

The right not to be called an Informal Carer

Care Alliance Ireland: Position Statement on Language Use

November 2017

The word 'carer' is used across many sectors, and to describe many different groups of people. However, the word 'carer' – and in particular, the term 'family carer' – is often very consciously not used in certain sectors and circumstances¹. Language evolves, and has different meanings and connotations depending on the speaker, the listener and the context. This is why we feel it is important to review the language used around caring and family carers, and to understand the impact that language use has.

Care Alliance Ireland has written and presented extensively on this topic in recent times, with the first of our Discussion Paper Series entitled "Defining Family Carers"² published in late 2015. More recently, we published an article in the International Journal of Care and Caring; "Defining and profiling family carers: reflections from Ireland"³ for an international audience.

With regards specifically to Irish policy, the National Carers Strategy⁴, which can reasonably be considered as the official state policy on the topic of family caring in Ireland, refers to those providing care in the home to a loved one as "carers", with no "family" prefix. However, we have noticed a creeping tendency in more recent documents, written by various government departments (and at events hosted by some government departments), and indeed some researchers, to use the term "informal carer" instead.

A recent example of this use include the Public Consultation on Home Care⁵, where the term "informal carer" is used throughout to distinguish a family member who provides unpaid care to a loved one, from a paid care worker. We have also been present at recent events across the sector whereby the term has been used in the same manner.

Why is the term "informal carer" so problematic? Primarily, it trivialises the work of family carers who provide significant levels of high quality care- arguably there is nothing "informal" about that care. It may not be paid, but that does not mean it is not of sound quality, and contributing significantly to the health and well-being of hundreds of thousands of people with various health conditions around the country.

¹ For examples, please see Paper 1 in our Discussion Paper Series: <http://www.carealliance.ie/discussionpapers>

² Available at <http://www.carealliance.ie/discussionpapers>

³ Available at <http://www.ingentaconnect.com/contentone/tpp/ijcc/2017/00000001/00000003/art00009>

⁴ Department of Health, 'The National Carers' Strategy' (Department of Health, 2012).

⁵ See the consultation paper at <http://health.gov.ie/wp-content/uploads/2017/07/Home-Care-Consultation-Paper-280717.pdf>

‘Guiding support for family carers’

In 2015, Care Alliance Ireland asked family carers directly what their preferred term for their position is; most preferred to be identified with regards to the relationship to the person they provide care and support for, rather than the work of being a carer.

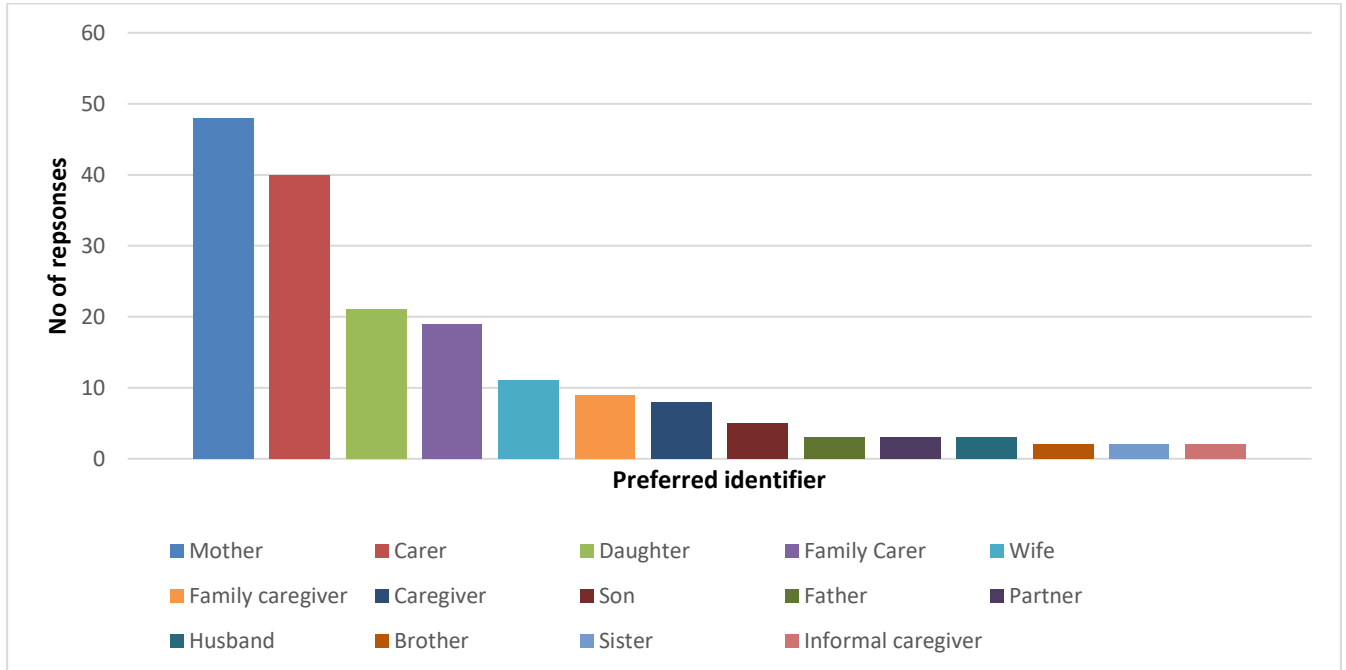


Fig. 1) Preferred terms as chosen by carers themselves (N=102)

You can see in the above graph (Fig. 1) that the least preferred term of all possible options provided was “informal carer”. In this instance only 2 respondents chose this as their preferred term, in comparison to 40 respondents choosing the term “carer”, and an additional 18 choosing the term “family carer”⁶.

One respondent summarised much of the feeling towards the term on behalf of family carers when they said;

“I feel that the term ‘informal carer/caregiver’ is rather dismissive, suggesting that care is second rate rather than primary and invaluable.”

To this end, we recommend that when discussing the work, contribution, needs and expectations of those who provide unpaid care and support to a loved one, the term “informal carer” is not used. Instead, we recommend one of the terms which carers themselves have identified as far more preferable, such as “carer” or “family carer”. Language matters, and in order for family carers to truly be included as “key care partners”, as per the National Carers Strategy, this is a small but necessary step to ensure the contribution of these family carers is acknowledged and celebrated.

⁶ Note that respondents could choose more than 1 term which they felt described them best.

