

The Lived Experience of Being a Caregiver for a Family member with a Terminal Illness

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“Just to be seen and experience that someone was interested in ME, and my story and my role in it, and how tough it actually is for me being his family caregiver. That was incredibly good.” (Nysaeter et al., 2024, p. 6).

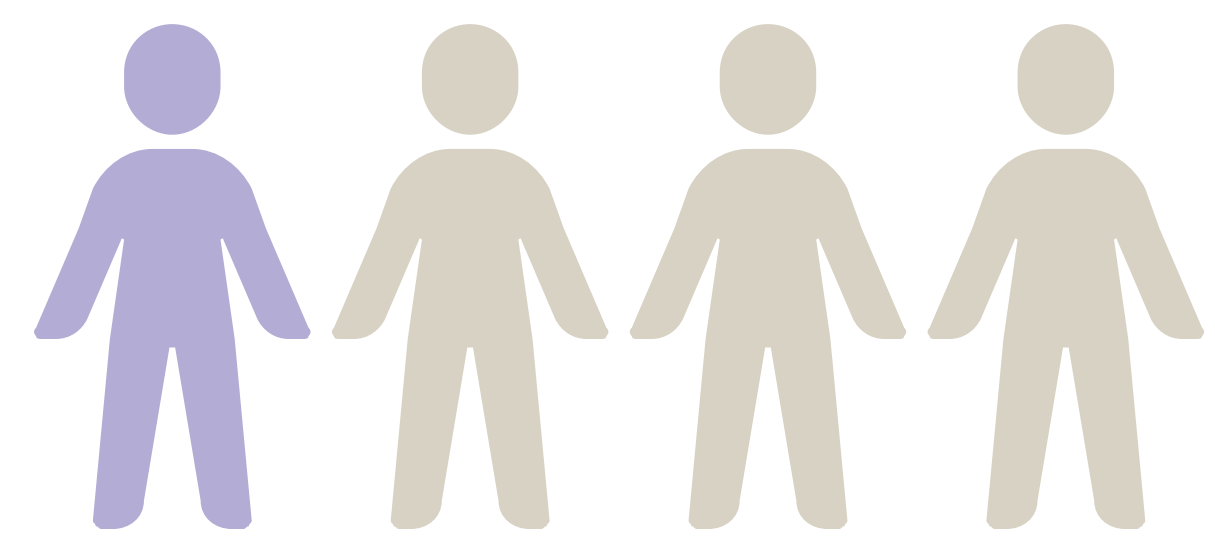
Course Assignment

My scholarly work was completed for a class and is based on the often-overlooked experiences of caregivers, specifically those **caring for loved ones at the end of life**. To capture the essence of caregiving, I had the privilege of interviewing my aunt, who shared her heartfelt story of caring for her terminally ill husband. Her lived experience is the cornerstone of my scholarly work, emphasizing the importance of personal narratives in fostering empathy and understanding. Through a comprehensive exploration of the literature, we will uncover caregivers' multifaceted roles and responsibilities and the profound impact of caregiving demands.

Through this scholarly work, I aspire to honour the narratives of caregivers like my aunt, shedding light on their resilience and dedication while advocating for greater awareness and support for caregivers.

A look Into Caregiving In Canada

What do you picture when you hear “caregiver”?



1 in 4 Canadians above the age of 15 are family caregivers⁽²⁾



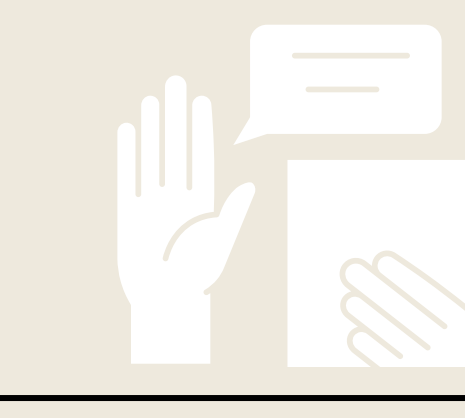
Family caregivers come from **all walks of life**. Anyone around us – a friend, neighbour, colleague, or even ourselves – may assume the role of a family caregiver at some point in life.

Caregivers are the **Invisible health care providers** within society

For every hour of professional care, caregivers provide **three hours of care to family**, making them essential contributors to the health care system.⁽²⁾

End of life caregiving

As the aging population grows in Canada, the demand for end-of-life care grows. The responsibility to provide care during this stage often falls upon family caregivers. The challenges and roles associated with caregiving at the end of life are unique and responsibilities tend to be more intensified.⁽¹⁰⁾

Roles and Responsibilities	Lived Experience
Physical Care 	<ul style="list-style-type: none"> Assistance with activities of daily living and intimate tasks such as bathing, clothing, feeding and bathroom assistance.⁽¹⁰⁾ Administering medications and treatments.⁽¹⁰⁾ 24-hour responsibility and demands constant vigilance.⁽¹¹⁾ Monitoring symptoms and alleviation of symptoms like pain and nausea.⁽⁹⁾
Emotional support 	<ul style="list-style-type: none"> Provide comfort by avoiding topics surrounding death or openly discussing death.⁽¹¹⁾ Use distraction methods and provide reassurance. Conceal their stress and suppress their emotions to remain "strong" for the patient.⁽⁹⁾ Maintain a visibly optimistic demeanour and internalize their suffering.⁽⁷⁾
Advocacy and decision making 	<ul style="list-style-type: none"> Responsible for making health care decisions and coordinating care.⁽¹¹⁾ Believe the patient's well-being depends on their choices.⁽¹¹⁾ Advocate to ensure that their loved ones' needs are met and they have quality care.⁽¹⁰⁾ Pressure to fulfill their loved ones end of life wishes.⁽³⁾

What is The Impact on The Caregiver?

Often, caregivers may neglect their own health and fail to take care of themselves and participate in self-care. The stress from the caregiving process can also have both emotional and physical impacts.

Physical impacts

- Caregivers experienced **poorer health outcomes** compared to the rest of the population.⁽⁵⁾
- Higher rates of physical pain, insomnia, forgetfulness, headache, reduced appetite and weight loss.⁽⁹⁾
- Higher rates of chronic diseases such as cardiac problems, high blood pressure, arthritis, and coronary artery disease.⁽⁴⁾

Emotional impacts

- Mental health challenges, including anxiety and depression, were prevalent among caregivers compared to the general population.⁽¹⁾
- Stress and mental exhaustion during the care process.⁽¹⁰⁾
- Post-traumatic stress disorder and long-term burnout after the death of their loved one.⁽¹⁾
- Increase rates of isolation.⁽⁵⁾

What can we do?

As a Society

- Policies and workplace support for caregivers, since caregivers often have to leave the workplace or reduce their hours.⁽¹⁰⁾
- Current financial support (EI benefits) must be more accessible and sufficient to adequately meet the needs of caregivers and their loved ones.⁽²⁾

As Health Care Providers

- Caregivers are patients as well. Thus, they also need to be supported and cared for.
- Allocate more funding towards community and home care services.⁽²⁾

As Individuals

- We can contribute by personally reaching out to a caregiver we know, offering our support and compassion.

Is there a caregiver in your own life that you can take care of?



“There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers and those who will need caregivers.”

Former U.S. First Lady Rosalynn Carter

1. Bijnstorp, F. M., Onwuteaka-Philipsen, B. D., Boot, L., van, & Pasman, W. (2022). Caregiver's burden at the end of life of their loved one: Insights from a longitudinal qualitative study among working family caregivers. *BMC Palliative Care*, 21(1), 142. <https://doi.org/10.1186/s12904-022-01031-1>
2. Canadian Centre for Caregiving Excellence. (2022, November 7). *Giving care: An approach to a better caregiving landscape in Canada*. https://canadiancaregiving.org/wp-content/uploads/2022/11/CCCE_Giving-Care.pdf
3. Carlinder, L., Sahlberg-Bloom, E., Hellström, L., & Britz-Maric, T. (2010). The modified self: Family caregivers' experiences of caring for a dying family member at home. *Journal of Clinical Nursing*, 20(7-8), 1097-1105. <https://doi.org/10.1111/j.1365-2702.2010.03331.x>
4. Kocak, N., Senel, G., Oğuz, G., Karaca, S., & Gökse, F. (2022). Quality of life and burden in family caregivers of patients with advanced cancer receiving specialized palliative care. *Indian Journal of Cancer*, 59(2), 187-193. https://doi.org/10.4103/ijc.11C_671_19
5. Kristianson, L. J., & Aoun, S. (2004). Palliative care for families: Remembering the hidden patients. *The Canadian Journal of Psychiatry*, 49(6), 359-365. <https://doi.org/10.1177/0874370404269004>
6. Limonero, J. T., Mate-Mendez, J., Gomez-Romero, M. J., Mateo-Ortega, D., Gonzalez-Barboteo, J., Bernaus, M., Lopez-Postigo, M., Sirgo, A., Viel, S., Sanchez-Julve, C., Bayés, R., Gómez-Batiste, X., & Tomás-Sábadó, J. (2020). Family caregiver emotional distress in advanced cancer: The DME-C scale psychometric properties. *BMJ Supportive & Palliative Care*, 13(1), e177-e184. <https://doi.org/10.1136/bmjspcare-2020-002608>
7. McCauley, K., McQuillan, R., Ryan, K., & Foley, G. (2021). Mutual support between patients and family caregivers in palliative care: A systematic review and narrative synthesis. *Palliative Medicine*, 35(5), 875-885. <https://doi.org/10.1177/0269216321999962>
8. Nysaeter, T. M., Olsson, C., Sandsdalen, T. et al. Family caregivers' preferences for support when caring for a family member with cancer in late palliative phase who wish to die at home – A grounded theory study. *BMC Palliative Care* 23(15), 1-11. <https://doi.org/10.1186/s12904-024-01350-5>
9. Saleh, F., & C. O'Neill. (2018). The experiences of caregivers providing home care for terminally ill family members at the end of life: A phenomenological study in Bahrain. *Clinical Nursing Studies*, 6(3), 57-57. <https://doi.org/10.5430/cns.v6n3p57>
10. Srisujahar, K. L. (2013). Burdens of family caregiving at the end of life. *Clinical & Investigative Medicine*, 36(2), 121. <https://doi.org/10.2501/cim.v36i2.1972>
11. Totman, J., Pistrang, N., Smith, S. A., Hennessey, S., & Martin, J. E. (2015). "You only have one chance to get it right": A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer. *Palliative Medicine*, 29(6), 496-507. <https://doi.org/10.1177/0269216314566840>

