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Journal

Social Work in Health Care, 61(3)

ISSN

0098-1389

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Publication Date

2022-03-16

DOI

10.1080/00981389.2022.2076764

Peer reviewed

HHS Public Access

Author manuscript

Soc Work Health Care. Author manuscript; available in PMC 2022 November 28.

Published in final edited form as:

Soc Work Health Care. 2022 ; 61(3): 169–183. doi:10.1080/00981389.2022.2076764.

Exploring dementia care in acute care settings: Perspectives of nurses and social workers on caring for patients with behavioral and psychological symptoms

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Abstract

This qualitative study compares perspectives of nurses (n=5) and social workers (n=12) about their role in caring for patients with dementia with behavioral and psychological problems in an acute care setting. A thematic qualitative analysis was conducted using the Rigorous and Accelerated Data Reduction Technique (RADaR). Three themes emerged: engagement of the patient and coordination with family and professionals, treatment and medical management of behavioral and psychological symptoms of dementia (BPSD) in the hospital, and barriers to care. Barriers to care are identified by both professions, with each having its own care niche. Social workers and nurses work as a team with the understanding that they face care challenges. Person centered care is a successful approach for the care team working with patients with BPSD.

Keywords

nurses; social workers; dementia care; acute care

Introduction

People living with dementia generally experience cognitive impairment and behavioral changes that can lead to disruptive behavior when they are hospitalized. These symptoms, known as behavioral and psychological symptoms of dementia (BPSD), contribute to greater difficulties in caring for persons living with dementia (PLwDs). As many as 75% of PLwDs who are admitted to an acute care hospital experience BPSD (Sampson et al., 2014; White et al., 2017), and often these symptoms can be exacerbated during the hospital stay (Dewing & Dijk, 2016). This is in part due to the change of environment (Barnes, 2006); hospitals are noisy, staff-centered, and focused on complex treatment of very sick patients with personnel stretched for resources and time (Borbasi, et al., 2006).

PLwDs are vulnerable and have medically complex conditions with significant comorbidities (Schubert et al., 2006). It is estimated that between 15–42% of older people admitted to the hospital have dementia, (Briggs et al., 2017), but they are typically not admitted with dementia as the primary reason (Alzheimer's Society, 2016) as their acute care needs are prioritized (Moyle et al., 2010). They are among the most frequent users of acute hospital services with 40% of their admissions occurring through the emergency department (ED) (Briggs et al., 2016).

PLwDs require more time from nurses and social workers during hospitalization from intake to discharge. Diagnosing the patient at admission can be problematic when the patient is unable to accurately describe their symptoms, and additional time is needed to obtain collateral information from family and friends (Mortenson & Bishop, 2016). More time is also required when PLwDs have difficulty following directions from medical staff resulting in the need for safety measures to be implemented (White et al., 2017). Additional support at discharge is often necessary due to the high risk for adverse events related to medication management and delays in acquiring community support (Belleli, et al., 2013). All too often, nurses and social workers are left balancing the demands from hospital administration for a shorter hospital stay versus the risk of early discharge without community support in place for the patient (Stockwell-Smith et al., 2018).

In the hospital context, nurses and social workers are faced with the challenge of managing both acute care needs and the BPSD of PLwDs (Dewing & Dijk, 2016). BPSD can complicate the acute medical care received in the hospital setting, and unfortunately, many health care professionals lack the knowledge, time, and training required to adequately address BPSD and provide quality dementia care (Chater & Hughes, 2013). This is a critical factor as social workers and nurses are the main professions providing care to PLwDs in medical care settings (Shinan-Altman et al., 2014) and managing daily care in the hospital setting. Information comparing the disciplines of nurses and social workers about their roles and problems they face in providing care to PLwDs in the acute care setting is insufficient (Tay, F. H. E., Thompson, C. L., Nieh, C. M., Nieh, C. C., Koh, H. M., Tan, J. J. C., & Yap, P. L. K. (2018).. This has implications for patient recovery and well-being (Tolson, D, Smith, M, Knight, P,1999).

The current study utilizes in-depth qualitative interviews of nurses and social workers in a major academic hospital system to understand barriers and facilitators to quality dementia care for patients with BPSD from a multidisciplinary perspective. Having different professional training in health care, social workers and nurses often approach patients and their problems with divergent goals while working on a team. Nurses focus primarily on the medical approach to care (Taft et.al., 1977) where care for acute medical needs is the priority. Social workers and some nurses take a primarily biopsychosocial perspective to care where social and biological elements of health are considered (Farre & Rapley, 2017). The paper examines the disciplinary perspectives and roles of nursing and social work in caring for PLwDs in hospital emergency (ED) and inpatient (IP) units to better understand how these two key professions view and manage BPSD.

The central research question explored was: How do social workers and nurses manage BPSD of PLwDs?

Methods

The Michigan Lean Thinking for Dementia Care (M-LEAD) study was aimed at quality improvement focused on dementia care within a major academic tertiary healthcare system (Leggett et al., 2019). Stakeholders (e.g. clinicians, managers) were asked to describe the structure of the care system within their unit, summarize the process of care for PLwDs and their families, and identify key strengths and challenges of providing care. This study focuses specifically on the interviews with nurses and social workers practicing within the ED and IP settings and how they manage BPSD.

Sample

Stakeholders were recruited from a large midwestern health care system through a combination of purposive and snowball sampling methods. The research team (multidisciplinary team of dementia care researchers at the hospital, the Health System and broader University) developed an initial list of stakeholders within the ED and IP units based on staff known to have a role in dementia care and who had worked at the hospital for at least one year. These stakeholders were asked if there was anyone else involved in caring for PLwDs who should be interviewed, and individuals not on the team-generated list were contacted for an interview. For the current analysis, the team used the cases identified in the purposive and snowball sampling approach consisting of the social workers (n=12: 3 in the ED and 9 in IP) and nursing stakeholders (n=5: 2 in the ED and 3 in IP) interviewed in 2016–2017 for the larger MLEAD study. Demographic data were not gathered on the sample in order to maintain confidentiality, as this information could be individually identifiable per the IRB.

Interviews

Nurse and social worker stakeholders were interviewed individually by the project manager, who recorded and transcribed the sessions. Interviews were conducted in a location of the participant's choice (e.g. office, hospital cafeteria) and names were removed from transcripts to maintain confidentiality. Interviews were conducted with note-taking and ongoing analysis informing the subsequent interviews consistent with a grounded theory interview approach (Strauss & Corbin, 1990). As the focus of the qualitative method was to capture the depth and quality of a participant's experience, interviews were conducted until theoretical saturation. Interviews varied in length (Social workers, range 15–31 minutes, average 21 minutes; Nurses, range 10–30 minutes, average 20 minutes).

Analysis

Interviews were audio recorded, transcribed and then thematically analyzed. In particular, the research team focused on participant responses to the interview question, "How are behavioral issues of dementia handled within your care setting?" or responses to any other questions where participants described care for BPSD. A team of four trained researchers (three graduate students and one faculty member) utilized the "rigorous and accelerated

data reduction" (RADaR) technique (Watkins, 2017) to organize, reduce, code, and analyze qualitative data (Watkins & Gioia, 2015) to explore the process of care among social workers and nurses for PLwDs with BPSD across a midwestern tertiary care system, with focus on ED and IP services. The RADaR process begins with an "all-inclusive data table" that gathers all interview transcripts into one spreadsheet (Watkins, 2017). Data are iteratively reduced by team consensus to include only text applying to the research question. Next, the open coding process is used to identify sections of text with overlapping concepts, followed by focused coding whereby codes are systematically applied, and consensus is reached by the team.

Results

In response to the research question of how social workers and nurses manage BPSD of PLwDs, three major themes emerged.

Theme 1: Engagement of the patient and coordination with family and professionals

When a PLwD is admitted to the ED or the IP units of the acute care hospital, the focus is on medical and behavioral issues. Social workers and nurses in both units find ways to engage the patient and coordinate with families, and friends, and gather the necessary patient history in order to recognize medical issues, undiagnosed dementia, and care for the PLwD with BPSD. Yet, each professional has their own role on the team to manage patient care.

Social workers see themselves as responsible for gathering information to provide guidance to hospital professionals regarding what works and does not work in communicating with the PLwD. Successful communication can reduce staff frustration as well as prevent escalating patient agitation. One ED social worker describes her role at intake:

> …my role specifically is to evaluate the patient and to obtain collateral information from family, other mental health providers, possibly primary care physicians; on occasion we may get a patient who resides in a facility- we would then attempt to get information, collateral information from the facility staff. So that we have a comprehensive presentation as to what brings them in. Following that it is my role to present the information to the psychiatrist.

Nurses also recognize the importance of knowing who the patient is by understanding their behavior and getting their story. When this is accomplished, nurses can provide more individualized care. An IP nurse explains:

> …I'm a firm, firm believer that all behavior is for a reason. So I'm really an adherent to the agenda of the behaviorist- that you have to find that agenda (of the patient) and you find that agenda to find out who the person really is. And so I do a lot of calls to families, facilities- what were they like? What did they respond to? You know that kind of thing.

To the extent that both RN and SW are trying to understand how best to communicate with the patient, they do share the same emphases.

Nurses' main focus is the medical care of the patient. The process of care administration is facilitated by obtaining information from families, monitoring medication, and observing patient behavior to evaluate comprehension. For instance, safety is by necessity a primary concern for nurses who are engaged in providing care on the floor but it may result in overlooking a compounding cause of the behavior. One IP social worker says:

> But sometimes they (nurses) look at things like falling out of the bed because that obviously is an adverse event (,) it could even be a sentinel event and …do they have dementia? You know it's like what are you really measuring here and how do you fix the systems' problems if your measure is falling out of bed and not (that) the person had dementia and wasn't toileted etc, was trying to wander, etc.

Social workers find it difficult to coordinate the care needs of the PLwD experiencing BPSD, and they recognize that the PLwD may not get the attention needed. A social worker describes the process and difficulties of providing care in the ED:

> I think the first line would be the bedside nurse- that would be the first person that would get contacted if a patient was agitated. … If that doesn't work then maybe the charge nurse and probably security would be the next step. And social work I'm sure would be contacted. … We have traumas and deaths and cardiac arrests and things that we have to attend to. As much as we'd like to be there for these patients and help them through and even sit with them- we often don't have time.

In summary, the nurses and social workers described how they gather information for patient diagnosis and interact with the patient and family throughout the hospitalization. Social workers see one of their major roles as determining the most successful manner to engage the patient and share the information with the medical team. This requires coordination with the family as well as professionals. Nurses also value understanding patient behavior, but nurses and social workers can have different priorities during the care process. Both social workers and nurses understand the difficulty of providing medical care when the patient has BPSD and feel that the psychosocial care may be more limited than would be ideal.

Theme 2: Treatment and medical management of BPSD in the hospital

If the PLwD can follow instructions, both nurses and social workers employ behavioral tactics -mainly redirection- in order to keep the patient safe during their hospitalization. When that does not work, other care arrangements in the patient's room or in other areas of the hospital are considered. An IP nurse describes the process from the nursing perspective:

> I think that we try to redirect them- we have the nurses taking care of them, we have some augmented staffing- we try to redirect and to maintain them safely in their room or in the milieu. If that doesn't work, we have an ICU. We probably first would try them on a 1 to 1 [i.e. hospital sitter/companion care] in the larger milieu. So if, then you have somebody who is constantly able to redirect them. We can put them in a private room- you know. If those things don't work- we look at meds….

Agitation or behavior problems experienced by the PLwD are addressed by hospital staff who are simultaneously exploring medical conditions that could be the cause of such symptoms. This is necessary in both the ED and IP settings. If the patient enters the hospital

through the ED, they are screened for altered mental status and medical stability. One ED social worker describes the management process.

> There is you know redirection, there's just calming words could be said, sometimes the family obviously knows the patient better than we do- they're able to intervene and calm the patient, other times we may need to get the physician involved to see if maybe some medication may be warranted to assist and prevent any further escalation of their behavior.

One IP social worker describes the role of social work as aiding the team's effectiveness when working with PLwDs throughout the hospitalization:

> …the social worker will likely have a consult and will talk with the team about how does that impact their care here, how is the patient coping, so a lot of clinical work will be around how is the patient coping, how is the family coping, it's a major change with that. And then figuring out with that then is there going to be a change when the patient discharges so if they are going home do they have all the supports that they need, or how do we hook them up with the correct resources to make sure that if there is a cognitive impairment they are taken care of.

Nurses acknowledge that drugs are used to control behavior. This may be due to lack of expertise in alternative methods of handling behavioral issues. Even with such knowledge, nurses contend that it takes a lot of work to handle these behaviors and some nurses may not have the motivation to do so. As one IP nurse says:

> …there are a core of nurses here who would do that (i.e. use workarounds). But there's also more nurses that are on the phone saying "I need an order for Haldol" but I know it's the nurses that are calling it in because the physicians have had it drilled into them that you just don't order for Haldol- and by the doses I know that the nurses are asking for it- and that's a shortcut.

There are also approaches and workarounds for agitation and aggressive behaviors other than drugs, redirection, and increased number of staff. One IP nurse explains the use of groups with PLwDs to aid in behavioral issues:

> …you know we do groups. Some of the groups are appropriate for [PLwDs]. We do stretching and movement groups, we do dance- we have music on the unit- and music groups- actually both. So, I think we try to, we have lower functioning groups, you know specifically we have geriatric groups. So I think we try to address their needs in that way. You know again we don't think of ourselves as treating primary dementia.

Social workers see a clear role for a team-based approach to help patients with BPSD. One IP social worker discusses the role of IP nurses, physicians and social workers when faced with wandering behavior or agitation identifying types of therapy and exercise that can deescalate behavior problems:

> … a lot of times if social workers are on floors and they know about a patient who wanders and they may see them wandering then they just guide them back to their room. Agitation is another big one. I know that there's a medical piece that

> gets addressed by physicians but as social workers we also try to see if there's any way to ease the agitation. Whether it's thinking about consulting for music therapy or pet therapy, or encouraging family members to bring in pictures of family, or encouraging people to visit- that sort of stuff. And then doing deescalating exercises with the patient so doing deep breathing or learning to pause before acting out if possible- things like that.

In summary, nurses and social workers face challenges in providing acute medical and psycho-social care for BPSD. Strategies for helping patients with BPSD typically involve non-pharmacological approaches and psychological strategies such as redirection, breathing exercises, yoga, music, and deploying sitters. Social workers face the additional challenge of managing the BPSD during hospitalization as well as through the discharge process. In some circumstances, nurses resort to calming medications to control wandering and agitation. Although there are some differences in care priorities, nurses and social workers' distinctive shared disciplinary perspectives on medical management and treatment are both needed to provide effective care to the PLwD experiencing BPSD.

Theme 3: Barriers to care

Although motivated to provide good care to PLwDs, social workers and nurses often face barriers to providing comprehensive dementia care in the acute care setting. Challenges to the placement process impact nurses' and social workers' care of PLwDs. One IP social worker explains the dilemma faced at the time of admission when there is concern for where the patient could be discharged:

> There have been occasions where you know let's say somebody comes from a group home or a skilled nursing facility or like assisted care and we find out that maybe they have an underlying dementia, but they are super agitated and clearly can't go back to place that they came from….So we sometimes feel kind of stuck with how do we adequately treat them? Because being on a medical floor probably isn't the best place for them either but a psychiatric admission isn't really appropriate either.

Nurses also find environmental barriers to providing good care. One IP nurse says, "so I would say …in a nutshell supervision (of the patient) and lack of protected open space are probably the two biggest things." Both professions find environmental barriers to their role in providing care.

Among the barriers central to the discharge process are those centering on resource limitation: families, and community support. One IP social worker describes the importance of receiving cooperation from family members and educating them about discharge options:

> The discharge can be very challenging to set up and to help the families understand that this is not going away and that this may be a permanent thing. And then helping them transition emotionally with that sort of realization. And the resources just aren't plentiful- so a lot of times we end up having conversations with families that maybe the patient has to go to a locked ward because they are a wanderer or something like that where that's the most appropriate setting…

Lack of training in dementia care poses yet another barrier to providing appropriate care. When the PLwD cannot communicate and wanders the halls, staff do not always know how to deal with the BPSD and are frustrated with the time it takes to provide the needed care. One IP nurse describes the problem:

> Like my overall observation about the staff here is that if someone cannot logically communicate verbally, the staff has very little thought, education, tolerance, patience for figuring out and implementing alternative communication methods. I'm not saying it's coming from a bad place, but I think, you know it could also be coming from the toll that sometimes these patients take on staff. Like are they too time consuming or do they wander all the time and nurses have trouble taking adequate care of their other patients because they feel like they're constantly having to run after someone- a dementia patient.

In summary, the poor fit between the patients' needs, the hospital setting, and the training of the nurses and social workers results in a care dilemma. Care cannot always be provided in a timely fashion, and it can be difficult to determine the best care environment for individual patients. Social workers need more time to support the patient throughout their stay. Social workers have to overcome barriers to incorporate families into the care team, while nurses have to effectively manage their time to ensure they can handle challenging behaviors like wandering while also caring for the rest of their patients. These challenges are further compounded by lack of training and resources for PLwDs with BSPD.

Discussion

This study used a qualitative approach to explore the perspectives of nurses and social workers who worked with PLwDs with BPSD in an acute care hospital. Three themes were identified in the data: engagement of the patient and coordination with family and professionals, treatment and medical management of BPSD in the hospital, and barriers to care.

Engagement of the patient and coordination with family and professionals

Initial contact with the patient and family for social workers and nurses focuses on medical and behavioral issues (Ludlow & Braithwaite, 2019). By establishing the patient's usual behavior patterns, staff can help the patient feel secure and calm (McCloske, 2004). When nurses and social workers learn a patient's life story, it facilitates meaningful interaction that enables the PLwD "to maintain a sense of self and personhood" (S12) (Fazio et al., 2018). While the perspectives of nurses and social workers are similar, their roles and goals often differ. Social workers perceived that the nurses' focus on medical needs and safety concerns can overshadow basic human needs of the patient, creating a care dilemma. Social workers feel that the patients may not get the support and understanding needed to provide appropriate care due to limited information on the best way to engage the patient, which could come from involvement of family or facilities. One possible solution is for social workers to help nurses better understand how to engage and communicate with the patient and support the medical role of the nurses by gaining an understanding of the patient's care values. Person-centered care to the PLwD promotes well-being (Dewing &

Dijk, 2016; Nilsson et al., 2019) and is also cost-effective (Tay et al., 2018). Future training for professionals on PLwDs' medical teams could include considering how to enhance personalized care.

Treatment and medical management of BPSD in the hospital

When PLwDs are treated in an acute care hospital, professionals play their own part in the care. Nurses may rely on drug treatment options as a strategy to treat BPSD as they may lack the knowledge or time to implement non-pharmacological approaches. They often face pressure to provide appropriate care and help calm the patient down, which may hasten their use of medications. Social workers rely on non-pharmacological approaches that decrease BPSD, but these approaches can require more time or information to implement.

Non-pharmacological strategies such as redirection and diversion, using music, dance, breathing and physical exercises, help reduce the patient's agitation. These interventions decrease BPSD and improve the well- being of the caregiver (Kales et al., 2015; Deudon et al., 2009; Livingston et al., 2005; Cohen-Mansfield, 2013).

Aggressive and disruptive patient behavior affects the team's approach to treatment. The initial step is educating the care team. The social worker or nurse makes the staff aware of how the patient is coping, and when possible gets information from the family about what calming approaches could be used. These personalized strategies to reduce BPSD can then be implemented by the team. Some examples of strategies that have worked include keeping a patient in their hospital room through use of frequent redirection and, if possible, having the patient in a room of their own. Providing companion care, where a family member or paid companion stays with the patient in their room, is also a successful strategy to calm the patient and facilitate care. While these techniques focus on non-pharmacological tactics and are utilized by nurses and social workers, nurses continue to use medications more as a way to address BPSD (Cohen-Mansfield, 2013).

Social workers face the additional challenge of discharging the patient from the hospital, which requires collaboration with families or facilities to create a smooth care transition. Social workers update care providers about the anticipated discharge, identify needed resources, such as medical equipment and supplies, and identify caregiver support and availability.

Barriers to care

Providing care for acute medical needs takes precedence over helping patients with behavior problems (Yous et al., 2019), but behavior problems can prevent or limit medical care and impact the care provided by nurses and social workers. The medical needs of the patient, lack of staff resources, and inadequate dementia training influenced nursing and social work involvement with the PLwD.

Nurses and social workers acknowledge that social workers are better trained to meet the behavioral and psychological needs of these patients, but there is still a need for adequate training of both nurses and social workers to properly care for PLwDs. A systemic review of the provision of dementia care (Evripdou et al., 2019) found that nurses in primary care

lacked knowledge, communication skills, and management strategies regarding dementia care and actually benefited from training programs to build such skills (Islam et al., 2020). This suggests that tailoring training programs for nurses and social workers for hospital care of PLwDs could improve care for PLwDs and appropriate management of symptoms of BPSD.

Strengths and Limitations

To date, no study has used in-depth interviews to compare the perspectives of nurses and social workers focusing on dementia care in acute settings. Using a qualitative research approach (RADaR), similar information was gathered from the two groups on their roles and care provision in ED and IP contexts.

Staff members interviewed in this study were key stakeholders within the healthcare system involved in dementia care and were specifically asked about barriers to care. Not all staff who cared for PLwDs were interviewed, so the information provided may not reflect the opinions of all staff or the health system, or the process of care for all patients. This study was conducted in a leading health system in the U.S. where care is considered excellent, but there are still challenges when it comes to the care of patients with dementia. Health care teams need adequate time and an incentive to coordinate care. Identifying barriers to health care and reimbursement provide a key context for decision making by nurses and social workers.

Recommendations for Improvement: Insights to better care

The acute care setting is not an ideal environment for PLwDs due to the poor fit between patients' needs and the hospital environment, and inadequate training for nurses and social workers. And yet, the two professions share similar perspectives though their goals diverge. Both nurses and social workers want to effectively treat the patient in the acute setting and successfully discharge the patient to an appropriate setting with adequate support. While the main focus for nurses is medical care and safety of the patient, social workers optimize communication strategies for staff and family, enlist family members to support and provide supervision in the hospital setting, and manage the discharge process and follow-up afterwards.

Environment.—The hospital environment can present challenges to providing appropriate care to the PLwDs. At admission in the ED or IP setting, the environment is busy with people and noise. Where the patient is housed as an IP can also be confusing, as in the hospital room there can be strangers coming and going frequently. Conducting the intake interview with the patient and family in a quiet area is ideal, expediting the admission process and reducing agitation in the patient (Alzheimer's, 2016). Reaching families earlier in the care process can facilitate an easier and more effective hospitalization and discharge process. Having both the medical staff and social worker together from intake through hospitalization to discharge can facilitate a common understanding of the patient and provide knowledge about how to communicate with the patient more effectively. This could lead to better care by gaining the patient's cooperation and limiting agitation, aggression and

wandering behavior. Additional research has shown that lighting as well as color on walls and spaces for socializing can reduce agitation (Alzheimer's Society, 2016).

Training.—Training is needed for all professionals who care for PLwDs. Nurses and social workers face different pressures and time constraints regarding treatment of the PLwD. While nurses can access drugs to control behavior and obtain cooperation of patients, social workers turn to non-pharmacological measures which may take longer, but have other benefits such as reducing BPSD symptoms and improving the well-being of the caregiver. Time and training affect how these two options are handled by the care team. Having a common understanding of each profession's approach to solving problems could facilitate more effective treatment. Training in dementia care needs to be more pervasive among professionals so that nurses and social workers have a common understanding of factors affecting the care of the PLwDs in the acute care setting. The training needs to be recurrent as new insights into care emerge.

Supports.—During the hospitalization, various supports can be instrumental in facilitating effective medical treatment. One major factor is connecting with family/personal supports to better understand the PLwD in an acute care setting. Providing information to the patient and family about the total hospital experience from admission to discharge is helpful. During hospitalization, family members can act as sitters in the patient's room to minimize wandering and communicate the patient's needs to the staff. Paid sitters are also helpful to minimize wandering, but they don't have as much personal information about the patient. Drug treatment is also a support to care, although nurses and social workers differ on when to use drugs.

Conclusion

This project interviewed nurses and social workers who share the same care space in the hospital to better understand the strengths and challenges that each faces. The two professions share common ground, but their distinct training promotes varying emphases regarding the use of drugs to handle behavioral issues, and their focus on medical care versus person-centered care. The findings of this study demonstrate the importance of exploring the issues around different types of professionals working in the same space with the same patients. While each profession has its own care niche, teamwork is key to successful treatment of a PLwD in an acute care setting.

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