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Between Worlds: The Experiences And Needs Of Former Family Carers

EXECUTIVE SUMMARY

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BETWEEN WORLDS: THE EXPERIENCES AND NEEDS OF FORMER FAMILY CARERS EXECUTIVE SUMMARY (EDITED PLAIN ENGLISH VERSION)

BACKGROUND TO THE STUDY

The Census 2006 defined a carer as someone who ‘provides unpaid, personal help for a friend or family member with a long-term illness, health problem or disability’ (Government of Ireland, 2007a, p.191). However, many people who provide care don’t identify themselves as ‘carers’. They see what they do as part of their role in the family, such as parent or partner (Hynes et al, 2008).

Because people with long-term illnesses are more likely to live longer thanks to advances in medical treatment, more of them will need to be cared for at home (Department of Health and Children, 2008). The specialist support services for these illnesses are still based mainly in hospitals so there is not much support for family carers in the community. As Ireland’s population is getting older and families are smaller, these changes will affect the way care is provided by the family (Fahey & Fields, 2008; Timonen, 2008). The lives of family carers in Ireland are also affected by higher unemployment and cuts in social welfare payments (Carers Association, 2010a). This is why it is so important to research family care in Ireland.

In Census 2006:

- 160,000 people identified themselves as carers (4.6% of the population),
- 60,000 males and 100,000 females,
- Carers are most likely to be aged 45-64 years,
- 93,000 carers provide one to 14 hours of caring a week, with 41,000 carers providing over 43 hours per week (Fahey & Fields, 2008).

The 2009 Quarterly National Household Survey included a special section on carers and used a broader definition (Central Statistics Office, 2010). This meant more people identified themselves as carers – from 4.6% in 2006 to 8% in 2009:

- 21% of 4,515 carers said they spent more than 57 hours caring per week,

- 38% of 8,170 carers said they felt their caring role was too much for them.

These findings suggest that family carers are under pressure and may not be able to continue in their role without support. Other research, by Hynes et al (2008), O’Brien (2009) and O’Sullivan (2008), has pointed to poor health and well-being among Irish carers. On top of this existing stress, the Government has delayed publishing the National Carers Strategy, and has cut social welfare payments for carers.

Because there is not much research on Irish carers, we need to find out more about some groups of carers. One of these groups is ‘former carers’ – where the person they care for has died or moved to a nursing home or hospice. This is called ‘post-caring’. Although there is not much research, there are two ‘models’ of post-caring that describe the stages former carers go through. Larkin’s 2009 model focuses on former carers after the person they care for has died. Davies and Nolan’s model (2003; 2004; 2006) outlines stages experienced by former carers after the person they care for has moved to a care home. This study looks at both of these post-caring experiences, but for most of the former carers we spoke to the person they cared for had died.

Aim of the study: To describe the experiences and needs of former family carers in the post-caring period.

Definition: We define former family carers as family members who cared for an ill or disabled family member at home for at least six months before they either died or moved into a nursing home or hospice.

Main research question: What are the experiences and needs of former family carers in the period after caring ends?

Specific research questions:

1. What are family carers' needs in the period after caring ends?
2. What are family carers' experiences of the period after caring ends?
3. What do family carers consider to be the factors that affect their quality of life in the period after caring ends?
4. What do family carers believe would improve their quality of life in the period after caring ends?

HOW WE CARRIED OUT THE STUDY

This was a qualitative study, which means we asked former carers about their experiences. Care Alliance Ireland and the Carers Association helped us to make contact with 40 former carers. There were two groups: a focus group of 14 carers, and 26 individual carers who took part in interviews.

Sample: Seven male and 19 female former carers took part in individual interviews. Their average age was 57 years but they ranged from 33 to 81 years old. The length of time they had spent caring ranged from six months to 27 years, with an average of seven years and nine months. Most had cared for either a parent or a spouse. Of the 26 interviewed, 25 had stopped caring because the person they cared for had died. At the time of interview, the length of time since their caring ended ranged from three months to six years, with an average of two years.

Approach: We worked with the focus group to explore two themes which we identified from other research:

- 1) When caring ended due to the cared for person moving to a nursing home – how the carer's role changed, stress related to the move, such as strained relationships with nursing staff and changes to the relationship with the person they cared for.
- 2) When caring ended due to death – how they prepared for this, and what emotional and financial support they had.

We recorded the focus group discussions on tape and listened back to them. This helped us to put together the questions for the interviews. These were 'semi-structured' which allowed us to gently guide the interviews while giving each person the freedom to talk about issues that were important to them. Some of the issues we raised were: the experiences of caring and the making the change to post-caring; the needs of former carers, factors affecting their quality of life, support they received or would like to have had.

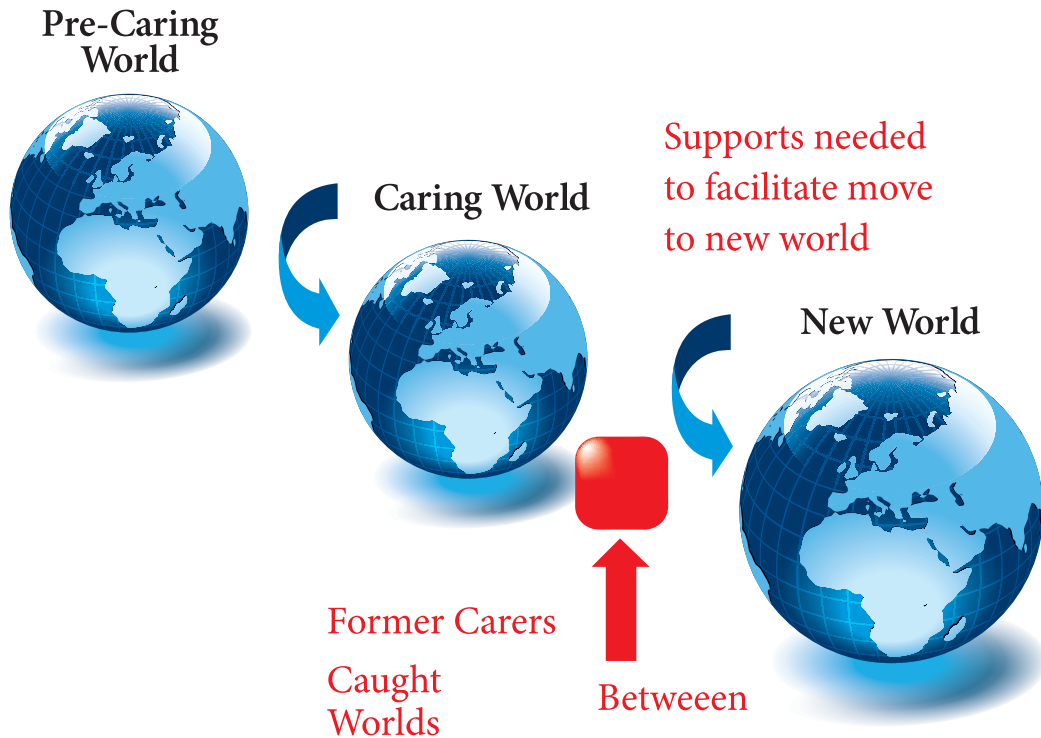
Analysis: We used template analysis (Crabtree & Miller, 1999; King, 2004) and NVivo 8 software to analyse the 26 interviews. We analysed the data directly from the tapes instead of writing it down. This meant we could capture the voice, tone and emotion of the participants.

FINDINGS

Two major themes emerged from the data: carers felt they were 'worldless' and 'between worlds'. We also identified three post-caring stages: 'the loss of the caring world', 'living in loss' and 'moving on'.

We have used the diagram below to illustrate the 'worlds' a carer moves through. When they become a full-time carer, they lose the 'pre-caring world' – the life they had with all its social contacts, work and other opportunities. The 'caring world' is their experience as a full-time family carer with its daily routines and close relationship with the person they care for. When the person they care for dies or moves to a care home, they lose this 'caring world' – they lose their identity and role as a carer, and the social network of health workers visiting their home disappears. Losing both these worlds creates a profound sense of loss and emptiness. As the loss of the pre-caring world is more distant; they need to make the transition between the 'caring world' that has just ended and a 'new world' they need to create for themselves after caring. At this stage, carers often feel 'worldless' or caught 'between worlds'; they do not belong to any particular place and don't have any particular label or identity that applies to them (see below).

Diagram 1:



The state of being ‘between worlds’ is shown by the pink rectangle in the first diagram. Diagram 2 (see next page) expands on this to illustrate the post-caring stages of (1) Loss of the caring world, (2) Living in loss, and (3) Moving on.

1. LOSS OF THE CARING WORLD

The loss of the caring world is the first stage of the post-caring period. The carer experiences many losses; loss of identity as carer, of their caring role, of the close bond with the person they cared for, and of the social network of healthcare workers.

2. LIVING IN LOSS

This is the stage of living in and continuing to experience the losses of post-caring. Former carers have emotional reactions such as guilt, relief, a sense of urgency and anger towards State services. This is made worse as they feel they have been ‘dismissed’ and devalued by State services and this can become a barrier to ‘moving on’ to a new world when caring ends. Other barriers include money problems as they lose carer allowances, and finding it hard to return to the workforce.

Although some former carers ‘move on’, it appears that others keep moving between the stages of loss of the caring world and living in loss. They become

‘stuck’ in the losses of post-caring and do not move on to the third stage – building a new life for themselves.

Those who ‘move on’ from this cycle move out of the ‘trapped’ space between worlds. They no longer see themselves as ‘worldless’ and start to build a new world. The factors that helped them to move on included family support and support from carers’ organisations.

3. MOVING ON

This is the stage where former carers begin to move on to a new world. They begin to care for themselves, keep active, become involved in their community, and ‘get out of the house’. For some former carers, ‘moving on’ involves taking on other caring roles, such as supporting other family carers or taking care of grandchildren.

We were surprised to find that, while male carers experienced the same challenges and stress in this stage, they also described the support they received from small, emerging male support groups. Two to three men, including widowers and former carers, meet for social outings or in each other’s houses, lending each other emotional support as part of the social occasions.

Diagram 2:



This second level of the model shows how former carers can continue to move between the stages of the post-caring period.

CONCLUSIONS

The former carers who took part in this study pointed out that the state does not provide any services for

post-carers. This is a major issue, considering the experience of being ‘stuck’ and the financial stress when caring ended. There needs to be support for former carers and support structures through carer groups, including bereavement support. There should be a ‘toolkit’ to help prepare carers for when

caring ends, with information on what to expect and where to go for help and advice. Finally, former carers know a lot about the health and social care services system and health workers in their area. They would like to be able to share this with new and current carers who could benefit from their advice and guidance.

Most local carers' support groups are attended by more women than men but men make up 40% of carers in Ireland. They are under-represented in carer groups and other services. The findings from our study may help carers' organisations and state services to develop options that may appeal to male former carers.

The approach we took in this study meant that the former carers who took part were linked to carers' organisations, so were receiving at least some support. Future research should reach out to former carers

who are not engaged with existing support services. Another factor is that for most of the former carers we interviewed, caring ended due to the death of the person they cared for. This meant that people whose caring ended due to the person moving to a nursing home or hospice were not well represented. However, most research focuses on these former carers. This study begins to address the lack of research on the experiences of former carers whose caring has ended due to death.

This study reveals that former carers have many strengths that are not well appreciated and utilised. Some find themselves stuck 'between worlds', and with mental health and money problems, yet they have many suggestions for supports that will make the difference to them and other carers. Future research and services must respond to these needs and ideas.

