Stop that Train! I Want to Get Off: Emergency Care for Patients with Advanced Dementia
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Abstract
The prevalence of advanced dementia (AD) is expected to increase dramatically over the next few decades. Patients with AD suffer from recurrent episodic illnesses that frequently result in transfers to acute care hospitals. The default pathway followed by some emergency physicians, internists and intensivists who see those patients is to prioritize disease-directed therapies over attention to the larger picture of AD. While this strategy is desired by many families, some families prefer a different approach. This essay examines the reason why there can be a failure to focus on the over-arching issue of AD and offers suggestions for improvement. Gaps in information and physician workload are important factors, but we argue that until physicians who see patients in emergency departments learn to pause first and ask “Why are we doing this?” they will revert to their comfort zone of ordering tests and therapies that may be unwanted. A separate emergency palliative care pathway may be one solution. Shifting the focus back to the larger picture of AD and away from the physiologic disturbance of the moment may alter the trajectory of care in ways that truly respect the wishes of some patients and their families.

Résumé
On s’attend à ce que la prévalence de la démence avancée (DA) augmente de façon extrêmement importante au cours des prochaines décennies. Or, il arrive que des patients atteints de DA soient aux prises avec des maladies épisodiques récurrentes qui entraînent fréquemment un transfert dans un hôpital de soins actifs. La voie suivie par défaut par certains urgentologues, internistes et intensivistes qui reçoivent ces patients consiste à donner la priorité à l’application de traitements axés sur la maladie plutôt qu’à aborder le problème plus large de la DA. Cette stratégie satisfait bien des familles, mais certaines préfèrent une autre approche. Cet article examine pourquoi on semble vouloir éviter de s’attarder au problème récurrent de la DA et offre des suggestions d’amélioration. Des lacunes en matière d’information ainsi que la charge de travail des médecins sont sûrement des facteurs importants qui mènent à cette situation. Toutefois, nous soutenons que tant que les médecins qui voient ces patients au service des urgences ne prendront pas le temps de s’arrêter et de se questionner sur leur choix d’actions, ils se limiteront à se retirer dans leur zone de confort qui consiste à prescrire des tests et des traitements qui risquent d’être inopportuns. Une voie distincte en matière de soins palliatifs d’urgence peut s’avérer être une solution. En déplaçant l’accent mis sur les troubles physiologiques du moment pour le mettre sur le problème plus large de la DA, la trajectoire des soins pourrait être modifiée de façon à mieux respecter les désirs de certains patients et de leur famille.
An 84-year-old bed-bound man with severe Alzheimer’s dementia presents to the emergency department with pneumonia, accompanied by his 3 daughters. He has been hospitalized 4 times in the past 2 years for antibiotic-associated *Clostridium difficile* diarrhea. Antibiotics and intravenous fluids were started by the first physicians who saw him. An internist was consulted to take over his care.

In 2016, 564,000 Canadians were living with dementia. Each year 25,000 new cases of dementia are diagnosed, and it is expected that by 2030 there will be close to 1 million Canadians who have dementia.\(^1\) People with advanced dementia (AD) suffer with cognitive deficits and are unable to communicate, ambulate and have incontinence. They are at high risk for imminent death,\(^2\)\(^3\) an under-recognized fact even among health care professionals.\(^4\)

In contrast to patients with terminal cancer and end stage heart disease, most patients with AD do not die from devastating acute events (like bowel obstruction, or heart failure) that result from the progression of their primary disease. Instead, they die from recurrent episodic illnesses that can be treated with relatively simple therapeutic responses (like intravenous fluids or antibiotics).\(^5\) These include pneumonias, urinary tract and skin infections, influenza, problems with eating (including aspiration) and dehydration. It is not surprising that in the United States 19% of nursing home residents with cognitive impairment experience at least one transfer to a hospital in the last 120 days of life.\(^6\)

When these patients arrive in the emergency department (ED), the default pathway is to prioritize disease-directed therapies (e.g., intravenous fluid and antibiotics) over attention to the larger picture of AD. The physiologic disturbances receive intense focus and the AD is seemingly forgotten. These patients often suffer from treatable symptoms, including pain and shortness of breath.\(^3\) In some (but not all) cases, patients may receive care they don’t really want, families may be afraid to express their true wishes, and health care professionals may deliver care they suspect is unnecessary, or even harmful. This essay examines the reasons why this phenomenon occurs and offers suggestions for improvement by encouraging acute care clinicians to pause and ask themselves, “Why are we doing this?” and by engaging family members in focused goals of care discussions that include outcomes of aggressive disease-directed treatments and palliative approaches.

There are many reasons why the physicians who treat these patients in acute care hospitals (primarily emergency physicians, internists/hospitalists and intensivists) prioritize life-sustaining therapies over relief of burdensome symptoms as the default strategy. Information gaps affect the process of care. These physicians likely assume that a transfer to an acute care facility indicates the (sometimes mistaken) desire for life-sustaining interventions by the patient’s relatives. Transfer decisions are a human endeavour, and thus are subject to error\(^6\) especially when personnel worry about blame. While nearly half of all transfers from nursing homes to the ED are for cardiovascular and respiratory problems,\(^7\) key factors influencing decisions to transfer as reported by family physicians include medico-legal concerns, family pressure, the capability of nursing home staff and the physician’s workload.\(^8\)

Even in Ontario, where nursing home residents are legally required to have annually updated instructions about whether transfer to acute care hospitals is indicated, the process only works as well as the nature of the counselling and discussion (which is often perfunctory) that takes place before the patients or their legal substitutes sign that document. In the United States, it is unclear how and whether the rapid uptake of Physician Orders for Life-Sustaining Treatment in nursing homes has affected end-of-life care in AD.\(^3\) From an economic and medico-legal perspective, there is no incentive for nursing homes or their staff to manage the acutely ill nursing home patient themselves, and every incentive to transfer care to an ED even when “no transfer” instructions are clearly recorded. The physician who meets the patient for the first time in the ED often lacks familiarity with the patient’s clinical course and his or her family, which coupled with a lack of communication training for these circumstances, inhibits addressing goals of care directly.\(^10\)

Physician workload is also an important factor. In a busy ED, an empathetic conversation that elucidates patients’ goals of care, educates families about the outcomes of care\(^11\) and offers the option of prioritizing attention to symptoms takes time and requires a higher cognitive load than ordering tests, intravenous fluids and antibiotics. In addition, the process of acute care, once initiated, may be a contributing factor. Family members see that life-prolonging therapies can be given, making it more difficult for them to decide to forgo disease-directed therapies once started without being overwhelmed by a sense of guilt. Finally, precise prognostication in a patient with AD is fraught with hazards.\(^12\) All of these factors play a role, but overall, until the physicians who see patients in the ED acquire the expertise to routinely address goals of care, and experience the rewards and sense of professional fulfillment that can be derived from sparing patients unwanted invasive care, the opportunity to prioritize comfort may not be offered. Those physicians will revert to their comfort zone of checking the electrolytes, obtaining a chest x-ray and urine culture which then results in a discussion that starts by asking families questions like, “Do you want us to treat the
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hypernatremia?” When phrased that way, few family members (even those who are physicians) are prepared to say “No.”

While assessing goals of care for patients with AD may currently be viewed as impractical in the busy ED, perhaps the right models have not been proposed. Complexity has not deterred the rapid response in EDs for patients with acute strokes and ST-elevation myocardial infarctions. One solution may be to develop a separate “emergency palliative care pathway” where the primary task is prioritizing relief of burdensome symptoms and eliciting true preferences.13 thus avoiding stressful lengthy stays in the chaotic ED where patients with AD are often of low priority. Interventions aimed upstream from the ED may include increasing resources for training of nursing home staff along with the provision of decision aids to assist caregivers in the clarification of goals of care prior to transfer to the ED.14

Some patients with AD and their families may prefer prioritizing comfort above all else but may not be offered the chance to make that choice. In a survey of elderly hospitalized Canadians, 70% reported wanting to focus on providing comfort rather than life-prolonging treatment, yet 54% of these patients are admitted to intensive care units at the end of life.15 Even if this circumstance occurs in a minority of the dementia patients who are sent to EDs, the substantial rise in the number of people with dementia means that it will occur much more commonly in the future. In these cases, emergency physicians and the consultants that they approach for help can play a critical role if they push the pause button before beginning empiric disease-directed therapies, and simply ask patients’ families, “What is your understanding of your loved one’s prognosis?” and, “What are you hoping for?” On the one hand, these conversations take time. On the other, they can be efficient, focus on these simple questions, and describe outcomes of care including potential discomforts associated with treatments. By shifting the focus back to the larger picture of AD and away from the physiologic disturbance of the moment, they may alter the trajectory of care, ultimately reducing the burden to patients and their families. We can facilitate patients’ wishes and honour the truly vital role that family members play as members of the health care team.

Competing Interests
None declared

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References