

The experience of healthcare professionals as informal cancer caregivers: Preliminary findings

Ariane Santerre-Theil, M.Sc.¹, Annett Körner, Ph.D.¹⁻⁴, & Carmen G. Loiselle, Ph.D., R.N.¹⁻³

¹McGill University, Montréal, QC ²Lady Davis Institute for Medical Research, Jewish General Hospital

³Segal Cancer Centre, Jewish General Hospital, Montréal, QC; ⁴Psychosocial Oncology Program, McGill University Health Centre

INTRODUCTION

- Informal caregivers (ICs) provide ongoing care and assistance, without pay, to family members or friends in need of support due to a health condition¹.
- IC-patient construed as a “unit of care”².
- IC-patient mental and physical health found to influence each other and evolve in a similar direction².
- ICs burden reduced by managing medical care at home, having emotional support, and receiving cancer-related information^{2,3}.
- ICs that are also healthcare professionals bring knowledge and skills that may buffer burden, enhance their IC role, and benefit patients. But also may put pressure on them to negotiate this dual role.

STUDY DESIGN AND GOAL

- Phenomenology to explore the lived experience of the dual IC-health care provider role.
- The main goal is to capture meanings attributed to this role in the context of cancer.

METHOD

Sample

- 12 to be recruited with 5 participants to date M_{age} = 42 years; 3 nurses and 2 physicians; 4 women; HCP's relation to patient: 2 were partners, 2 were children, 1 was a sister-in-law

Inclusion criteria

- At least 1 year of work experience as healthcare provider
- Having cared for a significant other with cancer within the last 5 years

Settings

- To date, JGH and Hope & Cope Wellness Center
- Recruitment using flyers, social media, information booths, and word-of-mouth

Procedures

- In-depth interviews conducted in person and 1 over the phone
- Open-ended questions (e.g., How does being a healthcare provider affect how you interact with your significant other and the healthcare system?; What do you think are the advantages/disadvantages for you and for the patient? Do you think that your professional role affects the medical care that your relative is getting?)

Analysis

- Interpretative phenomenological analysis (IPA): juxtapose, compare, and identify relationships among themes and factors

PROJECT TIMELINE



PRELIMINARY FINDINGS

PERCEIVED ADVANTAGES OF THE DUAL HCP/IC ROLE

Knowledge of the healthcare system

- Knowing what steps comes next
- Saving time and energy

More direct access to care

- Knowing people in healthcare system who can assist

Treated with more respect

- Healthcare providers are better received within healthcare settings

Creating a sense of security

- Reassuring presence for patient and family members

Understanding medical “jargon”

- Understanding and critically processing medical information

Latitude to propose tests and potential treatments

- Prescriptions, blood samples, wound care

“I can think of a few times that I would email physicians with whom I had been working with: Does it makes sense that we jump up to this level of fentanyl?”
- Nurse, 12 years of work experience

“C’est sur que, mettons qu’il y a des techniques à faire, comme enlever des broches, désinfecter une plaie, c’est moi qui le fait . . . Ça fait moins de voyage à l’extérieur.”
- Physician, 5 years of work experience

PRELIMINARY FINDINGS CONTINUED

PERCEIVED DISADVANTAGES OF THE DUAL HCP/IC ROLE

Expect to have more intense involvement in care

- Take an active role in cancer-related decisions

Remedy flaws in the healthcare system

- Expected to enact their professional role (e.g., pivot nurse, physician, etc.)

First responder when facing a health crisis

- Expected to enact their professional role (e.g., pivot nurse, physician, etc.)

Confronted with flaws in the healthcare system

- Awareness that things should be done a certain way

Heightened sense of professional responsibility

- Difficulty letting things go
- Wanting to do more

“So obviously ... I have given the same care to my grandmother, husband’s mother, my husband’s father, every family member, you become the caregiver.”
- Nurse, 30 years of work experience

“Tout devient dramatique, puis et ... parce que on est hyper vigilant et on devient stressé.”
- Physician, 45 years of work experience

PRELIMINARY CONCLUSIONS

- ICs’ professional knowledge helps advocate on behalf of patients
- This professional knowledge helps create a sense of control and reassures patients and family members.
- Dual role at high risk for being over solicited, resulting in potential role fatigue or burnout.

POTENTIAL RELEVANCE FOR RCN PARTNER HOSPITALS

- Findings begin to contribute to our understanding of the experiences of healthcare providers in their informal caregiver roles.
- If corroborated, findings should inform the development of supportive interventions for the unique dual role of being a healthcare provider caring for a relative with cancer.

Acknowledgements: Ariane Santerre-Theil’s work is supported by the Kuok Graduate Fellowship (2017-2019), Gerald Bronfman Department of Oncology (McGill University) & Rossy Cancer Network.

References

1. Canadian Caregivers Coalition. (2014). A Canadian Caregiver Strategy: Are We Making Progress? (pp. 32).
2. Kershaw, T., Ellis, K. R., Yoon, H., Schafenacker, A., Katapodi, M., & Northouse, L. (2015). The interdependence of advanced cancer patients’ and their family caregivers’ mental health, physical health, and self-efficacy over time. *Annals of Behavioral Medicine*, 49(6), 901-911.
3. Tolbert, E., Bowie, J., Snyder, C., Bantug, E., & Smith, K. (2018). A qualitative exploration of the experiences, needs, and roles of caregivers during and after cancer treatment: “that’s what I say. I’m a relative survivor”. *Journal of Cancer Survivorship*, 12(1), 134-144.