



COMMENTARY

Left Out in the Cold: Dementia Care Partners during COVID-19

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Abstract

The coronavirus disease 2019 has led to a reduction in hospital services across the globe in an attempt to manage existing and potential new cases of COVID-19. While Northern Ontario, Canada has not seen the influx in cases it had expected, many hospitals changed their visitor policies to limit or stop visitors from entering hospitals during this time period. Currently, many visitor policies in northern hospitals permit “essential care partners” for pediatric patients, laboring patients, palliative care patients or surgical patients. Left off the list, however, are the care partners for patients with dementia. Caregivers of dementia patients provide extensive services to their loved ones on a daily basis, including assistance for activities of daily living or instrumental activities of daily living, as well as offering emotional or psychological support. Many dementia patients are dependent on their caregivers to interpret cues and gestures, which may go unnoticed or unappreciated by busy hospital staff. While patients with dementia are at higher risk of becoming COVID-19 positive, the risks of isolation and worsening cognitive status must not be overlooked in an effort to provide an infection free hospital zone. The forcible separation of a patient with dementia from their primary caregiver has no added benefits and instead, may result in worsening behavioral or psychological symptoms. As hospitals begin to resume regular activities, it is highly recommended that visitor policies be revised to include caregivers of dementia patients on the list of “essential” or “designated” care partners.

Keywords

Dementia, Caregivers, Essential care partners, Visitor policies, Coronavirus, COVID-19

Introduction

Recent regional reopening in Ontario, Canada has meant a return to “a new normal” for some citizens during the COVID-19 pandemic. Hospitals have started rebooking elective surgeries, diagnostic imaging departments are increasing their testing capacity and non-clin-

ical staffs have begun to return to work [1]. In many hospitals, however, loved ones of patients can only visit if designated as an “essential care partner”. Most often, these policies only recognize the value of partners for patients in labor, pediatric patients, or palliative care patients [2]. Partners of dementia patients are simply left outside in the cold, even when they provide daily personal care and emotional support to the patient.

Picture this case scenario. Mr. X is a 72-year-old male with dementia presenting to the Emergency Department with concerns of increased confusion and agitation. Baseline behaviors have increased and his wife is worried about safely managing him in the home environment. His oral intake has been poor recently, leading to significant constipation even with the use of daily laxatives. He has severe dementia and is limited in his ability to communicate, as well as perform his activities of daily life. Once a report has been given to the triage nurse, his wife is asked to leave. The nurse explains that a COVID-19 visitor policy is in place for the protection of all patients and staff. Unfortunately, his wife simply does not meet the parameters of a designated care partner. With much reluctance, his wife leaves the department. Within a few hours, Mr. X becomes increasingly disoriented and anxious, shouting for his wife. He continually attempts to pull out his IV line, set up to deliver much needed hydration. Eventually, soft wrist restraints are ordered after his IV has been restarted twice by nurses. Mr. X is admitted to the medical floor for treatment of his delirium, although nurses share with his wife that his stay is “rough”. Daily phone calls do not make a difference for Mr. X, as he is no longer capable of carrying out conversation over the phone. The essential component which would likely have made a difference in this scenar-

is the physical presence of Mr. X's wife at the bedside.

Visitor Policies in Northern Ontario Hospitals

Northern Ontario has a population of 800,000 and encompasses 80% of the land mass in Ontario [3]. Very small communities may rely on nursing stations or locums to deliver physician and/or nursing services. Other rural communities often require patients to travel to larger urban centers to access specialist services or treatments not available locally, such as dialysis, oncology services or cardiac catheterization. Long term care beds may not be available in the community when needed, leaving families to make the difficult choice of continuing on at home with non-existent or limited homecare services or transferring their family member to a large facility in a different city entirely.

According to the Ministry of Health and Long-Term Care there are 35 health centers or hospitals in Northern Ontario [4]. Prior to the COVID-19 pandemic, many of these hospitals offered expansive visitor policies and welcomed friends and family alike. Visiting hours typically occurred during daytime or evening hours, with "quiet" hours identified in various policies [5,6]. Some hospitals differentiated between "visitors" and "care partners" [7]. Since care partners provided some level of physical, emotional or psychological support to the patient, traditional visiting hours did not apply and these individuals were welcomed at the hospital any time of day or night.

Given that hospitalized patients are at higher risk of contracting COVID-19 due to comorbid conditions, immunocompromised status or shared facilities (whether multi bed patient rooms or multi use bathrooms), many existing visitor policies came to an abrupt halt in the spring of 2020 as cases in Ontario began to rise. This has led to the separation of families for months at a time, which can be detrimental to the health and well-being of an individual with dementia [8]. Familiar faces, objects and places often serve in grounding a patient with dementia and a forced separation is likely to lead to worsening cognitive function over time. Additionally for some older couples, it may be the first period of extended time spent apart in a marriage, leaving the patient to feel abandoned by their partner.

In June 2020, an online survey was completed of current visitor policies for a select number of hospitals in Northern Ontario. While one hospital had a strict "no visitor" policy in place [9], the majority of sites limited essential or designated care partners to: patients in active labor, pediatric patients, critically ill patients, palliative care patients or surgical patients (emergent surgery, day surgery or admitted surgical patients) [10-15,2]. Only one hospital had recently changed their visitor policy to permit a dedicated care partner for all inpatients, although visitors were still prohibited from certain areas such as the emergency department and outpatient clinics [16].

Role of Caregivers

Typically, the role of caregiver is fulfilled by the female spouse [17]. While most caregivers are over the age of 65, there are a significant number of women who also care for their own families and children, known as "sandwich generation" caregivers [17]. Caregiving may encompass numerous duties, with more time required each day as the patient's dementia increases in severity. The average number of care hours provided on a daily basis ranges from 3 to 11 hours [18]. Caregivers may assist an individual with their activities of daily life (i.e., bathing, dressing, feeding) or instrumental activities of daily living (i.e., paying bills, food preparation, housekeeping or transportation). Additionally, a caregiver is often relied upon to provide emotional, psychological or spiritual support to their partner with dementia. Some caregivers may be contending with their own health problems which are often left by the wayside when dealing with the 24/7 nature of caring for an individual with moderate to severe dementia.

As the disease progresses, many caregivers may find themselves struggling to cope with distressing symptoms, such as manifested by the behavioral and psychological symptoms of dementia (BPSD). These symptoms are varied and may include anxiety, agitation, delusions, hallucinations, hypersexuality or episodes of verbal or physical aggression [19]. The presence of BPSD symptoms can negatively impact both the patient's and caregiver's quality of life, with more severe psychiatric symptoms leading to poor mental health on the part of the caregiver [20]. Complications of untreated BPSD include a decline in cognition, falls, fractures and higher rates of emergency department visits or hospitalizations [19]. While antipsychotics are part of the treatment regimen in the management of such symptoms, it is the caregiver who provides many of the non-pharmacologic interventions. This may include intercessions such as de-escalation techniques (deep breathing or other calming methods); offering distractions; providing the patient with beloved objects, fidget toys or blankets; assisting with simple chores around the house or listening to a favorite song. These activities can be invaluable in assisting an agitated patient to return to their baseline status.

Caregivers as Essential Care Partners

While many adult patients who are admitted to the hospital during the era of COVID-19 are able to cope without the presence of their partner, it is unlikely that the majority of patients with dementia will be able to do so. Chronic issues with short staffing in long term care homes and hospitals alike may mean that the minimal amount of care is provided to a patient with dementia, rather than focusing on what may be best for the patient. As discussed previously, the number of care hours provided by a caregiver can be equivalent to a full-time job. Since hospitals are simply not set up to provide de-

mentia patients with private nurses, value must instead be placed on the essential role of the caregiver. Some patients with moderate to severe dementia rely heavily on verbal or non-verbal cues or gestures which can be unfamiliar to hospital staff, leaving the patient to suffer in silence. Given the vast amount of time spent together, caregivers may also be the first to recognize initial changes in their loved ones which could herald the onset of a delirium. The majority of existing hospital visitor policies make allowances for parents and children, yet do not recognize the caregiving bond which exists between a patient with dementia and their caregiving partner.

Conclusion

Consider again the clinical scenario introduced earlier. Instead of being asked to leave, Mrs. X meets the criteria of essential care partner for an individual with dementia and has full visiting access, regardless of the time of day or night. She is aware only one designated care partner can be at the bedside, although another family member may replace her should she require a break. Mrs. X is also aware she will be screened for COVID-19 symptoms every time she enters the hospital. In addition, she will be asked to wear a mask while on hospital premises and perform routine hand hygiene. During his IV start, Mr. X demonstrates some agitation but settles after the procedure is complete. While he tends to pick at the site from time to time, his wife redirects him with little effort and his IV does not require numerous restarts. Restraints are no longer needed. Later, Mrs. X brings in her husband's glasses, hearing aids, several family photos and his favorite blanket, all of which serve to help orient Mr. X to his new surroundings. Although he does become anxious a few times during his hospital stay, Mrs. X is present for those moments and is able to assist Mr. X in deescalating to his normal baseline. Overall, Mrs. X is pleased with the care provided to her husband and he is discharged home a few days later.

During the COVID-19 pandemic, it may be felt that limiting the number of visitors will provide patients and staff with a safer hospital environment. Should an outbreak occur, the infection can be more easily contained if only "essential workers" are allowed into certain areas. Yet the argument must be made that caregivers of dementia patients are just as essential as other designated care partners, such as those individuals allowed to visit children, patients in labor or palliative care patients. Caregivers for patients with dementia not only spend a significant number of hours meeting daily physical needs but also provide emotional and psychological support, as in the case of Mrs. X. While patients with dementia are at higher risk of obtaining COVID-19, that risk must be managed similarly to the ongoing risks which may result from other designated care partners visiting their loved ones in hospital. It is no longer acceptable to leave dementia caregivers off the list of "essential care partners" and hospitals must

carefully look at their rationale to do so when adopting their COVID-19 visitor policies. We have not yet won the fight against COVID-19 and patients with dementia should not be inadvertent casualties of this war.

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Conflicts of Interest

The author declares no conflicts of interest exist.

References

1. Walters J (2020) Surgeries to resume this week at Thunder Bay Regional Health Sciences Centre.
2. Thunder Bay Regional Health Sciences Centre (2020) Thunder Bay Regional Health Sciences Centre implements further visitor restrictions in response to the COVID-19 pandemic.
3. Health Quality Ontario (2017) Health in the north: A report on geography and the health of people in Ontario's two northern regions. Toronto, Canada: Queen's Printer for Ontario.
4. Ministry of Health and Long-Term Care (2013) Hospital locations and classifications by LHINs.
5. Dryden Regional Health Centre (2020) Visiting the hospital.
6. Services De Santé De Chapleau Health Services (2018) Visitor information.
7. Thunder Bay Regional Health Sciences Centre (n.d) Visiting Hours.
8. Paris F (2020) COVID-19 takes heavy toll on people with dementia - Even those who survive.
9. Manitouwadge General Hospital (2020) Welcome.
10. Health Sciences North (2020) Visitor information.
11. Lake of the Woods District Hospital (2020) Guideline for visitor restrictions during COVID-19 pandemic.
12. Nipigon District Memorial Hospital (2020) What is COVID-19.
13. Riverside Health Care (2020) Coronavirus (COVID-19): What you need to know.
14. Sault Area Hospital (2020) Coronavirus COVID-19.
15. Sioux Lookout Meno Ya Win Health Centre (2020) Update on COVID-19 in region and SLMHC.
16. North Bay Regional Health Centre (2020) COVID-19 (Coronavirus).
17. Centers for Disease Control and Prevention (2019) Caregiving for a person with Alzheimer's Disease or a related dementia.
18. Brodaty H, Donkin M (2009) Family caregivers of people with dementia. *Dialogues Clin Neurosci* 11: 217-228.
19. Tible OP, Riese F, Savaskan E, Von Guten A (2017) Best practice in the management of behavioral and psychological symptoms of dementia. *Ther Adv Neurol Disord* 10: 297-309.
20. Thomas P, Lalloué F, Preux P, Hazif-Thomas C, Pariel S, et al. (2006) Dementia patients caregivers quality of life: The PIXEL study. *Int J Geriatr Psychiatry* 21: 50-56.