December 2019

EPAC Final Report

ICCER Team

iccer
INSTITUTE FOR CONTINUING CARE EDUCATION & RESEARCH

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Acknowledgements

Funding

The ICCER Team would like to thank the Canadian Foundation for Healthcare Improvement for providing the seed funding for this quality improvement project.

Canadian Foundation for Healthcare Improvement

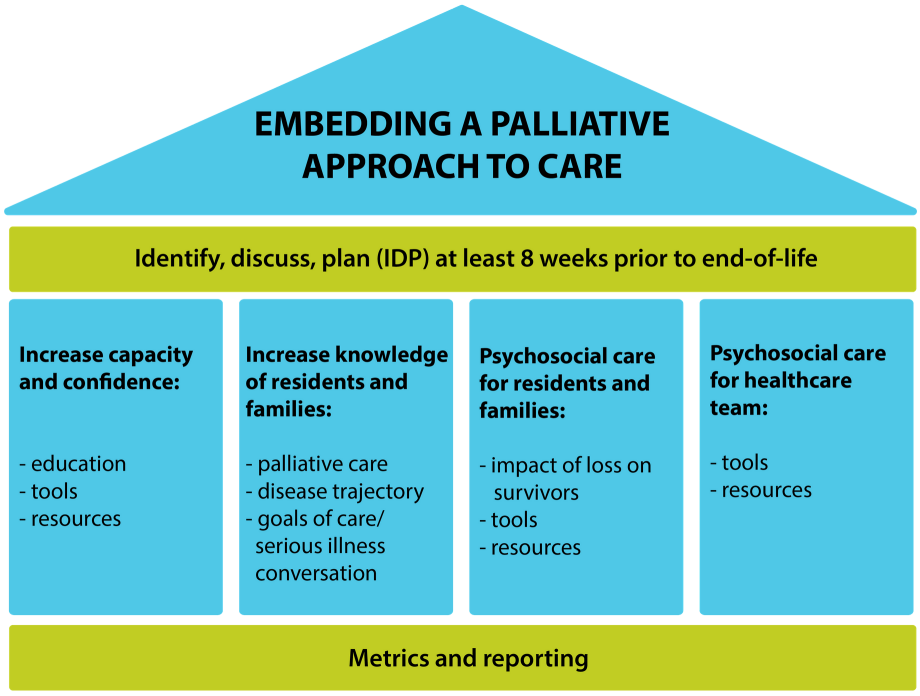
Fondation canadienne pour l'amélioration des services de santé

Participating Sites

- Bethany Airdrie
- Lifestyle Options Leduc
- Lifestyle Options Riverbend
- Lifestyle Options Terra Losa
- Lifestyle Options Whitemud
- St. Michael's Long Term Care Centre
- Wing Kei Crescent Heights
- Wing Kei Greenview Supportive Living
- Wing Kei Greenview Long Term Care

Embedding a Palliative Approach to Care

Embedding a Palliative Approach to Care (EPAC) was originally developed by Vancouver Coastal Health. The model of care is intended to improve the end-of-life (EOL) experience for residents in care, as well as for their family, surviving residents and healthcare staff. As represented in the figure below, EPAC has four pillars. It includes identifying residents who would benefit from palliative care, initiating early goals of care (GOC) discussions between residents, families and staff, and ensuring a personalized plan of care is in place for EOL. EPAC encourages a culture of care where death and dying is normalized and can be openly discussed and supported.



The Canadian Foundation for Healthcare Improvement (CFHI) initiated a spread collaborative to support healthcare teams to improve palliative and EOL care across the country using the evidence-based approach.

03 The objectives of the EPAC spread collaborative were to:

- Improve care staff's ability to have effective, timely GOC discussions with residents and their families/decision makers
- Improve the experience of EOL for residents, families, and care staff
- Reduce unnecessary transfers to acute care
- Improve capacity to provide EOL care in the location of the resident's choice
- Build quality improvement capacity in long-term care (and supportive living)

The Project

The ICCER team was one of seven teams selected by CFHI to participate in the EPAC spread collaborative. CFHI provided seed funding, as well as EPAC education and resources via an online desktop, informational webinars, networking opportunities and access to expert coaches.

Each site tracked a number of measures on a monthly basis:

- Percent and number of residents with documented GOC discussions
- Percent and number of residents with documented GOC discussions within 8 weeks of admission
- Length of resident stay (admission to death)
- Number of emergency department visits in the last 3 months of life
- Percent and number of residents who die in acute care

Scope of Project

The project included four ICCER member organizations with a total of nine sites. The sites represented both long-term care (LTC) and supportive living (SL). All were located in Alberta. ICCER's Program Coordinator, Emily Dymchuk, acted as Team Lead.

Organization	Site	Location	Level of care
Bethany Care Society	Bethany Airdrie	Airdrie, AB	Long-term care
Lifestyle Options Retirement Communities	Lifestyle Options Leduc	Leduc, AB	Supportive living
	Lifestyle Options Riverbend	Edmonton, AB	Supportive living
	Lifestyle Options Terra Losa	Edmonton, AB	Supportive living
	Lifestyle Options Whitemud	Edmonton, AB	Supportive living
St. Michael's Health Group	St. Michael's Long Term Care Centre	Edmonton, AB	Long-term care
Wing Kei	Crescent Heights	Calgary, AB	Long-term care
	Greenview	Calgary, AB	Long-term care and supportive living

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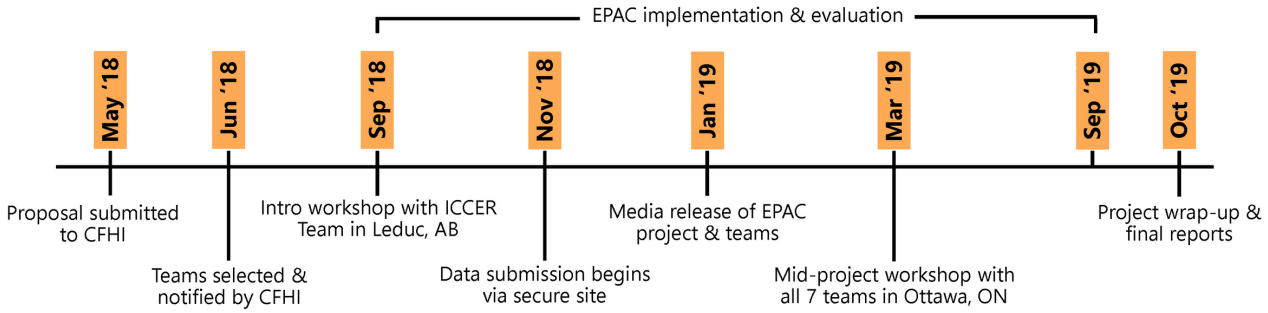
Timeline of Key Activities



Workshops

Sites identified EPAC leads among their staff to attend a two-day workshop in September 2018. This provided an opportunity for teams to meet their coaches, Jane Webley and Cynthia Sinclair, as well as CFHI team members Elan Graves and Diana Sarakbi. Staff were educated on EPAC as well as how to engage interprofessional teams, manage culture change, and engage stakeholders at their sites. Participants were also given opportunities to practice their new knowledge and skills and discuss implementation plans for their sites. Site champions were then given the freedom to implement the principles of EPAC how they felt would be most successful at their sites and best meet the needs of their residents.

A second workshop was held in March 2019. Members of the ICCER Team attended in Ottawa along with representatives from the other six teams across Canada. Each team presented their work on the project to date, and had the opportunity to learn from and share ideas with one another. Data on the progress made by all EPAC teams was also shared by CFHI as were additional learnings from the EPAC coaches.

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Coaching Calls

Teams had the opportunity to speak with their coaches throughout the project. Coaching calls provided a check-in for teams, as well as allowed sites to ask Jane and Cynthia specific questions if needed.

Webinars

A total of 11 webinars were held as part of the EPAC project. The first was an informational webinar regarding the intent of the project and how teams could apply to participate. Webinars were held to support implementation and provide information on topics requested by teams, including spirituality, engaging residents and families, supporting the care team, implementing culture change, change management, shared decision making, and medication management. A final all-teams webinar was held in September 2019. Each of the seven teams presented on their project results, resident, family and staff engagement and experience, success factors and challenges, as well as inspiring EPAC memories. All webinars were recorded and could be accessed by teams via the CFHI desktop.

Desktop

Teams were given access to a secure CFHI Desktop. The desktop provided a space to access workshop presentations or webinars, as well as any relevant resources and information on palliative and EOL care. Each organization was also given a login to a secure space to submit their monthly data for the project.

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Education

Each organization implemented education and training on EPAC in their own way. Some chose to make education mandatory, while others offered in-services as well as online modules for staff to complete when time allows. Often education was split into different topics and modified for different roles on the care team. While most sites addressed all four pillars of the EPAC model, culture change is ongoing. Those who had yet to address certain pillars at the end of the project period have plans to continue implementation.

All sites began initiating palliative care conversations from the time of resident admission, and in some cases, pre-admission. Conversations about GOC were also extended to those living in private SL settings. Training and practice of how to introduce and discuss palliative and EOL care and GOC with residents and families was provided to staff, and in some cases a conversation guide was given to staff to increase their confidence and comfort in having these discussions. Some sites also created a worksheet to be completed with residents and families to explore and document their goals and wishes for living and for dying.

Most sites did surveys with staff, and some with families, regarding their learning needs and education preferences. The majority of respondents indicated the need for education on what palliative and EOL care is and what it entails, as well as how to have effective conversations with residents and families. Sites used this information to shape staff education and training and information sharing with families. Some sites also held education sessions for residents and families on GOC and palliative and EOL care.

Brochures have been created by staff to provide more information to residents and families. Some sites have also started EPAC information boards in common areas. Checklists and policies have also been revised as a result of organizations' involvement in EPAC.

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Psychosocial Support

Many sites have created a memorial space and other processes to improve the emotional and spiritual support for all stakeholders. Spaces have been established in common areas to notify those in the home when a resident has died. They include a photo of the resident, as well as a flower and/or candle. The daisy is a symbol for EPAC and many organizations have created a paper daisy for staff to sign and share their well wishes with families after a resident has passed.

Most sites offer comfort carts to families at the bedside when a resident is at EOL. It has refreshments, as well as resources, magazines, and a music player. One site has a palliative care room on site to allow family members to stay with a resident at EOL, while another offers a special chair to family members that can be brought into the resident's room to sleep in.

Honour guards have been implemented at a few sites to acknowledge a resident's death. When a resident dies, those in the home (staff, residents, families) are invited to be part of the procession as the body leaves the building. To show respect for the individual, the resident is exited out the front door of the building, the same way they first came in.

Some organizations hold memorials for their residents annually or throughout the year as an opportunity for staff, surviving residents and family members to reconnect and remember those who've passed.

Facilitators & Barriers

Common factors that led to the success of EPAC across the four organizations were support from senior management/leadership, the ability to build on existing care practices and knowledge, and stakeholder engagement. The endorsement by those in leadership roles within each organization was necessary for project engagement and ongoing culture change. Having strong EPAC champions identified at each of the sites facilitated change through education and development of tools and resources. Many of the sites had some sort of palliative program in place, or had plans to implement one, before participating in the EPAC project. Being part of the project helped facilitate the improvement and implementation of even better policies and procedures, and ultimately resident care. Having engaged staff, as well as residents and families involved was key to the success of EPAC and will be necessary for continued practice change.

In terms of challenges, time is always an issue for staff. As many staff work in part-time roles, or on different shifts, opportunities for staff meetings and education are limited. One of the organizations experienced significant staff and leadership changes during the project period. This slowed the implementation process and impacted widespread culture change.

Some of the organizations were involved in several research and quality improvement projects at the same time as EPAC. This created a heavier workload for staff. Organizations also went through accreditation, audits, and the opening of new sites over the project period, all of which used resources and time.

Differences in cultural beliefs and values around death and dying need to be considered. Many organizations are faith-based or represent a culture or nationality. For example, Wing Kei is a Chinese, Christian-based organization. They had to consider unique values and traditions around death and dying

while implementing EPAC. While not a barrier to implementation, cultural differences require some adaptation to the model and perhaps some additional creativity in reaching the goals of EPAC.

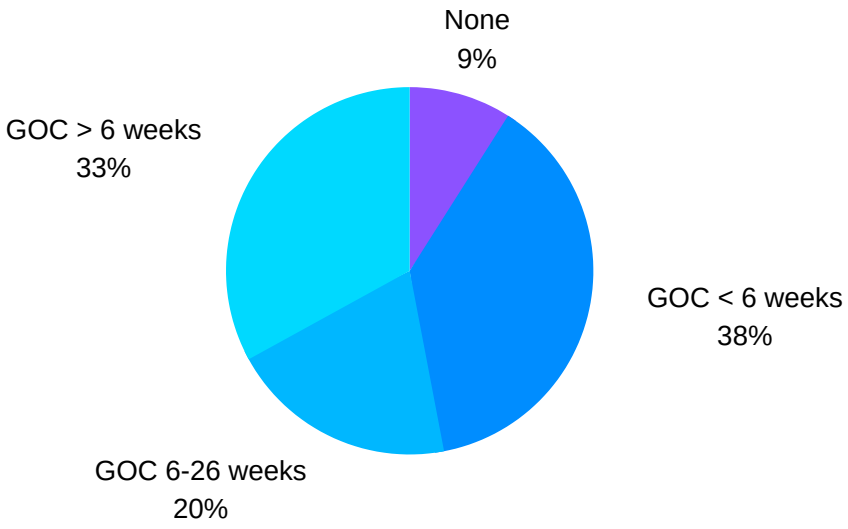
The SL sites involved in the project faced unique barriers when compared to LTC. As the residents in SL do not have the same care needs as those in LTC, some staff had less experience providing palliative and EOL care. To help SL staff in providing higher levels of care to residents, some sites strengthened their connections with external resources such as the Edmonton Zone Palliative Team and Treat and Refer program. The palliative care team helps to assess resident needs and inform the staff of necessary care practices. Unfortunately the current continuing care system does not support residents to age-in-place in SL settings and often residents are transferred from SL to LTC as they become more dependent. Further culture change is needed to support residents to age and die in their location of choice.

Outcomes

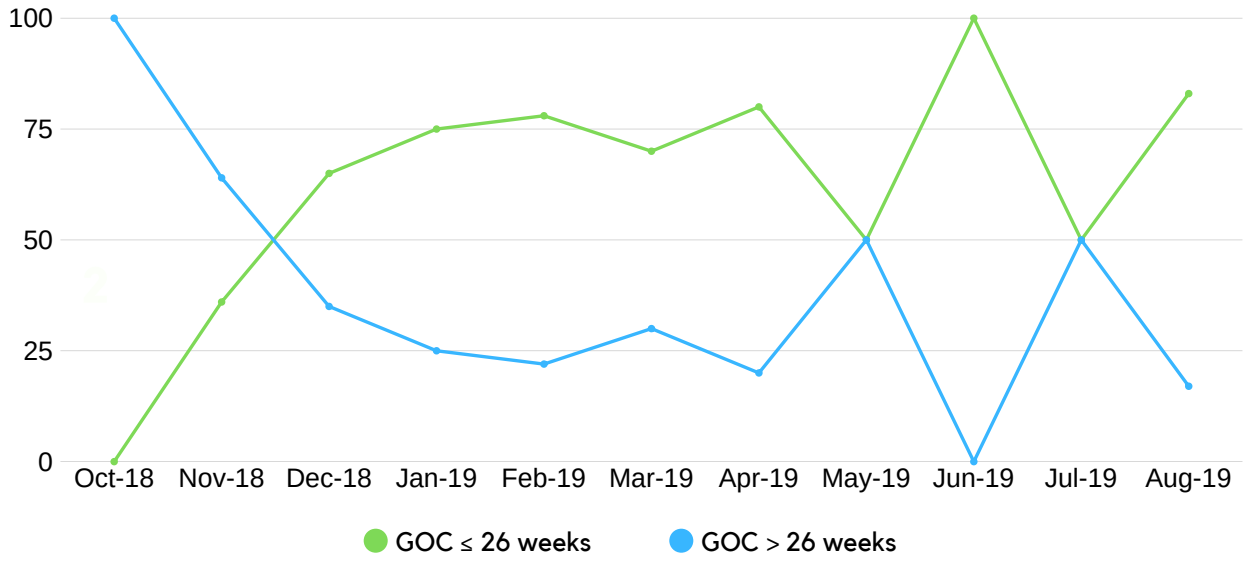
Data has been summarized based on the measures submitted by each site from October 2018 to September 2019. There were 109 reported resident deaths during the project period. Most deaths (92%) had GOC in place, but the timing varied with the highest percentage (38%) for GOC at less than six weeks before death. There was an improvement between October 2018 and August 2019, where a gradual decrease in noted in percentage of monthly resident deaths with GOC greater than 26 weeks. The majority of resident deaths (72%) occurred in the care home rather than in hospital. There was a gradual decrease in the percentage of resident deaths in hospital since June 2019. The majority (72%) of residents who died had no emergency department visits in the last three months of life. There was minimal variation between the months of October 2018 and September 2019. The majority of resident deaths (77%) had no hospital transfers in the last three months of life with some monthly variation during the project period.

EPAC measures	Org 1	Org 2	Org 3	Org 4	All sites
# Reported deaths	21	21	37	30	109
Average LOS (in years)	5.1	2.7	4.8	4.6	4.4
% Deaths with GOC	57% (12)	100% (21)	100% (37)	97% (30)	92% (100)
% Deaths with GOC <2 weeks	0% (0)	29% (6)	32% (12)	37% (11)	29
% Deaths in the home	19% (4)	86% (18)	95% (35)	70% (21)	72% (78)

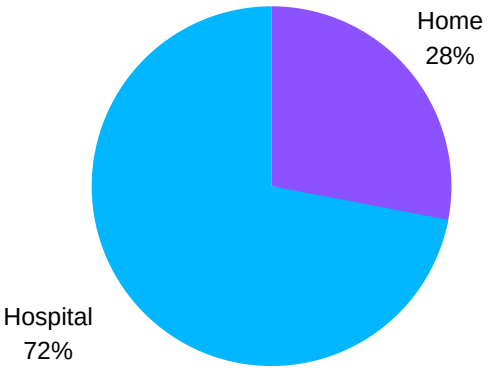
GOC Timing (Overall)
Oct 2018 - Sep 2019 (N=109)



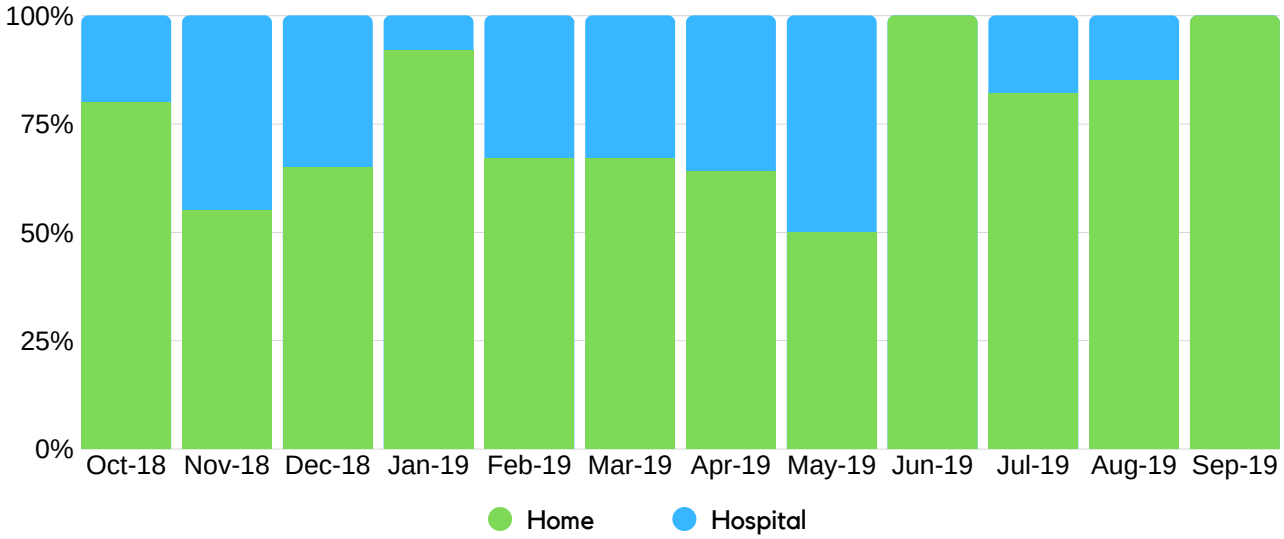
% Monthly Residents Deaths & GOC Timing
(N=99 *excludes residents with no GOC)



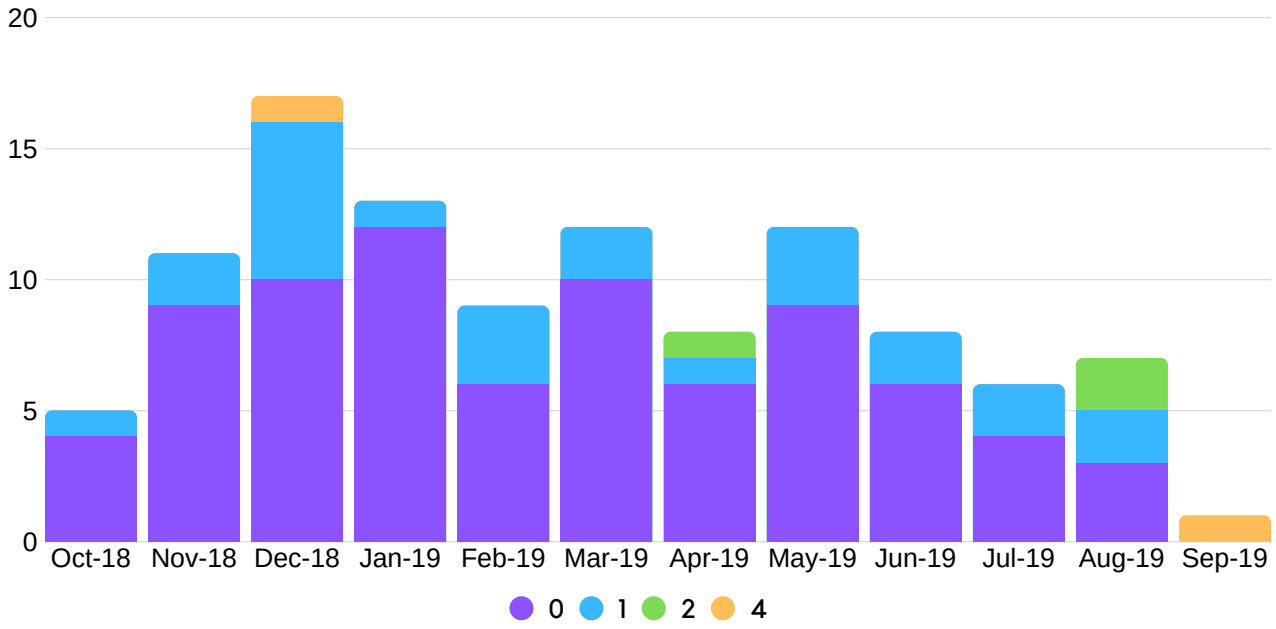
Location of Resident Death (N=109)



Location of Resident Death (N=109)

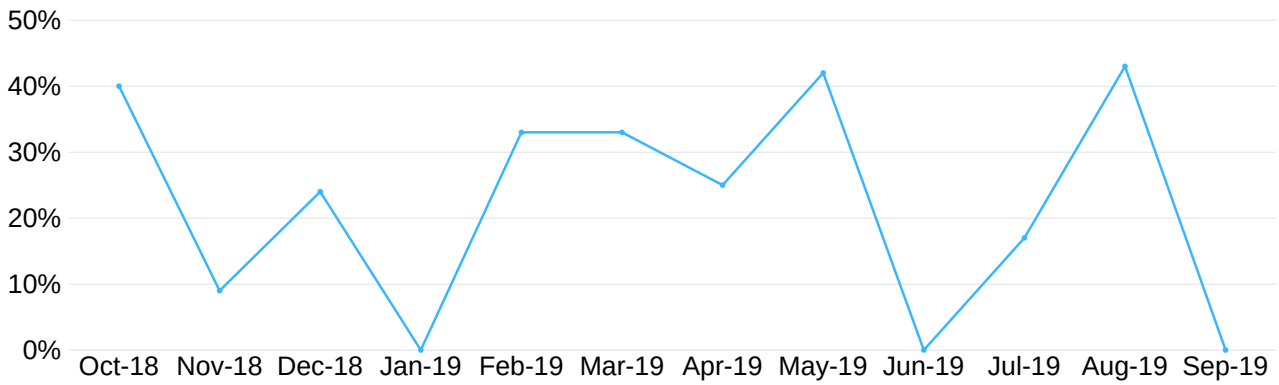


Number of ED Visits/Resident Deaths in the Last 3 Months of Life (N=109)



% of Monthly Resident Deaths with Hospital Transfers* in the Last 3 Months of Life (N=109)

*Direct hospital admissions or via the ED



Evaluation

Staff

Focus groups were held at seven sites as part of the evaluation of the project. We spoke to staff at various levels (Administrators, Educators, Social Workers, Case Managers, Chaplains, Registered Nurses, Licensed Practical Nurses, Health Care Aides, Physical Therapists, Occupational Therapists, and Recreation Therapists and Assistants) at each site, as well as to family members. Residents were invited to participate at all sites, but only residents from two sites attended the focus groups. Each group provided their perspective on the EPAC project and their experiences at the care homes more generally.

Not all staff knew about the EPAC project or were involved in its implementation. Staff who were familiar with the project were from sites that were further along in education and practice change. Although some were unaware of the project, all staff we spoke to recalled receiving some education on palliative and EOL care. They felt the education resulted in a greater understanding of palliative care, but indicated the need for more training on EPAC. Staff acknowledged the challenges of having difficult conversations with residents and families regarding palliative and EOL care and wanted more opportunities to role play and practice these discussions.

Most staff had experience and were comfortable providing palliative and EOL care to residents. For HCAs, this mainly involves providing comfort care including repositioning the resident, managing pain, and mouth care. Some HCAs with less experience expressed feelings of fear when caring for a dying resident. Often those with more experience helped guide and support new staff. Nurses are often the ones informing families of changes in resident health, and would be the ones to notify a family when a resident died. Only one nurse we spoke to expressed being uncomfortable talking to families

about death and dying. This was not because of lack of education, but instead the fear that they would come off as telling the families what to do in such a difficult and sensitive situation.

Staff expressed the desire for more time to connect and interact with the residents and families. They recognized they were often task-oriented and in a rush to complete their duties. Lack of time also meant that staff did not feel they had the ability to put their new education and training into practice. Recreation staff shared their desire for more resources to allow them to spend 1:1 time with residents.

Care conversations are improving as staff become more comfortable talking about death and dying. Families have also been open to earlier discussions with staff. Generally families are understanding and realistic about their loved one's health, however, some are in denial and need to be approached multiple times before having the conversation. Staff at one site said earlier care conversations are helping to reduce the stigma around death and dying, and has led to a calmer work environment as family members have a greater understanding of their loved ones condition and what to expect.

All levels of staff spoke about the close relationships they have with residents and their families. They expressed the emotional difficulty of seeing a resident's health decline and caring for them in their final days. Staff across all organizations felt they could lean on colleagues for emotional support if needed, however, formal supports were lacking. Some staff mentioned opportunities to attend resident funerals or speak to a counsellor if needed. Those who had the opportunity to attend an honour guard felt it was a meaningful way to say goodbye to a resident.

There seemed to be no formal process on how staff were notified of a resident's death. Some staff members spoke about receiving an email while others heard from their colleagues. Most indicated they would prefer to be told in-person when a resident has passed. Although it can be difficult for staff to grieve the loss of a resident while on shift, staff recognized they had to continue doing their jobs.

Residents & Families

Most family members and residents were unaware of their site's involvement in the EPAC project. There were some who indicated they participated in information sessions or discussions with staff regarding palliative and EOL care, but did not realize it was a result of the project. Family members were generally open to speaking to staff about palliative and EOL care for their loved ones. Although it can be a difficult discussion, family members recognized the importance of planning ahead. They also noted the importance of staff being sensitive in the way they approach the conversation, and the use of language that families can understand.

Majority of family members we spoke to were unfamiliar with the meaning of palliative care and how it differs from EOL. Families were not aware of what resources were available to their loved one and indicated the need for more information. Residents also seemed to be uncertain of the meaning of palliative care, and the importance of GOC. Many of the residents we spoke to thought only about having a power of attorney and DNR orders, and were unsure whether their wishes were recorded in their care plans.

Family members felt comfortable bringing concerns forward to staff and felt acknowledged. They spoke highly of the care provided to their loved ones, recognizing the thoughtfulness of staff. Many described the sites as having a family atmosphere.

Many staff felt their organizations could do more to care for families. While some hold memorials, honour guards, or other traditions for family members to be a part of, there are some sites that don't currently have supports in place. Family members felt it was important for sites to consider cultural and religious differences when offering support to them and their loved ones. The creation of a support group for family members was proposed at multiple sites.

It was recognized that residents are often affected by the death of another resident at the care home, however, organizations lacked a formal process

for notifying them when a death occurs. Staff were unsure about whether they should tell residents when someone has died, and if they did, they were uncertain of the approach to take. The residents we spoke to stated they would prefer to be told by staff when someone died, especially if it was someone they knew. Residents were encouraged to see a chaplain or counsellor if needed, and some had attended other residents' funerals. The idea of introducing a support group for grieving residents was brought up at multiple focus groups.

Next Steps

As was noted by staff at most sites, more education and training is needed on a palliative approach to care, including practicing of difficult conversations with residents and families. More practice will help staff feel more confident and comfortable talking to residents and families about palliative and EOL care. Staff also mentioned having refreshers on their education and training to help sustain practice changes. This was mentioned for all education, not just EPAC. Education and training should be provided to all members of the care team as well as volunteers.

Meetings between different levels of care staff could help improve communication and ultimately resident care. Although staff are restricted for time, utilizing existing meetings or huddles could ensure members of the care team are on the same page and resources are being utilized in the most beneficial way.

Formal supports are needed for all stakeholders. Often staff are told via email when a resident has died. Notifying staff of a resident's death in-person rather than by email may help increase their sense of comfort. More consistency is also needed in the support staff receive for managing their grief. Staff at all sites talked about becoming attached to the residents and the difficultly of dealing with their deaths. Implementing opportunities to debrief with a counsellor or chaplain may be beneficial.

The sites lacked a consistent strategy to support grieving residents. A support group or debriefing could be offered as part of a formal process to support surviving residents after another resident has died. It may also be important to some residents to be informed in-person by staff when a fellow resident has died, rather than be notified by a message board. These ideas should be explored further with residents at each site to best suit their needs.

Some of the staff felt there was not enough in place to support grieving families. The creation of a support group at the sites could help increase psychosocial support for family members. Other suggestions for improvement were the creation of a space for families in the care home to stay with a resident at EOL and the use of comfort carts for those sites who hadn't implemented them yet.

Family members expressed their desire for more information about palliative and EOL care. Additional education and information for families can help manage their expectations regarding changes in resident health and the process of palliative and EOL care. Information should be provided in many forms including brochures, online, and in-person. More information should also be provided to residents regarding GOC and the green sleeve, including examples of the documentation being discussed. As GOC conversations continue to happen early on, family and resident understanding will likely increase.

To help sustain the changes already made and continue to improve practice, sites are encouraged to continue to monitor the percentage of residents with GOC conversations and set a target for 100% of residents to have GOC at the time of admission. Staff may also want to track resident acute care transfers within the last 3 months of life and reasons for transfer to manage unnecessary hospital visits. Continued tracking of resident deaths and location of death can help monitor success as well.