

Investigation Summary

Resident Experience of Palliative Care in Long-term Care Home

This investigation summary allows Patient Ombudsman to publicly share the outcome of a formal investigation to raise awareness of important issues and specific circumstances negatively impacting health care experiences in Ontario. More importantly, the resulting recommendations are intended to be a catalyst for systemic change and improvement.

Patient Ombudsman has decided not to share identifying information so that the focus remains on the complaint, the issues, and the resulting recommendations. Only those individuals and organizations directly involved with the investigation were provided with the full investigation report. Patient Ombudsman continues to follow-up with the health sector organization on its efforts to implement these recommendations.

Complaint

An elderly person living with dementia and other comorbidities in a long-term care home experienced a sudden change in health status due to a COVID-19 infection. The home's staff was requesting the power of attorney's (POA) consent to transfer the resident to the local emergency department as the resident was having extreme difficulty breathing and the home had maximized the dosage of the available supplementary oxygen in the home. The resident's three children in their role as POAs had agreed earlier in the year to the resident no longer being sent to the hospital and the home providing comfort care measures only. One of the POAs ultimately consented to transfer the resident to the local emergency department as they did not want the resident to continue "gasping for air." A different POA submitted a formal complaint to Patient Ombudsman upset that the home did not adhere to their wishes for comfort care, despite being told at the time the home discussed the transfer that the interventions required by the resident could not be initiated in a long-term care home.

Investigation

Patient Ombudsman investigated the resident and family's experience with the home in its provision of palliative care. The focus of the investigation was:

- How were the resident's end-of-life wishes received, communicated, and supported in the long-term care home?
- What factors led to the resident being admitted to hospital contrary to the substitute decision-maker's expectations and understanding of the end-of-life care plan?

Patient Ombudsman interviewed 18 witnesses, including the POAs, representatives from the home's management team, frontline nurses, physicians and members of the wider interdisciplinary team at the

long-term care home. We also interviewed clinicians from the local hospital who were involved in the care the resident received after the transfer.

Patient Ombudsman reviewed more than 3,300 pages of documentation received from the long-term care home and the hospital. The documents included the excerpts of medical records from all hospital admissions in the last year of life; the long-term care home's electronic medical record for the resident; all progress notes entered by the home's interdisciplinary team for the resident; copies of the resident's care plan; the home's policies and procedures related to palliative care; the home's statistics on transfers to hospital by month; and complaint data for the last five years.

Patient Ombudsman wishes to thank all the witnesses, including the family, frontline staff, organizational leaders, clinicians from the long-term care home and the local hospital, including subject matter experts in palliative care. All these individuals contributed to our understanding of the long-term care home's processes and procedures, what occurred in this case, and the system challenges with providing high-quality palliative care regardless of setting.

Findings

Patient Ombudsman found the following:

Identification and assessment of needs

- Palliative care is not discussed with every resident upon admission to the home.
- The delivery of palliative care is inconsistent with the long-term care home's Palliative Care Program policy.
- The delivery of palliative care is inconsistent with the education on palliative care that was provided to staff in the home.

Goals of care discussions and consent

- There is variation in documentation practices to capture goals of care conversations.
- Care conferences did not consistently facilitate goals of care conversations.
- The home has good practices to build on to help the health care team consistently understand a resident's values and provide care in alignment with these values.

Education for people with a serious illness, substitute decision-makers, families, and care partners

- Information about illness progression provided to POAs was insufficient.
- Information about palliative care is only provided to POAs verbally in care conferences.
- Family members did not fully understand palliative care and the family's adherence to comfort care measures wavered.

Interprofessional team-based care

- The home did not use internal or external palliative care expertise available to them in this case.
- Communication between the home and the hospital clinicians was not effective in promoting continuity in care decisions.

Conclusions

In this case, a Level of Care form with four distinct categories of care was presented on the day of admission as part of a checklist approach to the home's admission process. One of the resident's children in the role as the POA for personal care for their parent selected "level 4," which directs the home to perform CPR and send the resident to acute care for treatment as needed. These expectations remained in place for seven years even as the resident's illnesses and care needs changed. Despite the form no longer being in use at the home, the language and process to review goals of care at the annual care conference continued to mimic the expectations that were previously selected on the Level of Care form such as code status and if acute care interventions were still wanted.

An unintended consequence of relying on this categorization may be a bias against doing a more comprehensive palliative care assessment and an underutilization of palliative care approaches in the home. Based on the evidence, a broader exploration of wishes with respect to resident goals, values and wishes did not take place in this case. Changes to the wishes were only triggered in reaction to an acute care admission as the resident's health deteriorated.

The resident may have benefited from a holistic approach much earlier in their disease progression. Because of the resident's rapid decline in health due to COVID-19, the home's stepwise progression in its provision of palliative care did not proceed to the third and final component. As a result, the home's resources devoted to palliative care at end-of-life do not appear to have been available to the resident (e.g., palliative sedation).

In the end, this resident was sent to the hospital for acute care treatment as the family was not confident in the home's ability to keep their parent comfortable as they entered the final phase of their life. This transfer could have been avoided if the family better understood the palliative care services and supports available to them and if the goals of care conversation on that day was better facilitated.

Recommendations

Patient Ombudsman makes the following six recommendations to the home:

Policies and Procedures

1. Patient Ombudsman recommends that the home develop supporting materials to supplement the existing policies on palliative care to reflect the procedures followed by staff in the home (e.g., activating the Expected Death in the Home (EDITH) protocol when a resident is considered end-of-life).

Care Conference Conversations

2. Patient Ombudsman recommends that the home initiate a conversation about palliative care with every resident and their substitute decision-makers in the initial care conference regardless of their existing status. The conversation should explore the resident's values, wishes and fears associated with living with their serious illness. This conversation can also integrate education about a person's illness progression and how the home's palliative care program can support all of the resident's needs along the way.

3. Patient Ombudsman recommends that all care conferences, including the annual care conference, revisit goals of care conversations to update care wishes. The documentation should have sufficient

detail that captures what was discussed and what was decided. Summaries of care conferences should be shared proactively with residents or their substitute decision-makers and caregivers, as appropriate, to ensure everyone is aware of what was discussed regardless of who was in attendance.

Education

4. Patient Ombudsman recommends that education/training be offered to staff responsible for facilitating goals of care conversations, which provides opportunities for participants to practice having these conversations especially in moments of emotional intensity, such as during an emergent change in health status. In addition to “classroom” training, the home could explore opportunities for staff to observe or shadow more experienced palliative care clinicians, for example, those working in the nurse-led outreach team, the hospital’s palliative care department, or with the home’s physicians.

5. Patient Ombudsman recommends that the home use a variety of modalities to educate residents, caregivers and substitute decision-makers on palliative care and the various components of palliative care that are available in the home. This education should be in addition to what is discussed during care conferences.

Interprofessional Team Collaboration

6. Patient Ombudsman recommends the home meets with local hospitals to formally discuss and review cases of emergency department transfers that may be avoided to identify and test interventions that could improve communication, clinical treatment collaboration, or continuity of palliative care conversations from one setting to another.