

Survey Says - Language Matters!

by Lynn Butler

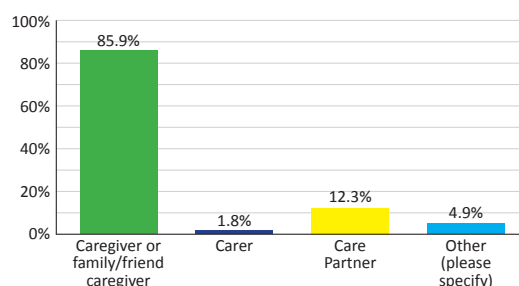
There are various words and phrases that can be used to describe the role of providing unpaid care for a family member or friend. Are some terms more appropriate than others? Does it really matter?

The words we use for the different roles we play in our lives can have negative as well as positive effects both on how we perceive ourselves and on how the world and society perceive us. So, it is important to be aware of and attentive to language, especially with respect to how caregivers wish to describe their role.

At Caregivers Nova Scotia (CNS) we give our membership opportunities to express their opinions on various issues. Recently we conducted a survey of our members to find out their thoughts on language relating to the caregiving role.

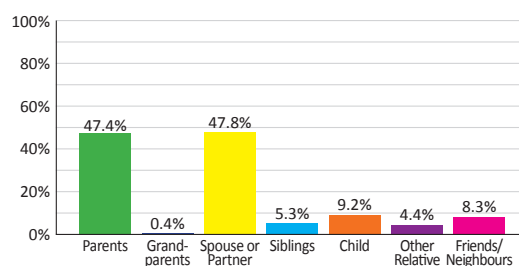
We received 228 responses, from 186 women and 42 men. The results are as follows.

Q1 Thinking about your caregiving experience/situation, which of the following terms do you feel best describes your role?



Eleven people answered that they were both a spouse or child in addition to being a caregiver or care partner.

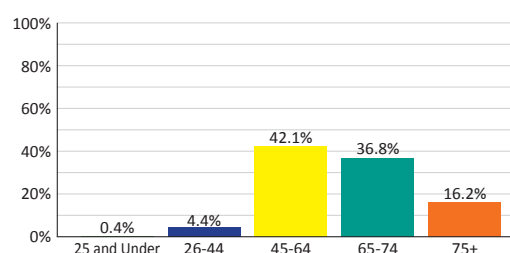
Q2 Who do you give care to?



These results confirm what we have heard on many occasions.

- Our members overwhelmingly self-identify with the term “caregiver”.
- In our sample, very few relate to “carer”, a term which is used in the United Kingdom, Ireland, Australia, and New Zealand.
- The phrase “care partner” is both confusing and

Q3 Please Indicate Your Age Category



misunderstood by many. We have heard, for example, from some healthcare professionals such as nurses and doctors that they believed they were the care partners. One individual commented that they assumed that care partner meant that the caregiver and the care recipient weren’t legally married – were partners rather than spouses.

CNS also believes that it is important to align with terminology used in the federal and provincial governments. The Canada Revenue Agency (CRA) offers the Canada Caregiver Credit, Employment Insurance (EI) offers Family Caregiver Benefits for adults and children, and Veterans Affairs Canada (VAC) offers the Family Caregiver Relief Benefit. In our province the Department of Health and Wellness (DHW) offers the Caregiver Benefit for lower-income Nova Scotians.

Consistency in language is important for three reasons.

- When caregivers do not identify as caregivers, they often will not seek help or resources. Considering that 1 in 3 Nova Scotians is giving some form of unpaid care, and knowing how demanding that can be, it is essential for caregivers to know what supports are available and how to access them.
- Healthcare professionals need to speak with caregivers in a language they understand. Inventing new terminology or adopting phrases from other countries without broad public consultation is merely confusing.
- As a society we need to recognize and support caregivers for the range of care they provide and the responsibilities they handle each and every day – often to their own health and financial detriment.

Having terminology that people easily recognize and that they feel best represents them and the vital role they play is important. Language does matter.

**Care Recipient + Caregiver + Healthcare Team
= Partners in Care**