

Supporting Elders' Preferences for Palliative Home Care and Home Death



Émilie Lessard¹, Population Health PhD (c) and Isabelle Marcoux¹, Associate Professor

1- Interdisciplinary School of Health Sciences, Faculty of Health Sciences, University of Ottawa, Canada

Background

In the province of Québec, Canada, ageing population mean that there will be more deaths than births by 2032¹. While the majority of seniors wish to be care and die at home (especially in the COVID era), the number of home death does not reflect their preference despite an increasing access to specialized palliative home care (SPHC).

Aim

To explore SPHC experiences from a three-fold perspective: elderly at the end of life (E-EoL), bereaved caregivers (BC) and SPHC team in Québec, Canada. Theoretical framework of health promoting palliative care² was used.

Objectives:

1. To identify issues and to understand factors influencing the choice of a place for palliative care and death;
2. To create solutions tailored to the needs and preferences of E-EoL and their loved ones.

Methods

Anthropological participatory action research was conducted within SPHC service in the Greater Montreal area. Data collection took place between April and December 2018: participant observation (n=8); focus group with SPHC team (n=4); semi-structured interviews with E-EoL (n=8) and BC (n=18).

Sample (n=45)

E-EoL (n=12) over 65 years-old (convenience sampling).

BC (n=18) were recruited from the administrative database and must have lost their loved one within 3 to 9 months prior to recruitment.

SPHC team (n=15) at least 2 years of experience (convenience sampling).

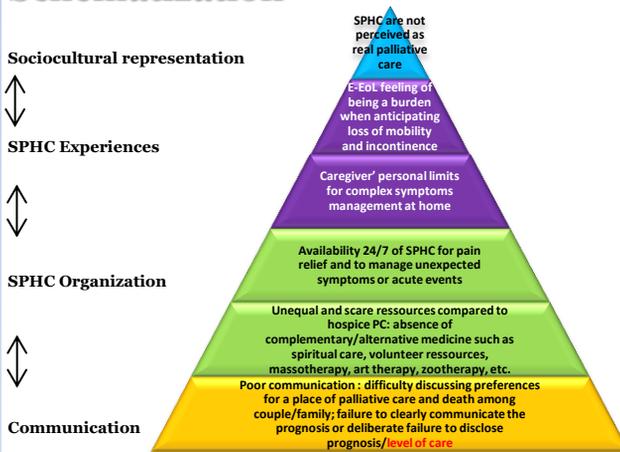
Findings

Using general inductive approach³, a collaborative thematic analysis was carried out through meetings and discussions with SPHC team and BC (performed with NVivo v12). Four themes have been identified:

1. **Sociocultural representations of palliative care, dying and death;**
2. **SPHC experiences;**
3. **SPHC organization;**
4. **Communication.**

Issues in maintaining SPHC until death were identified across themes. One specific finding demonstrates the complexity and interrelatedness of issues that transcend themes to gain an in-depth understanding of the factors influencing the choice of a place for palliative care and death: as a sociocultural representation of palliative care, the **perception that SPHC are not “real palliative care”**. The figure below illustrates how sociocultural representations of palliative care, SPHC experiences, SPHC organization and communication are shaped by each other.

Schematization



Discussions

Why SPHC are not perceived as real palliative care?

SPHC was not consistent with the participants' representations of hospice palliative care, which is associated with the very last moments of life (hours/days) and as a place of death instead of a place of care.

Home is not perceived as a place where it is possible to have full management of complex symptoms because of the role/duties of the family caregivers and lack of 24/7 availability of SPHC



Conclusion

This participatory action research demonstrates the importance of good communication practices to temporally frame palliative care in the dying process and to allow discussions about preferences for the place of palliative care and death. We are currently developing a communication tool adapted to the E-EoL and based on the spectrum of dying experiences. Since this requires in-depth cultural changes, actions are oriented towards the development of compassionate communities to better identify the needs and resources to be put in place to promote dying at home for those who wish to do so.

References

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Émilie Lessard :
elles005@uottawa.ca
<https://www.linkedin.com/in/emilie-lessard-0b593673/>
Isabelle Marcoux:
imarcoux@uottawa.ca