs or mission of the facility subculture. This may be especially true for faith-based facilities.

It is also important to have a working definition of inappropriate sexual behaviors (ISB) in order to distinguish ISB from consensual behavior (see Appendix A). Training staff to evaluate unexpected situations involving sexual behavior according to a simple algorithm such as that found in the Hebrew Home policy is essential.

The role of families will be part of any policy on sexual consent determination. While the rights of privacy and autonomy of the resident are paramount, as sexual consent capacity diminishes the legal and ethical priorities can become murky. It is important to build collaborative relationships when working with families, especially in such a sensitive area. Families can be engaged in policy formation discussions. Any policy on sexual consent in dementia should be communicated to the family before admission to the facility. Communication with the family should respect the privacy and autonomy of the resident when sexual capacity is deemed present, while engaging the family when consent capacity is unclear or diminishing. Striving for a shared decision making model between family and facility when the resident is losing capacity may cultivate a healthier and more satisfying outcome for all involved.

One final issue which sometimes is raised is the idea of sexual advance directives. Some individuals may wish to direct that they be “protected against the waywardness created by dementia.”[22] Conversely, an advance directive could also be used to promote one’s choice in advance for continued sexual activity beyond the loss of capacity, provided that activity was consensual for the partner. While this theoretical concept has not attained much traction yet, it is possible that changes in the LTC culture over time may motivate some individuals to pursue this mechanism to preserve a sense of control over their values and actions when their capacity has waned.

As the legal, societal, cross-cultural, and individual understanding of, and approach to, sexual consent in dementia develops in subsequent years, PALTmed should remain in the forefront of designing appropriate and effective policies to address the issues raised in this paper. A periodic review by the PALTmed Ethics Committee is warranted. It is apparent that the definition and assessment of capacity for sexual consent will be an increasingly relevant challenge for medical directors, LTC facilities, families, and most of all the residents in LTC in days ahead.

APPENDIX A

ABUSE or INTIMACY

Older Adult Sexuality

Aging does not mean a loss of sexual intimacy, but when an older adult is cognitively impaired (Alzheimer's, dementia) it can be difficult to determine whether he/she is engaged in a healthy sexual relationship or is a victim of a sex crime.

Is there an in between? What is it and how do you know? What happens when a 3rd party gets involved?

Older adults should be actively involved in the assessment process to protect their rights and choices.

1. Has a crime occurred?

Example: rape or forced sexual act by a perpetrator of any age

Report to law enforcement immediately if a violation of the law is suspected. Each state has specific laws defining sex crimes.

2. Has sexual abuse occurred?

Example: non-consensual sexual behavior between vulnerable older adults; no clear intention by perpetrator to commit sexual offense

Follow regulatory reporting even if there is no violation of a specific law

3. Has inappropriate sexual activity occurred?

Example: hyper-sexuality or poor impulse control in older adult with dementia

Intervention and care planning is required to prevent inappropriate conduct, even when a law or regulation has not been violated.

4. Has a real relationship occurred?

Example: sexual activity which appears to be consensual between older adults with cognitive or physical conditions

No intervention is required when older adult is able to express some evidence of consent to participate in a healthy relationship. Monitoring is advisable to ensure continued consent.

(From Hebrew Home at Riverdale Sexual Rights Program. Available at www.hebrewhome.org.

APPENDIX B

Assessing Consent to Sexual Activity in Older Adults

1. Ability to express choices/consent

Ask:

- What are your wishes about this relationship?
- Does your sexual partner make you happy?
- Do you enjoy sexual contact?

Consider:

- Observations and non-verbal clues when older adult is unable to verbalize choices (facial expressions and body language)
- Emotion and mood, before and after sexual contact

2. Ability to appreciate sexual activity

Ask:

- Do you know what it means to have sex?
- What does it mean to you/your partner?
- What would you do if you wanted it to stop?
- What if your partner wanted it to stop?

Consider:

- Nature of the relationship (monogamous)

- Emotion and mood, before and after sexual contact

3. Personal quality of life choices in the here and now

Ask:

- Was and is intimacy important in your life?
- What are your social and companionship needs?
- What brings happiness or fulfillment to your day?

Consider:

- Past and present relationships (including family)
- Impact of cognitive impairment (not an automatic reason to deny relationship)
- Privacy and intimacy rights
- Responsibility to uphold older adults' choices
- Policies for staff education and practice
- Impact of third party objectives or values on assessment process

(From The Weinberg Center and The Hebrew Home at Riverdale, Sexual Rights Policy. Available at www.hebrewhome.org.)

APPENDIX C

P. Lichtenberg – Suggestions for Assessing Sexual Consent Capacity[30]

1. Patient's awareness of the relationship:

a. Is the patient aware of who is initiating sexual contact?

b. Does the patient believe that the other person is a spouse and, thus, acquiesces out of a delusional belief, or [is he/she] cognizant of the other's identity and intent?

c. Can the patient state what level of sexual intimacy [he/she] would be comfortable with?

2. Patient's ability to avoid exploitation:

a. Is the behavior consistent with formerly held beliefs/values?

b. Does the patient have the capacity to say no to uninvited sexual contact?

3. Patient's awareness of potential risks:

a. Does the patient realize that this relationship may be time limited (placement on unit is temporary)?

b. Can the patient describe how [he/she] will react when the relationship ends?

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