Global Journal of Medical Research - Section K
GJMR

The Physicians Are Not at Fault

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Abstract

This perspective piece argues that physicians are not at fault for inadequate dementia care in hospitals; rather, the systemic lack of training and support is to blame. The author, a person living with dementia, describes his own hospital experiences and those of others, and presents a proposal for a national hospital designation program to improve dementia care. The paper includes reflections from multiple physicians and dementia experts, highlighting the need for systemic change and evidence-based training programs such as the Cognibility Hospital Dementia Accreditation.

Keywords: *cognitive impairment, dementia, dementia training, healthcare system, hospital care, patient advocacy, physician education, quality improvement*

1. Introduction

Hospitals in the United States generally do not effectively support those living with dementia. As an individual living with dementia, I have been hospitalized three times for issues unrelated to dementia, and on each occasion I felt that the hospital and staff failed me. My experience prompted me to speak with others living with dementia and their caregivers, and I discovered that I was not alone; my encounter was not an isolated case. The individuals I spoke to all responded extremely negatively about their hospital experiences. It became apparent that many of the hospital challenges I had, and those voiced by others, could not be understood or appreciated unless one was living with dementia. Because most US hospitals do not have well-established procedures for effectively supporting patients who are living with dementia, I decided to create a group to focus on creating changes to the hospital system.

2. Dementia DREAMM Team

- **D**etermined
- **R**esourceful
- **E**ngaged
- **A**dvocates
- **M**oving
- **M**ountains

2.0.0.1. Mission

Advance a national designation program for hospitals that meet specific quality measures related to identifying and treating patients experiencing cognitive issues, supported by organizations like the National Quality Forum and the Centers for Medicare and Medicaid Services.

2.1. Key Objectives

1. Identify and promote routine utilization of structured cognitive assessments during the Medicare Annual Wellness Visit.
2. Identify and promote mandatory requirements of all hospitals treating Medicare beneficiaries to adopt quality measures that ensure the best care for patients; these measures would include identification and performance improvement related to patients experiencing cognitive changes.
3. Recommend a method for identifying patients living with cognitive changes using a verification system to ensure accuracy (i.e. wristband, door signage).
4. Identify and promote programs that teach empathy to healthcare professionals and hospital staff (e.g., simulating what it is like to live with dementia) to increase understanding of the need for dementia-specific training.
5. Identify and promote training requirements related to supporting individuals living with dementia for both healthcare professionals and their care partners.

2.2. Benefits and Outcomes

1. Positive competition will be created among hospitals with the designation of implemented quality measures related to cognition.
2. Individuals living with cognitive changes will be given appropriate and evidence-based care when they are in hospital settings.
3. Individuals living with cognitive changes will have a more positive, accurate, and safe outcome in hospital settings.
4. Family care partners will be actively involved in the discharge planning process and will be provided detailed, written care plans and instructions to help prevent hospital readmissions.
5. For those newly suspected of cognitive changes, recommendations for following up with a full cognitive assessment will be provided.
6. A cost savings for hospitals will be provided due to fewer unnecessary readmissions and patient incidents.

EARLY VIEW

3. Physicians' Perspectives and Systemic Challenges

As a person living with dementia, over the years I have had many interactions with healthcare providers and medical organizations. Based the experiences I had and the experiences of others who are living with dementia, I became increasingly aggravated and angry with physicians. As I have now become a world-renowned dementia advocate and an expert in many issues related to dementia, my perspective has changed. After having the opportunity to speak to many physicians, as friends, I started to realize most of the issues were actually not their fault, but a fault of the system. As one example, few have received in-depth education about dementia during their training. How can we expect physicians to provide effective care for those living with cognitive changes when they are not set up for success upon graduation?

I had heard a world-renowned physician and medical educator admit mistakes he had made related to dementia care. I was so impressed with his candor and willingness to admit this publicly. I decided to reach out to other physicians to invite them to share their personal comments and experiences. Specifically, I emailed each of them and asked them to describe three situations related to dementia whereas they later realized that they were using an ineffective approach. The individuals have consented to have their professional roles and unedited statements published in a peer-reviewed journal. I am hopeful that this information helps bring a new understanding to the issues they face as physicians, and that this will help inform teaching institutions on the importance of educating our future health care professionals about dementia.

> "I think there is a greater need than ever to use "practice" to describe medicine, which is what physicians are forced to do due to so much misinformation both taught and published. The way doctors are taught is that you are essentially given a seemingly infallible collection of knowledge. Because there is so much information to disseminate, the instructors skip over invalid assumptions and other biases intrinsic to large bodies of observations. Every so often, you are reminded (or you read on your own) that materials described as cold hard facts in medicine are entirely proven wrong because someone dares to challenge the dogma. For example, prior to 1984, senile dementia was considered a normal part of aging and only pre-senile dementia was considered abnormal. 40 years later, others want to call a trace of asymptomatic Alzheimer's pathology the first stage of Alzheimer's disease. These polar opposites can't both be true, yet no one would ever acknowledge one is wrong. Instead of each new opinion being structured as a **hypothesis** which needs to be tested and proven (at least the 1984 inclusion of senile dementia as abnormal was), terms like "framework" are used to elevate their scientific and clinical merits. As a result, many patients with subjective memory concerns who were called worry-wells are now suddenly considered patients needing immediate immunotherapy; how do we reconcile that as a field, and how do we expect patients to trust us when we flip flop without any sound science beyond random p-values?
> Another example of how we lost the public's trust is the reliance on syndromic diagnosis in dementia. Patients were told they did or did not have Lewy body dementia or behavioral variant frontotemporal dementia based on imperfect criteria derived from a small set of physicians and neuropsychologists who saw self-selected patients (who could afford to go to a 3rd or 4th opinion). Patients would then be told to undergo tests which usually performed well in very artificial settings without much real-world validation, and specialty physicians (usually at research centers where these patients go) would further solidify their biases after subjectively interpreting these tests. If non-patient facing scientists question these practices, specialty physicians would then go find other scientists who would agree with them for a share of the fame (and grant dollars). This leads to the current (mal)practice of pathologists and biochemists describing what neurologists should look for during dementia diagnosis (at least they haven't waded into dementia care yet), even though these "key opinion leaders" don't ever, nor are they trained to, medically care for people living with dementia."
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> —*Professor of Neurology*

> "1. Speaking with a family member about the person living with Alzheimer's disease, in the presence of the person, as if he/she is not there (not thinking how it makes the person feel).
> 2. Assuming that complaints made by a person living with Alzheimer's must be inaccurate because of their cognitive disability ("written off" / don't even bother speaking with them / "She doesn't know what she is talking about" / "She makes things up").
> 3. Using demeaning terms to describe a person living with dementia such as "He is out of it" / "He is no longer there."
> 4. Giving a diagnosis of "dementia" when "dementia" per se is not a stand-alone diagnosis (a specific form of dementia such as Alzheimer's disease, vascular dementia, or frontotemporal dementia needs to be diagnosed).
> 5. Thinking that once diagnosed with Alzheimer's, the person is necessarily not safe driving a car and automatically must stop driving / Telling a person with Alzheimer's disease they must stop driving without giving hope that transportation arrangements will be made to ensure that they can get to their desired destinations.
> 6. Thinking that Alzheimer's causes aggression (when the truth is that in the vast majority of situations unmet emotional, medical, and other human needs primarily drive these understandable behavioral expressions, intersecting with the person's cognitive processing disabilities).
> 7. Assuming that people living with Alzheimer's don't feel emotions (when they are able to experience and feel the same range of emotions cognitively intact people feel).
> 8. Not giving a person with Alzheimer's disease enough time to formulate their thoughts to answer questions asked / Rushing the person.

IN REVIEW

9. Using biomedical and harmful terms to describe the person living with Alzheimer's disease: "Dementia patient" and "Demented" (as opposed to "a person living with a cognitive disability" / "a person living with cognitive changes" / need to focus on the person first).
10. Not assessing the person's remaining abilities and thus not focusing on them when developing a care plan (a missed opportunity to enhance the person's psychological well-being and physical function).
11. Doing something for the person with Alzheimer's disease (When the person is able to do it on their own), causing "Excess Disability."
12. Diagnosing and telling the person that she/he has Alzheimer's disease without giving them hope regarding what the person can do to live a meaningful life despite cognitive disabilities.
13. Giving the person with Alzheimer's disease false hope that a new medication is effective, in making a real, noticeable difference in their memory and cognitive function, when it is not.
I can go on but maybe some of it is useful to you..."

—Gerontologist, Dementia Behavior Specialist, and Elder Mistreatment Researcher (PhD)

Dr. first response: "For some of the doctors, they very much are at fault. They delay diagnosis, they are afraid of the diagnosis, the fail to make a diagnosis. Even those who treat sometimes won't treat folks with APOE44, so they are engaging in genetic discrimination.
I get not wanting to beat up doctors in general. Many are trying to help. Some are indifferent. Some are actively horrible. Sometimes medicine advances retirement to retirement."

My reply: *Is that what you want me to use above? I have to say I am a bit surprised by your answer. Is it because you may have had more education than the others? Do you think the doctors are educated properly to deal with dementia after graduation?*

Dr. reply: "Yes, easy to criticize others. But in an age of disease modifying therapy, time is brain, and delays result in worse outcomes. Sad to say many doctors are complicit in this."

—Neurologist and Clinical Researcher

"One of the biggest things I got wrong early in my career was assuming that evidence from randomized controlled trials could be applied too literally to individual patients. As physicians and scientists, we are trained to think from population data outward. We learn what works for the "average" patient. That science is essential, but it is only a map. The patient in front of us is the terrain: one person with a unique body, history, family, priorities, and social, medical, behavioral, and genetic context. I also came to realize that dementia care should not be thought of as a fixed treatment plan. It works best as a personalized, measurement-based, treatment-to-target process. The evidence gives us a starting point, but the real work is translating population-level knowledge into an individualized plan that aims for the right balance of benefit and harm for a particular person. In practice, this often becomes a series of n-of-1 trials: try a change, measure what matters, evaluate the trade-offs honestly, adjust, and repeat as goals evolve. Finally, I underestimated the importance of implementation. Through developing, evaluating, implementing, disseminating, and delivering collaborative dementia care, I learned that good care is not only about knowing the evidence. It is about creating systems that allow clinicians, patients, and care partners to apply that evidence in a way that is longitudinal, adaptive, and person-centered. The challenge is not simply discovering what works on average. It is helping each patient find what works for them."

—Geriatrician

"My primary suggestion would be think about expanding your criticism of physician / clinician education so that it's also about the entire system of care, including how care for people living with cognitive symptoms are cared for. The GUIDE Model [2] is a demonstration project from CMS to test if paying for dementia care in a different way will improve quality of care, save money, and reduce caregiver strain. The reason to do this GUIDE model test is because the traditional "fee for service" medicare model has historically not included ways to pay for education of caregivers and education of people with cognitive symptoms about how to plan strategies to help themselves.
For my own experience, for my first job, I worked in a psychiatry hospital and people would sometimes be admitted in a crisis and I would wonder/believe that the crisis could have been avoided if the person/patient and family had been able to connect with a dementia specialist months earlier. So, my criticisms were not so much of the education of providers but more about the overall system of care. It was this concern about the importance of improving care in the community, to prevent hospital mental health crisis, which led to my personal motivation to work in dementia care policy and health systems improvements."

—Professor of Psychiatry

"I do think the medical system has been improving in its explanation of dementia; although not perfect yet. I think one area the system could improve is by sharing more details about the prevalence of the disease and the effects that the disease has on caregivers."

—Neurology Resident

> One doctor chose not to participate even though he is considered a world-renowned Neurologist. In fact, his statement at a conference was what inspired me to write this article. Although I don't remember exactly, his statement conveyed that he realized, after 20 years, his understanding of Alzheimer's patients was wrong. And he had been advising other physicians on this topic for all of that time.
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> —*Professor of Medicine, Geriatrics*

4. Developing a Hospital Dementia Training Program

Since physicians, along with other medical and non-medical hospital staff, often do not receive adequate dementia knowledge during their education, it is clear that hospital systems need to step in to provide this training. As I was aware that this would be a massive undertaking, I divided it into a sequence of steps.

The first step was to inform hospital leaders and administrators on the financial benefit of such training. I assembled a team of leaders to form the Dementia DREAMM Team, and we drafted a white paper entitled, "The Business Case for Dementia-Competent Hospitals: Analyzing the Financial Return on Investment of Specialized Staff Training and Care Models," which was published in August of 2026 [1]. This paper is a analysis of how hospital systems can better serve patients who are living with dementia. It identifies structural and operational gaps and offers an evidence-based framework for building dementia-competent care environments. The work was reviewed and accepted by the Global Journal of Medical Research, an open-access, peer-reviewed journal.

The next step was to identify and create an educational model that could be used across all of hospital systems. While many currently exist, I did not feel that most of them are truly effective. I reached out to one of the dementia care experts on my team. She wrote the following:

> "We write to express our strong support for a national initiative for hospital dementia training. The U.S. population is aging rapidly, with the number of Americans aged sixty-five and older expected to nearly double by 2060. With age being the biggest risk factor for most forms of dementia, it is a condition that is becoming increasingly prevalent. Unfortunately, our current health care infrastructure is drastically underprepared for screening, diagnosing, and supporting those living with various forms of dementia.
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> At present, many individuals are not diagnosed with dementia until they are well into life-altering symptoms of the disease, missing opportunities for early risk reduction of mitigation interventions and enhanced environmental, social, and health support. The delayed recognition of the presence of dementia can and does impede effective hospital care and health condition management. Missed awareness of developing dementias often contributes to physiological and/or psychological crises that result in hospitalization. Once admitted, many hospital systems are ill-equipped to recognize the possibility of dementia or other concurrent conditions such as delirium, depression, and anxiety. They also often lack adequate programs to reduce the incidence of negative sequalae. Without adequate follow-up screening for cognitive change and accurate multi-condition diagnoses and support upon discharge, the risk of readmission is extremely high. The devastating physiological and psychological effects on caregivers is another related effect. This issue is expected to worsen as the incidence of dementia increases, unless a program to address the situation is implemented.
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> The recent pandemic and the risk of cognitive changes post-COVID, as well as the higher rate of anxiety, depression, and long periods of social isolation with minimal in-person medical support, have further exacerbated these issues. Thus, there is even more urgency in implementing a more robust program to screen for the possibility of dementia, delirium, depression, anxiety, or other complex combination conditions. The age range of possible concerns should also be addressed, with young onset forms of dementia being missed for an average of two to five years.
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> Because dementia is a unique chronic and progressive condition affecting many aspects of both body and mind, it requires a specialized approach and training structure to adequately prepare hospital teams to screen and support effectively. We strongly recommend required cognitive screening for those aged sixty-five and older, or for anyone younger than sixty-five who is experiencing cognitive or behavioral symptoms. Screening for related and often concurrent conditions of delirium, depression, and anxiety should also be mandated, using existing specific screening protocol. By doing so, the number of individuals who will receive early diagnosis, intervention, and support will be significantly increased.
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> If an individual is suspected to have a cognitive condition after admission intake screening, we strongly recommend the use of an identifier such as a uniquely coded hospital bracelet and/or door sign. Use of a code so that the identification that does not outwardly label the person is recommended. The identifiers should provide hospital health care providers with the necessary information about decision-making regarding treatments and medical interventions, and deploy the resources and support to provide effective, person-centered in-patient care. At discharge, the patient should be referred to a health provider with expertise in providing evaluation and care for people who are living with complex health conditions, for further follow-up and continued care management. Clear and concise care plans, including medication programs, should be provided and confirmed with both the person and their provider/caregivers, in both verbal and visual formats, as appropriate for the situation.
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> All hospital staff, even those that are not health care professionals, should receive basic mandatory dementia care training. This training should include methods of effectively communicating with and supporting those living with various forms of dementia, including de-escalation of situations of distress. It would be strongly recommended that all hospitals also designate individuals to serve as a consultant, coach, and trainer for the or-

EARLY VIEW

> ganization. These individuals would receive specialized skill training for these roles. This training must include hands-on rehearsals to optimize performance in real-life situations.
> Adoption of these recommendations will not only result in significantly improved care for those living with dementia and their care partners, but will also result in improved staff and patient safety and satisfaction. It is possible that lengths of stay can be reduced with better in-hospital programming and readmission rates can be decreased, resulting in a financial benefit for the hospital, as well as improved reputation."
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> —*Teepa Snow, MS, OTR/R, FAOTA*

I needed an evidence-based training program that would address the following key challenges:

1. There is a lack of awareness that symptoms of cognitive changes often actively interfere with communication between hospital personnel and the person or family seeking care.

2. Due to insufficient dementia-focused education and training, many staff in acute care settings find it challenging to support those living with cognitive changes due to differences in sensory and cognitive processing, possible extreme reactions and unexpected responses to procedures and protocols, and the need for modifications to mitigate risk and promote improved interactions and outcomes.

3. Upon noticing symptoms of cognitive changes in the hospital, there is an absence of dedicated skill training and precepted practical application of techniques to effectively evaluate, monitor, and support the individual during the stay. Also, there is a deficiency in consistently creating and following patient-centered care plans and discharge plans that optimize outcomes, minimize negative hospital events (fall-related injuries, antipsychotic use, elopement attempts, and refusals), and reduce rehospitalizations.

I reached out to three organizations: Second Wind Dreams® (SWD) Virtual Dementia Tour® (VDT®), CARES® Dementia 5-Step Method (CARES 5-Step), and Positive Approach to Care® (PAC™), which have successfully demonstrated their ability to provide effective dementia education programs. At my request, these three independently operating organizations have formed a collaborative under the name *Cognibility*. The collaborative group provides the following:

- Improved attitudes and appreciation of the experience of those living with cognitive changes in a hospital setting through a simulated experience and short discussion session (VDT).

- Essential knowledge and awareness of the shifts needed to provide support and care in hospital settings through a self-paced, online training and certification course (CARES).

- Use of newly acquired skills and strategies in the practice setting to improve communication patterns, de-escalate situations, and promote effective evaluations that reduce hospital events of concern (PAC).

5. Cognibility® Hospital Dementia Accreditation

Proposed Evidence-Based Dementia Programs Transforming Hospital Care:

5.1. Virtual Dementia Tour (Second Wind Dreams®)

The world-renowned Virtual Dementia Tour is a patented, evidence-based scientific method of building a greater understanding of neurodiversity by building awareness and empathy in individuals caring for people with dementia. The Hospital Virtual Dementia Tour is specifically designed for use with staff caring for those coming into the Emergency Department and beyond who are exhibiting confusion possibly associated with a change in mental status.

5.2. CARES® Dementia 5-Step Method for Hospitals

CARES® Dementia 5-Step Method for Hospitals™ program provides evidence-based dementia care training nursing assistants, dietary, housekeeping, transportation, lab techs, and other hospital worker. It was specifically designed with the goals of reducing costly adverse events such as delirium, falls, urinary tract infections, aspiration, pressure ulcers, elder abuse, and hospital readmissions.

5.3. In-Person Coaching to Improve Dementia Care Skills (Positive Approach to Care®)

A group of staff from each hospital would be selected to form a skilled intervention team. This team would receive in-person training in interactive skills and approaches, as well as training in the Positive Approach to Care Coaching model. This team will then be able to coach hand-on skills in real time on the hospital units, starting with one unit as its pilot site, then expanding to other units.

6. Center of Excellence Designation for US Hospitals

With the educational team created, I also needed a way to reward the hospitals that meet specific criteria and standards of care. As a center for excellence designation related to dementia did not exist, I decided to begin the process of creating it. I gathered a larger team of about forty-five experts from the fields of dementia education, hospital administration, healthcare, and the Center for Improvement in Healthcare Quality (CIHQ); and we are in the process of drafting the first Center of Excellence designation for US hospitals. Early in the process, this team identified three domains to be considered in structuring the standards:

6.1. Healthcare Staff Education and Training

This domain focuses on establishing evidence-based dementia education across all levels of hospital personnel. Training encompasses mandatory foundational instruction for non-clinical and support staff, advanced dementia-capable communication and de-escalation strategies for nursing staff, and specialized coaching models (such as CARES and Positive Approach to Care) to embed hands-on competencies directly into acute inpatient units.

6.2. Standardized Screening for Cognitive Impairment

This domain addresses routine admission intake screening to identify cognitive changes, delirium, depression, and anxiety early during hospital presentation. Utilizing validated screening protocols for patients aged sixty-five and older (or younger patients

IN REVIEW

presenting with cognitive symptoms), hospital teams can differentiate acute confusional states from progressive neurocognitive conditions and establish timely clinical safeguards.

6.3. Standards of Quality of Care During Admission

This domain outlines inpatient care standards and quality metrics designed to prevent adverse events, including fall-related injuries, inappropriate antipsychotic prescribing, catheter-associated infections, and elopement. It further establishes individualized care plans, non-stigmatizing identification systems, and coordinated discharge planning involving family care partners to prevent avoidable hospital readmissions.

This work is currently underway, and the document is expected to be completed by the end of 2026.

Competing Interests

The author has no organizational, financial, or governance role with Cognibility and featured commercial partners. Members of the DREAMM and Cognibility team do have commercial affiliations with dementia care training products.

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EARLY VIEW

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Declarations

Generative AI

No generative AI was used for analysis or results.

Funding

No external funding was declared for this work.

Competing interests

The authors declare no conflict of interest.

Data availability

Not applicable for this article.

Ethics approval

No ethics committee approval was required for this article type.

Consent

Not applicable for this article.

Trial registration

Not applicable.

EARLY VIEW