



Guiding support for family carers

**Discussion
Paper 1**

Defining Carers

October 2015



1. Introduction

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 circumstances. 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. This paper will briefly review the term ‘carer’ with regard to general usage and how it is understood by society.



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The purpose of this paper is less to answer questions than to ask them, and less to define ‘carers’ than to understand who they are. In particular, its purpose is to ask why the label ‘family carer’ may be rejected by some of them, or by particular groups who traditionally were thought of as needing such care from family members. In contrast, many family carers find solace and support in claiming the identity of ‘family carer’. The acceptance or rejection of the term itself can have a huge impact on whether the supports which are available to family carers in Ireland are in fact available to all those providing care, or just to those who accept the term as a descriptor of their situation.

As a discussion paper, much of this paper is written in the form of a literature review, which is presented along with data collected as part of two online surveys administered by Care Alliance Ireland in early 2015¹.

¹ The first of these was administered online in March 2015 and was a wide-ranging survey on the general thoughts and experiences of family carers in Ireland in 2015. The second was administered online in September 2015 to give family carers a chance to describe the language they would prefer to see used to describe them.

2. The Term ‘Family Carer’ – and Who It Refers to

In order to begin exploring these issues, with particular regard to the Irish context, it would be remiss not to clarify to whom this paper refers, particularly when using the term ‘family carer’.

The most recent Census of Population of Ireland defines a ‘carer’ as someone who

... provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability (including problems which are due to old age). Personal help includes help with basic tasks such as feeding and dressing.

(Central Statistics Office, 2011)

Broadly speaking, this paper focuses on those individuals who provide care and/or support to a family member in that person’s own home on a regular basis, regardless of time spent doing so. Those needing this care and/or support includes older people with general aging concerns, people with dementia and memory loss, people with intellectual, physical, sensory and neurological disabilities, and people with life-limiting conditions and/or terminal illnesses. These individuals may be children or adults – as may be those caring for them.

Internationally, numerous phrases are used to describe the cohort of people providing care as described above. In the UK² and Australia³, the prevailing descriptive term seems to be ‘carer’, with no ‘family’ designation⁴; this is a more inclusive term, but is it too inclusive or too wide a definition? Could it be interpreted widely as also referring to those who provide paid care and support? In an Irish context, a ‘carer’ generally refers to a paid care worker. Indeed, the carer movement in Ireland explicitly uses the term ‘family carer’ to differentiate between carers who are family members or friends, and others in caring roles, such as paid home care support workers, nurses, and indeed those working in the wider so-called ‘caring professions’. In the US⁵, the terms ‘caregiver’ or ‘family caregiver’ prevail. In some countries, there is no particular word or phrase to capture the work done by family carers, while in others, specific words have evolved to describe certain facets of paid care work, for example, the word ‘badante’⁶ in Italian.

² See for example www.carersuk.org.

³ See for example www.carersaustralia.com.au.

⁴ This is based on a review of previous documents published by these groups, and their usage on their respective websites.

⁵ See for example www.caregiving.org.

⁶ Meaning ‘carer’ or ‘care worker’.



Whilst these are minor differences across national boundaries, the nuances highlight the difficulties inherent in categorising those who provide care on a regular, unpaid basis to friends or family. In Ireland, how is the term ‘family carer’ received both by those it refers to directly (those providing care) and indirectly (those receiving that care)?

Broadly speaking, when asked to imagine a typical ‘family carer’, much of society brings to mind a woman in her 40s or 50s, caring for her aging parents. Whilst the cohort of people most likely to be carers are indeed women in that age range (nearly 12% of all women aged 45–49 are providing care to a family member or friend (Central Statistics Office, 2012)), those receiving care are not as easily identifiable. The National Quarterly Household Survey in 2009 indicated that 40% of carers looked after a parent or parent-in-law, and one-third of carers were caring for a person who required that care due to old age (Care Alliance Ireland, 2015). This leaves 60% of carers caring for someone other than a parent, and two-thirds of carers providing care for reasons other than aging.



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In a recent survey undertaken by Care Alliance Ireland, a considerable 47% of respondents indicated they were caring for a child, with 12% caring for a spouse, and 31% caring for a parent⁷. The majority (69%) of respondents were aged between 36 and 55. The reasons identified⁸ as to why the person being cared for requires help were:




- Physical disability (34.18%)
- Long-term health condition (25.67%)
- Intellectual disability (25.54%)
- Dementia (21.60%)
- Needs that arise from being older (19.70%)

⁷ This survey was carried out online using Survey Monkey, with 789 respondents.

⁸ Respondents could choose more than one.

-  An autism spectrum disorder (18.93%)
-  A mental health condition (12.83%)
-  A neurological condition (12.07%)
-  Cancer (4.70%)
-  Alcohol or substance abuse (1.52%)
-  An eating disorder (1.27%)
-  Other reason (10.80%).

What this serves to illustrate is that many assumptions about those who provide and receive care in a family setting are inaccurate.



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Of course, the key aspect of these studies (the Census, the National Quarterly Household Survey, the Care Alliance Ireland study, etc.) is predicated on family carers identifying themselves as such. As discussed in the following sections, there are numerous factors which call into question some carers' willingness and ability to self-identify as 'family carers'. Currently, for many, taking on the identity and label of 'family carer' is 'the gateway through which supports are accessed' (Molyneaux, Butchard, Simpson, & Murray, 2011). A reluctance to assume this identity can affect the support they themselves receive in their role as carer, a role which has of course been acknowledged to have many challenges for individuals in terms of physical and mental health (O'Sullivan, 2008; Stokes, 2010; The Carers Association of Ireland & Royal College of Psychiatrists, 2009), social isolation (O'Sullivan, 2008), finance (OECD, 2011; O'Shea, 2000) and employment.



3. Self-identity

Identity is a deeply personal thing, which impacts decisions, self-confidence and other key aspects of personality. In identifying as part of a particular social, economic or other group, one gains or loses prestige in accordance with that identity. In understanding what it means to identify or to be identified as a family carer, there are a number of issues to be considered.

3.1 Stigma

Although stigma is decreasing as awareness-raising campaigns become more successful, certain conditions which necessitate family members becoming involved in caring for loved ones are still viewed in negative terms by some of society. In particular, noticeable levels of stigma or misunderstanding still exist in the areas of mental health, intellectual disability, addiction and eating disorders. By identifying themselves as family carers, family members may risk further stigmatising their loved ones, particularly those with conditions such as those mentioned above. In some cases, assuming the identity of 'family carer' may in fact 'out' those being cared for, particularly if the condition necessitating care is hidden. Consequently, in these sectors, many family carers and those for whom they care reject the term, declining to identify either as a 'carer' or as someone being 'cared for' (Henderson, 2001).



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3.2 Loss of previous identity

In identifying as a family carer, the label of 'daughter', 'son', 'husband', 'wife', etc. may be lost, or at risk of being lost. Some researchers advise caution when labelling or identifying a person as a family carer, in particular if that signals an end to a previous relationship (Henderson, 2001).

While the large-scale Care Alliance study outlined above was not specifically designed to test the notion of identity and caring, responses highlighted the difficulties many parents in particular have with assuming the role of family carer:

'Change the name carer. Some of us have no choice if we want to be a carer or not. A carer in my eyes is someone who wants that role. I want to be a mother.'

'[I] feel like I'm everything else except a Mum.'

'Sometimes [it's hard] to be just the carer when other family members have careers.'

'I am still a Mum'

These comments show that navigating the world of being a family carer can be stressful not simply because of the tasks which become part of daily life, but also because of the need to become reconciled to a new identity, an identity which may supplant a previous identity developed over decades prior to this life change. Parents, in particular, seem to have difficulty reconciling being a family carer with being a parent raising their children, and are not keen to relinquish the role and identity of parent for that of 'carer' (Robinson & Williams, 2002).



4. Paternalism

Within certain sectors, the use of the term ‘family carer’, whilst well intentioned, is often not welcomed by those who receive the support and care of family members. The term is seen as paternalistic, and not in keeping with the dominant ideology of the social model of disability (Goodley, 2001). A 2001 study in the UK found that people with intellectual disabilities rejected the term ‘carer’, preferring the term ‘support’ instead (Williams & Robinson, 2001). Pilgrim (1999) advocates a shift away from the term ‘carer’ altogether, and a move towards situating the support according to specific roles, relationships and contexts.



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Even the fact of ‘having a carer’ can undermine the independence of individuals, and as the role of ‘carer’ may not change as individuals age, parental carers may find it difficult to accept their child’s adult identity, continuing to exert inappropriate levels of parental control (Williams & Robinson, 2001). In an Irish context, this can muddy the waters of the parental relationship, in particular with regard to adults with intellectual disabilities. Whilst the National Carers Strategy (Department of Health, 2012) is explicit in seeing a role for family carers as partners in care involved in the process of support to the greatest extent possible, the National Disability Strategy Implementation Plan (National Disability Strategy Implementation Group, 2013) does not use the words ‘family’, ‘carer’, or ‘caregiver’ at all. In contrast, the word ‘support’ or its derivatives (supports and supporter) are used 74 times.

5. Gender

Traditionally, care work is often seen as ‘women’s work’ – indeed much of the modern ‘carers movement’ has developed from a push to have the value of the work of female family carers recognised (Molyneaux et al., 2011). In contrast to this ‘traditional’ view of family carers, the percentage of male carers increased to 39% in Census 2011 (Care Alliance Ireland, 2015; Central Statistics Office, 2012), an increase of 16.8% on the figures in 2006. Male carers are the demographic group with the highest percentage increase in Ireland – a fact which creates its own challenges.

However, relatively few male carers seem to publicly identify themselves as such, or to take part in carer support groups, etc. Just 11% of the followers of the National Carers Week Facebook page, for example, are male⁹. This can be partially accounted for by the differing types of support which men, traditionally, prefer. Whilst female carers enjoy speaking with others about challenges, and daily routines and tasks, many men prefer to share an activity unrelated to their caring role (West Cork Carers, 2013). Male carers have reported a 1.6 times greater chance of a lower quality of life than female carers (O’Sullivan, 2008).

Ribeiro, Paul and Nogueira’s study (2007) indicated that men fail to identify with the term ‘carer’, seeing the tasks and status involved in caring duties as part of a relationship. In that study, participants integrated their ‘caring’ identity with their sense of masculinity, taking pride in that role. In other studies, male carers appear to have developed a vision of masculinity that not only de-emphasised certain traditionally ‘masculine’ elements (such as not revealing emotions etc.), but which also emphasised others, such as taking charge, and ‘male-to-male’ bonding (Campbell & Carroll, 2007). More recent work in Ireland has shown that male carers, when telling their personal stories, were resisting traditional discourses surrounding masculinity. For example, they expressed satisfaction in skills learnt as part of their caring role which are traditionally not associated with masculine behaviour, such as dealing with household tasks. The gentle and tender way in which men described their involvement with and responsibility for intimate personal care also de-emphasised hegemonic masculinity (Stokes, 2015).

As will be outlined below, Irish male carers identify more strongly with the relationship than with the identity of ‘family carer’, which mirrors the findings of previous studies (Molyneaux et al., 2011; Ribeiro et al., 2007).

⁹ Care Alliance Ireland coordinates National Carers Week and the allied Facebook page.



6. Irish Family Carer Preferences

In a recent survey¹⁰ undertaken by Care Alliance in which family carers were specifically asked about their preferred identity when it came to describing or 'labelling' themselves with regard to their caring role, it became clear how difficult it is to understand the importance of the use of language in this area. Respondents were asked to pick from a list of commonly used terms to describe themselves, and could pick more than one term.

The phrase/word most commonly chosen by respondents was 'mother' (45%), followed by 'carer' (39%) and 'daughter' (21%), which reflects the fact that 90% of responses came from female carers. For male carers, the top three responses were 'son' (57%), husband (42%) and 'family carer'/'family caregiver' (both 28%). In both instances it is clear that those providing care to a family member prefer to identify themselves by their relationship to the person 'cared for' rather than by the tasks or duties of 'caring'.

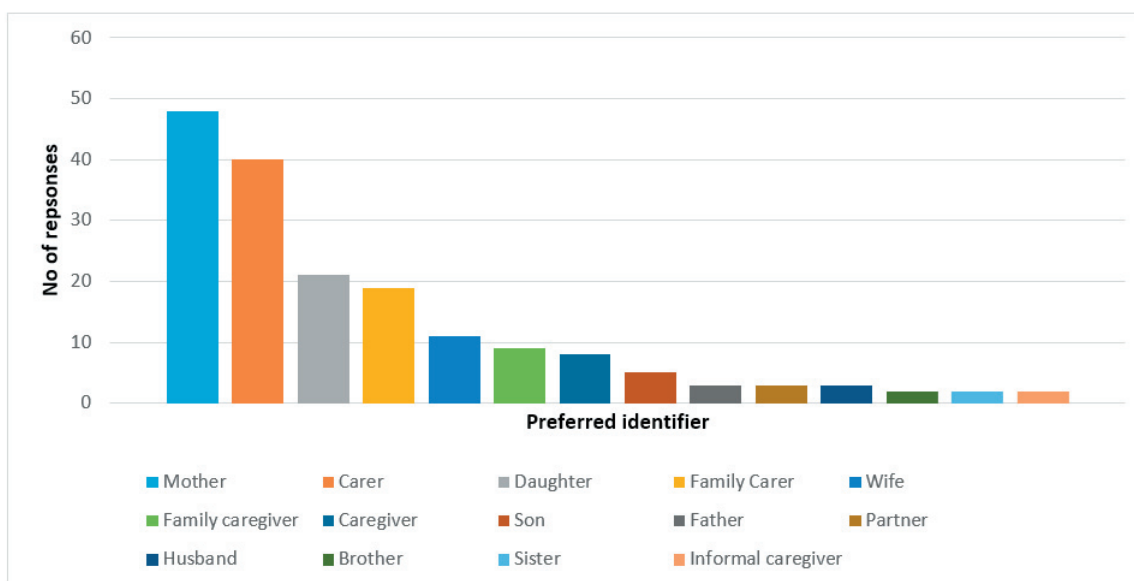


Fig. 1: Language preferences (all respondents. N-102)

¹⁰More information on this study available on request (zoe@carealliance.ie).

As discussed previously, it is important to understand the nature of the existing relationship. When those who care for a spouse or partner were asked this question, two terms were equally popular – ‘wife’ and ‘carer’ (38% each). This is somewhat surprising, given the desire of many partners and spouses to keep the original nature of that relationship to the fore, as discussed above.



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Perhaps unsurprisingly, when those caring for a child were asked which term they preferred, the overwhelming majority chose ‘mother’, with 88% of respondents choosing this term. In addition, these respondents were most likely to reject other terms, by adding to their answers comments such as the samples below:

‘The word ‘carer’ is ok when it’s not a family member. A mother is always a mother to all her children and I ‘care’ for all my children.’

‘I prefer to be known as mammy before carer. I care for my son who ... is three years (old). Himself and his older sister know me as mammy and not as a carer.’

‘I think all mothers are family carers, I’m a mammy first, carer second.’

Only those caring for a person with a mental health difficulty identified the term ‘family carer’ as their preferred identifier, which contrasts with many of the comments emphasising the importance of the pre-existing relationship with the person receiving care. The general term ‘carer’ was one of the top two choices in all other areas (with the exception of cancer and alcohol and substance abuse situations).

When the respondents were given an opportunity to expand on their responses, a number of overarching themes emerged – in particular the feeling that some of the commonly used terms do not adequately describe them or the role they play in their loved ones’ lives:



'I feel that the term "informal carer/caregiver" is rather dismissive, suggesting that care is second rate rather than primary and invaluable'

'The formal carers in the HSE need a different title as everyone seems to think us family caregivers are the same as employee carers'

'I am not totally happy with any of the terms as none adequately describe me however I have not found a better alternative'



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The personal preferences of those being 'cared for' also have an impact on the words family carers use to describe themselves, as they take into consideration the impact that identifying as a 'carer' has on how those they care for are viewed:

'I know what I do is regarded as caring but my partner doesn't like this term. He is well aware of what I do and appreciates what I do, but I think it makes him more aware of his illness/es, so I try not to refer to myself as his carer.'

'Both persons [I care for] are sensitive about discussing the fact they need care'

Others reject the term 'carer' and other similar terms outright, citing the lack of understanding of what the terms really mean and how the role of carer has affected them:

'Most people who are carers didn't plan to be carers, it just happened, it's our lot in life, so "family carer" implies we choose to be that, when in fact it was foisted on us.'

'One word labels do not communicate the scope of my caring role. Feel I always have to explain as people undervalue what I do.'

'Personally I don't like being called a Carer. Having to leave my job and salary behind and take on this new role has dented my confidence and my sense of self worth and my standing in the community. I will probably get used to it in time but I hate using the Carer word.'

7. Conclusion

The purpose of this discussion paper was not to answer the question ‘what term should be used to describe those who care for family members’, but rather to acknowledge the challenges in attempting to use one or two unifying phrases to describe a heterogeneous group of individuals. There are clear differences in views between different ‘types’ of carers, as outlined in the above sections.

It is clear from the research undertaken by Care Alliance that there is no unifying phrase or term which those who care for family members feel describes their role well. For some, having an identity as a ‘carer’ is important, allowing them to feel that they have a true role in their loved one’s life, as encapsulated in the comment of one respondent:

‘I think the word ‘carer’ helps to acknowledge what I am doing ... Where as if it was just ‘daughter’ it doesn’t acknowledge the changes made to my life to care for Mum.’

For others, the label of ‘carer’ overshadows their existing relationships, and they much prefer to be seen as a mother or husband first. The challenge for those supporting family carers is to acknowledge that there will be many individuals who are ‘family carers’ who refuse to see themselves in that light, and therefore who may be rejecting opportunities for accessing the vital supports (financial, social or health) which are available to them. The question is: how can supports be made available to those individuals who do not wish to assume the identity which often acts as the gateway to those support?

The final word can be left to a ‘family carer’:

‘Really the words used are unimportant. More real help and support is needed.’



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