‘Life After Care: Transitional Pathways, Reconstruction of Life Post Care and Outcomes for Former Carers’

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CARL Research Project

CARL
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RESEARCH LINKS
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Abstract

To date, much of the research conducted in the area of informal family care concentrates on either those in receipt of care or those engaged in active caregiving roles; consequently, there is a dearth of information and research that comprehensively examines the ‘post care’ stage of the caregiving career. This study, in collaboration with The Carers Association, aims to make a contribution to the limited research pool regarding former carers, through an in-depth exploration of the post care transition and an investigation of the factors that support or impede a positive reconstruction of life post care.

Through the medium of seven semi-structured interviews, this research examines the issues that confront and exist for those who may evolve into a post caring role, largely an evolution of which is outside of their control. It is aspired that this study will highlight the necessity for a social and political response in order to make advancements towards alleviating the challenges faced by former carers in Irish society. The culmination of comparable studies and reiterated recommendations could, in time, feed into social and governmental policy with regard to the acknowledgement, treatment and social protection of former carers and ultimately, contribute towards combating the developing marginalisation of this cohort of individuals.

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This chapter seeks to discuss the participatory approach to the research design and the theoretical perspectives employed within this study. An examination of the use of qualitative research, which directed the data collection and analysis methods, is also presented. Following this, the ethical considerations and boundaries and limitations of this study will be explored.

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Chapter One

Introduction and Background

1.1 Introduction

In contemporary society, the discourse of carers and family caring is receiving increased exposure within the context of research and policy. However, to date, the recognition of life 'post care' is continuing to be overlooked as a significant phase of the caregiving career (Larkin, 2009). The purpose of this chapter is to introduce the study by presenting the background to the research and the rationale for undertaking this study through the Community Academic Research Links (CARL) initiative. The objectives of the study and the accompanying research questions will also be presented, followed by an exploration of my reflexive positioning within this research.

1.2 Background to the Research

While several societies have endeavoured to place the responsibility of caring on the State, Irish society has been inclined to place more of a focus on family members and the collective community to be responsible for the care of its most vulnerable members (Timonen and McMenamin, 2002). It has been argued that the historical Catholic influence has impacted greatly upon the conceptualisation of family caring and as a result, familial obligations to undertake caring duties have been endorsed in policy as well as in practice (O'Riordan and O'hAdhmaill, 2014; McDonald *et al.,* 2006). The latest Census statistics from April 2011 reflected this positioning by noting that 4.1% of the overall Irish population was providing unpaid care to friends or family members in need of assistance (Central Statistics Office, 2011).

Undertaking a primary caring role can be demanding and all encompassing; it is estimated that full-time carers provide an average of 110 hours of care per week (McCarron *et al.,* 2011). The impacts of such an intense level of caring can generate detrimental and persisting consequences for the carer during and subsequently after the caring role (The Carers Association, 2013). In a report by The Carers Association, (2013, p. 10), 66% of family carers expressed that their own lives were negatively impacted by their caring role and 38% reported feeling 'completely overwhelmed' as a result of the demands of full-time care responsibilities. Orzeck and Silverman (2008, p. 211) stress the importance of acknowledging carers as holistic human beings, with requirements that are separate to that of their care recipients and not simply as 'instruments for providing care'.

1.3 Rationale

This research study has been undertaken in collaboration between The Carers Association and Community Academic Research Links (CARL). CARL connects students with opportunities to conduct research with and on behalf of a Civil Society Organisation (CSO) and offers 'independent, participatory research support in response to concerns experienced by civil society' (CARL, 2012, p. 1). The Carers Association, the CSO who proposed this research is a voluntary organisation 'for and of family carers in the home' (The Carers Association, 1987, p. 1). This organisation endeavours to advocate on behalf of Irish carers and ensure that they receive the necessary supports to care for their care recipients in their own homes for as long as is feasibly possible; an arrangement that is supported by the Irish Government (Department of Health, 2011, 2012).

A key feature of community-based participatory research involves a community group proposing a research question, which is derived from their day-to-day practice, often with an end goal of some form of social action. The Carers Association approached CARL with a request for research to be conducted on the experiences of former carers; a group that they feel are becoming increasingly marginalised and of which there is very little Irish research available. Existing research on informal family carers tends to focus predominantly on those in the active caregiving stage (O'Sullivan, 2008; Roberto *et al.,* 2008; Stokes, 2009). Carers who have ceased their caring role have not been afforded a similar level of significance and attention from researchers; consequently, there is a scarcity of research that comprehensively examines the 'post care' stage of the caregiving life course. This study aims to make a contribution to addressing the existing void in the research concerning those who no longer fulfill caring roles, while highlighting the need for governmental support and policies to cater for this currently unrecognised group in our society. Owing to the lack of recognition of former carers in the *National Carers Strategy*, *Recognised, Supported, Empowered* (Department of Health, 2012), The Carers Association felt that presenting a research study that highlights the voices and experiences of former carers would facilitate a more evidence-based approach towards pursuing practice and policy developments for these individuals. As it stands, within Irish policy, supports and services for former carers are conspicuous by their very absence.

My own interest and experience in the area of family care also encouraged me to undertake this study in collaboration with The Carers Association. Many individuals in my own family engaged in multiple caring roles in various capacities throughout their lives. Observing the magnitude of struggles faced by these family members in their active and post caring lives has afforded me the opportunity to acknowledge the importance of supporting carers both during and after their caring role. Professionally speaking, this research will provide me with an opportunity to act as an advocate and enhance my understanding of a current and pertinent social issue.

1.4 Aims and Objectives of the Research

The objective of this study is to elicit the views of former carers in an attempt to explore and understand their unique interpretations of their post care transition. It will also provide a greater understanding of what supports and services are required for former carers in order to encourage a positive transition following the end of the caring role.

1.5 Research Questions

1. What opportunities and challenges do former carers encounter in the transition and period following the cessation of the caring role?
2. What do former carers feel is necessary in order to engage in a positive post care transition and conversely, what factors serve to impede this transition?
3. How can policy and practice be developed to better recognise and support former carers in the transition and period following the cessation of the caring role?

1.6 Definitions

This section defines the key terms that will be used throughout this study.

Carer

A carer can be defined as *'someone who is providing an on-going significant level of care to a person who is in need of that care in the home due to illness or disability or frailty'* (Department of Health, 2012, p. 8).

Informal Carer

An informal carer can be defined as *'a carer that looks after family, partners, friends or neighbours in need of help because they are ill, frail or have a disability; the care they provide is unpaid'* (Eurocarers, 2010, p. 1).

Former Carer

Former carers are defined as *'partners, relatives, friends or neighbours who have completed their caring role because of the death of the person they were supporting or because the carer no longer has any involvement in caring'* (NSW Carers Australia, 2006).

Community-based Participatory Research

Community-based participatory research (CBPR) is '*an applied collaborative approach that enables community residents to more actively participate in the full spectrum of research (from conception, design, conduct, analysis, interpretation, conclusions and communication of results) with a goal of influencing change in community health, systems, programs or policies'* (National Institute of Health, 2015).

1.7 My Reflexive Positioning as the Researcher

Through conducting a study such as this, I feel that it is imperative to ensure that my reflexive positioning within the research, combined with any influences I may bring is transparently discussed. As a social work student, I have gained a valuable amount of experience in the areas of children in care and young person's probation. As a result, my personal and professional values have developed and a new sense of appreciation for family relationships and family support has emerged. My personal life experience of family caring has certainly shaped the lens through which I view the world and most importantly, my perspective in relation to the struggles that family carers may encounter.

Nevertheless, I consistently remained open to the possible positive and negative perceptions of the active care and post care experiences of former carers; this openness was extended to the data collection and data dissemination stages of the research. Ultimately, however, my reflexive positioning within this study was shaped by the overarching principles of activism and social change, combined with my belief that support should be provided to those who are in a position of vulnerability.

1.8 Conclusion

In this chapter, an introduction to the background of family caring and the significance of informal family carers to Irish society has been presented. This chapter also outlined the genesis of the study, the aims of the research and the consequent research questions. My reflexive positioning within this research has been offered, as a means of making transparent any influence that I may have on the study. The following chapter serves to familiarise the reader with the methodological underpinnings of the research design of this study and sets the context for the practice of community-based participatory research.

Chapter Two

Research Design

2.1 Introduction

As this study focuses on exploring the personal experiences of former carers, this chapter serves to outline the research design approach that was employed to meet this objective. The philosophical and theoretical underpinnings, which directed the data collection and analysis methods, will be examined, as will the role of community-based participatory research in the design of this study. This chapter will conclude with a dissemination of the ethical considerations and an exploration of the boundaries and limitations of this study.

Figure 1: Dimensions of Research Design

2.2 Philosophical and Theoretical Underpinnings

At the core of any research study are central philosophies that enable the researcher to uncover the nature of the phenomena under investigation (Ritchie & Lewis, 2003). As illustrated in Figure 1, the dimensions of research design comprise ontology, epistemology, methodology and research methods. Similar to the cohesion between jigsaw pieces, each dimension interacts with one another in order to construct a method of research design that is sequential, interrelated and generates the most authentic understanding of the research topic (Carey, 2009). The ontological and epistemological approaches utilised will now be discussed in further detail.

2.2.1 Social Constructionist Approach

Research literature suggests that in the social sciences specifically, the aim is 'to understand the subjectively meaningful experiences' of those whom we wish to research (Ritchie & Lewis, 2003, p. 7). The ontological position of this study adopts a social constructionist stance; in contrast to positivism, which assumes that there can be a comprehensible objective understanding of certain social phenomena (Alvesson, 2009). Within this approach, Alvesson (2009, p. 25) explains that individuals' interpretations of the social world are inconsistent, reality is subjectively created and as a result, there may exist 'several different realities' of similar social contexts. Through employing a social constructionist approach, the aim was to explore how former carers interpreted and understood the meaning they attributed to their experiences and how these meanings shaped the perception of their post care transition.

2.2.2 Interpretive Phenomenological Analysis

Interpretive theory is an epistemological approach, which embraces the effort to better understand the unique interpretations and 'lived experiences' of the research participants' social worlds (Ritchie & Lewis, 2003, p. 7). Supplementary to this, phenomenology explores, through the collection of primary data, the participants' personal awareness of their social experiences. Within this approach, the researcher allows the participants to lead the research process and avoids attributing a subjective meaning to the data (Carey, 2009). A combination of interpretive theory and phenomenology results in interpretive phenomenological analysis (IPA). Essentially, IPA aspires to explore 'how people make sense of their major life experiences' (Smith *et al.,* 2009, p. 1). IPA was regarded as being the most suitable epistemological approach, as this study focuses upon the subjective experiences of former carers, combined with a method of research enquiry that values the contribution of the participants.

2.3 Qualitative Research

Through discussion with The Carers Association, it was decided that the objectives of this study would be best served using small-scale qualitative research. Carey (2009) explains that small-scale qualitative research involves an exploration of the detailed experiences of a limited number of participants, combined with a critical investigation of the associated literature. Fundamentally, qualitative researchers attempt to incorporate 'the use of people's life stories in understanding experiences and social constructions' (Ritchie and Lewis, 2003, p. 8). Qualitative research was selected, as The Carers Association was specifically interested in the personal experiences of former carers and intended to utilise this study to provide these individuals with a voice; a fundamental feature of their overall agenda.

2.4 Sampling

The recruitment of participants was conducted by means of a purposive sampling approach. Purposive sampling involves selecting a number of participants who share similar characteristics applicable to the area of study (Carey, 2009). Abiding by the purposive sampling approach, recruitment was based upon relevant criteria. The chosen sample aimed to ensure diversity in regard to age, gender, length of time caring and relationship to the care recipient; however it was agreed that the participants should be over the age of eighteen to ensure full and informed consent. The exclusion criterion of those whose caring role had ceased in the last year acted as a means of being mindful towards the grief and loss that participants may be experiencing, as is discoursed within the literature (Larkin, 2009). After a period of discussion, it was decided that the coordinator of The Carers Association would provide potential participants with an outline of the study and subsequently advise of the process by which they could become involved (Appendix 1). The demographic profile of the participants will be further illustrated in Chapter Four.

2.5 Data Collection

In designing the data collection methods, it was decided that semi-structured interviews would be the most appropriate vessel by which the subjective meanings and experiences of former carers could be explored. Darlington & Scott (2002, p. 48) contend that;

> *'The in-depth interview takes seriously the notion that people are experts in their own experience and so are best able to report how they experienced a particular event or phenomenon'.*

The possibility of incorporating focus groups was discussed in the early stages of the research design; however, it was decided that semi-structured interviews would yield a richer source of data and would accommodate the theoretical positioning of the research. The interview process was divided into: structured questions, as a means of obtaining basic demographic details of the participants (Appendix 4); and unstructured interview topics/discussion guide, which provided the participants with an opportunity to provide a comprehensive analysis of their unique perspectives, while facilitating flexibility in terms of further exploration during the interview (Whittaker, 2009) (Appendix 5).

The initial interview questions originated from pertinent themes that emerged throughout the literature review and through discussion with the coordinator of The Carers Association. Seven semi-structured interviews were conducted, generally lasting between 1-1.5 hours and a combination of audio recording and note taking was utilised. Following this, the seven interviews were transcribed into a verbatim written format in order to provide accessibility to the data for the analysis of the findings.

2.6 Data Analysis

The data analysis section of the research attempts to create an understanding, meaning and explanation of the findings derived from the empirical research (Ritchie & Lewis, 2003). The method of data analysis, which was most suitable in this study, was that of thematic analysis. Thematic analysis attempts to uncover themes that emerge within the data collected or to expand upon themes raised in related literature (Carey, 2009). The emerging themes were identified and then combined to formulate an extensive depiction of the collective experiences of the participants. Following this, the themes were compared to the relevant literature and critically analysed.

2.7 Community-based Participatory Research

Montero (2000) suggests that participatory research alters the individualistic pattern of carrying out research 'on people' and instead aspires to create research 'with people', (cited in Evans *et al.,* 2014). This form of research is conceptualised and developed in collaboration between community members and the academic researcher, with the mutual aim of attending to a need identified within the community and moreover, in an endeavour to link academic and advocacy interests (Strand *et al.,* 2003). The ideology that community members are 'owners of skills, knowledge and expertise' is an inherent element of the community-based participatory approach and therefore, was a principal consideration throughout this process (Munck, 2014, p. 11). As such, a collaborative approach was employed in all facets of the research process, from the original research design to the analysis and presentation of the findings. Furthermore, community-based research is highly relevant to the field of social work, in which the pursuit of social justice remains a consistent feature. Ferguson and Woodward (2009) suggest that it is incumbent upon social workers and researchers alike to actively engage with community members' experiences of social inequality; this was the primary motivation in choosing a dissertation grounded in community-based participatory research.

2.8 Ethical Considerations

Bryman (2012, p. 30) asserts that a fundamental component of ethical research is the responsibility upon the researcher to question, 'how should we treat the people on whom we conduct research?'. Accordingly, an ethical review form was submitted to the School of Applied Social Science, which outlined the proposed framework of the ethical considerations of the research. The main ethical concern was the delicacy and sensitivity of the topic, which essentially involves the retrospective discussion of the participants' care recipients for whom they are no longer caring. As mentioned previously, the exclusion of participants whose caring role had ceased in the last year acknowledged the vulnerability of participants in the early stages of their post care transition (Larkin, 2009). At the end of each interview, a de-briefing conversation was held with each participant and it was ensured that they were provided with information in relation to available support services.

2.8.1 Informed Consent

It was necessary that the participants were made aware of the following aspects of the research: the purpose of the study; voluntary participation; representation of the data; confidentiality and anonymity; and the option to withdraw from the study following the interview (Silverman, 2004). Prior to the interviews, each participant was provided with a detailed information sheet and subsequently advised of the consent form, which all participants agreed to sign (Appendix 2 and 3). All of the participants also agreed to the recording, transcription and use of quotations within the study.

2.8.2 Confidentiality and Anonymity

The responsibility to safely secure data and maintain the participants' anonymity was a principal consideration throughout this study. As such, a pseudonym was chosen for each participant at the outset and all information provided by the participants was stored in this format throughout the data dissemination phase. As a means of safeguarding the data, information derived from the data collection phase was stored on an encrypted computer and also on the secure UCC student server.

2.9 Boundaries and Limitations

Through the application of an interpretivist framework and the utilisation of semi-structured interviews, methodological limitations on the study will invariably be imposed. Although an endeavour was made to maintain a position of objectivity throughout the research process, May (2001, p. 127) contends that ‘it is difficult to create the right environment to gain qualitative data, while also being detached and objective’. The literature recommends that the researcher adopts ‘empathic neutrality’, a position that acknowledges that research cannot be unbiased, however, that it is the responsibility of the researcher to make their preconceptions transparent (Ritchie & Lewis, 2003, p. 13).

Furthermore, due to the constraints in terms of the time and scope of this dissertation, it was only feasible to conduct a small-scale research study. It must be clearly noted that the findings derived are restricted to the sample of participants who were involved in this research process. As such, the findings and recommendations do not qualify to be applicable to the wider population of former carers.

2.10 Conclusion

Within this chapter, it has been discussed how a qualitative research method underpinned by a social constructionist ontology and an interpretivist epistemology was the most suitable approach towards achieving the objectives of this study. This research design facilitated an emphasis upon the individual ‘lived’ experience, understandings and meanings that former carers ascribed to their post caring lives. Additionally, the ethical considerations and limitations of conducting a study through the medium of qualitative research has been discussed and explored. The following chapter will serve to provide an outline of the existing policy and literature relating to the overall context of family caring, theoretical frameworks of the post care trajectory and the factors that support and impede a positive reconstruction of life post care.

Chapter Three

A Review of the Literature

3.1 Introduction

The purpose of this chapter is to examine the central themes within the literature relating to this study including: an illustration of the overall context of informal family caring; the implications of the caring role on life post care; theoretical models of the post care transition; and the factors that support or impede a positive reconstruction of life post care. A proportion of this literature review will be assigned to the active caring stage, as it is widely acknowledged that this stage of the caregiving career has insurmountable implications on the post care transition (Aneshensel *et al.,* 2004; Orzeck and Silverman, 2008, Schulz *et al.,* 1997, 2003).

3.2 Who Cares?

Larkin (2009) asserts that it is an almost accepted reality that the family of an individual in need of care is fundamentally responsible to voluntarily provide that care. Inglis (1998) contends that, in Ireland specifically, the Catholic ideology of the family as being responsible for its own welfare has cemented the enduring conceptualisation of family caring. It appears that this ideology has been closely adhered to, as Governmental policy has consistently endorsed their partiality towards home care above residential care arrangements (Department of Health, 2011, 2012).

There are an estimated 274,000 individuals providing care in some capacity in Ireland at any one time (The Carers Association, 2008) and informal family carers provide 80% of all care across the EU (Glendinning *et al.,* 2009). However, Hynes *et al.* (2008) highlight a discrepancy within the statistics due to the fact that many carers do not report or categorise themselves as being carers, rather they perceive their role to be a natural aspect of their familial responsibilities. As documented by the Central Statistics Office (2012), females are more likely to undertake caring duties and provide two-thirds of all caring hours. Yet, McCarron *et al.* (2011) affirm that awareness should be developed towards the increasing level of male participation in care related activities, as male carers currently comprise 38% of the overall caregiver population (CSO, 2012). The majority of family carers are within the 45-64 age bracket and it is noted that the average time spent caring escalates with the age of the carer, thus illustrating the contribution of the ageing population in providing informal family care (The Carers Association, 2009; CSO, 2012). Moreover, there is a developing awareness of young carers in Irish society, who at present are termed ‘invisible carers’ (Department of Health, 2010, p. 2). It was reported that 4,228 children under the age of 15 were providing care to a family member in the 2011 census, which accounts for 2.3% of the overall caregiver population (CSO, 2012).

3.3 The Social and Economic Contribution of Family Carers

On average, each year, a full-time carer saves the State a total of €62,000; in the latest census in 2011, a total of 182,884 family carers were recorded, effectively saving the State approximately €4 billion per annum (Care Alliance Ireland, 2013; CSO, 2012). While considering the cost of residential care at €800-€1500 per week and €7000 per week for hospital care (HSE.ie), the above savings to society become starkly apparent.

Supplementary to the caring role subsidising State expenditure, carers contribute to the social care of vulnerable members within our society. Orzeck and Silverman (2008, p. 211) determine that family carers provide physical, emotional, practical and personal care to their care recipient and that the family caring role ‘goes beyond the call of duty’. *The National Action Plan on Social Inclusion* (2007, p. 17) recognised the significance of family carers to Irish society by stating;

> *‘Informal and family carers play a valuable role in our society, particularly in enabling older people and people with disabilities to remain in their own homes for as long as possible’.*

3.4 Future Trends in Informal Family Caring

The family as the main resource for care is undergoing a period of uncertainty due to the rapid demographic changes in our society (Fahey and Fields, 2008). In a report by McGill (2010) it was estimated that those aged 65 and over will increase from its current rate of 700,000 to an expected 1,900,000 in 2041; this is related to life expectancy rates generally rising by 20-25 years since the 1920’s. Care Alliance Ireland (2015) indicate that a combination of a rapidly ageing population, changes in family structure and an upsurge in women’s participation in the employment sector will invariably have implications upon the future landscape of informal family caring in Ireland. Cahill *et* *al*. (2012) called for consideration of the unsustainability of home care and the potential implications this will have on Governmental expenditure if alternative means of care are to be required in the future.

3.5 Recognition and Supports for Family Carers in Ireland

Traditionally, the focus of Governmental support and policy has been on those in receipt of care; it is only quite recently that acknowledgement has been afforded to informal family carers. This recognition materialised in the form of the *Towards 2016 Social Partnership Agreement* and the subsequent introduction of *The National Carers' Strategy, Recognised, Supported, Empowered* (Department of Health, 2012); hitherto absent from previous Governmental policies. The strategy ultimately gave an assurance to acknowledge, empower and deliver essential supports to family carers in Ireland, hence finally acknowledging their contribution. Nevertheless, key arguments remain in regard to the expectation upon the family unit to undertake the primary caring responsibility with minimal contribution and support from the State (The Carers Association, 2010). Let us now consider what State supports are currently available for Irish family carers.

3.5.1 Carers' Allowance and Carers' Benefit

The State aims to support family carers financially by means of the The Carers' Benefit and The Carers' Allowance. Full-time carers are qualified to receive the Carers' Allowance at a rate of €204/week for carers under 66 and €239/week for those over 66 (welfare.ie, 2015). As these benefits are means-tested, a proportion of carers in fact, do not receive regular financial assistance from the State. The means-testing procedures are also characterised by invasive levels of assessment criteria and high refusal rates and furthermore, many carers are unaware of its existence (O'Riordan and O'hAdhmaill, 2014). To put it into perspective, The Carers Association (2005) explains that the Carers' Allowance constitutes about a third of the average net weekly income in Ireland. Essentially, the literature argues that financial supports for carers are inconsistent and insufficient. The Joint Oireachtas Committee (2002, p. 6) succinctly described the state of financial aid by commenting;

> *'There are economic and fiscal advantages to the State where the family are key providers of care, but these savings have not been re-distributed to the carers in an equitable manner'.*

3.5.2 Respite Care and Home Help

Respite is generally regarded as a formal or informal service intended to provide carers with relief from their caring duties (Hanson, *et al.,* 1999). All full-time carers receive the Respite Grant; however, this grant was cut by a staggering 19% in the 2013 budget and now stands at €1,375 per year (McCarron *et al.,* 2011; HSE.ie, 2015). Care Alliance Ireland (2009) reported that even prior to the budget cut, this grant did not cover the cost of providing carers with four weeks of holiday entitlements, which the majority of employees receive.

The literature acknowledges issues within the current respite system; this was summarised by the Joint Oireachtas Committee (2002, p. 18) who stated that respite services are 'minimal, unevenly distributed and inequitably apportioned'. Additionally, Hoare *et al.* (1998) points out that many carers believe that accessing respite services signifies their incapability to cope with their caring role. It has also been contended that respite care is often perceived as a last resort in periods of crisis, rather then an on-going necessity to alleviate carers of their demanding duties (Roberto and Jarrot, 2008).

Home help entails formal carers going to the home of the care recipient and carrying out personal care related duties. *The Health Act* (1970), the legislative framework underpinning home help services, recommends but does not oblige the HSE to provide such a service to carers. As such, home help services have been widely criticised in terms of their discretionary allocation and varied standards (O'Riordan and O'hAdhmaill, 2014).

3.6 Implications of Caring on Life Post Care – 'Role Engulfment'

It is only in the last twenty-five years that research has begun to consider the repercussions of caring on family carers (Guberman *et al.,* 1991; Lawton *et al.,* 1991; Choi *et al.,* 2012; Care Alliance Ireland, 2015). This warrants significant consideration, as research has illustrated that the physical, psychological and social impacts of active caring may persist following the end of the caring role. Cairns & Brown (2012) report that during their caring career, carers may prioritise the care recipient and in turn, neglect their own health, needs and well being; consequently, the role of 'caregiver' may dominate all facets of the carers' life. This is referred to as 'role-engulfment', as coined by Skaff and Pearlin (1992). As a consequence of role-engulfment, many carers make enormous sacrifices in terms of employment, relationships, social networks and personal interests. Incidentally, these are all essential aspects of sustaining an individual identity, which is a prerequisite for engaging in a positive post care transition (Aneshensel *et al,* 2004; Orzeck and Silverman, 2008).

3.6.1 Implications of Caring - Physical and Mental Health

The literature extensively examines how the impact of such a demanding role may serve to induce long-term physical and psychological health penalties for the carer, which may persist and become exacerbated when the caring role ends (O'Shea, 2000; Hynes *et al.,* 2008; Choi *et al.,* 2012). Assuming multiple roles and responsibilities, encountering various crises and providing possibly years of daily care is correlated with high levels of psychological distress (NESF, 2005; Care Alliance Ireland, 2010). In a study conducted by O'Sullivan (2008), carers reported a less positive outlook on quality of life, had comparatively increased levels of depression and anxiety and furthermore, were at a higher risk of stress and emotional strain as a result of taking on the role of family carer. Correspondingly, Singleton *et al.,* (2002) note that family carers are three times more likely to experience ill-health than the general population. The limited social interactions, leisure time and isolation from the 'outside world' were discussed as being the primary culprits of poor health and quality of life. Furthermore, three quarters of those involved in Larkin's (2009) study reported that their lives felt quite restricted whilst caring for their dependant and they could not simultaneously live their own lives whilst caring.

3.6.2 Implications of Caring - Finances

'Caring on a regular and substantial basis leads to financial hardship' (Combat Poverty Agency, 2009, p. 8). The all-encompassing nature of family caring can result in serious financial repercussions for the carer, which may persist into their post care lives. Financial difficulty manifests in terms of: lost or postponed career opportunities; costs of care; medical expenses; the low rate or absence of the Carers' Allowance; limitations on pension entitlements; and the struggle of re-entering the workforce after an extended period of time in a caring role (McLaughlin and Ritchie, 1994; NESF, 2005; Care Alliance Ireland, 2013). It is imperative to relay that the Carers' Allowance is terminated six weeks after the end of the caring role; The Equality Authority (2005) argues that this is insufficient time in order for former carers to adapt to their post care lives and attempt to source an alternative income. Essentially, when the caring role ends, a long-term carer who is not entitled to an occupational pension or supplementary welfare payments may be at risk of poverty (O'Riordan and O'hAdhmaill, 2014, CPA, 2009).

McLaughlin and Ritchie (1994) conclude the implications of caring by contending that the significant physical, psychological and social impacts of the caring role may leave the carer poorly equipped to deal with their post care transition; a topic which will now be discussed.

3.7 Transitioning Into The Post Care Phase

There are many terms proposed throughout the literature in relation to the post care phase of the caregiving career, such as: 'The Exit Stage' (Lindgren, 1993); 'Taking the Next Step' (Brown and Stetz, 1999); and 'Reaching The End' or 'A New Beginning' (Nolan *et al.,* 2003). All of these terms are based upon the caring role ending due to the death of the care recipient or the transition into a residential care home. The term used in this study will be that of the 'post care' stage.

3.7.1 Immediately Following The End Of The Caring Role

Many complex difficulties arise for the carer as a result of the transition into the post care stage. During this period, the carer is forced to adjust to a sudden discontinuation of their caring role and propelled into a period of complete lifestyle adjustment (McCarron *et al.,* 2011). Simultaneous experiences of potentially complicated mourning and attempting to construct a new identity are hallmarks of this stage, and which differentiate former carers from other mourners (Orzeck & Silverman, 2008). This stage can also comprise multiple experiences including feelings of isolation; financial insecurity; loneliness; loss of identity; loss of personal and social life; and the loss of the bond with their care recipient (Orzeck & Silverman, 2008)._Although there is not extensive research available in relation to the post care transition, Larkin (2009) and McCarron *et al.* (2011) have proposed explanatory theoretical models of the post care stage of the caregiving life course, which will now be explored.

3.7.2 Theoretical Models of the Post Care Transition - Larkin's Post Care Trajectory

Larkin's (2009) research offers a theoretical framework of the 'post care trajectory' of former carers. It must be noted that although this piece of research was conducted within the context of carers who have transitioned into post care due to the death of their care recipient, it is certainly applicable to former carers whose care recipients have transitioned into alternative care. In Larkin's framework, three phases are explained, which comprise a unique set of experiences in the period following care. The first is that of the 'post caring void', which instigates an immensely challenging period coinciding with grief and a loss of identity, purpose, role and social networks. As a result of the decline in the already limited social interactions, Larkin reports that the former carer is at an increased risk of social isolation. During this phase, a sense of ‘disequilibrium’ may also occur when the former carer experiences a state of uncertainty regarding their future.

The second of Larkin’s phases is termed ‘closing down the caring time’ (p. 1033). This is a period of intense transition in which the former carer faces substantial transformations in their routine and daily life. In the weeks after the end of the caring role, former carers were also required to carry out ‘closure activities’ such as dealing with possessions, funeral arrangements and financial/legal issues. Personal responsibilities that could not be completed whilst caring may be focused upon, and on a fundamental level, the former carer attempts to adjust to their new way of living.

Larkin’s third phase is known as ‘constructing life post caring’, which is depicted as ‘getting life together again’ and ‘coming up to the surface’ (p. 1035). Essentially, this period entails the former carer constructing a new identity through considerations such as routine, social networks, personal interests and career opportunities.

3.7.3 Theoretical Models of the Post Care Transition - McCarron et al. Post Care Trajectory

McCarron *et al.* (2011) also proposed three main dimensions of the post care transition, the first of which is the ‘loss of the caring world’. Similar to Larkin’s observations, this phase occurs immediately following the end of the caring role and is characterised by intense grief and multiple losses including: loss of role or vocation; loss of identity; loss of the relationship with the care recipient; and a diminishing of social relationships with healthcare professionals. The second phase is termed ‘living in loss’, which entails a period of powerful emotional responses such as grief, relief, anger, urgency and a consideration of the former carers’ future financial state. McCarron *et al.* (2011) suggest that due to the perceived dismissal of the former carer by the State, these emotional reactions are exacerbated and may cause severe distress for the former carer. Comparable to Larkin’s model, the third phase is identified as ‘moving on’. This is a time in which the former carer contemplates their future and actively begins to reconstruct their life by becoming involved in activities, interests and further caring roles.

It is imperative to communicate that not all carers transition through the post care stage successfully; as such, these theoretical models may be considered an overly optimistic view of the experiences of former carers (Larkin, 2009; McCarron *et al.,* 2011).

3.8 Factors that Support and Impede a Positive Reconstruction of Life Post Care

The post care transition can be experienced in a variety of different ways, depending upon what protective factors or risk factors are present for the former carer. Factors that aid in a positive reconstruction of life post care include, positive physical and mental health, an adequate income and being sufficiently integrated into the local community (Aneshensel *et al.,* 2004; McCarron *et al.,* 2011). In terms of income, Choi *et al.* (2012) report that carers with a higher income encounter lower levels of emotional distress following the end of the caring role. Additional factors include that of support from family and friends, paid employment and possible further caring roles. As a whole, it was suggested that former carers began to reclaim their lives after the end of the caring role by pursuing activities such as education, hobbies, volunteering and returning to paid employment. Conversely, the risk factors towards a positive reconstruction of life post care include an absence of the above protective factors, high exposure to stress during caring, adverse experiences during caring and access to available resources when the caring role ends (Aneshensel *et al.,* 2004).

3.8.1 The 'Serial Carer'

In Larkin's (2009) research, the concept of the 'serial carer' was presented, which was initially introduced by Lewis and Meredith (1988) as a 'vocation carer'. This describes the cyclical nature of the post care trajectory in which carers engage in a further caring role after their initial caring role has ended, out of choice or out of necessity and often on multiple occasions. Half of the participants in Larkin's (2009) study undertook another voluntary caring role and many reported that carrying out caring related duties for friends and neighbours aided in the positive reconstruction of their lives post care.

3.9 The Current Status of 'Former Carers' in Ireland

There is an abundance of information, which communicates the struggles and uncertainties that are an inherent element of sacrificing one's life to care for another. Yet, when caring ends, new adversities present themselves, which are unfortunately underappreciated in terms of research, policy and practice.

It has been argued that this may be a consequence of the tendency to disregard the post care phase as a significant stage of the caregiving career (Bodnar and Kiecolt-Glaser, 1994). Regrettably, the lack of consideration and acknowledgement towards those who have ceased their caring role is a global issue and has resulted in a situation whereby former carers are becoming increasingly marginalised (McCarron *et al.,* 2011).

Care Alliance Ireland (2013) contend that this is certainly reflective of the Irish State in terms of their failure to adequately respond to the needs of former carers. Despite the T*owards 2016 Social Partnership Agreement* (2006, p. 54) additionally pledging that ‘consideration will also be given to enhancing economic and social inclusion supports to people whose caring responsibilities have concluded’, this has yet to recognised as a priority within Governmental policy. The support that may have been abundant during the active caring stage through the State and service agencies invariably dissipates once the carer is no longer actively caring. Consequently, those who arrive at the end of their caring role are generally left with no support, services or protection. As it stands, ‘there are no statutory health or social care services in place for former carers’ (Care Alliance Ireland, 2013, p. 40).

Chapter Four

Analysis and Discussion of Findings

4.1 Introduction

This chapter presents and analyses the primary research findings derived from interviews conducted with seven former carers. The themes that emerged were quite extensive; as such, prominent themes will be focused upon and explored in relation to the relevant literature. The themes that emerged naturally corresponded with the proposed research questions; consequently, this chapter will be structured in this format. For reasons of confidentiality and anonymity, the names of the participants have been substituted with pseudonyms.

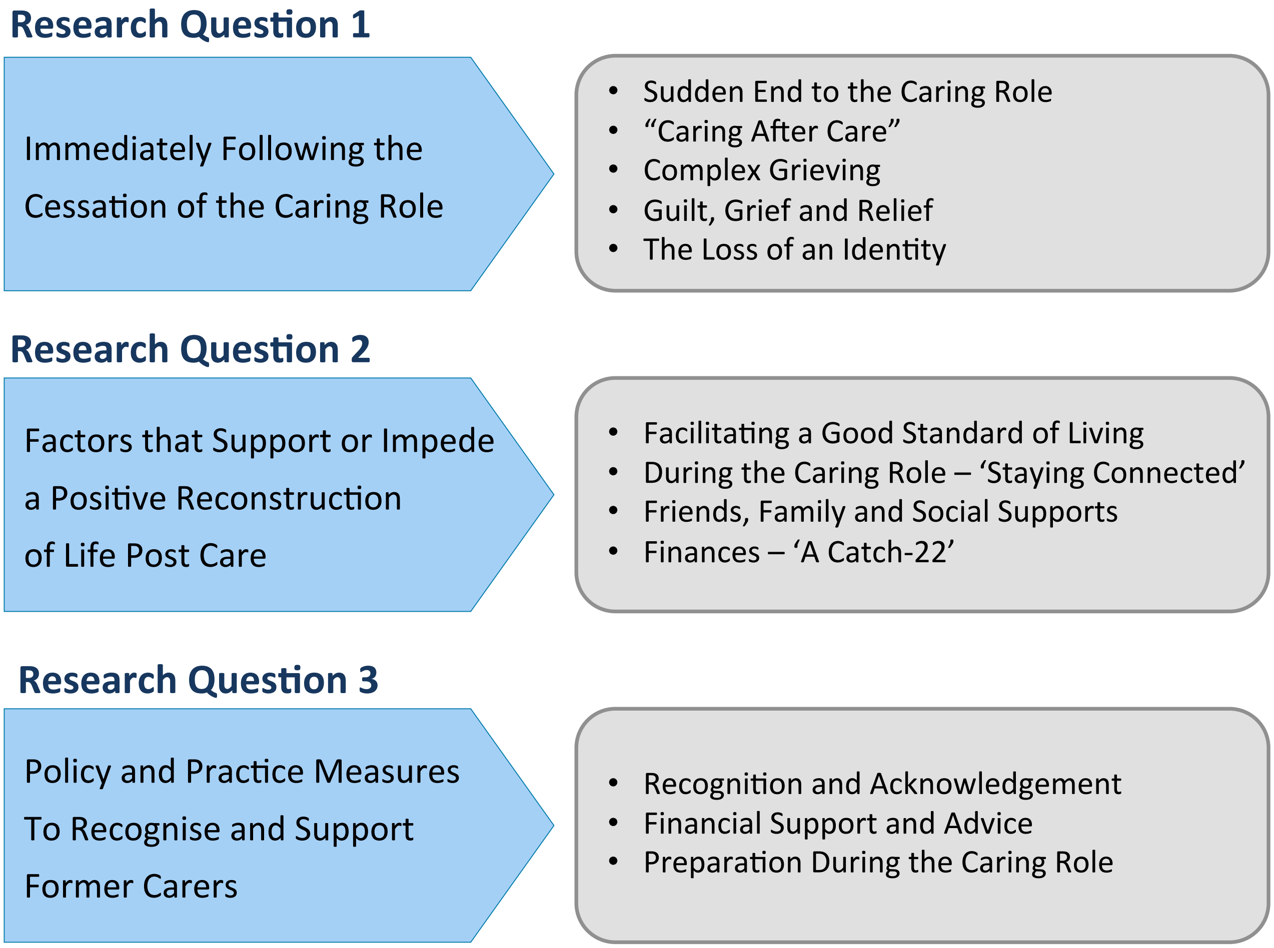
The following table illustrates the profiles of the seven former carers that participated in this study:

Table 1: Demographic of Participants

Demographic of Participants						
Participant	Gender	Age Range	No. of Care Recipients	Care Relationship	Accumulated Length of Time Caring (Years)	Reason for Cessation of Caring
Participant 1	Female	50+	1	Parent (1)	3	Care Home
Participant 2	Male	50+	2	Parent (2)	27	Deceased
Participant 3	Female	50+	2	Sibling (2)	25	Deceased
Participant 4	Male	40-50	1	Parent (1)	8	Deceased
Participant 5	Female	50+	1	Parent (1)	3	Care Home
Participant 6	Female	50+	1	Parent (1)	5	Deceased
Participant 7	Female	50+	1	Spouse (1)	47	Deceased

The following illustration outlines the key findings that emerged within the research.

Figure 2: Key Findings



4.2 Research Question 1: What opportunities and challenges do former carers encounter in the transition and period following the cessation of the caring role?

This particular section of the analysis aims to bring the reader through the advancement from the active care stage into the post care stage, as narrated by the participants. McCarron *et al.* (2011) suggest that upon initial entry into the post care phase of the caregiving career, former carers encounter a range of powerful emotional responses such as grief, relief, guilt, anger, and a loss of purpose and identity. The objective of this research question is to determine whether the former carers in this study had similar experiences to that of which is proposed in the literature.

4.2.1 A Sudden End to the Caring Role

While recalling the transition into the cessation of their caring role, six of the seven participants asserted that their role adjustment was quite abrupt and unanticipated. This sudden transition was either as a result of the death of their care recipient or a rapid deterioration in health, whereby their care recipient was required to relocate into a residential care home. Orzeck and Silverman (2008) explain that as a consequence of an abrupt end to the caring role, carers are involuntarily propelled into a period of uncertainty. Sophia and Kate voiced their recollections;

> *"…my role changed overnight... It really, it was overnight, it was stark and it was scary"* (Sophia)

> *"…there was no transition, it just happened suddenly. It was kind of like, today I do it, tomorrow I don't, I didn't know what was happening"* (Kate)

4.2.2 'Caring After Care'

The literature stipulates that following the end of the caring role, while concurrently dealing with intense loss, former carers may be expected to undertake further caring related tasks in respect of their care recipient (Larkin, 2009; Care Alliance Ireland, 2015). All of the participants in this study strongly resonated with the literature and reported that they were immediately obligated to carry out additional responsibilities, which Ben fascinatingly described as *"caring after care"*. Grace and Kate commented;

> *"…it doesn't just end. The caring doesn't end, there's all the paperwork and funeral arrangements and basically representing them. Because you were caring for them before, this automatically becomes your new job as well"* (Grace)

> *"…you think it's all over, and then comes more"* (Kate)

For the participants in this study, these responsibilities comprised: funeral arrangements; the 'fair deals' scheme; part-time caring responsibilities; notifying the State of the care recipients' death or relocation; and moreover, *"tying up loose ends"* (Catherine).

4.2.3 Complex Grieving

Jones and Martinson (1992) suggest that the grieving process of former carers is quite complex, as grieving may not only begin following the death or relocation of the care recipient; rather it may commence during the active caring phase as a result of the care recipient declining in health, losing personality traits and deteriorating in daily functioning; Jones and Martinson (1992) described this process as 'dual dying'. Four of the participants strongly identified with this theory, including Sophia who remarked;

> *"...I think you do a lot of your grieving while that person is going down that road. You know they're not getting better and each day you see a massive decline so that by the time they actually go, you've been grieving for quite a while"* (Sophia)

While certain studies have advised that former carers confront grief more easily due to the possible anticipation of the care-recipient's death (Schulz *et al.,* 2003), other studies have suggested that former carers encounter a more complicated grieving process as a result of losing the close bond with their care recipient (Robinson-Whelan *et al.,* 2001). Four of the participants identified with the latter study and emotively explained that they had lost their "*life partner"* (Catherine), *"lifelong companion"* (Ben) and *"best friend"* (Kate).

4.2.4 Guilt, Grief and Relief

The majority of participants described a multitude of conflicting emotions including grief and relief, combined with guilt at experiencing relief when their caring role ended. Interestingly, those whose care recipient had passed away and those whose care recipient had transitioned into residential care shared similar feelings of guilt, grief and relief. Kate and Ben had divergent circumstances surrounding the cessation of their caring role, however they encountered similar experiences;

> *"...I felt kind of guilty that I couldn't do it (care) anymore, because of her health and her circumstances. I grieved for losing her but in another way, it was a relief for me"* (Kate)

> *"...I felt sorry, I felt grief, but I had the most peculiar feeling of a sense of relief. Now it was a physical sense of relief, it was almost as if a weight had been lifted off my shoulders. And as a result, I felt guilty over feeling relief"* (Ben)

The literature corroborates the narrative that as a result of the relentless physical and emotional strain that caregiving exacts on the carer, many former carers may react with a blend of grief and relief following the cessation of their caring role. (Schulz *et al.,* 1997; Bass and Bowman, 1990; Orzeck and Silverman, 2008). The literature also indicates this relief may ascend from the care recipient's suffering coming to an end (McCarron *et al.,* 2011; McLaughlin and Ritchie, 1994)

4.2.5 The Loss of an Identity

In this study, the issue of 'role-engulfment' complicated the participants' bereavement, as many expressed that their identity was entirely governed by their caring role. The literature indicates that former carers not only grieve the loss of their care recipient, but also simultaneously face the loss of their existing identity as 'carer' (Orzeck and Silverman, 2008). Five of the participants, including Catherine and Matthew mirrored the literature surrounding the discourse of multiple losses by stating;

> *"…it's not just the death of the person, your companion, it's the death of a huge part of your life and nobody says that it's ok to grieve that. It was very hard"* (Catherine)

> *"…the minute the caring role is gone, your person is gone. Your life is gone"* (Matthew)

Collectively, the participants expressed that following the end of their caring role, they encountered immense difficulties comprising multiple losses. This is an exceptionally significant consideration as three of the participants revealed that the combination of the loss of their care recipient and the loss of their role/identity prompted thoughts of suicide.

4.2.6 Discussion

The commencement of the post care stage generally coincides with the death of the care recipient or relocation into a residential care home. Nevertheless, the majority of carers were also expected to assume responsibility for 'caring after care' tasks following the end of their active caring role. The immediate losses encountered by former carers are multi-dimensional and comprise the loss of the care recipient, loss of a role or vocation and a loss of the identity that encompassed the active caring stage. Guilt, grief and relief are characteristic features of this phase; the participants in this study explained that not only did they have to deal with bereavement, they were also confronted with the solitary task of reorganising their entire lifestyle and purpose. The participants' entry into the post care stage was highly comparable to the McCarron *et al.* (2011) study, which depicted the initial stages of life post care as a 'loss of the caring world' and 'living in loss'; essentially, the theme of loss entirely dominating this period. The psychological struggles surrounding this transition, such as thoughts of suicide among three of the participants serves to highlight the intense emotional turmoil that former carers may encounter following the end of their caring role. Catherine succinctly described this initial period as being "*wicked to the world"*.

The participants in this study had vastly dissimilar circumstances, however held both conflicting and comparable ideas as to how to confront the next phase of the transition, that of reconstructing life post care. The factors that supported and impeded this process will now be discussed through research question two.

4.3 Research Question 2: What do former carers feel is necessary in order to engage in a positive post care transition and conversely, what factors serve to impede this transition?

Through a review of the research, it has emerged that the presence or absence of considerations such as: positive mental health; further caring responsibilities; retaining an identity during the caring role; social supports; and financial stability are the primary determinants of a positive reconstruction of life post care (O'Sullivan, 2008; Boccaletti *et al.,* 2010; Care Alliance Ireland, 2015; McCarron *et al.,* 2011). The participants in this study identified with many of the above considerations, however, the most prominent themes that emerged will be focused upon.

4.3.1 Facilitating a Good Standard of Living for the Care Recipient

While there tends to be a emphasis upon the adversity of the post care transition, when asked what supported the positive reconstruction of life post care, the participants' unanimous consensus was that the facility to be able to care for a family member alleviated some of the negative associations with their post care transition. Sophia recalled;

> *"…I took great comfort from knowing I did everything I could…My mother was allowed to have a happy life and know that she was cared by someone who loved her"* (Sophia)

This theme is not widely recognised within the literature, aside from the notion that caring can be a very rewarding experience (Carers Scotland, 2011; Care Alliance Ireland, 2010). Ultimately, no specific research was found, which suggests that enabling the care recipient to have a 'happy life' directly enhanced former carers' perception of their post care transition.

4.3.2 Life During the Caring Role- 'Staying Connected'

> *"…what you have during the caring role determines how you will survive after you stop caring. You have to make sure that your life is sustainable and constructive"* (Sophia)

As repeatedly suggested, the manner in which a carer transitions into their post care lives is largely influenced by their active caregiving experiences (Aneshensel *et al.,* 2004; Orzeck and Silverman, 2008). All of the participants strongly voiced their awareness that retaining some sort of link to an individual identity and to the 'outside world' during the active caring stage, are vital components of a positive reconstruction of life post care. Anna and Grace explained;

> *"…it is just so important to stay connected to the outside world because you'll meet it again in the future"* (Anna)

> *"…without my life, my link to the outside world, I would have been lost when I stopped caring. It allowed me to not lose myself in the caring role… it was my lifeline. Having my own life, my own role, my own identity helped me more than can be imagined"* (Grace)

Although the participants recognised the significance of maintaining a life outside of caring, many commented that this had to be actively pursued and required significant effort, as is mirrored within the literature (Life After Care, 2010; McCarron *et al.,* 2011). Conversely, as again comparable to the theme of 'role-engulfment' (Skaff and Pearlin, 1992), three of the participants felt that they were unable to maintain a connection to their own lives due to the intense demands of their caring role, and subsequently acknowledged that this put them at a significant disadvantage post care. Matthew fittingly explained;

> *"…it's very different from being out in the world, meeting people, working, you become completely detached, so secluded from life outside the house, then afterwards, you're lost"* (Matthew)

For the three participants who were unable to maintain a connection to their own lives whilst caring, all remarked that they actively began to pursue their *"life again"* once their role came to an end in terms of reclaiming their interests, hobbies and social connections. These pursuits are echoed within the literature as being vital prerequisites of a positive identity reconstruction (Bond *et al.,* 2003; McCarron *et al.,* 2011). Furthermore, three of the participants also engaged in further paid or unpaid caring roles, which Larkin (2009) advises is a common evolution for former carers

4.3.3 Family, Friends and Social Supports

It is extensively documented within the literature that the presence of social supports serve to alleviate the complications and negative impacts of the post care transition and are highly influential in the reconstruction of life post care (Crow, 2009; Choi *et al.,* 2012; Aneshensel *et al.,* 2004). For the participants in this study, only three mentioned that they had any form of social support following the end of their caring role. For those who did, it was mentioned that family, friends, their G.P., public health nurses and carers associations were indispensible sources of comfort and support during this period. Catherine recalled;

> *"…well, I was lucky I had my family to support me and my G.P. was very good to me, that gave me a lift out of the hole I was in really"* (Catherine)

Conversely, four of the participants mentioned that the difficulties they experienced were compounded by the fact that they felt entirely alone and did not have any supports in their endeavour to practically face this period. Kate commented;

> *"…I felt that when I had completed my role, after I had looked after someone, then everyone was done with me. There was no support whatsoever"* (Kate)

Crow (2009) corroborates this statement by articulating that former carers often find themselves instantly cut off from the State, the healthcare system and other supportive persons following the end of their caring role and consequently, former carers may face a significant risk of social isolation.

4.3.4 Finances – 'A Catch-22'

Of all the responses received from the participants, the vulnerability of their financial state following the end of their caring role was regarded as being the primary barrier towards a positive reconstruction of life post care. Kate recollected;

> *"…I was getting the Carer's Allowance and then that stopped, the pension stopped. So you know I was financially, in complete limbo"* (Kate)

The literature reiterates that as a result of the immediate drop in household income owing to the cessation of financial aid, former carers may face severe financial difficulties and subsequently, may be at risk of poverty (Boccaletti *et al.,* 2010; O'Shea, 2000; Care Alliance Ireland, 2010). Five of the participants professed that following the end of their caring role, their financial state induced anxiety in terms of the requirement to hurriedly source an alternative income and furthermore, constrained their ability to socialise and reclaim their interests and hobbies. Anna interestingly labelled this issue as a 'catch-22';

> *"…the funny thing is that you have the freedom finally, but you don't have the money. An utter financial catch-22"*

4.3.5 Discussion

The above findings and the associated literature depict what former carers document as being factors that support or impede a positive reconstruction of life post care. The most collective response towards what ameliorated the impact of this transition was the notion that the participants facilitated their care recipient to have a high standard of living. This provided them with great comfort and sustained them in their pursuit of reconstructing their lives. Another central theme surrounded how their experiences prior to and during the active caring phase had considerable implications on the post care transition. Grace affirmed;

> *"…I should have held stronger ties to my own identity as the caring role has the ability to strip you of everything that makes you wonderful and unique"*

Family, friends and wider social networks were also characterised as influences that were central to how former carers experienced this transition. Conversely, the factors, which hindered a positive perception of this transition included carers becoming isolated and detached from the 'outside world', combined with the absence of adequate supports to assist them in this vulnerable period. Financial difficulties that were evident in the active caring stage invariably worsened for the participants, which O'Shea (2000) confirms is a vulnerability that former carers may encounter.

4.4 Research Question 3: How can policy and practice be developed to better recognise and support former carers in the transition and period following the cessation of the caring role?

Within this research question, former carers were asked to 'optimistically' describe what would have supported them in the transition and period following the end of their caring role. Unexpectedly, the participants advocated for extremely modest and practical reforms.

4.4.1 Recognition and Acknowledgement

The participants in this study collectively remarked that they simply desired recognition and acknowledgement for their role as a carer; however all responded that they felt dismissed and *"thrown to the wayside"* (Kate) following the end of their caring role. Ben commented;

> *"…there was no acknowledgement for the life that I spent caring. Now, you don't seek rewards, but at the same time, there should be some sort of recognition. (Ben)*

The participants associated the perceived dismissal by the State as reflecting a lack of recognition and acknowledgement for the service they provided; which is extensively outlined in the literature (Crow, 2009; Hynes *et al.,* 2008; McCarron *et al.,* 2011). In a study conducted by McCarron *et al.* (2011), former carers indicated that the perceived dismissal by the State was specifically owing to the absence of services and supports following the cessation of the caring role. Unanimously, the participants strongly resonated with the above study in relation to the absence of State supports, including Catherine, who quite poignantly recalled;

> *"…I had support for cancer, for child-rearing, this was worse than any of that and I had nothing"* (Catherine)

4.4.2 Financial Support and Advice

The Joint Oireachtas Committee (2002) reports that financial insecurity is a source of anxiety for long-term carers; this was significantly reflective of the participants within this study. Financial difficulty manifests in terms of: many years of foregoing an income; insufficient levels of PRSI contributions; and limitations on pension entitlements (McLaughlin and Ritchie, 1994; Stokes, 2010; McCarron *et al.,* 2011). Five of the participants encountered significant financial difficulties following the end of their caring role and suggested practical initiatives that the State could adopt in order to lessen the risk of poverty for former carers. Anna advised;

> *"…because you made a massive economic contribution to society, caring should be considered as stamped employment. The years you have spent caring should be added on as employment, even though it isn't, but for pension purposes yes, it should be acknowledged"* (Anna)

The inadequate provision of a social protection system by the Irish State for former carers is extensively documented within the literature (Stokes, 2010; Hynes *et al.,* 2010). The participants in this study advised that they did not want *"handouts"* (Kate) or *"monetary rewards"* (Ben); however they suggested that caring should be considered as stamped employment and moreover, that the timeframe for the payment of the Carers' Allowance should be extended following the end of the caring role.

4.4.3 Preparation During the Caring Role

All of the participants in this study expressed that life satisfaction post care was entirely contingent upon the coping strategies they developed during the active caring stage; as is acknowledged within the literature (Lifelong Learning Programme, 2010; Boccaletti *et al.,* 2010). Five of the participants suggested that interventions should be put in place during the active caring stage, to enable carers to actively prepare themselves for life post care. Kate recalled;

> *"…I would have liked that I had more time during the caring role to build myself up for when the time came that I wasn't caring anymore. You know, to see what's out there for me and prepare for what I would do after, as opposed to a complete standstill"* (Kate)

The literature also endorses the implementation of early intervention supports during the active caring stage as a means of ameliorating the psychological distress, ill-health and negative outcomes following the end of the caring role (Jardim and Packenham, 2009; Choi *et al.,* 2012; Jeon *et al.,* 2007). According to the participants, more structured and adequate levels of respite and home help were regarded as being the fundamental mechanisms through which preparation for life post care could be facilitated.

4.4.4 Discussion

The above findings have been consistent with the hypothesis that caregiving can deplete carers' resources, thus making it more difficult to positively adapt to their post care lives (Robinson-Whelan *et al.,* 2001). However, the participants expressed strong reactions and suggestions as to the policy and practice developments, which are necessary to facilitate a positive reconstruction of life post care. Recognition, acknowledgement and State supports were regarded as features that were starkly absent from their post care experiences; Sophia remarked, '*there is nothing out there and if there was, I wouldn't have known about them'*. Financial support and advice was reiterated by all of the participants as being a genuine need; they felt that the Carers' Allowance was terminated too quickly and as caring did not count as stamped employment, their pension entitlements were severely affected. The majority of participants challenged the current respite and home help system and argued that they were an inadequate means of providing them with an opportunity to effectively prepare for life post care. The participants suggested further recommendations; however, due to the remit of this study, they could not be comprehensively examined. Nevertheless, these recommendations will be outlined in Chapter Five.

4.5 Conclusion

This chapter endeavoured to explore the experiences of former carers in regard to: the transition following the end of the caring role; the factors that support and impede a positive reconstruction of life post care; and policy and practice modifications to recognise and support former carers. The contribution of the participants through sharing their extensive personal experience assisted in terms of addressing the proposed research questions. The following chapter serves to respond to the findings through closing comments on the study, combined with recommendations derived from the participants and an analysis of the related literature. Following this, the implications for social work practice and a reflective enquiry on the process of engaging in this study will be presented.

Chapter Five

Recommendations and Conclusion

5.1 Introduction

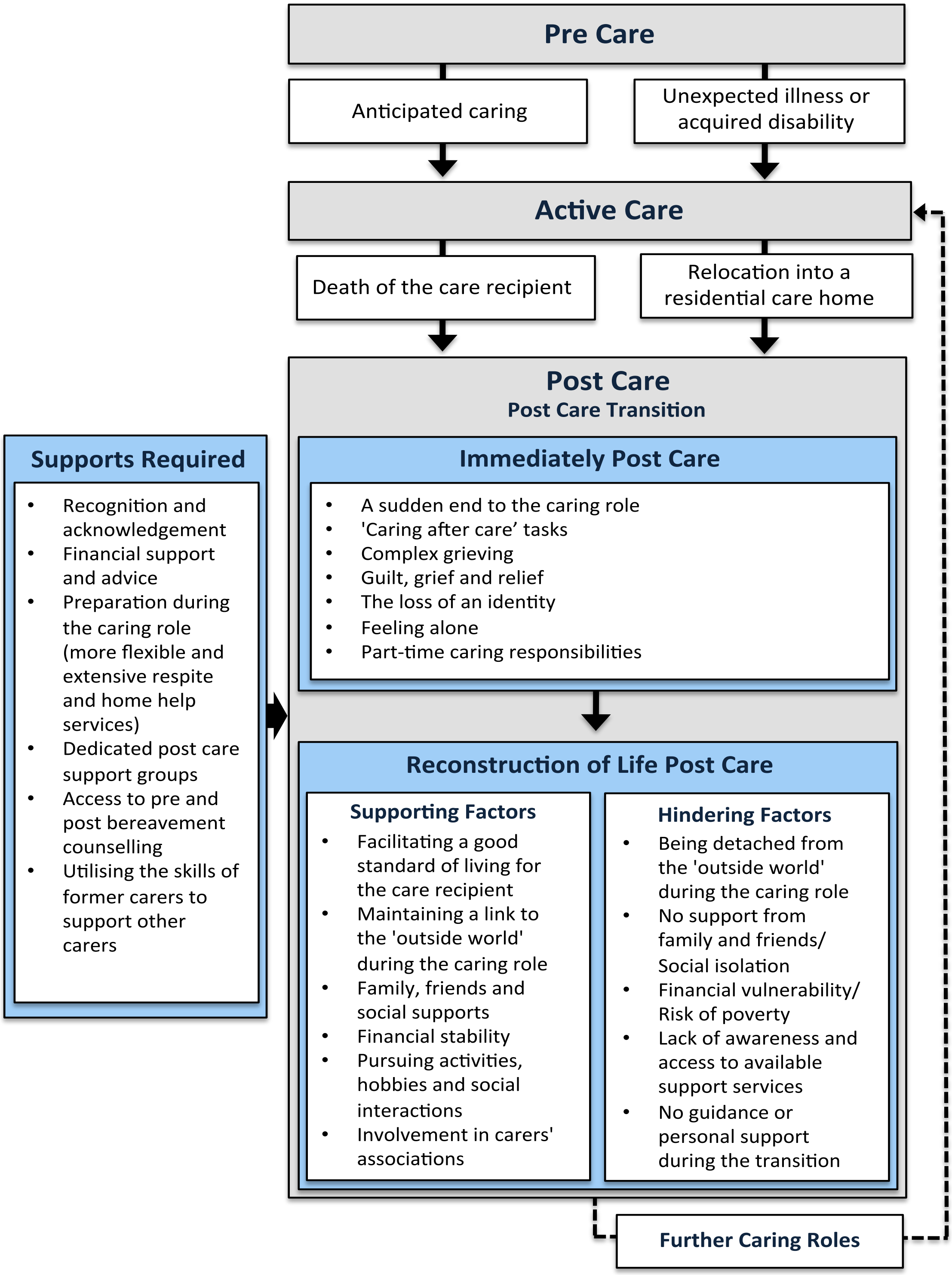
This chapter presents the closing comments on this study and proposes the recommendations derived from the research findings and an analysis of the related literature. The implications for social work practice and the opportunities for further research will also be discussed. Following this, the study will conclude with a reflective enquiry on the process of engaging in this research process through collaboration between The Carers Association and Community Academic Research Links.

5.2 Closing Comments

Throughout this research study, it has been continually reinforced that the enduring physical, emotional, psychological and social repercussions of the active caring stage serve to induce substantial difficulties following the end of the caring role. During the post care transition, the former carer is involuntarily propelled into a period of uncertainty, dominated by multiple losses, whilst they must simultaneously confront the mammoth task of reconstructing their entire identity. This period can prompt such insurmountable difficulties that thoughts of suicide manifested among three of the participants in this study. The adverse ramifications of the post care transition are further exacerbated by experiences of social isolation, financial insecurity, a disconnect from the world outside of caring and a complete absence of State supports. As such, the importance of recognising and addressing the post care requirements of former carers simply cannot be overstated and cannot continue to be overlooked. Targeted supportive interventions are essential if the position, health and security of both active carers and former carers are to be safeguarded. It is aspired by the researcher, that the above findings and the related literature have fortified the argument that a social and political response towards former carers is immediately warranted.

Despite this research study being of a small scale, an in-depth illustration has been created as a means of representing all aspects of the post care transition and the outcomes for the former carers who participated in this study.

Figure 3: The Post Care Transition



5.2 Research Recommendations

Although Ben commented that there is not *"a one size fits all solution"*, the following recommendations aim to address the requirements of former carers, as articulated by the participants, and through an analysis of the findings and associated literature. As adequate support during the active caring stage can serve to alleviate the challenges encountered post care, a proportion of the recommendations pertain to active carers. It must be again emphasised that as this study was of a small scale, these recommendations do not qualify to be applicable to the wider population of former carers.

5.2.1 State Recommendations

1. A significant recommendation that arose was the necessity to recognise the post care stage as a fundamental stage of the caregiving career. Consequently, former carers should be explicitly acknowledged in all future policies or strategies directed towards informal family carers.

2. It was identified within the literature that 'there are no statutory health or social care services in place for former carers' (Care Alliance Ireland, 2013, p. 40). As such, this study implores that targeted support systems should be developed at a statutory level designed to respond to the specific needs of former carers following the end of their caring role.

3. Anna relayed; *"from a welfare point of view, or state support, there is absolutely none. But I think there is definitely a need there, for a governmental response"*. This study emphasises that a State system of financial support should be made available following the cessation of the caring role, which takes into consideration the risk of poverty that former carers may face.

4. This study and the accompanying literature highlight the necessity for an extension of the six-week timeframe for the payment of the Carers' Allowance post care (CPA, 2008). Catherine stated; *"if there was something there that they could bring you down more gradually… They say you need time, but they don't give you time"*. This could have the potential to alleviate former carers of the burden and anxiety involved in hurriedly attempting to source an alternative income.

5. A number of participants asserted that the caring role should be considered as stamped employment; or alternatively, the establishment of a system whereby pension entitlements for former carers would not be as severely affected.

6. A consideration of the Respite Care Grant being increased to €2,000 per year, to cover the costs of providing carers with four weeks of holiday entitlements warrants significant consideration (CPA, 2008). This would facilitate carers to receive a necessary break from their caregiving duties, which is essential for their ongoing physical, psychological and emotional well being.

7. The participants in this study proposed that if the existing support systems for active carers were reformatted to act as a means of early intervention and preparation for the period following care, this could have the potential to alleviate some of the difficulties that arise for former carers. It was suggested that there is an indisputable need for more extensive and flexible respite and home help services to ensure that carers are facilitated to retain an independent role during the active caring stage.

8. This study strongly advocates for the development of an Irish based 'information kit for carers', which provides:
   1. Active carers with information in relation to The Carers' Allowance, respite and home help services and furthermore, keeping well during caring.
   2. Former carers with information in relation to the post care transition, what to expect, what supports and services are available and information regarding carers' associations. Successively, this information kit should be made available to all healthcare professionals and service agencies that may interact with carers and former carers such as hospices, hospitals, carers' associations, public health nurses and general practitioners.

5.2.2 *Recommendations to The Carers Association*

1. A number of participants voiced their desire for a dedicated post care support group and further access to pre and post bereavement counseling. As the theme of suicide was encountered within this study, adequately responding to the mental health requirements of former carers warrants significant attention.

2. The male participants in this study asserted that the current active and post care services were not targeted towards the specific requirements of male carers and thus, expressed the need for more male-oriented services to be established. If this is to be achieved, research and consultation with male carers concerning their specific needs is necessary.

3. Utilising the skills of former carers emerged as a noteworthy recommendation from the participants, including Anna who said; "*I do feel like I've a lot to offer carers and former carers now, by way of experience and I wouldn't like to just walk away from that". As the participants in this study were open to utilising their extensive experience to support other carers and former carers, it is recommended that this should be further explored.

5.3 Targeted Supports for Family Carers

In 2010, Dr Gail Ewing (University of Cambridge), in partnership with Professor Gunn Grande developed 'The Carer Support Needs Assessment Tool' (CSNAT). Dr Ewing noted that this tool 'offers a framework that recognises the important role they (carers) play and legitimises their own needs' (p. 1). Fundamentally, this tool serves to identify what supports and services are needed specifically for the carer during their active caring role and what shortfalls are evident in current service provision. An adoption of this tool in all States could potentially have insurmountable benefits for carers' psychological and physical health during the caring role; a chief indicator of how they will transition into their post caring life.

"Support provided to Family Carers is vital if older people and those requiring care are to continue living in their own homes and communities" (The Carers Association, 2009).

Treneman *et al.* (1997) suggest that the first steps in developing support services should involve ascertaining the most important needs of carers and whether current provision is meeting those needs. The Report of the Irish Commission on the Status of People with Disabilities (1996) recommended that 'services should be flexible, including a range of options including home support, organised holidays and residential care' (p. 23). Nonetheless, current provision for Irish family carers continues to fall short, as such, it would be highly beneficial if the Irish State looked to other States for best practice initiatives in terms of supporting family carers.

5.4 Opportunities for Further Research

Many gaps within the existing research emerged throughout the course of this study; consequently, four proposed research opportunities will be presented.

1. It would be worthwhile to conduct an investigation into the psychological forces that underpin carers becoming intertwined with the identity of 'carer' and moreover, how carers may proactively maintain their personal identity throughout their caring career.

2. As male carers currently constitute 38% of the caregiver population, a study on the specific transition and experiences of male carers would be welcomed. A comprehensive analysis of the divergences between the male and female perceptions of the post care transition was infeasible due to the limitations of this study.

3. This study explored the transition from the active care into the post care stage of the caregiving career. It may be a meaningful undertaking to explore how individuals experience the transition from pre care into an active caring role and subsequently, the effects of this transition.

4. Finally, the limited scope of this research did not allow for a more diverse range of participants such as those caring for children with an illness or disability, described by Pilnick *et al.* (2011) as 'perpetual parenthood'. This would be a significant topic to explore through further research as it involves the complex dynamic of the 'parent identity' being intertwined with the 'carer identity'.

5.5 Implications for Social Work Practice

Throughout this research process, I have contemplated whether some of the above findings may be applicable to: foster carers who no longer have the primary caring responsibility of a long-term foster child, through a process of reunification with the birth parents; or alternatively, parents whose children have entered into the care of the State. I am of the opinion that the theme of caring and the cessation of caring has a wide reach and can be considered applicable to many social work contexts. As such, it would be valuable for social work professionals to adopt an ecological perspective in considering the cause and effect of caring upon the surrounding individuals of the person in receipt of care, in order to take into account the on-going needs of those whose caring role has ended.

Furthermore, one of the principal values inherent in the role of social work is the commitment to address societal inequalities and injustices. The responsibility to advocate for and engage in social and political action is explicitly specified within many of the professional social work standards, including the CORU *Code of Professional Conduct and Ethics for Social Workers* (2011). As such, it is imperative that social work professionals retain an awareness of issues of social inequality and utilise their knowledge, skills and resources to advocate for marginalised groups in our society.

5.6 Reflective Piece

Throughout the MSW programme, it was continuously requested of the students to contemplate and actively engage with the wider socio-political context of social work; however, prior to this experience, this concept was almost intangible. Through connecting directly and deeply with those who have experienced societal marginalisation, I was enabled to understand this concept in a comprehensive and meaningful way. The National Association of Social Workers (2006, p. 1) emphasise that;

> *"Students must be educated about the social and political aspects of social work practice from the outset and must be offered field experiences that enable them to take an active role in working for social change. Teaching the connections between direct client services and the larger sociopolitical context and providing avenues for students to learn and practice social action skills will bring social work back to its roots".*

I felt extremely privileged to work collaboratively with The Carers Association, in terms of achieving our shared aspiration, 'to empower former carers to tell their stories and voice their needs'. Personally speaking, hearing and analysing the participants' stories allowed me to realise the strength and resilience of certain individuals faced with incredible hardship. It would have been desirable to delve deeper and articulate the participants' vast range of experience, however, the previously mentioned limitations of this research did not allow for such a comprehensive analysis.

Finally, this process has highlighted the undeniable significance of research and will certainly shape my future practice in terms of my responsibility to be evidence-based in my approach. Throughout this study, I have become more adept at methods of research and understood how valuable it is to ascertain knowledge to underpin my practice; this closely relates to personal responsibility and accountability in my future social work practice. Overall, this experience has motivated me in an unforeseen way and I have vowed to adhere to the appreciated values, skills and knowledge that I have obtained.

5.7 Conclusion

This collaborative research study sought to explore the experiences of former carers in every facet of their post care transitions. The subsequent findings illuminated the multitude of challenges that confront and exist for those who arrive at the end of their caring role and has highlighted that an adequate response from the Irish government is immediately warranted. It is hoped that this research will assist in The Carers Association's on-going campaign to achieve recognition and acknowledgement for former carers and furthermore, assist in their objective of securing the improvement of policy and practice governing the entire cohort of informal family carers.

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Appendices

Appendix 1: Overview of the Research

Appendix 2: Information Sheet for Participants

Appendix 3: Consent Form

Appendix 4: Structured Interview Questions

Appendix 5: Semi-Structured Interview Guide

‘Life After Care: Transitional Pathways, Reconstruction of Life Post Care and Outcomes for Former Carers’

Trisha Barrett

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
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The objective of this study is to explore how former carers experienced the transition following the end of their caring role. Main research questions include:

1. What opportunities and challenges do former carers encounter in the transition and period following the cessation of the caring role?
2. What do former carers feel is necessary in order to engage in a positive post care transition and conversely, what factors serve to impede this transition?
3. How can policy and practice be developed to better recognise and support former carers in the transition and period following the cessation of the caring role?

Through questionnaires and interviews, participants will be invited to provide an account of their own unique experience of their transition into life post care. The data collected will then be used to communicate the views of the participants and the study will reflect what the participants feel most strongly about. This research will also consider the main issues/concerns that the participants may have experienced following the end of their caring role and will subsequently explore how Irish policy and practice can be developed in order to make an advancement towards responding to the needs of former carers.

Information Sheet for Participants

Purpose of the Study

As part of the requirements for the Masters of Social Work (MSW) at University College Cork, I am required to carry out a research study. The aim of this study is to explore and discuss the experiences of former carers in relation to their transition into life post care. Areas discussed will be that of: the implications of the caring role on life post care; role/identity; social networks; financial situation; and any additional pertinent topics that emerge. The information collected directly from participants will be used to provide a detailed understanding of the experiences and needs of former carers through the medium of a research study. Subsequently, the findings derived from the research will be utilised to recommend appropriate supports and provide guidance towards enhancing the lives of those who are no longer engaging in a full-time caring role.

What will the study involve?

The study will involve conducting interviews with former carers, as a means of exploring their unique personal experiences of their transition into life post care. Following the interviews, the information will then be used to produce a study, which represents the overall findings derived from the participants. This study will subsequently be shared with The Carers Association and may assist in their on-going campaign to achieve recognition and supports for former carers.

Why have you been asked to take part?

As the objective of this study is to formulate an account of the personal experience of carers whose caring role has come to an end; you have met the selection criteria chosen specifically for this research.

Do you have to take part?

Participation in this research is completely voluntary. Each prospective participant will have the opportunity to meet with the researcher prior to taking part, as a means of obtaining further information in regard to what the process will entail. If a participant agrees to partake in the study, they will be asked to review and sign a consent form, which outlines the purpose of the research, the confidentiality procedures and how the information from the interviews will be represented in the study. A copy of this consent form will then be provided to the participant. The participants will also have the choice to withdraw from the study up to two weeks following the data collection phase (interview) has commenced.

Will your participation in the study be kept confidential?

Confidentiality is a primary consideration and every effort will be made to ensure your anonymity throughout the duration of this study. I will ensure that no indications as to your identity will appear in the final research paper; any quotes derived from the interviews will be entirely anonymous. Each participant will be provided with a pseudonym at the beginning of the process and this pseudonym will be used throughout the entirety of the data collection and data analysis stages.

What will happen to the information which you give?

The information you provide will be kept confidential throughout the duration of the study. The recordings from the interviews will be transcribed and stored on a secure UCC server and the researcher will be the only individual who has access to this data. Upon completion of the study, as per UCC regulations, the information will be held for an additional seven years and then destroyed.

What will happen to the results?

The information derived from the interviews will be presented anonymously in the research paper. This will be viewed by my supervisor, a second marker and the external examiner. The study will be published on The Carers Association's website and the Community Academic Research Links (CARL) website. This research will also be presented at a UCC student conference in May 2015 and may be accessed by other students on the course.

What are the possible disadvantages of taking part?

I don't foresee any harmful implications for you through participating in this study. However, talking about your past experiences may potentially cause some distress. Prior to participating in the study, this should be considered.

What if there is a problem?

At the end of the interview, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, you will be provided with information in relation to available support services and you can also contact The Carers Association or your G.P for support.

Who has reviewed this study?

Approval has been provided by the School of Applied Social Studies for this study to take place.

Any further queries?

If you require any further information, you can contact me:

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Supervisor Details:

Name:	Kenneth Burns
Department	School of Applied Social Studies
E-mail address:	k.burns@ucc.ie

If you agree to take part in the study, please sign the consent form overleaf.

Consent Form

I ____________________ agree to participate in Trisha Barrett's research study.

- The purpose and nature of the study has been explained to me in writing.
- I am participating voluntarily.
- I give permission for my interview to be tape-recorded.
- I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.
- I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.
- I understand that anonymity will be ensured in the write-up by disguising my identity.
- I understand that disguised extracts from my interview may be quoted in the dissertation and any subsequent publications if I give permission below:

(Please tick one box)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed ______________________________ Date ___________________

Structured Interview Questions

Gender

Male ☐

Female ☐

Age

18-25 ☐

25-30 ☐

30-40 ☐

40-50 ☐

50+ ☐

Care Recipient’s Relationship to You

Parent ☐

Child ☐

Relative (please state) ☐ ________________________________

Other (please state) ☐ ________________________________

Length of Time Caring

0-5 Years ☐

5-10 Years ☐

10-15 Years ☐

15+ Years ☐ Please state: _______________

Continuing to care part-time ☐

Reason for Cessation of Care

Care Recipient passed away ☐

Residential Care Home ☐

Other ☐

Please Explain:

____

____

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Semi-Structured Interview Guide

(a) Warm-up Questions - The Caring Role

1. Can you tell me about how you came to be a carer and for whom were you caring?

2. Could you describe a typical day/week when you were caring for _____________?
   -prompts: hours, role, activities, assistance, supports.

3. What did you enjoy about your role as a full-time carer?

4. What were the challenges involved in being a full-time carer?

5. What does being a carer mean to you?

(b) Changes in the Caring Role - The Period of Transition

6. Can you tell me about how your role changed from caring full-time to no longer caring and the circumstances surrounding this change?

7. Do you continue to have care responsibilities? Can you tell me about your current caring role? (*Optional- if care recipient has transitioned into alternative care)*

8. How did you feel about this transition from caring full-time to no longer caring/caring part-time?
   -prompts: how did you personally change, focus on feelings.

9. What was significant about the transition from caring full-time to no longer caring/caring part-time, in terms of: (*these can be positive or negative changes*)

- Identity- *prompts*: how did you view/cope with your new role?

- Changes in routine- *prompts*: day-to-day activities.
- Social relationships- *prompts*: people calling, going out to socialise.
- Finances- *prompts*: Carer's Allowance, employment, and sources of income.
- Employment- *prompts*: employment before/after caring, subsequent employment opportunities.
- Other/further caring responsibilities?

10. If you were to rank the changes you experienced within this transition, what would you describe as being the most significant change?
-*prompts*: what was the one aspect of that period that was the most significant or challenging/what stood out as being a particularly memorable feature of this phase?

(c) Supports for Former Carers

11. What supports, if any, did you receive whilst you were in a full-time caring role?
-*prompts:* financial assistance, family support, services, respite, home help.

12. What supports, if any, did you have at the time that your caring role ended?
-*prompts*: support services, family/friends, financial assistance, counselling.

13. What type of supports would you have liked at this time to assist you in the period of transition?

14. What did you feel helped/hindered this period of transition for you?
-*prompts*: information, support services, relationships, finances, feelings associated with no longer caring.

15. _____________ months / years on, what has changed and what would you have done differently if you could approach this period of transition again?

(d) Recommendations for Policy and Practice

16. What do you think carers require during the initial period when their caring role changes significantly or comes to an end?

17. What do you think are the most important components of making a positive transition into a non-caring role/lifestyle?

18. In your experience, do you think there are enough supports/services for former carers? –*prompts*: were you aware of these services?

19. Optimistically, what would you like to see in terms of recognition, supports and services specifically for former carers?
–*prompts*: changes in policy/service provision.

20. Is there anything else that you feel I should have asked you or that you would like to comment on?

Thank the participant for taking part in the interview and ask how they are feeling after the experience. Relay information in relation to support services if at any time in the future they may experience repercussions as a result of this process.