



Palliative care day  
centre service offer for  
users and caregivers

## EXECUTIVE SUMMARY

of the abridged ETMI report

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## ISSUE

The World Health Organization (WHO) defines palliative care as a range of acute, progressive and comprehensive care dispensed to people who have an established, progressive disease with a guarded prognosis (Gouvernement du Québec, 2014). The main objective of such care is to provide the best possible quality of life to people who are sick and their families (Gouvernement du Québec, 2014). In addition to home based palliative care, some countries, including Canada, offer care and services in day centres to respond quickly to the various needs of users and their families in accordance with a principle of complementarity of services (Gouvernement du Québec, 2014; Hasson et al., 2021; INESSS, 2015).

Palliative care day centres (PCDCs) have the common objective of making it possible for users to stay in their home by improving their quality of life and providing support to their caregivers (Vandaele, Chambaere and Devisch, 2017). The approaches adopted in the different PCDC models tend to be holistic and humanistic, valuing the provision of individualized and personalized services (Hasson et al., 2021; Mitchell et al., 2020; Vandaele et al., 2017). The services, activities and the eligibility criteria for PCDCs are heterogeneous and are generally provided by a specialized interdisciplinary team (Hasson et al., 2021; INESSS, 2015). They are socially oriented (they increase opportunities for social interaction and promote peer support) or therapeutic (Davies and Higginson, 2005; Higginson et al., 2000) and meet physical, psychosocial and spiritual needs (Vandaele et al., 2017).

## CONTEXT

The 2015-2020 orientations of the Ministère de la Santé et des Services sociaux (MSSS) relating to palliative and end of life care promote home care for users who have an established, progressive disease with a guarded prognosis. Their goal is also to recognize and support caregivers by ensuring that the necessary resources are available close to their living environment (MSSS, 2015). These services are provided in a variety of locations, in particular in PCDCs. The first PCDC in Quebec was inaugurated in the Capitale Nationale region in 2000 for people with cancer. Due to its specific mission, distance and difficulties related to transport, the centre is not very accessible for users outside the Capitale Nationale region, especially those in the Côte de Beaupré territory. Thus, in keeping with the ministerial orientations and to ensure the delivery of services to these “remote” users, the first PCDC funded entirely by the MSSS was established recently in the Côte de Beaupré territory.

The Direction du programme Soutien à l'autonomie des personnes âgées (DSAPA) mandated the Assessment of Technologies and Methods of Intervention in Health and Social Services Unit (UETMISSS) of the CIUSSS de la Capitale Nationale to document the interdisciplinary clinical practices offered in palliative care day centres for users and caregivers. In order to further explore this model of care, the results of the assessment of technologies and methods of intervention will be used to improve the service offer of the Côte de Beaupré PCDC by identifying the services offered by different professionals and by determining the service offer that needs to be put in place for guests and caregivers in order to provide them with appropriate support services and meet their needs.

## OBJECTIVES

The purpose of this abridged assessment of technologies and methods of intervention is to answer the question: *“What palliative care day centre service offer promotes clients’ (users and their families) well being and quality of life?”*. This question gives rise to two assessment questions:

1. How effective are the care and services provided in PCDCs in promoting well being and quality of life? (effectiveness dimension)
2. What care and services are available in PCDCs in Quebec and elsewhere? (social and organizational dimensions)

**For more information, see the report at:**

[ciusss-capitalenationale.gouv.qc.ca/sites/d8/files/docs/Aproposdenous/Publications/ETMI-ABREGEE-OFFRE-SERVICE-USAGERS-SOINS-PROCHES-AIDANTS.pdf](https://ciusss-capitalenationale.gouv.qc.ca/sites/d8/files/docs/Aproposdenous/Publications/ETMI-ABREGEE-OFFRE-SERVICE-USAGERS-SOINS-PROCHES-AIDANTS.pdf)

## METHODOLOGY

Two sources of data were used: (1) scientific literature (bibliographic databases: Embase, CINALH [EBSCO] [OVID], PsycINFO [OVID] and Social Care Online) and grey literature, published between 2014 and 2021; (2) contextual data that provide a portrait of the four PCDCs operating in Quebec at the time of the assessment.

## RESULTS

Fourteen scientific studies and one grey literature publication were retained. Contextual data was collected from the managers of four PCDCs in Quebec in order to develop a portrait of them. Summaries of the results for the two assessment questions are presented in tables 1 and 2.

**Table 1: Summary of the results for the first assessment question**

| HOW EFFECTIVE ARE THE CARE AND SERVICES PROVIDED IN PCDCs IN PROMOTING WELL BEING AND QUALITY OF LIFE? (EFFECTIVENESS DIMENSION) (LITERATURE) |   |
|---|---|
| <b>Impact on physical well being</b>  | <ul style="list-style-type: none"> <li>› Attending a PCDC improves physical well being as measured by overall health, symptom severity and physical performance.</li> </ul>   |
| <b>Impact on psychological well being</b>   | <ul style="list-style-type: none"> <li>› Attending a PCDC improves the quality of life of guests and their families.</li> <li>› PCDCs have a positive impact on overall psychological well being and respite.</li> <li>› Symptoms of depression or anxiety are alleviated and guests and their caregivers have a greater sense of security as a result of the care and services received at the PCDC.</li> <li>› The care and services offered in PCDCs provide an opportunity for respite for guests and their families and help reduce the mental load for families.</li> </ul> |
| <b>Impact on interpersonal well being</b>   | <ul style="list-style-type: none"> <li>› Participation in activities offered in a PCDC promotes social interaction by breaking social isolation and providing social and emotional supports.</li> </ul>   |
| <b>Impact on spiritual well being</b>   | <p>Attending a PCDC:</p> <ul style="list-style-type: none"> <li>› Facilitates the transition to palliative care.</li> <li>› Allays apprehension about palliative care and end of life when the PCDC attended is near a hospice.</li> </ul>  |

**Table 2: Summary of the results for the second assessment question**

| WHAT CARE AND SERVICES ARE AVAILABLE IN PCDCs IN QUEBEC AND ELSEWHERE? (SOCIAL AND ORGANIZATIONAL DIMENSIONS) (LITERATURE AND CONTEXTUAL DATA) |   |
|--|---|
| <b>Main objectives</b>   | <ul style="list-style-type: none"> <li>› To allow people in similar situations to socialize, break their isolation and support one another in a non clinical environment.</li> <li>› To make it possible for people who are sick to stay in their home.</li> <li>› To provide respite and support to caregivers.</li> <li>› To improve quality of life through interventions that promote comfort, happiness and a certain level of health in people who need palliative care.</li> <li>› To provide early palliative care.</li> <li>› To facilitate the transition to end of life care.</li> </ul> <p>In Quebec, all PCDCs are close to a hospice (users can go back and forth) compared with some of the PCDCs described in the literature.</p> |

|   |   |
|---|---|
| <b>Service offer model</b>                              | <ul style="list-style-type: none"> <li>› The services offered are seen as complementary to the medical and social services already offered.</li> <li>› Services are offered in a hybrid (medical and social) model open to the community, often with a social focus.</li> <li>› The service offer is similar across PCDCs: psychosocial services, medical care, symptom and medication management services, pastoral and spiritual services, creative therapies, recreational and sports activities, rehabilitation, complementary therapies and personal care, beauty care, respite services and support for families, transportation, meals and breaks, consultation with a psychologist or doctor on request.</li> <li>› Only the data from the PCDCs in Quebec also report offering services for the bereaved.</li> </ul> |
| <b>Approaches and interventions</b>                     | <p>Very similar approaches and interventions:</p> <ul style="list-style-type: none"> <li>› Interventions are individualized (holistic, person centered approach) to meet guests' wishes.</li> <li>› Community approach inspired by caring communities.</li> <li>› According to the data on PCDCs in Quebec, a humanist approach is also recommended.</li> </ul>   |
| <b>Guest profile, referral and eligibility criteria</b> | <p>According to the data in the literature:</p> <ul style="list-style-type: none"> <li>› Guest profiles are heterogeneous (often with a cancer diagnosis).</li> <li>› An increase in the number of guests with chronic non malignant conditions has been observed.</li> </ul> <p>In the portrait of PCDCs in Quebec:</p> <ul style="list-style-type: none"> <li>› Eligibility criteria: adult clientele, diagnosis of cancer or an incurable disease, live at home, have a minimum level of autonomy, able to get around and participate in activities, interest, able to function in a group, case by case assessment.</li> <li>› The referral process and eligibility criteria need to be reviewed.</li> </ul>  |
| <b>Professionals and volunteers involved</b>            | <ul style="list-style-type: none"> <li>› Services are provided by an interdisciplinary team.</li> <li>› In Quebec, some professionals work both in a PCDC and in the nearby hospice.</li> <li>› Volunteers have a crucial role and are selected for their soft and hard skills.</li> <li>› According to the data on PCDCs in Quebec, professionals work full time in a single PCDC.</li> </ul>  |
| <b>Attendance and use of services</b>                   | <ul style="list-style-type: none"> <li>› In some cases, the number of days of attendance is unlimited and the groups are open.</li> <li>› The modalities of attendance and use of services vary widely across PCDCs. In Quebec, the number of guests per day varies between 6 and 15 plus relatives (12 to 30 people maximum).</li> <li>› According to the data in the literature, there are waiting lists in some PCDCs, which is not the case in PCDCs in Quebec.</li> </ul>  |

|  |  |
|--|--|
| <p><b>Description of the physical facilities</b></p> | <p>The physical facilities are poorly described in the literature. It was noted:</p> <ul style="list-style-type: none"> <li>› Warm atmosphere.</li> <li>› Availability of rooms allowing a certain level of privacy.</li> </ul> <p>In PCDCs in Quebec:</p> <ul style="list-style-type: none"> <li>› The dining room and living room are described as places conducive to get together and exchanges.</li> <li>› Separate rooms for care, activities, care providers and training activities.</li> <li>› Special attention is given to the outdoor environment.</li> </ul>  |
| <p><b>Organizational aspects</b></p>                 | <p>According to the literature and in PCDCs in Quebec:</p> <ul style="list-style-type: none"> <li>› There are challenges related to the recruitment of qualified staff, transportation and funding.</li> <li>› Mixed private and public sector funding.</li> <li>› Resource optimization philosophy (e.g., maximum occupancy at all times), which is not recommended for PCDCs.</li> </ul> <p>Challenges identified only in the portraits of PCDCs in Quebec:</p> <ul style="list-style-type: none"> <li>› Demystification of the palliative approach in PCDCs.</li> <li>› Raising awareness of the palliative care pathway.</li> <li>› Proximity to hospices.</li> <li>› Certain admission criteria (prognosis of less than one year, referral from a physician required).</li> </ul> |

## FINDINGS

### On the effects of PCDCs (effectiveness dimension)

Attendance at a PCDC resulted in an improvement in at least one category of the variables measured in relation to well being among guests and caregivers:

- › Improved social interaction, quality of life and overall health among guests and caregivers who attend a PCDC.
- › Attendance at a PCDC could lead to an improvement in overall psychological well being and respite among guests and caregivers.

### On the description of PCDCs (social and organizational dimensions)

The information available in the literature and the portrait of PCDCs in Quebec shows that the service offer in PCDCs is heterogeneous. Nevertheless, the following observations can be made:

- › Despite a number of commonalities, it is difficult to draw a single portrait of the services offered in PCDCs.
- › The services offered in PCDCs focus on individual needs and are part of a holistic and individualized approach that respects the needs and wishes of guests.
- › The services available in PCDCs are offered according to a hybrid model of care that combines health care and psychosocial services.
- › PCDCs offer a variety of services that are complementary to what is available in other palliative care services and which would not otherwise be provided.
- › The daily programming of activities in PCDCs is flexible and adapted to:
  - Take into account the guest's general condition, energy level, events during the day (e.g., death of another guest) and the desired pace of health care.
  - Leave free time to allow for informal support between guests.
  - Adapt services that require reorganization of the pace of work of professionals.
  - Provide transportation for certain guests who would not otherwise be able to participate in activities at the PCDC.

- › Volunteer involvement is crucial to the functioning of PCDCs; they have a role as carers (welcome and accompany guests) and employees (provide some services to guests).
- › Several PCDCs are located near or in the same facility as a hospice, which has both positive and negative effects:
  - Given the challenges of recruiting qualified staff who are trained to work with a palliative care clientele, this proximity means that part time staff can be shared between the two care settings.
  - This proximity can lead to confusion about the mission and types of services offered at each location, highlighting the need to demystify the purpose and objectives of PCDCs.
- › Since PCDCs are often largely unknown, it is important to promote their mission and objectives.
- › The referral process and eligibility criteria need to be reviewed to ensure that:
  - Users are referred by health professionals or can access them on their own (self referral).
  - Referrals are made in a timely manner, earlier in the service continuum.
- › Several PCDCs encounter funding issues that have an impact on the supply and sustainability of services. Funding is not always recurring or is based on the occupancy rate of the previous year.

## CONCLUSION

Since the advent of PCDCs is relatively recent and since they offer specific services for a targeted clientele, their mission and objectives are often largely unknown or misinterpreted. By providing early palliative care, PCDCs can help users stay in their home, avoid the use of certain resources (emergency room visits, hospitalization, etc.), improve overall health and promote continuity of services. Some issues are highlighted regarding the referral process and the fluidity of collaboration with the health and social services actors concerned. Considering the positive impact on guests and caregivers, PCDCs must continue their work in order to make themselves better known.

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