Family Carers of Older People
Results of a National Survey of Stress, Conflict and Coping
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Glossary of Terms

ADLs: Activities of Daily Living

At least sometimes: Occurring sometimes/most of the time/all of the time

Care recipient: A person aged 65 years and older for whom the carer provides care and receives a carer’s allowance

Carer: A person who receives a carer’s allowance for care provided to an older person

Carer’s allowance: A means-tested form of income support which is available to eligible carers who provide care for people in need of full-time care and attention

CSO: Central Statistics Office

DoH: Department of Health

DSP: Department of Social Protection

HREC: Human Research Ethics Committee

HSE: Health Service Executive

IADL: Instrumental Activities of Daily Living

NCPOP: National Centre for the Protection of Older People

Person in your care: Refers to the person to whom the carer provides full-time care and receives a carer’s allowance

Potentially harmful carer behaviour: Carer behaviours that may be deemed potentially abusive, but are not considered serious enough to warrant the attention of formal services

Respondents: Family carers who participated in this study

SPSS: Statistical Package for the Social Sciences

UCD: University College Dublin
Executive Summary

Introduction
Family carers have traditionally assumed the responsibility of caring for dependent older relatives living in the community. With changing population demographics, there is an increased reliance on families to provide care for the growing number of older people in Ireland. The Central Statistics Office (CSO) reported that since 2006 the number of older people has increased by 14.4 per cent, rising to approximately 535,393 older people (CSO 2012a); older people now account for 11.7 per cent of the general population (CSO 2012a). In particular, there has been a significant rise in the older old. While a large proportion of older people live happy, healthy and active lifestyles, older people are more likely to become frail, dependent and develop chronic health problems as they age (Department of Health and Children 2008). Moreover, it has been estimated that there are approximately 23,058 older people with dementia in Ireland and this figure is expected to rise exponentially (Cahill et al. 2012).

Approximately 164,000 community-dwelling people aged 50 years and older require care and support with some aspect of their activities of daily living, with those aged over 80 years requiring the most support (Kamiya et al. 2012). Data from the Survey of Health, Ageing and Retirement in Europe (SHARE) longitudinal study indicates that over one fifth of people aged 65 years and over is in receipt of informal support with personal care and practical household tasks (National Economic and Social Forum 2009). It is estimated that 4.1 per cent of the total population in Ireland are unpaid carers and that carers are predominantly female, married, and aged between 40 and 59 years (CSO 2012b). The majority of carers provide between one and fourteen hours of care per week and approximately one fifth of carers provide care for 43 hours or more on a weekly basis (CSO 2012b).

Family carers in Ireland have faced uncertainties and challenges as a consequence of the austerity measures introduced by the Irish Government in 2010. Associated with the national financial crisis of 2008, these measures involved reductions in funding to the HSE, to state-funded income supports paid to carers and reduced funding to carer support organisations. Furthermore, with changing family structures and decreasing family sizes, family carers are facing additional pressures, with individuals having to assume caregiving roles on their own, often as they themselves become old and experience poor health. The demands of day-to-day caregiving on family carers have been well documented. Irish studies have shown that almost two thirds of carers report poor health, with many reporting feeling mentally and emotionally exhausted as a result of caregiving and having a lower quality of life when compared to the general population (O’Sullivan 2008; O’Brien 2009). Carers who experience high levels of burden in their caregiving role may be at increased risk for engaging in abusive behaviours towards the older person in their care (Sasaki et al. 2007; Kishimoto et al. 2013). The literature indicates that the prevalence of abusive behaviours reported by family carers ranges from 11 per cent to as high as 62 per cent (Cooper et al. 2008; Yan and Kwok 2011).

While a recent study reported conflicts between paid carers and older residents in residential care settings for older people (Drennan et al. 2012), to date there has been no systematic study of family carers of community-dwelling older people in Ireland. The present study focused on ‘potentially harmful carer behaviours’ that may be considered psychologically or physically harmful to an older care recipient, but that may not be deemed serious enough to require formal service intervention. Such carer behaviours serve as early warnings of more serious cases of elder abuse and may be amenable to early, preventive interventions (Williamson and Shaffer 2001; Beach et al. 2005).

Aims of the study
The overall aim of the study was to examine family carers’ experiences of caring for an older person in the community and to explore the impact of caregiving on the carer and the conflicts that may arise within the caregiving relationship.

The objectives were:

1. To examine the nature and type of care provided by family carers to older people
2. To measure carer burden among family carers who provide care to an older family member
3. To measure the extent to which family carers experience conflict in the caregiving relationship
4. To measure the extent to which family carers engage in potentially harmful behaviours towards older family members
5. To identify factors associated with potentially harmful behaviours engaged in by family carers
6. To examine family carers’ experiences of support and coping in their role as caregiver.
Research methods

The study involved an anonymous postal survey of a national cross-sectional sample of family carers in receipt of a carer’s allowance for care provided to a person aged 65 years and older. A self-completion questionnaire was administered to a random sample of 4,000 carers, and 2,311 completed questionnaires were returned, yielding a response rate of 58 per cent. Information was collected on carers’ profile, carers’ health and wellbeing, caregiving activities, carers’ experiences of conflict, support and coping, and care recipients’ profile. The questionnaire comprised several instruments, as follows: the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff 1977), the Zarit Burden Interview (ZBI; Zarit et al. 1980), a modified version of the Conflict Tactics Scale (M-CTS; Straus 1979; Beach et al. 2005), a modified version of the Activities of Daily Living (ADL) scale from the Older Americans Resources and Services (OARS) assessment instrument (Fillenbaum and Smyer 1981; Pillemer and Suitor 1992) and positive value and quality of support subscales of the Carers of Older People in Europe (COPE) Index (The EUROFAMCARE Consortium 2006).

Facilitated by the Department of Social Protection, distribution of the questionnaires consisted of three mail-outs, comprising an initial pre-notice letter informing respondents to expect the questionnaire and inviting them to participate in the survey, a questionnaire with a return stamped addressed envelope and a final reminder letter with a spare copy of the questionnaire. This method was used to ensure a high response rate and was informed by best practice in survey research (Dillman et al. 2009). No identification codes were used to track the questionnaires, thereby ensuring the anonymity of the respondents. Data collection took place over the summer months of 2013.

Findings

Profile of carers

The age and gender profile of the 2,311 respondents matched the profile of the population of those in receipt of a carer’s allowance for care provided to an older person. Respondents’ age ranged from 19 to 92 years, with a mean age of 57.1 years, and approximately one third of carers (32.2%) were aged 65 years and older. The majority of respondents were Irish (95.6%) and female (71.8%), in the 46 to 64 years age category (48.0%), married or in a civil partnership (62.5%) and in receipt of a full-rate carer’s allowance (56.8%). The majority of carers (62.3%) had no other dependants and resided with the care recipient (72.4%). Approximately a quarter of respondents (24.0%) reported that they had received no formal education/primary education and a third of carers (32.6%) reported that their highest educational qualification was the Junior/Intermediate Certificate. Half of the respondents (50.8%) lived in a rural location and the largest social class group represented in the sample was semi-skilled or unskilled (27.2%). The vast majority of carers (88.4%) indicated that they did not engage in work and/or study outside of the home.

Carers’ health and wellbeing

The majority of carers (68.9%) described their health as good or very good. In total, just over two fifths of carers (43.7%) were found to be at risk of depressive symptoms, with carers aged between 46 and 64 years at greatest risk. In addition, female carers were at greater risk for developing depression than male carers. A third of carers (33.2%) reported that they experienced moderate to severe or severe burden, with female carers significantly more likely to experience higher levels of burden than male carers. Family carers aged between 46 and 64 years reported experiencing higher levels of burden than carers in any other age groups.

The vast majority of carers (84.6%) reported that they often or always coped well as a caregiver and over three quarters (78.8%) indicated that they often or always found caregiving worthwhile. The vast majority of the study respondents (91.5%) reported that they ‘often or always’ had a good relationship with the care recipient. Just over half of the respondents (56.6%) reported that they often or always felt appreciated as a caregiver.

Caregiving activities

Just over half of the carers (51.5%) were adult children of the care recipient and nearly a third (31.1%) were spousal carers. Respondents indicated that they had been providing care for between one month and 52 years, with the mean time spent on caregiving at seven years. The majority of carers (64.7%) reported that they provided care for 60 hours or more in an average week. The vast majority of carers reported that they provided the care recipient with help, mostly with housework (97.0%), walking (85.8%) and dressing/undressing (81.4%). A quarter of the respondents (25.6%) indicated that they received some form of training to support them in their role. The most frequently reported training received was manual handling training, followed by training in first aid.
The vast majority of respondents (87.6%) indicated that they perceived the quality of the current relationship as good or excellent.

Just over half of the respondents (54.1%) indicated that they often or always felt well supported by friends and/or neighbours and the majority (63.8%) indicated that they often or always felt well supported by their family. In addition, half of carers (50.4%) indicated that they never or only sometimes felt well supported by public, private and voluntary health and social services. Overall, 56.7 per cent of respondents indicated that they often or always felt well supported in their role of caregiver.

Profile of care recipient
Care recipients’ age ranged from 65 to 103 years, with a mean age of 80 years. The majority of the care recipients (59.2%) were female and a fifth of care recipients (21.5%) were reported to have been diagnosed with dementia. Care recipients had relatively high dependency scores, with most care being required with activities such as housework (e.g. cleaning floors) (92.6%), taking a bath or shower (82.7%) and walking (79.1%).

Mistreatment of carers by care recipients
More than half of carers (56.3%) reported that they experienced some form of mistreatment by the care recipient, with just over a third (37.1%) reporting that the mistreatment occurred ‘at least sometimes’ in the previous three months. The most frequently reported psychological form of mistreatment was a care recipient using a harsh tone of voice, insulting or swearing at the carer. Reports of being physically mistreated by the care recipient were much lower; one in seven carers reported being physically mistreated by the care recipient with a smaller number (5.6%) reporting that the behaviours occurred ‘at least sometimes’ in the previous three months. The most frequently reported form of physical mistreatment experienced by carers was feeling afraid that the care recipient might hit or hurt them.

Potentially harmful carer behaviour
Over a third of respondents (36.8%) reported engaging in potentially harmful behaviours in the previous three months, with almost one in six carers reporting that they had engaged in such behaviours ‘sometimes’ or more frequently, the threshold used to indicate greater risk for elder abuse. In addition, just over a third of carers (35.9%) reported engaging in potentially harmful psychological behaviours, with one in six carers indicating that these behaviours occurred at least sometimes in the previous three months. Verbal abuse was the most commonly reported form of potentially harmful psychological carer behaviour. Overall, 8.0 per cent of carers indicated that they engaged in potentially harmful physical behaviour, with 2.7 per cent reporting that they engaged in such behaviours sometimes or more frequently in the previous three months. Overall, 1.0 per cent of carers reported engaging in ‘actual direct’ physical behaviour at least sometimes in the previous three months.

Factors associated with potentially harmful carer behaviour
Several carer, care recipient and caregiving factors were found to be associated with potentially harmful behaviours engaged in by carers. Carer characteristics associated with potentially harmful behaviours included being a male carer, an older carer, non-Irish, in the professional/managerial social class group, living in an urban area and co-residing with the care recipient. Other carer factors found to be significantly related to potentially harmful carer behaviours were carer self-reported poor health, higher levels of depressive symptoms and higher levels of burden.

Caregiving factors associated with potentially harmful carer behaviour included a greater number of hours of care provided per week, a greater number of years of providing care, a spousal relationship, a poor quality caregiving relationship and higher levels of help provided by the carer. Lower appraisal of the caregiving experience and lower perceived levels of the adequacy of professional and social support were also found to be significantly associated with potentially harmful carer behaviours. Care recipient factors associated with greater potentially harmful carer behaviour were: being in the ‘younger old’ age category (65–74 years), having a diagnosis of dementia, and having higher levels of dependency.

A logistic regression analysis found that the strongest predictor for potentially harmful carer behaviour, including both psychological and physical behaviours, was carer burden. More than 1 in 4 carers reported moderate to severe burden, making them over 13 times more likely to report that they engaged in potentially harmful behaviours towards an older person when compared to carers who experienced little or no burden. Other predictors of potentially harmful carer behaviours
were being a male carer and perceiving a poor overall quality of relationship with the care recipient.

The findings from this national study provide important new evidence about family caregiving in Ireland, including detailed profiles of carers and their care recipients and insights into the carer-care recipient relationship. The study findings indicate the extent to which carers experience conflict within their caregiving role, and identify a number of carer, care recipient and caregiving factors that are associated with potentially harmful carer behaviours. These same factors can be used to identify family carers who are at greatest risk for engaging in behaviours that may be harmful to the older person and that may compromise the quality of the care provided. Accordingly, the findings from this study offer important evidence that may inform health and social policy and professional practice in the area of family caregiving.

In line with the National Carers’ Strategy, the findings highlight the need for continued support for carers, who are often trying to deliver the best care they can within the means and resources that are available to them. Carer burden was found to be the strongest predictor of potentially harmful behaviours engaged in by carers. Accordingly, preventive intervention efforts need to focus on ways of alleviating carer stress and burden. Existing services in place to support family carers need to be sustained so that the valuable services provided to family carers can enable them to provide good quality care to older people living at home. Services need to be community-based and accessible to both the older person and their carer, and respite services in particular are needed to permit carers to have time and physical space away from caregiving. Moreover, income supports need to continue to be paid to eligible carers so that they do not become further financially burdened.

The findings of this study also highlight the need for healthcare professionals to engage in routine screening, not only of the older person, but also of their carer. Family carers do report potentially harmful behaviours, and if screened early in caregiving, efforts can be directed at preventing such behaviours from deteriorating into more serious abusive carer behaviours. Healthcare professionals also need to monitor carers’ health and wellbeing, which should be assessed regularly so that their physical and mental health does not deteriorate and impact negatively on the quality of care being provided to an older person.

Education and training is also important for family carers, who may unexpectedly find themselves providing care to an older person with complex health needs. Carers need to be educated about dementia in particular, so that they can recognise the indicators, avail of the services available and be able to manage dementia-related behavioural problems appropriately. Efforts need to be invested in promoting healthy relationships between family carers and the older care recipient, through interventions such as family counselling and sharing in social activities together, so that the quality of the relationship can be enhanced.

The findings of this study highlight the need for further research. While the present study was the first large-scale study undertaken with family carers of older people in Ireland, the sample included only those in receipt of a State-funded carer’s allowance; therefore further research is needed to examine other cohorts of carers and their experiences of caregiving, including carers who are in full-time employment. In addition, longitudinal studies are needed to establish the prevalence of potentially harmful behaviours over time. Research is needed to measure the extent to which family carers engage in other potentially harmful behaviours such as financial abuse, sexual abuse and neglect. A qualitative study involving interviews with family carers would yield rich, contextual information that would complement the findings reported in the present study.

In essence, family carers should be respected and supported for the difficult and challenging care work they engage in when caring for an older relative. Carer burden in particular needs to be tackled and alternative means of alleviating carer burden should also be explored. Such efforts may help to prevent carer behaviours that could be considered potentially harmful to an older person from deteriorating into more serious abusive behaviours and, in turn, help to enhance the quality of life for the older person as well as their carer.
1.1 Introduction
This chapter presents an overview of ageing trends in Ireland and information relating to family caregiving. Carer demographics and the caregiving activities engaged in by Irish carers are outlined together with the challenges facing many carers. The chapter concludes with a brief overview of the supports and services available to family carers in Ireland.

1.2 Ageing in Ireland
As ageing trends change and the proportion of older people continues to rise worldwide, so too does the growth in the number of people aged 65 years and older in Ireland. Since 2006, the population of older people has increased by 14.4 per cent, growing to an estimated 535,393 in 2011 (Central Statistics Office 2012a). Older people now account for 11.7 per cent of the general population (Central Statistics Office 2012a). Moreover, there has been a 22 per cent increase in those aged 85 years and older in the same period (Central Statistics Office 2012a). Population projections predict the continuing growth in the proportion of older people in Ireland, in particular among the oldest old. By 2041, the population of people aged 65 years and older is expected to grow to 1.4 million (Central Statistics Office 2012a). The exact number of older people with dementia in Ireland is unknown. However, it has been estimated that there are as many as 89,000 community-dwelling older people in need of care, with an estimated 15 per cent having high dependency needs and 35 per cent requiring high or continuous care (O’Shea 2000). Results drawn from The Irish Longitudinal Study on Ageing (TILDA) indicated that 11 per cent of men and 14 per cent of women over the age of 50 years have at least one limitation of an instrumental activity of daily living (IADL), such as dressing, walking, bathing, eating, preparing hot meals and shopping (Kamiya et al. 2012). Extrapolated to the general population of older people, these figures suggest that approximately 163,700 community-dwelling people aged 50 years and older require care and support, with those aged over 80 years requiring the most support (Kamiya et al. 2012). Analysis of data from the Survey of Health, Ageing and Retirement in Europe (SHARE), a longitudinal study of 1,103 people aged 50 years and over in Ireland, undertaken by the National Economic and Social Forum (NESF), reported on the health status of people aged 65 and over in Ireland (National Economic and Social Forum 2009). The survey found that almost a quarter (25%) had difficulties carrying out at least one Instrumental Activity of Daily Living (IADL). This difficulty rose with increasing age, with 17 per cent of people aged 65 to 75 reporting difficulty with at least one IADL compared to 52 per cent of those aged 85 and over. One fifth of those aged 65 and over (20.7%) received informal support with personal care, practical household tasks or paperwork. Overall, four per cent of older people reported needing support with personal care. Again this rose with age, from 2.1 per cent among the 65 to 75 age group to almost one fifth (19.2%) for people aged 85 years and over (National Economic and Social Forum 2009).

The exact number of older people with dementia in Ireland is unknown. However, it has been estimated that there are approximately 23,058 older people with dementia currently living at home in the community, many of whom are unaware that they even have the disease, and an estimated 50,000 family carers caring for someone with symptoms of dementia (Cahill et al. 2012). The Programme for Government 2011-2016 included a commitment to developing a national strategy on dementia. Although the strategy is currently being developed, preliminary work has been undertaken. The first phase involved a research review to inform and provide the evidence base for the strategy. Entitled Creating Excellence in Dementia Care, the review was published in 2012 and included guidelines on the future direction of public policy for dementia in Ireland (Cahill et al. 2012). One of the guidelines arising from the review

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was that the strategy should focus on developing and expanding services across all care sectors, including a focus on developing family support programmes. The second phase of the development of the strategy involved direct consultation with a range of stakeholders. A summary report derived from written submissions to the Department of Health was published in 2012 (Department of Health 2012a). In 2013, the Department of Health also convened a working group to develop the key components of the strategy as well as an implementation plan.

With the challenge of ageing populations, many countries are developing policies to enable older people to remain living in the community. A report of consultations undertaken with older people in Ireland for the National Positive Ageing Strategy revealed that older people expressed a desire to remain living in their own home for as long as possible (Department of Health 2010). With the increasing demand for care provision in the domiciliary setting, attention has turned to the role of family carers, who tend to be the primary caregivers to older people in the community. In 2000, O’Shea estimated that approximately 97,500 households in Ireland contain an unpaid carer providing care to an older person. As the proportion of older people continues to rise and their dependency needs increase, the role of the unpaid carer becomes even more pertinent in the provision of care.

1.3 Family caregiving in Ireland

According to the definition adopted by the Central Statistics Office (CSO) in the 2011 census, a ‘carer’ is a person, whether in receipt or not of a carer’s allowance or benefit, who provides ‘regular unpaid, personal help for a friend or family member with a long-term illness, health problem or disability (includes problems which are due to old age)’ (CSO 2012a, p.127). Personal care was defined as including help with basic tasks such as feeding or dressing. CSO figures show that a substantial 327 million hours of care are provided by unpaid carers in Ireland each year (CSO 2012b). Adopting the CSO definition of carer, it is estimated that 4.1 per cent or approximately 182,884 of the total population in Ireland are unpaid carers aged 15 years and over; a further 4,228 carers aged under 15 years brings the total number of unpaid carers aged 15 years and over to 187,112 (CSO 2012b).1 The CSO data indicate that carers are predominantly female (61.0%), married (62% of female carers; 61% male carers) and aged between 40 and 59 years (52%) (CSO 2012b). The majority of carers provide between one and fourteen hours of care per week (58%) and approximately one fifth of carers (21%) provide care for 43 hours or more on a weekly basis. Nearly 60 per cent are reported to be in employment.

The 2011 Census reported that approximately 13 per cent of carers are aged 65 years and older (CSO 2012a). The Census data also showed that the largest increase in carers between the 2006 and 2011 censuses occurred in the number of older carers, with a rise of 34 per cent in the 60 to 74 age group and 40 per cent in the over 75 age group (CSO 2012b). These figures illustrate the increasing importance of the role of the older person in the provision of family care. It is likely that the majority of older carers are the primary caregivers of another older person (Hellstrom and Hallberg 2001; McGee et al. 2008). According to findings from The Irish Longitudinal Study on Ageing (TILDA), 80 per cent of primary carers to people over the age of 50 years are themselves aged 50 years and older. Furthermore, one in five carers is aged over 65 years and is predominantly the spouse of the person being cared for (Barrett et al. 2011).

A special module on carers was included in the Quarterly National Household Survey (QNHS) in the third quarter of 2009. Using structured interviews, caregiving by the unpaid carer in Ireland was examined (CSO 2010). The QNHS used a much broader definition of a carer compared to that used in the National Census, describing a ‘carer’ as someone ‘looking after or giving special help to a person’ (CSO 2010). Approximately eight per cent (n=1971) of the population studied identified themselves as a carer. Similar to the Census statistics, the survey findings showed that the majority of carers were female (64%) and married (61%), and that 28 per cent were aged 30 to 44 years, with just under half aged 45 to 64 years (48%). The main type of care reported by carers included ‘keeping an eye’ on the care recipient, ‘keeping them company’ and providing ‘help’ or ‘other practical help’ (CSO 2010, p.18). Over a third of carers were found to be providing care for someone who required care because of old age and this person was most likely to be living in a separate household to the carer (CSO 2010).

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1 Statistics relating to carers who provide care to ‘an older person’ were unavailable.
Changing population demographics have a major bearing on the future provision of both formal and informal care, including family care (Barrett and Bergin 2006). Although concern has been expressed about the impact of population ageing on family carers, recent analysis of family trends in Ireland indicates that there is a renewed capacity among families in Ireland to provide care for relatives. This capacity is due to the shift in the family status of older people in recent decades from one in which a large proportion of older people were single and had no children to one in which a large proportion are married and have adult children. However, this model of care, underpinned by family networks of support and care, may yet weaken and become unsustainable as a result of gradually changing family structures and sizes in Ireland, and trends in women’s participation in the labour market (Care Alliance Ireland 2013). Furthermore, the preparedness and resilience of families to provide care is largely unknown and may be undermined by the growing number of older people with high dependency needs (Fahey and Fields 2008).

The pressures and demands of family caregiving have been well documented in the literature, as has the increased risk of abusive behaviour by carers who experience burden in their caregiving role (Sasaki et al. 2007; Kishimoto et al. 2013). Experts in the field of elder abuse assert that the majority of elder abuse occurs in the home (Bonnie and Wallace 2003). Family carers, particularly adult children, have been identified as the main perpetrators of abuse of older people living in the community in Ireland (Naughton et al. 2010; Lafferty et al. 2012).

To date there has been no systematic study undertaken with family carers of older people in Ireland to examine the conflicts that may arise within the caregiving relationship. Instead, large-scale research studies have examined conflicts using data collected from older people themselves and paid carers in nursing homes. A national survey of over 2,000 community-dwelling older people undertaken in 2010 found that 2.2 per cent of older people experienced abuse in the previous year, with financial abuse being the most commonly-reported form of abuse experienced (Naughton et al. 2010). A survey of over 1,300 paid carers (nursing and care staff) working in residential care homes for older people (Drennan et al. 2012) examined conflicts and interactions in the staff-resident relationship and found that over half of the staff (57.6%) admitted that they had observed one or more neglectful behaviour by another member of staff. Just over a quarter (27.4%) admitted to engaging in a neglectful act in the preceding year. The authors identified a number of factors that were significantly related to the abuse of older residents, such as the size of the nursing home, the nationality of the carer, level of job satisfaction and the presence of burnout (Drennan et al. 2012).

1.4 Supports for family carers in Ireland

It has been acknowledged that family carers do not always recognise themselves as carers; instead caregiving is often viewed as a normal part of being a family member or an inherent part of a loving spousal relationship (Ekwall et al. 2004; Hynes et al. 2008; Kamiya et al. 2012). Not identifying oneself as a carer may be a barrier to carers accessing available services and supports to which they may be entitled (Department of Health 2012). A number of supports and services are available to families who find themselves caring for an older family member at home in Ireland. The Health Service Executive (HSE) and the Department of Social Protection (DSP), as well as voluntary agencies supported by the HSE, provide a range of services and financial assistance to enable older people to remain in their homes and continue to be cared for by their families. The HSE offers home care packages, which comprise community services, such as community-based nursing, therapies, home help services, day care and respite care, which are tailored to meet each individual dependent older person’s needs and circumstances. The public health nursing service plays an important role in providing older people and their carers with essential links to services. Respite services in particular are perceived as hugely important as they provide family carers with an opportunity to spend some time away from the demands of caregiving.

In July 2012, the Department of Health released a National Carers’ Strategy, which provided a roadmap for implementing a strategy that ‘ensures that carers feel valued and supported to manage their caring responsibilities with confidence and empowered to have a life of their own outside of caring’ (Department of Health 2012b, p.3). The strategy recognised carers as the ‘backbone’ of care provision in Ireland and identified ‘a carer’ as someone ‘who is providing an ongoing 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 2012b, p.8).
The strategy document sets out a number of priority areas (Department of Health 2012b, p. 10), which included the following:

- Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for
- Support carers to manage their physical, mental and emotional health and wellbeing
- Support carers to care with confidence through the provision of adequate information, training, services and supports
- Empower carers to participate as fully as possible in economic and social life.

The strategy acknowledged that caregiving can often mean personal, health, social and financial sacrifices for the carer. One particular objective set out by the strategy was to ‘recognise the needs of carers by provision of income supports’ (Department of Health 2012b, p. 11). Carers frequently give up work to become full-time carers and may experience additional financial costs because of their caregiving role, such as fuel costs, medical expenses and so forth.

In Ireland, carers may apply for income support from the governmental Department of Social Protection (DSP). The Carer’s Allowance is a means-tested form of income support which is available to carers who care for people in need of full-time care and attention. If a person is providing full-time care to more than one person, the weekly payment is increased by 50 per cent. A half-rate Carer’s Allowance is a means-tested payment for people who care for a person(s) in need of full-time care and attention and who are in receipt of another social welfare payment (e.g. state pension, one-parent family payment). The Carer’s Benefit is a payment for people who have paid social insurance contributions and who leave the workforce for up to two years to care for a person(s) in need of full-time care and attention. Other financial supports, such as the Respite Care Grant and Domiciliary Care Allowance, are also available to eligible carers.

Approximately 55,682 people are in receipt of a Carer’s Allowance either full-rate or half-rate (DSP, Personal Communication May 2013). At the time of reporting, an eligible carer under 66 years of age was entitled to €204 a week or €306 if they provided care to more than one person and eligible carers aged 66 years and older were entitled to €239 a week or €358.50 if they provided care to more than one person. A further 1,608 carers received a Carer’s Benefit payment (DSP, Personal Communication May 2013). Both payments continue to be paid for up to six weeks after the caregiving has ceased. In May 2013, approximately 44 per cent (24,484) of recipients of the Carer’s Allowance provided care to a person aged 65 years and older (DSP, Personal Communication May 2013).

According to the large-scale research being undertaken as part of The Irish Longitudinal Study on Ageing (TILDA), the vast majority of care received by people aged 50 years and older is provided by unpaid informal carers (89.5%). Just 10.5 per cent of the carers received a payment for the care they provided and just 13 per cent of carers received a Carer’s Allowance or a Carer’s Benefit (Kamiya et al. 2012).

The Department of Social Protection income support welfare payments for carers have been subjected to cutbacks in recent years. The financial crisis of 2008 saw the Government introduce a programme of austerity, which included cuts to income support welfare payments for carers. In the budget of 2010, the Government reduced the Carer’s Allowance, the Carer’s Benefit and the half-rate Carer’s Allowance payments, while a Christmas bonus previously paid to carers was withdrawn. In the budget of 2013, the Carer’s Respite Grant was reduced by 19 per cent and further cuts were made to other allowances, including telephone, electricity and gas, and prescription charges, all of which impacted on family carers’ income.

A number of national support organisations have been established to provide support to family carers in Ireland. The Carers Association and Caring for Carers are two national voluntary support organisations for family carers working in the home, with the aim of helping to increase the quality of life of both the carer and the care recipient. These organisations also advocate and lobby on behalf of carers, offer drop-in resource centres, carer support groups and a national Freephone confidential Care Line is provided by the Carers Association. Home respite services, information on carers’ rights and entitlements, and training are also provided by these organisations.
Care Alliance Ireland is the national network of voluntary organisations which support family carers. The network supports around 85 member organisations in their direct work in enhancing the quality of life of carers by providing information, raising awareness, and engaging in research and policy development. Coordinated by Care Alliance Ireland and supported by other non-governmental organisations, National Carers Week takes place in June each year to raise awareness about family caregiving. A number of other national organisations support family carers, such as The Alzheimer Society of Ireland, which provides a range of specialised services throughout Ireland to help people with Alzheimer’s or dementia and their carers.

1.5 Conclusions

With an ageing population that is growing exponentially, the demand for family care provision will continue to increase. With changing family structures, smaller family sizes and ongoing threats to state-funded income supports for carers, family caregiving in Ireland faces significant challenges and much uncertainty. Reliance on family carers to provide good quality care to older family members living at home will need to be prioritised as part of national social policy and will require greater provision of physical, emotional, social and economic supports.
2.1 Introduction

This chapter presents a review of the literature pertaining to family carers of older people. A review of models of caregiving is presented followed by an overview of Irish and international research on the impact of caregiving on family carers. The chapter also provides an overview of the theoretical models which relate to conflict in caring for older people and discusses the literature in relation to prevalence and the factors associated with abusive and potentially abusive behaviours by carers towards older care recipients. The chapter concludes by examining family carers’ experiences of being mistreated by the care recipient and carers’ experiences of coping with caregiving.

2.2 Models of family caregiving

Family members tend to be the main providers of care for the growing number of older people requiring help and support in the community (Fahey and Murray 1994; Garavan et al. 2001; McGee et al. 2008; MacNeil et al. 2010). There has been considerable discussion surrounding the conceptualisation and operationalisation of ‘caregiving’ (Bowers 1987; 1988; Nolan et al. 1995b). A universally-accepted understanding of informal caregiving generally involves providing care with instrumental activities of daily living (IADL), such as housekeeping, cooking, shopping, etc., so that a person can live independently in a community setting (Lawton and Brody 1969). It can also involve the provision of personal care, such as assistance with personal hygiene, feeding, dressing, toileting, etc. (Katz et al. 1963).

A widely accepted model of family caregiving is that proposed by Nolan et al. (1995b) who viewed caregiving as a process and identified seven dimensions of family caregiving. These are: (1) anticipatory care, which relates to decisions and actions based on possible future needs; (2) preventative care, which concerns preventative measures to prevent illness, injury, and physical and mental deterioration; (3) supervisory care, involving checking in on the care recipient and providing practical help; (4) instrumental care, involving help with shopping, cooking and cleaning; (5) preservative care, which concerns help with maintaining the self-esteem of the person cared for and includes help with personal care, such as eating, getting dressed and personal hygiene; (6) (re)constructive care, which relates to building identity on the foundation of the person’s past; and (7) reciprocal care, which relates to help with improving physical function, such as walking or memory training.

2.2.1 Understanding caregiving and stress

Predominant among conceptual models of caregiving is one that assumes that the onset of chronic illness, frailty and functional decline becomes stressful for the carer and the care recipient over prolonged periods; this model tends to be examined empirically within the traditional stress and health framework (Schulz and Martire 2004). Several theoretical models have been proposed in an attempt to understand caregiver stress (Lazarus and Folkman 1984; Poulshock and Deimling 1984; Pearlin et al. 1990). For example, Lazarus and Folkman (1984) developed a transactional model of caring where stress is considered the condition that results from a person-environment transaction, leading the individual to perceive discrepancy between the demands of the situation and his/her resources or ability to cope with those demands. Another model of caregiver stress is the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin and McCubbin 1993), in which an appraisal and resiliency approach is taken to explain family stress, where family adaptation and illness as stressors affecting family life are emphasised. The resiliency emphasises the family’s ability to adapt and considers the illness as a stressor affecting family life while the appraisal component considers optimal problem-solving for managing illness situations (Yeh and Bull 2012). Pillemer and Wolfe (1986) discuss the role of social norms, such as reciprocity and solidarity, in creating stress associated with family caregiving. While these social norms are usually balanced in ordinary circumstances, if one becomes frail and dependent, an inequality can occur in the relationship leading to personal stress.

The most widely-cited model used to understand the stress experienced by carers of older people is that developed by Pearlin and colleagues (Pearlin et al. 1990), which was originally used to examine problematic areas in caring for patients with Alzheimer's disease. This model aims to identify the conditions associated with stress and how these relate to each other, and therefore considers psychological distress as the outcome of the stress process. The model examines the interrelationship of the carer’s socioeconomic background, both primary and secondary stressors, and the effect of these on the carer, while coping and social supports are considered as...
mediating factors (Pearlin et al. 1990). The objective primary stressors relate to indicators, which reflect the demands of the caring role and are anchored in the needs and demands of the care recipient, such as cognitive status, problem behaviour and dependency. The subjective primary stressors concern direct hardships subjectively experienced by caregivers, such as perceived overload or burnout and relational deprivation where the caregiver becomes separated from different parts of his or her life. The secondary stressors relate to role strain concerning roles and activities outside of the caregiving situation, such as family conflict, job-caregiving conflict, economic problems, and constriction of social life. Secondary intrapsychic strains relate to self-esteem, mastery, loss of self, role captivity, competence and gain. Carers’ outcomes include depression, anxiety, irascibility, cognitive disturbance, physical health and yielding of role.

Pearlin et al.‘s original model has since been developed and modified by others (LeBlanc et al. 2004; Gaugler et al. 2008). For example, Lee et al. (2006) modified the model, maintaining the same individual concepts of the original model and adding five basic domains to explain the stress process in caregiving; these were background; objective stresses; subjective stressors; coping and social support as mediators; and psychological distress as the outcome.

2.3 Impact of family caregiving

For many carers, providing care to a family member can be a positive and enriching experience (Finch and Mason 1993; Raschick and Ingersoll-Dayton 2004). Caregiving can make a person feel wanted, useful, and good about themselves (Cohen et al. 1995). Research findings suggest that giving support or helping others can be just as beneficial to a person’s health as receiving support (Brown et al. 2003). However, taking on the role of caregiver can bring with it a number of challenges and adverse consequences for different aspects of a carer’s life. Managing full-time care for a person often means that carers may not be able to engage in activities that most people take for granted, such as being able to relax, socialise or work (Department of Health 2012b). Furthermore, carers themselves often experience illnesses and disabilities. Recent figures showed that more than one in ten (11.4%) primary carers of people aged 50 years and older in Ireland is permanently sick or disabled (Kamiya et al. 2012).

Family carers are not unlike paid carers. Both sets of carers engage in difficult, challenging and demanding caregiving roles, and often receive little training and preparation (Prince et al. 2013). It is common for paid carers to receive minimum wage and experience low job satisfaction. There is often high staff turnover among paid carers, while family carers receive no payment, are unlikely to be in any form of employment and are often financially burdened by caregiving. Consequently, family carers frequently feel undervalued (McKee et al. 2003), which can impact negatively on the quality of care that they provide (Prince et al. 2013).

Caring for dependent people can be a source of major strain and psychological and emotional distress (O’Shea 2000). As a person’s health deteriorates, the demands on the carer increases and may reach a critical point, with the carer experiencing adverse physical, emotional, social or financial consequences, commonly known as ‘caregiver burden’ (Nerenberg 2008; George and Gwyther 1986), ‘care stress’ (Lee et al. 2012) or ‘care strain’ (Robinson 1983). Most research on family care of older people tends to focus on the ‘burden’ experienced by family caregivers (Nolan et al. 2006).

In Ireland, the Quarterly National Household survey (QNHS) found that two thirds of carers2 reported that their health and/or lifestyle had been affected by their caring responsibilities (Central Statistics Office 2010). Those who provided care for more than 57 hours a week were more likely to report that they felt completely overwhelmed by their caregiving duties. Carers also reported feeling confined in their caregiving role, and considered that they had less free time and were unable to visit friends and family. Many carers also reported having had to make adjustments to their family life, as caregiving disrupted their usual routine and they also reported that they had little privacy due to their caregiver role (Central Statistics Office 2010).

A postal survey of 1,990 family carers undertaken by the Royal College of Psychiatry of Ireland and The Carers’ Association examined the experience of informal caregiving and the effects of caring on carers’ physical and mental health.

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2 The Quarterly National Household Survey defines a ‘carer’ as someone who lives or does not live with a person who ‘is sick, disabled or elderly whom you look after or give special help to, other than in a professional or paid capacity (for example, a sick or disabled (or elderly) relative/husband/wife/child/friend/parent etc.).’ (CSO 2010, p.4). This includes all types of caring tasks self-defined by the carer.

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The study reported that almost two thirds (63%) of carers felt mentally and emotionally drained while carrying out their caring role, while over half (55%) of the carers reported experiencing sleep disturbances, feeling physically drained (57%) and feeling frustrated (55%) (O’Brien 2009). Based on the findings from a national postal survey of 1,411 carers who were in receipt of a carer’s allowance payment, O’Sullivan (2008) reported that when compared to the general population, carers were more likely to have a less positive picture of quality of life and to report poorer health.

Almost one third of carers (29.5%) indicated that their caring responsibilities affected their health. Carers indicated that they experienced stress/tension (40.8%), headaches (29.8%), lower back pain (26.3%) and aching joints (25.8%) in the preceding 12 months. Nearly one in every two carers indicated that their leisure time had been limited ‘quite a lot or a great deal’ as a result of their caregiving responsibilities (O’Sullivan 2008).

Providing care to people with dementia can be particularly demanding and stressful work (Schulz and Martire 2004; Bertrand et al. 2006; Owens and Cooper 2010) and can result in poor carer health and early nursing home placements for dementia care recipients (Etters et al. 2008). A survey of 297 community-dwelling carers in Ireland found a very high level of psychological distress among carers, particularly those caring for people known to have Alzheimer’s disease (O’Shea 2000).

Several studies have been published on carer burden and associated factors in families in the international literature. An EU-funded project entitled EUROFAMCARE (2003–2005) was conducted to examine aspects of family care of older people, with the aim of raising awareness around the needs and circumstances of family carers and to raise political awareness in all European countries (The EUROFAMCARE Consortium 2006). The study was undertaken with six countries, Germany, Greece, Italy, Poland, Sweden and the UK, to examine the direct and indirect costs associated with family care. Findings showed that over half of carers experienced a high level of burden (54%) and half of the carers (50%) reported poorer quality of life in the previous two weeks. Carers in the UK and Sweden tended to have higher ratings of better health and quality of life compared to the other countries.

A follow-up study conducted one year later showed that there was no clear trend for either improvement or deterioration in carers’ wellbeing. The results indicated that around half of carers surveyed experienced no change in either their quality of life or health status over 12 months; however, those that did tended to experience changes for the worse rather than the better (The EUROFAMCARE Consortium 2006). The study findings indicated that diminishing quality of life and health among carers together with an increase in burden of care influenced carers’ willingness to care for older family members over time.

An understanding of family caregiving and the factors related to the strain associated with the caregiving experience is essential to the development of suitable and effective interventions aimed at meeting the needs of family carers and supporting them in providing quality care to older family care recipients (Nolan et al. 1995b; Lee et al. 2006). Previous studies have identified a range of factors associated with higher levels of burden among carers of older people. For example, some care recipient factors may impact on carer stress levels (Pinquart and Sörensen 2003; Molyneux et al. 2008). Older people who require higher levels of support place greater demands on carers for help and assistance (Dale et al. 2008; Yeh and Bull 2012), who conducted a study with 50 carer-care recipient dyads, found a positive relationship between older people’s levels of frailty and dependency and the demands placed on family carers for help with activities of daily living and family caregiver burden. This suggests that as care recipient dependency levels increase, so do levels of carer burden (Yeh and Bull 2012).

A study among 143 carers of older family members in Finland found that care recipients’ physical mobility problems were associated with greater levels of stress among the carers (Salin et al. 2009).

Behavioural disturbances exhibited by older care recipients have been reported to influence carer stress levels. Authors of a Japanese study of 46 carers of dependent older people reported that carers providing care to older people with behavioural disturbances were more likely to report a ‘heavier burden’ (Arai et al. 1999; 2004). A number of studies have also reported higher stress levels in carers who provide care to older people with increased cognitive impairment (Aguglia et al. 2004; Bruce et al. 2008; Kuo and Shyu 2010), memory loss (Salin et al. 2009) and other mild cognitive impairments, which can sometimes lead to tension and conflict in the caregiving relationship (Kuo and Shyu 2010).
Chapter 2: Literature Review

The nature and extent of the care provided can be indicative of carer stress. Studies have shown that full-time carers experience lower life satisfaction than those who provide care on a part-time basis (Broe et al. 1999). Consistent with this finding, the Quarterly National Household Survey (QNHS) in Ireland indicated a positive relationship between the number of hours of caregiving and the impact on the carer’s life, with those more heavily engaged in caregiving more likely to report that their caring responsibilities impinged upon their health and lifestyle (Central Statistics Office 2010).

A meta-analysis of 168 empirical studies found that spousal carers were more likely to experience depressive symptoms, greater financial and physical burden, lower levels of psychological wellbeing and higher levels of psychological distress (Pinqurt and Sörensen 2011). This may be explained, in part, by the higher levels of care provision provided by spousal carers. Additionally, older family carers, including spousal carers, are reported to be less satisfied with their quality of life than younger carers, which may be attributed to their own declining health (Salin et al. 2009).

The carer’s role can be further burdened by financial pressures. This has been particularly true for Irish carers, who have experienced reductions in their carer’s allowance and carer’s benefits associated with Government budgetary cuts (The Carers Association 2010). Kang (2012) found that the onset of conflict and violence is much more likely to occur in families where there is unemployment and lower household income. A poor socio-economic situation among caregivers has been found to be a strong predictor of low mental quality of life among caregivers (Ekwall et al. 2004). Pinqurt and Sörensen (2011) reported that spousal carers are more likely to experience financial burden than adult children carers of older people. In addition, studies have shown that the competing demands of being both an employee and a caregiver can create further stress for caregivers (Anastas et al. 1990). Referred to as ‘sandwiched employees’, these carers are responsible for both the care of their own children as well as the care of their parents and are at greater risk for depression (Neal and Hammer 2007).

Caregiver stress can sometimes be related to family discord, resulting from changes in living circumstances (Thobaben 2001). Tensions that may occur within a caregiving relationship may be exacerbated when both parties have a shared living situation (Pillemer and Suitor 1992). The QNHS 2009 reported that caregivers who lived with the care recipient were more likely to score higher on the Caregiver Strain Index than those who lived in a different household to the care recipient (Central Statistics Office 2010). Furthermore, the level of stress experienced by the caregiver can be influenced by the level of formal and family support provided to the carer. For example, a study of carers of older people in Japan found that carers who received temporary respite from caregiving reported lower levels of burden (Arai et al. 2004). Another study reported that significant positive associations were observed between lack of family support and family caregiver burden (Yeh and Bull 2012).

In contrast to these findings, the European EUROFAMCARE study on family carers of older people reported that service use did not demonstrate any significant improvement in carers’ wellbeing, health or burden (The EUROFAMCARE Consortium 2006).

2.4 Theoretical models of mistreatment in caregiving

Carer burden tends to be viewed as an outcome of the stress and pressure frequently experienced as a result of caregiving (Thompson et al. 1993). Higher levels of burden among family carers of older people can result in lower quality of life, poorer health and wellbeing, and many are at risk of developing depressive symptoms. Some authors have indicated that carer stress, strain and pressure frequently experienced as a result of caregiving and thus engage in abusive care practices. The underlying assumption suggests that the more care older people require from their carers, the more stress their carers experience. Based on this premise, elder abuse researchers postulate that should caregiver burden reach a level whereby a critical point of stress is experienced, carers may then resort to abuse or neglect (Nerenberg 2008).
That is, the abuse is attributed to carer stress or to the burden of the caregiving itself, rather than to malicious intent on the part of the caregiver to mistreat the older person (Sengstock and Barrett 1993; Marshall et al. 2000).

The caregiving stress theory focuses not only on the needs of the care recipient but also on the needs of their carers. Advocates of the theory look to alleviate caregiver stress levels as a means of ameliorating the problem of elder abuse. However, this theory has been challenged on the grounds that it fails to acknowledge that some victims of elder abuse are in fact healthy and do not require care, or that in some cases the carer is the victim and the care recipient the abuser (Phillips et al. 2001). Furthermore, interventions aimed at reducing carer stress and improving communication may do little to protect the victim if the dynamics of abuse are rooted in power and control (Brandl et al. 2007). It has been argued that the continued use of the carer stress model may have inhibited the development of better alternative or supplementary explanatory models (Jackson and Hafemeister 2013).

One theory, proposed by Wolfe and Pillemer (1989) to explain mistreatment in the care of older people, is that the abuse may be due to the long-standing familial patterns of violence or abuse. Based on the Social Learning Theory (Bandura 1973), also known as the Cycle of Violence Model and the Intergenerational Transmission of Violence Model, this theory asserts that the use of violence and abusive practices has been learned by the carer through modelling at an earlier stage to resolve conflicts or obtain a desired outcome. Engaging in such negative behaviours may be the only way that some families know how to deal with conflict and discord (Paveza et al. 1992). Moreover, caregivers may engage in potentially harmful behaviours as they may not be aware of alternative approaches to managing a particular situation, or they simply may be unaware that their behaviour may be considered abusive (Williamson and Shaffer 2001; Beach et al. 2005).

A traditional approach to understanding caregiver stress is the idea of ‘generation inversion’, whereby the older person becomes increasingly dependent on the carer for their physical, emotional, and financial needs (Kleinschmidt 1997). This theory suggests that family caregiving is not generally a role that is aspired to or anticipated (Moen et al. 1994). Carers who believe that they have been ‘burdened’ with the caregiving responsibilities and who may experience physical, financial or emotional stresses as a consequence of caregiving, may feel justified in the mistreatment of their family member (Nadworny 1994); additionally, they may feel resentful of the demands of caregiving and may withdraw basic needs over time (Kleinschmidt 1997).

According to the Social Exchange Theory (Homans 1966), when the sociodynamic balance within a relationship is upset or perceived to be upset, the disadvantaged person in the relationship may resort to violence to restore that balance. When applied to caregiving of older people, carers who perceive themselves as not receiving their fair share from the relationship may engage in potentially harmful behaviours or violence in an attempt to reinstate equilibrium. The Power and Control Theory (Brandl 2002) highlights the use of coercive tactics as a means of gaining and maintaining power and control in the caregiving relationship. It has been used primarily to explain abuse among elderly couples, but it has also been applied to adult children who have reluctantly assumed the role of caregiver.

Another factor that may play a role is reciprocal abuse, whereby aggression exhibited by the care recipient may be responded to in the same manner by the carer (Pillemer and Suitor 1992). Steinmetz (1988) was among the first to highlight the issue of reciprocal abuse in the carer-care recipient relationship and its role in abusive behaviours by some carers. Steinmetz (1988) explains that the verbal and physical abuse that a carer may experience may, in turn, evoke an abusive response from the carer, who is then more likely to mistreat the older care recipient. Paveza et al. (1992) found that 15.8 per cent of older relatives with Alzheimer’s disease reported that they had been violent towards family caregivers in the year since their diagnosis.

In some cases, carers may simply lack an understanding of the ageing process. Carers may become frustrated and come to expect too much from their older family member (Thobaben 2001). There may be a lack of knowledge of the symptoms of chronic illnesses that are common in older age, such as dementia, which can sometimes lead caregivers to engage in conflict with the older care recipient (Thobaben 2001; Bruce et al. 2008). Family carers are often untrained, may have limited external support and can struggle to care for their older family relative who may have a condition that they may not fully understand (Owens and Cooper 2010). Several other factors have been suggested in explaining elder mistreatment by family carers, including carer attitudes,
the quality of premorbid relationships and disruptive behaviours by the care recipient. Some studies have also found that abusive carers are more likely than non-abusive caregivers to report that they were not receiving adequate support from family or social services (Anetzberger 1987; Compton et al. 1997).

2.5 Abuse of older people by family carers

Many authors in the field of elder abuse have highlighted the pressures and demands of family caregiving and have asserted that it is a major cause of abuse by carers. Earlier studies have focused mainly on measuring direct aggression, abuse and violence by family carers towards older people for whom they provide care (Homer and Gilleard 1990; Pillemer and Suitor 1992; Coyne et al. 1993; Pot et al. 1996). However, more recent studies have focused on less severe cases, which involve ‘potentially harmful behaviours’ by family carers; these are carer behaviours that may not require professional service intervention, but that may still compromise the quality of care and may serve as a precursor to abuse or as ‘early warning signs’ that may be amenable to early, preventive intervention efforts (Williamson and Shaffer 2001; Beach et al. 2005; Sasaki et al. 2007; Cooper et al. 2009; Kishimoto et al. 2013). Several authors have taken the view that poor quality care relates to any caregiving behaviours that may be considered potentially harmful to the care recipient, either physically or psychologically (Beach et al. 2005; Williamson and Shaffer 2001).

The literature indicates that abusive and potentially abusive behaviours among carers of older family members are relatively common (Cooper et al. 2009; Paveza et al. 1992; Yan and Kwok 2011), particularly among those who care for older people with dementia, who are considered at greater risk of abuse due to increased vulnerability (Owens and Cooper 2010). Family members are prepared to report elder abuse, with some studies reporting that carers experience a sense of relief from sharing their problems and discussing the conflicts in the caregiving relationship with someone else (Homer and Gilleard 1990). However, few professionals broach the subject because of its sensitive nature and because it may necessitate referral to protective services for older people, which may result in the separation of the older person from their carer (Oswald et al. 2004; Cooper et al. 2009). Consequently, many cases concerning potentially abusive behaviours by carers escalate into more severe forms of elder abuse before coming to the attention of formal services (Cooper et al. 2009). The literature indicates the prevalence of abusive behaviours by family carers and identifies a number of care recipient, carer and caregiving factors associated with the abuse of older people by family carers.

2.5.1 Prevalence of abuse as reported by family carers

Published by Cooper et al. (2008b), a systematic review of the literature on the prevalence of elder abuse and neglect found that the prevalence of elder abuse reported by family carers ranged from 11 to 55 per cent. The review authors highlighted the fact that few studies used reliable psychometric tools to measure prevalence rates and that a number of different definitions of abuse have been adopted and, accordingly, the findings of these studies must be interpreted with caution (Cooper et al. 2008b). Just one study was identified that measured abusive behaviours among family carers using a valid and reliable measure. Using the severe violence subscale of the Conflict Tactics Scale (Straus 1979), Paveza et al. (1992) reported that 5.4 per cent of carers of older people with Alzheimer’s disease (N=184) reported that they engaged in physically abusive behaviours towards the care recipient in the year since diagnosis; behaviours included kicking, hitting, punching, biting and threatening with or using a weapon.

Cooper et al. (2008b) identified five studies that adopted the criteria for abuse proposed by Pillemmer and Finkelhor (1988), which defines verbal abuse and neglect as occurring ten times or more in the previous year and physical abuse as occurring once in the previous year. Pot et al. (1996) recruited 169 carers of people with dementia through a day hospital and memory clinic in the Netherlands, and found that 30.2 per cent of carers reported that they were verbally aggressive and 10.7 per cent reported that they were physically aggressive towards the care recipient. A small-scale study conducted in Northern Ireland by Compton et al. (1997), involving structured interviews with 38 carers of older people with dementia, reported that the prevalence of verbal abuse by carers was 34.2 per cent (n=13), with 13 per cent (n=5) reporting physical abuse (Compton et al. 1997). Using an anonymous postal survey, Cooney and Mortimer (1995) conducted a small pilot study with 67 carers of people with dementia in the UK and found an overall prevalence rate of 55 per cent for abuse; verbal
abuse was reported by 52.5 per cent of carers and physical abuse by 11.9 per cent. Subsequent to this pilot study, Cooney et al. (2006) conducted domiciliary interviews with 82 carers living with people aged 65 years and older with dementia and found that 52 per cent of carers reported having engaged in some form of abuse; half of the carers (51%) admitted to verbal abuse and one in five reported physical abuse. Based on structured interviews with 56 carers of older people recruited through geriatric services in the UK, Homer and Gillear (1990) found that 45 per cent of carers admitted to perpetrating some form of abuse; 13.7 per cent reported physical abuse and 41.1 per cent reported verbal abuse.

Cooper et al. (2008b) reported that the remaining studies in the review used invalid and unreliable measures, had poorly-defined target populations and/or used different criteria for carer abuse. The prevalence of any form of abuse in these various studies ranged from 12 to 35 per cent (Sasaki et al. 2007; Grafstrom et al. 1993), with the prevalence of physical abuse ranging from 5.9 to 12 per cent (Pillemer and Suttor 1992; Coyne et al. 1993).

Several studies measuring the prevalence of abusive behaviours by family carers of older people have been published subsequent to Cooper et al.’s (2008) systematic review. For example, Cooper et al. (2009) undertook the first representative study using a cross-sectional survey of 220 family carers in England, who provided care for four hours or more per week to older people with a clinical diagnosis of dementia. Using the modified Conflict Tactics Scale (M-CTS), Cooper et al. (2009), measured the prevalence of five potentially harmful psychological behaviours (screamed or yelled, threatened with a nursing home placement, threatened with physical force, threatened to abandon, verbally abused (used a harsh tone of voice, insulted, called names or swore at); and five potentially harmful physical behaviours (hit or slapped, handled roughly in other ways, withheld food, shaken, or felt afraid that they might hit or try to hurt the care recipient) (Beach et al. 2005; Cooper et al. 2009). These behaviours were deemed less serious and not warranting formal service intervention. The authors found that 52 per cent of family carers of people with dementia reported that they engaged in some physically or psychologically abusive behaviour towards the care recipient with dementia and a third of the carers (34%) met the criteria for significant abuse (Cooper et al. 2009). One third of the carers (33%) reported that psychological abuse had occurred sometimes in the previous three months, with verbal abuse being the most commonly-reported form of abuse. Just 1.4 per cent reported that physical abuse had occurred sometimes (Cooper et al. 2009). A one-year follow-up with the same carers found that the self-reported abusive behaviours had increased (N= 131); 48.1 per cent of the carers who participated in both studies reported abusive behaviours at baseline, as compared with 61.8 per cent one year later (Cooper et al. 2010a).

As part of a US longitudinal study, The Family Relationships in Later Life project (FRILL), a number of researchers have explored carer-care recipient dyads using the same ten-item M-CTS (Williamson and Shaffer 2001; Beach et al. 2005; Mac Neill et al. 2009; Morse et al. 2012). Williamson and Shaffer (2001), who reported data from a survey of 142 carers of spouses aged 60 years and older found that the most-frequently reported form of potentially harmful behaviour was psychological; half of the carers reported screaming and yelling at the care recipient at least sometimes, while just over two fifths (43%) reported having used a harsh tone of voice, insulted, called names or sworn at the care recipient. Just five per cent of carers admitted to hitting or slapping their spouse; seven per cent roughly handled the care recipient in other ways, and eight percent reported being afraid that they might hit or hurt their spouse (Williamson and Shaffer 2001).

In a Japanese study of 123 carers of care recipients who had been referred to a hospital-based memory clinic, Kishimoto et al. (2013) found that the self-reported prevalence of abusive behaviours occurring at least sometimes was 15.4 per cent. Approximately one third (33%) of the family caregivers reported engaging in some form of abuse, with 15 per cent reporting psychological abuse and 1.6 per cent reporting physical abuse.

The highest prevalence rate of abusive behaviours engaged in by family carers was reported in a Chinese study based on structured interviews with 122 family caregivers of older people with dementia (Yan and Kwok 2011). Using a 12-item revised Conflict Tactic Scale (CTS2), the authors found that 62.3 per cent of carers admitted to engaging in abusive behaviours in the previous month. Nearly two thirds (62.3%) reported at least one incident of verbal aggression (e.g. insulting, humiliating and intimidating an older person) and 18 per cent reported physical abuse (e.g. slapping, grabbing, and using a knife). Yan (2014) also used the CTS2 to examine the prevalence of abuse by 149 family caregivers of community-dwelling older people with dementia and
found that 42.3 per cent admitted to engaging in some form of abusive behaviour towards the older person in the previous month. Verbal abuse was the most common type of abuse reported, with 40.3 per cent of carers admitting to at least one incident of verbal aggression and 15.4 per cent admitting to physical abuse.

In summary, the literature demonstrates that family carers are willing to report abusive behaviours towards older relatives to whom they provide care. The prevalence of abusive and potentially abusive behaviours ranges widely, with verbal abuse being the most frequently-reported form of abuse engaged in by family carers. Few previous studies have measured neglect by family carers and few have reported sexual or financial abuse by family carers (Lee and Kolomer 2005). Reported differences in prevalence rates may be attributable, in part, to varied definitions of abuse, the type of instruments used to measure self-reported abuse and the data collection methods. The vast majority of studies reporting abuse by family carers consisted of relatively small sample sizes, recruited carers through community dementia and memory services, used structured face-to-face interviews and collected data mostly from carers of older people with dementia.

2.5.2 Factors associated with the abuse of older people by family carers

Understanding the factors associated with the abusive and potentially abusive behaviours engaged in by family carers of older people enables targeted services and more effective interventions to be developed, which, in turn, enables family carers to continue to care for their older relative at home. This, in turn, can improve the quality of life of both the carer and the care recipient and the older person can benefit from better quality care (Cooper et al. 2010b). A number of factors associated with abusive behaviours by family carers have been identified in the literature. These include: care recipient factors, such as gender, dependency levels, cognitive impairment, and disruptive behaviours; carer factors, such as age, gender, living arrangements, caregiver stress and physical and mental health problems; and caregiving factors, including the nature of caregiving and the caregiving relationship, quality of the relationship, and professional and social supports.

Care recipient factors associated with abuse of older people by family carers

A range of care recipient factors have been identified as being associated with higher levels of abusive carer behavior, including gender, dependency levels, cognitive impairment and disruptive behaviours. For example, Pot et al. (1996) reported that verbally and physically aggressive carers were more likely to care for a male care recipient. As older people become frail and dependent, they become increasingly reliant on family carers and this, in turn, increases the likelihood that they will experience elder abuse (Thobaben 2001).

Studies have demonstrated a significant positive association between older people's frailty and dependence on family carers for help with activities of daily living, and carer abuse (Thobaben 2001; Beach et al. 2005). In an effort to understand the risk factors for violence in caregiving relationships, Pillemer and Suitor (1992) undertook a study with 236 family caregivers of older relatives with dementia and found that carers who feared becoming violent cared for older people who were more functionally impaired and who required greater levels of help with activities of independent living. Others studies have also reported a relationship between carer abusive behaviours and care recipient functional impairment and greater need for care and support with activities of daily living (Coyne et al. 1993; Beach et al. 2005). In a study of 412 carer-care recipient dyads in Japan, Sasaki et al. (2007) reported an association between abusive carer behaviour and the care recipient's physical and sensory dependencies. Carers of disabled older people with more severe physical impairments and hearing difficulties were more likely to report engaging in potentially harmful carer behaviours. However, in a study of 182 carers of older people with Alzheimer's disease, Paveza et al. (1992) reported that the physical dependency of the care recipient was not a risk factor for abusive interactions in the carer-care recipient relationship. Pot et al. (1996) similarly found no association between care recipient dependency on help with ADLs and carer aggression.

Much of the extant literature on abuse by family carers indicates that caring for an older person with a cognitive impairment such as dementia is stressful and can lead to conflict in the family. Studies have reported increased stress and burden among caregivers who provide care to older people with higher levels of cognitive impairment (Aguglia et al. 2004; Bruce et al. 2008; Kuo and Shyu 2010), which places them at greater risk of committing...
carer abuse or violence (Anetzberger 1987; Steinmetz 1988). However, the evidence remains inconclusive. Homer and Gilleard (1990) failed to show any association between carer abuse and dementia or the level of cognitive impairment in the older person. Paveza et al. (1992) concluded that a person with Alzheimer’s disease is 2.25 times at greater risk of abusive behaviour by a carer than an older person living in the community. Lachs et al. (1997) also found cognitive impairment to be a main predictor of abuse and neglect by family carers.

Behavioural disturbances are frequently the most challenging aspects of dementia and are exhibited in almost all people with dementia. Such disruptive behaviours among older care recipients have been suggested as one of the main predictors of caregiver burden (Arai et al. 1999; 2004). Pillemer and Suitor (1992) found that disruptive behaviours exhibited by the care recipient were predictive of violent feelings in the carer. Other studies have also established an association between potentially harmful behaviours towards older people by family caregivers and care recipient behavioural disturbances (Compton et al. 1997; Sasaki et al. 2007; Kishimoto et al. 2013). Based on a study undertaken with 82 carers of older people with dementia in the UK, Cooney et al. (2006) reported that carers who admitted to abuse reported significantly higher levels of behavioural disturbances in the care recipient than carers who did not admit abuse. Yan and Kwok (2011) similarly found that agitated behaviour in the care recipient was associated with the carer’s abusive behaviour.

Carer factors associated with the abuse of older people by family carers

In addition to care recipient characteristics, abusive behaviours by carers are also associated with carer characteristics (Homer and Gilleard 1990). Such factors include the carer’s age, living arrangements, gender, level of education, carer burden, general health and depression.

Some studies have examined the relationship between the age of carers and abusive carer behaviour. For example, a study of psychological abuse among 92 carers of older relatives in Taiwan found that younger carers engaged in more psychologically abusive behaviours than older carers (Wang et al. 2006). In contrast, Pillemer and Suitor (1992) who conducted a study with 236 family carers of older people with dementia found that older carers were more likely to engage in violent behaviours towards the care recipient than their younger counterparts. In addition, Pillemer and Suitor (1992) also found that a shared living arrangement with the care recipient was a predictor of violent feelings in carers. This finding is supported by other studies, which have found that carers who admitted to engaging in abusive behaviours were more likely to live with an older person (Homer and Gilleard 1990; Pot et al. 1996; Yan and Kwok 2011). Paveza et al. (1992) reported that older people with Alzheimer’s disease who resided with their family caregivers, and who were without a spouse, were almost three times at greater risk of violence from the carer (Paveza et al. 1992). Yan and Kwok (2011) reported that physical abuse, but not verbal abuse, was related to greater number of co-residing days.

Another carer factor that has been linked to abusive behaviours by carers is gender. Wang et al. (2006) reported that female carers were more likely to engage in psychologically abusive behaviours against older care recipients. However, a study of Japanese family carers of older people with a cognitive impairment found that male carers scored higher on the modified Conflict Tactics Scale, indicating that males engaged in more abusive behaviours than female carers (Kishimoto et al. 2013). Pot et al. (1996) failed to find a relationship between the gender of the carer and abusive carer behaviours. Kishimoto et al. (2013) reported that carers with higher levels of education were more likely to engage in potentially harmful behaviours, while Cooper et al. (2010b) reported that higher educational qualifications were a significant predictor of carer abuse (Cooper et al. 2010b).

The relationship between carer burden and abusive behaviours by family carers of older people has been well documented. In a study of 92 carers of older people in Taiwan, Wang et al. (2006) showed that higher levels of burden among carers were related to psychologically abusive behaviours against older care recipients. Two Japanese studies have also reported a link between carer burden and abuse by family caregivers. In a study of 412 carer-care recipient dyads, Sasaki et al. (2007) found that carers who had engaged in potentially harmful behaviours experienced higher levels of burden than carers who had engaged in no potentially harmful behaviours. Using the modified Conflict Tactics Scale (M-CTS) with 123 carer-care recipient dyads, Kishimoto et al. (2013) also reported a positive correlation between higher scores on the M-CTS and higher scores on the Zarit Burden Interview Scale. Cooper et al. (2010b) also found carer burden to be among the main predictors of
abuse by family carers of older people with dementia in the UK. In a study of Chinese caregivers, Yan and Kwok (2011) reported that caregiver burden was a significant predictor of verbal, but not physical abuse towards older care recipients.

Carers who feel burdened and stressed by caregiving may experience physical and mental health problems, which may, in turn, impact on the quality of care they provide. Beach et al. (2005) reported a positive association between carers who reported poorer self-rated health and the likelihood of engaging in potentially harmful carer behaviour. Contrary to this finding, Cooney et al. (2006) reported that carers who admitted to being physically abusive towards the care recipient were significantly more likely to rate their physical health better than carers who reported no physical abuse.

Carers’ mental health has been found to correlate with abusive behaviours by carers (Pot et al. 1996). According to MacNeil et al. (2010), poor mental health puts them at greater risk for engaging in potentially abusive behaviours towards the older people in their care. For example, Compton et al. (1997) found a relationship between carers’ level of anxiety and abuse by carers.

There is strong evidence of a relationship between carer depression and poorer quality of care (Beach et al. 2005). Several researchers have found that depressed carers are at risk of engaging in behaviours that might harm the care recipient (Paveza et al. 1992; Williamson and Shaffer 2001). In a study of 142 spousal carers of people aged 60 years and older, Williamson and Shaffer (2001) found that more depressed carers were more likely to treat their spouses in potentially harmful ways. Paveza et al. (1992) reported that carer-care recipient dyads were three times at greater risk for violence when carers scored above the threshold for risk of clinical depression on the Center for Epidemiologic Studies Depression Scale (CES-D) than carers who scored below this threshold.

Other studies have also noted higher levels of depression among carers who report abusive behaviours towards the older person in their care (Homer and Gilleard 1990; Coyne et al. 1993). Cooper et al. (2010b) found that an increase in carer abusive behaviour towards older people with dementia was strongly predicted by an increase in depression and anxiety in the carer. Beach et al. (2005) also noted that family carers who experience depression are more likely to be investigated by social services for suspected elder abuse than non-depressed carers.

(Bonnie and Wallace 2003). Carers of older people with dementia may develop poor mental health due to a sense of ‘losing the person’ to dementia, as well as a lack of confidence in providing adequate and appropriate care (Cooper et al. 2010a). Additionally, Pillemer and Suitor (1992) point to a link between carers who are more likely to become violent and carers who report lower self-esteem. Other mental health problems commonly found among abusive carers of older people are alcohol and drug addictions (Homer and Gilleard 1990; Peri et al. 2008; Naughton et al. 2010).

Caregiving factors associated with the abuse of older people by family carers

The nature of the caregiving relationship itself can sometimes play a role in the abuse of older people by family carers. For example, Cooper et al. (2010b) found higher carer abuse scores among carers who provided more hours of care per week. Similarly, Pot et al. (1996) reported that verbal aggression by carers was associated with providing more care. However, the evidence for this relationship is weak, as several studies have failed to find any relationship between carer abuse and the amount of care provided or the duration of the care (Pérez-Rojo et al. 2009; Sasaki et al. 2007; Yan and Kwok 2011; Kishimoto et al. 2013).

A number of studies have explored whether the type of kinship relationship between the carer and the care recipient is associated with abusive behaviours by the carer. Prevalence studies undertaken with community-dwelling older people suggest that family members are most likely to be the primary abuser of abused older people. A prevalence study undertaken with over 2,000 community-dwelling older people in Ireland found that half of the main perpetrators identified were adult children of the older person (Naughton et al. 2010). A number of studies undertaken with family carers of older people have reported similar results. In a study of 412 carer-care recipient dyads in Japan, Sasaki et al. (2007) found that carers who were adult children of the care recipient were more likely to engage in potentially harmful carer behaviour towards the care recipient. However, not all studies undertaken with family carers found that adult children are more likely to engage in abusive behaviours towards their parents. Both Beach et al. (2005) and Pillemer and Suitor (1992) found that spousal carers in the USA were more likely than non-spousal relatives to report becoming abusive towards the older care recipient. Kishimoto et al. (2013) similarly reported that spousal carers scored higher on abuse than
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The quality of the relationship between the carer and the care recipient may also be associated with abusive carer behaviour. A number of studies have shown abuse of the carer by the care recipient to be related to abuse of the care recipient by carers (Pillemer and Suitor 1992; Coyne et al. 1993). Pillemer and Suitor (1992) found that family carers who experienced physical aggression from the care recipient were more likely to reciprocate the abuse. Similarly, in a study of 45 carers of relatives with dementia in Spain, the frequency of provocative and aggressive behaviours by the person being cared for predicted the risk of elder abuse (Pérez-Rojo et al. 2009). A number of studies in the UK have reported similar findings, with abuse by the carer significantly related to abusive behaviour by the care recipient (Cooper et al. 2010b; Homer and Gilleard 1990). Compton et al. (1997) found an association between verbal and physical abuse by the care recipient, and verbal and physical abuse by the carer in a study of carers of older people with dementia in Northern Ireland. While it is not possible to establish a causal relationship between the mistreatment of carers by care recipients and verbal or physical abuse by their carers based on cross-sectional studies, there is strong evidence to suggest that abusive behaviours by care recipients towards carers is associated with increased rates of verbally and physically abusive behaviours by the carer (Cooper et al. 2010b; VandeWeerd et al. 2008; Coyne et al. 1993).

All carers are liable to feeling unappreciated and unrewarded in caregiving (Williamson and Shaffer 2001). However, the quality of the relationship between the carer and the care recipient in the past may determine the quality of care provided. Abuse by caregivers tends to be less prevalent when there has been mutual responsiveness to the carer and the care recipient’s needs prior to a decline in health of the care recipient (Williamson and Shaffer 2001). Some researchers assert that as the care recipient grows older and becomes increasingly dependent on the carer, the costs of the relationship rise and the rewards previously gained from the relationship may diminish to the extent that the relationship is no longer deemed to be rewarding for the carer (George 1986). According to Williamson and Shaffer (2001), the nature of pre-caring relationships may determine whether caregivers perceive their current caregiving relationship as rewarding, which, in turn, may predict depression and thus potentially abusive behaviours among caregivers.

Cooper et al. (2010b) found that higher abuse scores among carers correlated with fewer past relationship rewards. Homer and Gilleard (1990) reported that abusive carers were more inclined to report a poorer pre-caring relationship than non-abusive carers; this was particularly true if verbal abuse was already present in the caregiving relationship before the caregiving commenced. Compton et al. (1997) also found that a poor premorbid relationship was a key factor in predicting carer abuse. Cooney et al. (2006) reported that verbal abuse by carers was significantly related to carer-care recipient relationships in which there was a certain level of discord and disagreements in the relationship prior to caregiving; however, this was not found to be significant for physical abuse. In contrast, in relationships in which the care recipient had previously been physically abusive towards the carer, carers were not more likely to report physical abuse towards the care recipient than those who had not been physically abused (Cooney et al. 2006).

There is some evidence to suggest that social support and the availability of respite or other forms of assistance with caregiving may act as moderators of abuse (Beach et al. 2005). While Pillemer and Suitor (1992) failed to find that social support provided any protection against violent feelings in caregiving situations, Cooper et al. (2010a) found that less social support, in the form of domiciliary care, was associated with increased abusive behaviours by family carers of older people with dementia. Yan and Kwok (2011) also found that a lack of assistance from a home helper was a significant predictor of verbal abuse and Compton et al. (1997) found that merely the perception of receiving little help from social services was significantly associated with carer abuse. A lack of financial support may also play an important role...
in the risk of carer abuse, as the onset of conflict and violence is much more likely to occur in families where there is unemployment and lower household income (Kang 2012).

2.6 Mistreatment experienced by family carers

While the majority of the studies focus on the abuse of older people, conflict within caregiving relationships includes not only carer-to-care recipient aggression, but also care recipient to carer aggression (Wolf 1998). Severe violence directed at a family carer by the care recipient is not unusual (Paveza et al. 1992). Behaviours on the part of the care recipient can include verbal abuse (Cooper et al. 2010c; VandeWeerd et al. 2008; Compton et al. 1997) and physical aggression, such as hitting, spitting and kicking (Compton et al. 1997; Coyne et al. 1993; Pillemer & Suitor 1992).

Cooper et al. (2010c), who investigated abusive behaviours experienced by 220 family carers of people with dementia, found that nearly half of the carers (47.3%) reported that the care recipient was abusive in the previous few months and over one third (37.3%) reported that the care recipient was abusive ‘at least sometimes’. The family carers mainly experienced psychological mistreatment (36.4%) and, to a lesser extent, physical mistreatment (5.9%) from the care recipient. Similarly, in a study of 262 persons with Alzheimer’s disease, Eastly and Wilcock (1997) reported that 35 per cent of care recipients were verbally aggressive, while a further 18 per cent had physically assaulted their carers. In addition, a study of 184 Alzheimer’s care-care recipient dyads reported by Paveza et al. (1992) found that 15.8 per cent of care recipients had engaged in severe violent behaviour towards their carers, while Coyne et al. (1993) reported that 33.1 per cent of care recipients with dementia exhibited physically abusive behaviours.

Some researchers assert that it is the care recipients’ aggressive behaviour that triggers the abusive behaviour by the carer (Wolf 1998; Pillemer and Suitor 1992). Steinmetz (1988) reported that more than 34 per cent of care recipients exhibited verbal abuse, while 18 per cent demonstrated physical violence towards their carers. In an intervention study undertaken with 83 family carers to reduce mistreatment by care recipients, Phillips (2008) identified several forms of verbal and psychological aggression on the part of the care recipient, including imposing guilt, arguing, manipulating, pouting and sulking, crying and yelling. Care recipients also exhibited physical aggression towards their carers, including pushing, grabbing and shoved, slapping, trying to hit the carer with an object, hitting, kicking and biting (Phillips 2008). This study also highlighted care recipient aggression outside of the context of Alzheimer’s disease or dementia, as less than one third of older people in the study exhibited symptoms of dementia.

2.7 Coping with caregiving

The ability to cope is fundamental to the stress experienced in the caregiving process (Milne et al. 1993). It has been suggested that the carer’s ability to adjust to and to cope with caring responsibilities is the best indicator of the likelihood of abuse occurring (Bender 2006). Evidence suggests that the range and style of coping strategies adopted by caregivers affect the level and type of stress they experience (Nolan et al. 1995a). Carers frequently develop strategies to cope with the pressure and strain induced by their caregiving responsibilities. Studies show that more anxious carers tend to use more dysfunctional coping styles and thus report higher levels of carer burden (Cooper et al. 2006). Salin et al. (2009) found that the most commonly used problem-solving strategies adopted to help informal carers of older people to cope better included ‘establishing priorities’ and focusing on them, followed by having confidence in one’s own competence and experiences. Other stress-management strategies were linked to the carer’s perspective on their situation and included ‘taking life one day at a time’, ‘having a positive outlook’ and ‘taking one’s mind off things for a while’ (Salin et al. 2009). O’Sullivan (2008) found that the most commonly-reported strategies adopted by carers to help them to cope were talking to friends (65.7%), watching television (62.5%), praying/faith (39.6%) and exercise (35.9%).

Kuo and Shyu (2010) described ‘ambivalent normalisation’ as a strategy used by Taiwanese families caring for older people with mild cognitive impairment; this comprised three main components: subtle changes, optimistic appraisal and ambivalent anticipation. Those
that adopted ‘ambivalent normalisation’ were inclined to adopt multiple behavioural management strategies to help to reduce conflict in the carer-care recipient relationship. In response to the conflict experienced, carers changed their behaviour to reduce the level of conflict experienced by using verbal techniques and creating space for the older person (Kuo and Shyu 2010).

A number of interventions have been developed targeted at carers to reduce burden and to enable them to cope better with caregiving. These have included psychotherapy, education programmes, support groups, respite, family counselling, and case management (Sorenson et al. 2006). The evidence for the effectiveness of caregiver support interventions is inconsistent (Lopez-Hartmann et al. 2012). Psychotherapy and psychoeducational interventions appear to produce the most consistent positive effects in relation to caregivers’ wellbeing (Sorenson et al. 2002).

The literature suggests that intervention effects are often limited to domain-specific outcomes, with some interventions appearing more effective in some domains than in others (Sorenson et al. 2002). For example, individual cognitive behavioural therapy appears to be effective for carers with significant levels of depression, while group cognitive behavioural therapy-based interventions are effective for those who are highly stressed (Gallagher-Thompson and Coon 2007). Similarly, while respite care appears to alleviate caregiver burden to some extent, psychosocial and educational interventions may be more effective in strengthening the carer’s coping ability (Lopez-Hartmann et al. 2012).

2.8 Summary

This chapter provided an overview of the literature relating to family caregiving and the theoretical models for understanding family caregiving, carer stress and conflict within the caregiving relationship. One of the most widely cited models of family caregiving relates to caregiver stress, which focuses on the demands involved in providing care to a dependent person. As a result of the ongoing strain on the carer, those who experience high levels of burden may experience psychological distress and physical health problems, which in turn, may compromise the quality of care that they provide to an older person.

The literature indicates a shift in focus, with earlier studies directing attention to violence and serious abusive behaviours perpetrated by family carers, whereas more recent studies have turned their attention to carer behaviours that may be potentially harmful to an older person and that may compromise the care they receive, but that may not be serious enough to warrant formal service intervention. Authors indicated that this approach has been adopted as it helps to identify carers at risk of engaging in potentially harmful behaviours and therefore prevention interventions can be introduced. The literature indicates that abusive and potentially harmful behaviours among carers of older relatives are relatively common, particularly among those who care for older people with dementia, and family carers are willing to report such behaviours. The prevalence of abusive and potentially abusive behaviours by family carers was outlined along with care, care recipient and caregiving factors associated abusive carer behaviour.
Chapter 3: Research Methods

3.1 Introduction

This study examined family carers’ experiences of caring for an older person in the community, including self-reported experiences of stress, conflict and coping. This chapter describes the methods used to investigate these experiences and also to profile family carers and the care recipients. The sampling strategies, data collection instruments and data collection procedures were chosen to ensure that the most appropriate research design was selected to answer the study questions. The chapter outlines the study aims and describes the research design, the data collection procedures and the instruments used to measure stress, conflict and coping among a national sample of family carers.

3.2 Study aims

The overall aim of the study was to examine family carers’ experiences of caring for an older person and explore the impact of caregiving on the carer and the conflict that may arise within the caregiving relationship.

The study objectives were:

1. To examine the nature and type of care provided by family carers to older people
2. To measure carer burden among family carers who provide care to an older family member
3. To measure the extent to which family carers experience conflict in the caregiving relationship
4. To measure the extent to which family carers engage in potentially harmful behaviours towards older family members
5. To identify factors associated with potentially harmful behaviours engaged in by family carers
6. To examine family carers’ experiences of support and coping in their role as caregiver.

3.3 Research design

The study design was a survey of a national cross-sectional sample of family carers in receipt of a carer’s allowance for care provided to a person aged 65 years and older. The anonymous survey was conducted through a postal questionnaire, administered in the summer of 2013. The questionnaire comprised a battery of instruments that measured aspects of family carers’ experiences of caregiving, including carer burden, coping and potentially harmful carer behaviours. The questionnaire also profiled carers and their care recipients. The sample was selected randomly from a national database of recipients of a carer’s allowance, a Government scheme that provides financial support to those providing care in the home to a family relative.

3.4 Sampling strategy

Few studies published to date have reported potentially harmful carer behaviours in a representative population of family carers of older people (Cooper et al., 2009). Obtaining a representative sample increases the ability to make robust inferences about the study findings, which can then be generalised to the wider population of interest. The Department of Social Protection (DSP) is a Governmental department, which, among other functions, has responsibility for maintaining a national database of carers who receive a state-funded carer’s allowance. Approximately 55,682 carers are in receipt of a carer’s allowance (DSP, Personal Communication May 2013) for the full-time care that they provide to a person(s) in need of full-time care and attention. The eligibility criteria for carer’s allowance stipulate that carers must:

- Reside in the Republic of Ireland
- Be aged 18 years or over
- Satisfy a means test by the Department of Social Protection
- Satisfy a Habitual Residence Condition, i.e. have a proven close link to Ireland
- Live with the care recipient or can be contacted quickly
- Provide full-time care to a person(s) in need of full-time care and attention who does not normally live in hospital, a home or a similar situation.
Carers who are in receipt of a carer’s allowance are permitted to engage in paid work and/or study outside of the home for up to 15 hours a week. Approximately 24,484 carers who fulfil these criteria receive a carer’s allowance, either full-rate or half-rate, for the care they provide to a person(s) aged 65 years and older (DSP, Personal Communication May 2013). This national cohort of carers of older people provided the sampling frame, from which a total of 4,000 carers were randomly selected for the current study.

In order to obtain an accurate representative sample of carers in receipt of a carer’s allowance for care provided to an older person, several factors were taken into account in determining the sample size. These included the rate of abusive behaviours by family carers reported in the literature, the older age profile of the target sample and the sensitive nature of the topic under investigation. Additionally, consideration was given to subsamples of carers such as younger carers, male carers and carers of older people with dementia, to ensure that these groups would be sufficiently represented in the final sample. The sample size was calculated using 95 per cent confidence limits for the expected rates, based on the expected size of each subset.

3.5 Data collection
In order to measure carers’ experiences of caring for an older person, the study used an anonymous postal survey with a national cross-sectional sample of carers in receipt of a carer’s allowance for care provided to an older person. The Department of Social Protection (DSP) distributed the questionnaires through its postal service to the randomly-selected sample of 4,000 carers on behalf of the research team. No identification codes were used to track the questionnaires; therefore study respondents’ anonymity was assured. Such assurances of confidentiality and anonymity were included in the design to minimise the possibility of socially-desirable responding by the sample and to enhance the validity of the responses (Dillman et al. 2009). Data collection was completed over the summer months of 2013.

3.5.1 Procedures
As the DSP had responsibility for the distribution of the questionnaires, the researchers did not have access to the names or contact details of carers registered on the DSP database. Similarly, the DSP did not have access to the completed questionnaires which were returned to the research team. This method was used to ensure high response rates and was informed by best practice in survey research (Dillman et al. 2009). Using a modified approach to the Dillman method, the national survey was conducted in three phases.

Phase 1 involved the DSP posting a pre-notice letter to the randomly selected sample of carers who met the survey’s eligibility criteria. The letter informed carers that they would receive a questionnaire within a few days and that they would be invited to participate in the survey. The letter also emphasised that their decision to participate would in no way affect their welfare payments or services and assured them of their anonymity. Phase 2 involved sending a cover letter together with a questionnaire and a stamped addressed envelope to the sample one week after the initial letter was posted. A participant information sheet and a list of support organisations and help lines were also enclosed. Conducted at approximately 10 to 14 days following the administration of the postal questionnaire, phase 3 involved a second blanket mailing to all 4,000 carers with a cover letter, a replacement questionnaire and a stamped addressed envelope enclosed. A participant information sheet and a list of support organisations and helplines were again enclosed. The cover letter thanked those respondents who had already completed and returned their questionnaires and invited those who had not yet responded to do so. Follow-up and reminders have been shown as the most effective means of enhancing survey response rates (Dillman 2007). A blanket mailing approach was necessary to ensure respondent anonymity. The blanket mailing method has previously been used in large scale surveys (Webster et al. 1992; Butterfield et al. 2000) and is particularly important when the research concerns a sensitive topic (Randall and Fernandes 1991). A total of 2,422 questionnaires were returned, of which, 2,311 were deemed eligible for inclusion in the study. Returned questionnaires were excluded in cases where large sections were incomplete or where the carer was ineligible to participate in the study. This yielded a 58 per cent response rate. The sampling design and response rates are summarised in Figure 3.1.
### 3.5.2 Instruments

The self-completion questionnaire was designed to examine the nature of caregiving, to ascertain carer burden levels and to measure the extent to which carers both experienced mistreatment by the care recipient and engaged in potentially harmful behaviours themselves when caring for an older person. The instrument also contained items that profiled the carer and the care recipient. The questionnaire was pretested with a number of family carers of older people and was reviewed by representatives of several advocacy groups of family carers.

**Pretesting the questionnaire**

As part of the work of preparing the final survey questionnaire, the research team met with members of Caring for Carers, Care Alliance Ireland, the Alzheimer Society of Ireland, the College of Psychiatry of Ireland/RCSI and the Carers Association. The purpose of these meetings was to inform the organisations of the study and to obtain feedback on the questionnaire and survey procedures prior to distribution to the sample. With the support of these organisations, four carers of older people living in the community volunteered to take part in pre-testing the questionnaire. Each carer participated in a one-to-one cognitive interview, which lasted approximately one to two hours.

The cognitive interview is a method of pretesting questionnaires prior to their distribution to the sample of interest and is useful in establishing how respondents interpret, comprehend, and respond to questions. It provides the respondent’s perspective on the questionnaire and thereby functions to identify sources of response error in questionnaires and increase questionnaire response rates in surveys (Drennan 2003). During the cognitive interviews, information was gathered on the following: lexical problems, inclusion and exclusion problems, temporal problems, logical problems, and computational problems (Conrad et al. 1999). The carers gave feedback on the suitability, sensitivity, comprehensibility and the length of the data collection instruments. This information was then used to refine the final questionnaire.

Throughout the questionnaire, the term ‘the person you care for’ was used to refer to the older person to whom the carer provided full-time care and for whom they received a carer’s allowance. If the carer provided care to more than one older person, then they were asked to respond to the questions with only one person in mind, namely the person to whom they provided the most care.

The questionnaire comprised seven sections which measured the demographic and social profile of respondents, carers’ health and wellbeing, carers’ role and caregiving activities, carers’ experiences of caregiving, carers’ experience of conflict, carers’ experience of support and coping, and the care recipients’ profile (Table 3.1).

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<th>Table 3.1 Questionnaire Categories</th>
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<td>Section 5</td>
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<td>A) Carers’ experiences of mistreatment</td>
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<td>B) Potentially harmful carer behaviour</td>
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<td>Section 6</td>
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Section 1: Carers’ profile

The first section of the questionnaire collected demographic information about the carer. Respondents were asked to provide information on gender, marital status, number of other dependants (in addition to the older person to whom they provide care), age, ethnicity/cultural background, occupation, whether they received training to support them in their caregiving role, highest educational qualification and whether they lived in an urban or rural location. Respondents were also asked to indicate the type of carer’s allowance they received and whether they undertook paid work and/or study outside the home for up to 15 hours per week.

Section 2: Carers’ health and wellbeing

Section 2 of the questionnaire contained questions that measured the health and wellbeing of carers, using the Center for Epidemiologic Studies Depression Scale (CES-D) and a single carer self-rating health question.

Carer depressive symptoms

Carers’ psychological health and wellbeing have received extensive attention in the literature and depression, in particular, has been found to be prevalent among carers of older people (Beach et al. 2005; Neal and Hammer 2007; Pinquart and Sörensen 2011). The Center for Epidemiologic Studies Depression Scale (CES-D) is one of the most widely-used survey instruments for identifying symptoms of depression. The 20-item instrument was originally developed to identify depressive symptomology in the general population (Radloff 1977). It has previously been used to identify groups at risk of depression including family carers of older people (Beach et al. 2005; MacNeil et al. 2009; Morse et al. 2012) and those caring for people with dementia (Paveza et al. 1992; Perez-Rojo 2009). The CES-D measures affective components of depression, such as depressed mood, feelings of guilt, worthlessness and hopelessness, psychomotor retardation, loss of appetite and sleep disorders. Studies report good levels of reliability when the instrument has been used with general adult populations and family caregivers (Radloff 1977; Beach et al. 2005) Radloff (1977) reported alpha coefficients of 0.85 for general population samples and Beach et al. (2005) reported a Cronbach’s alpha of 0.91 in a study with a sample of carer-care recipient dyads, indicating good levels of reliability.

The CES-D instrument contains a list of symptoms associated with depression and respondents were asked to indicate the frequency with which they experienced each symptom during the past week using a frequency scale from rarely or none of the time (0) to most or all of the time (5-7 days) (3). Responses are summed to give an overall score which ranges from 0 to 60, with higher scores indicating depressive symptoms. A score of 16 or greater is used to identify those at risk of clinical depression in caregivers (Weissman et al. 1977; Beach et al. 2005). This score is equivalent to experiencing six symptoms for most of the previous week, or a majority of the symptoms on one or two days (McDowell 2006).

Carer self-rated health

A single question was used to ascertain carers’ self-rated perception of their overall health. Respondents were asked to describe their health in general on a scale ranging from poor (1) to very good (4). A single-item question has been shown to be a valid measurement of a person’s self-perceived health status (McDowell 2006).

Section 3: Carers’ role and caregiving activities

Section 3 of the questionnaire measured the carer’s role and caregiving activities. Respondents were asked to indicate the number of hours of care that they provided in an average week and the length of time they have been providing full-time care to the care recipient. In order to ascertain the nature of the care provided, a modified version of the Activities of Daily Living (ADL) scale was used. Taken from the Older Americans Resources and Services (OARS) assessment instrument (Fillenbaum and Smyer 1981; Pillemer and Suitor 1992), the scale measured the care recipient’s dependency levels and the level of help provided by the carer.

The scale comprises six questions and assesses the level of help that the care recipient requires with housework, cutting and eating food, dressing and undressing, walking, taking a bath or shower and using the toilet. Response options on the scale are: can do with no help (1), can do with some help (2) and cannot do at all (3). The responses are summed to create an overall dependency scale on which scores range from 6 to 18. Higher scores indicate greater care recipient dependency. The scale has demonstrated good levels of internal consistency, with a reliability alpha coefficient of 0.85 previously reported when used with a sample of family carers of older people with dementia (Pillemer and Suitor 1992).
Respondents were also asked to indicate the frequency with which they provided help with each of the six ADLs, with response options ranging from never (0), sometimes (1) to all of the time (2). The responses were then recoded into never provide help with ADLs (0) and provide help with ADLs (1). This procedure involved amalgamating the scores for ‘sometimes’ and ‘all of the time’ and allows responses to be summed to create a helping scale with scores ranging from 0 to 6 (Pillemer and Suitor 1992). This scale has previously been shown to have a reliability coefficient of alpha of 0.71 with a sample of caregivers of older people with dementia (Pillemer and Suitor 1992).

**Section 4: Caregiving experience**

Section 4 of the questionnaire examined carers’ experiences of providing care by measuring the level of burden experienced and examining the overall caregiving relationship.

**Carer burden**

Carer burden has frequently been documented in the literature (O’Shea 2000; MacNeil et al. 2009; Perez-Rojo et al. 2009; Yan and Kwok 2011; Kishimoto et al. 2013). Carer burden was measured using the Zarit Burden Interview, which is reported to be a useful tool for researchers and clinicians due to its ‘user-friendliness, extensive validation and international use’ (Van Durme et al. 2012, p.490). The Zarit Burden Interview (ZBI) was originally designed to measure stresses experienced by caregivers of patients with dementia (Zarit et al. 1980). It is a 22-item self-report instrument and is the most consistently-used measure of perceived burden and the impact of the caregiving process on the carer in relation to their physical and emotional health, finances, social life and interpersonal relationships. Respondents are presented with a list of experiences and are asked to indicate the frequency with which they felt that way, using frequency responses from never (0) to nearly always (4). The items are deliberately worded in a subjective way so as to obtain the carer’s affective responses to the consequences of caregiving. Scores on the ZBI range from 0 to 88, with higher scores indicating higher levels of burden. The instrument has previously been shown to have strong content and construct validity, high internal consistency measures and good test-retest reliability (Vitaliano et al. 1991; Hebert et al. 2003). Thompson et al. (1993) previously reported an alpha coefficient of 0.93 when the tool was used in a study with family carers of frail older people.

**Relationship rewards**

The nature of pre-morbid relationships may influence whether carers perceive their current relationship as rewarding and may impact the quality of care they provide (Williamson et al. 2001). Williamson et al. (2001) developed a four-item scale to assess rewarding aspects of relationships between carers and care recipients pre and post-illness. This scale was adapted to measure the extent to which carers perceived the caregiving relationship to be rewarding. The instrument contains four questions which ask carers to indicate the frequency with which they perceived the relationship as rewarding pre-caregiving, and since they commenced caregiving, using four response options: never (1), rarely (2), sometimes (3) and always (4). Carers were asked: how often prior to caregiving, 1) did you feel happy with your relationship with the care recipient, 2) did the care recipient make you feel good about yourself, 3) did you feel very emotionally close to the care recipient, 4) did you feel bored or in a rut being with the care recipient. Total summed scores indicate the extent to which the relationship was perceived as rewarding prior to caregiving. Carers were then asked to respond to the same four questions with reference to relationship rewards since caregiving, producing an index of current relationship rewards. Cronbach’s alpha has been reported as 0.81 and 0.84, respectively (Williamson et al. 2001). In addition to the relationship rewards scale, a single question was used to measure carers’ perceived quality of the current relationship with the care recipient on a scale ranging from poor (1) to excellent (4).

**Section 5: Experience of conflict**

Section 5 of the questionnaire measured the carers’ experiences of conflict within the caregiving relationship. Carers were asked to indicate the frequency with which they experienced mistreatment by the care recipient and the frequency with which they themselves engaged in potentially harmful carer behaviours. Questions were based on a version of the Conflict Tactics Scale (CTS) (Straus 1979, Straus et al. 1996; Pillemer and Bachman-Prehn 1991), which has been modified for use in studies with carers of older people (Beach et al. 2005; Cooper et al. 2008a; 2010; Kishimoto et al. 2013). The CTS is the most widely used scale to measure conflict within families and was initially developed based on the premise that ‘conflict is an inevitable part of all human association, whereas violence as a tactic to deal with conflict is not’ (Straus et al. 1996, p.284).
Mistreatment experienced by the carer

The first part of Section 5 of the questionnaire (Section 5: Part A) presented respondents with the statement: ‘Sometimes conflicts occur when caring for an older person. We would like to find out how many times you have experienced the following in the past three months’. Respondents were then asked to rate the frequency with which they were psychologically or physically mistreated by the care recipient in the previous three months using the following response options: never (0), almost never (1), sometimes (2), most of the time (3), all of the time (4). Psychological mistreatment included being screamed or yelled at; threatened with physical force; spoken to in a harsh tone of voice; insulted or sworn at; made to feel afraid of being hit or hurt; and being shouted at in anger. Physical mistreatment included being hit or slapped; having something thrown at; being kicked or hit with a fist; being threatened to be hit or have something thrown at; or pushed, grabbed, shoved or pinched.

Potentially harmful carer behaviour

The second part of this section (Section 5: Part B) presented respondents with the following statement: ‘Sometimes conflicts occur when providing care to an older person and caregivers can respond in different ways to the demands of caregiving. We would like to ask you about the ways you have responded in the past three months’. Carers were then asked to indicate the frequency with which they engaged in five potentially harmful physical behaviours and five potentially harmful psychological behaviours using the following scale: never (0), almost never (1), sometimes (2), most of the time (3), all of the time (4). The physical behaviours were: hit or slapped; handled roughly in other ways; withheld food; shaken; and felt afraid that they might hit or try to hurt the care recipient. The five potentially harmful psychological behaviours were: screamed or yelled; threatened with a nursing home placement; threatened with physical force; threatened to abandon; verbally abused, i.e. used a harsh tone of voice, insulted, called names, or sworn at. Beach et al. (2005) reported these behaviours as ‘potentially harmful behaviours’ that may impact the quality of care received by an older person and may act as precursors to more serious abusive behaviours, but may not be deemed serious enough for formal service intervention.

Beach et al. (2005) reported a Cronbach’s alpha of 0.67 for the ten items summed as a scale with a sample of community carers of older people, and Kishimoto et al. (2013) reported a Cronbach’s alpha of 0.72 with a sample of carers who provided care to older people with mild cognitive impairments. The internal consistency level reported by Beach et al. (2005) is slightly low, but is generally deemed acceptable. Responses on the ordinal scale were dichotomised for further analysis. A score of two or more indicates ‘important abuse’ or ‘potentially harmful behaviours occurring sometimes or more frequently’ and is deemed to be of greater clinical significance than those for which ‘never’ or ‘almost never’ occurred (Beach et al. 2005; Cooper et al. 2009). Accordingly, responses were categorised as ‘engaging in no potentially harmful behaviours’, based on a summation of ‘never’ and ‘almost never’ responses, and as ‘engaging in potentially harmful behaviours’, based on a summation of ‘sometimes’, ‘most of the time’ and ‘all of the time’ responses.

Section 6: Carers’ experience of support and coping

The Carers of Older People in Europe (COPE) Index was initially developed to measure the needs of carers of older people (McKee et al. 2003). This self-completion tool was developed with data collected from family carers of older people in five European countries. The index comprises three subscales of which two subscales were used in this survey. The ‘Positive Value’ subscale comprises four items and measures aspects of caregiving which are often valued by caregivers. The four items comprising this subscale have a relatively low Cronbach’s alpha ( = 0.65), which is nevertheless deemed acceptable (The EUROFAMCARE Consortium 2006).

The ‘Quality of Support’ subscale, also comprising four items, examines the perceived adequacy of social and professional support available to carers. This subscale produced a similar internal consistency level ( = 0.66) (The EUROFAMCARE Consortium 2006). Responses on both subscales were measured on a four-point scale which ranged from never (1) to always (4) and responses were summed to give scores ranging from 4 to 16. Higher scores indicated greater levels of positive value of caregiving and greater levels of perceived adequacy of professional and social support.
Section 7: Care recipient profile

Previous studies that have measured potentially harmful behaviours have profiled the older care recipient by accessing care recipients’ medical notes or by collecting the information directly from the care recipient (Beach et al. 2005; Cooper et al. 2009). The present study used carer self-reports, in which five questions were asked about the care recipient. These pertained to the care recipient’s age, gender, whether they had been diagnosed with dementia by a doctor, the nature of the relationship and whether the carer lived with the care recipient.

3.6 Ethical considerations

Ethical approval to undertake the survey was granted by the UCD Human Research Ethics Committee (HREC). The study involved a postal survey in which there were no codes or identifiable information entered onto the questionnaires; therefore, the survey was entirely anonymous. The questionnaires were distributed by the Department of Social Protection (DSP) on behalf of the research team and completed questionnaires were returned directly to the research team. At no point in the process did the research team have access to carers’ details and the DSP did not have access to the dataset of questionnaire responses.

Carers’ participation in the survey was voluntary and this was clearly stated in all correspondence. It was also stated that the decision to participate in the survey would in no way affect respondents’ welfare payments or services. Completion and return of the questionnaire were taken to indicate respondents’ informed consent to participate in the survey. The ten questions relating to conflict were potentially sensitive and were therefore placed near the end of the questionnaire to reduce the likelihood of having an adverse impact on the respondents. Similar placement of sensitive questions has been used in previous studies (Cooper et al. 2008b; Beach et al. 2005; Paveza et al. 1992; Pot et al. 1996). A list of helplines and support organisations accompanied each questionnaire, and all carers were supplied with the contact details of the research team should they have any questions.

3.7 Data analysis

All completed questionnaires were analysed using Statistical Package for Social Science (SPSS), version 20 for Windows database (SPSS Inc. Chicago IL). Following the data cleaning process and data checks, data analysis was conducted using parametric and non-parametric statistical tests. Frequency distributions, measures of central tendency and measures of variability were calculated to summarise and present the data. Pearson’s Chi-square tests were used to analyse associations between the dependent variable potentially harmful behaviours and independent categorical data. Paired t-tests, independent sample t-tests and analysis of variance (ANOVA) were used to compare carer groups on continuous variables. Logistic regression models were used to examine predictors of potentially harmful behaviours occurring ‘at least sometimes’.

3.8 Summary

The study design involved a cross-sectional national postal survey of family carers of older people. The survey was conducted using a self-completion questionnaire containing several instruments and scales to measure carers’ experiences of stress, conflict and coping, including the CES-D, the ZBI and a potentially harmful behaviours scale. The questionnaire was administered to a national random sample of 4,000 family carers in receipt of a carer’s allowance from the Department of Social Protection. The data collection procedure was based on best-practice evidence concerning the distribution of postal questionnaires. A modified Dillman method, using three contacts with the sample, was used to maximise the response rates from the study sample. This involved an initial personalised letter alerting respondents to expect the questionnaire and inviting them to contribute to the study (contact 1), the mailed questionnaire with a return stamped addressed envelope (contact 2) and a reminder letter with a second copy of the questionnaire (contact 3).
4.1 Introduction
The aim of the study was to examine family carers’ experiences of caring for an older person, including their experiences of stress, conflict and coping, and to examine how caregiving can impact on the individual caregiver and the caregiving relationship. The Department of Social Protection (DSP) maintains a database of approximately 24,484 carers who receive a carer’s allowance for care provided to an older person (DSP, May 2013) and this database provided the sampling frame for this national survey. Questionnaires were distributed to 4,000 randomly selected carers and a total of 2,311 eligible completed questionnaires were returned, yielding a response rate of 58 per cent. This chapter presents the results of the survey relating to carers’ profile, carers’ health and wellbeing, the caregiving role and activities, care recipients’ profile, carers’ perceptions of the support they receive, and the extent to which they cope with their role. The chapter also presents the results in relation to the prevalence of mistreatment experienced by carers in their caregiving role.

4.2 Carers’ profile
Table 4.1 summarises the profile of respondents by age and gender, and compares it to the profile of the total population of carers in receipt of a carer’s allowance. Overall, the sample closely matched the profile of the population from which the sample was drawn. Respondents’ age ranged from 19 years to 92 years, with a mean age of 57.1 years (SD=13.0). The majority of respondents were female (71.8%, 1627/2264) and in the 46 to 64 years age category (48.0%, 1089/2264). Approximately one third of carers (32.2%, 727/2264) were aged 65 years and older.

The vast majority of respondents indicated that their ethnic/cultural background was white Irish (95.1%, 2185/2298), that they were married or in a civil partnership (62.5%, 1441/2304) and that they had no other dependants (62.3%, 1248/2004) (Table 4.2). In addition to the older person for whom the respondent receives a carer’s allowance, over a third of respondents (37.7%, 756/2004) reported that they also provided full-time care to one or more other person(s); over one fifth (22.5% 451/2004) reported that they provided full-time care to one other person; seven per cent (141/2004) to two other people and 8.2 per cent (164/2004) to three or more others.

Social class was based on the respondents’ main occupation before becoming a full-time carer or their occupation while acting as a full-time carer. If a carer did not report an occupation, their partner’s occupation was recorded. The largest occupational group was semi-skilled or unskilled occupations (27.2%, 538/1978), followed by skilled manual (21.6%, 428/1978). Half of the respondents (50.8%, 1141/2248) reported that they lived in a rural area.

Table 4.1 Comparison of Survey Respondents with DSP Carer’s Allowance Recipients by Age and Gender

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th></th>
<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Females</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Survey respondents</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>% (N)</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Survey respondents</td>
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<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>% (n)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;46 years</td>
<td></td>
<td>21.7 (3809)</td>
<td>19.7 (321)</td>
<td>21.7 (1478)</td>
<td>19.9 (127)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46–64 years</td>
<td></td>
<td>47.7 (8446)</td>
<td>48.5 (789)</td>
<td>45.2 (3067)</td>
<td>47.1 (300)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥65 years</td>
<td></td>
<td>30.6 (5435)</td>
<td>31.8 (517)</td>
<td>33.1 (2249)</td>
<td>33.0 (210)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>100 (17690)</td>
<td>71.8 (1627)</td>
<td>100 (6794)</td>
<td>28.2 (637)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 DSP database includes all carer’s allowance recipients who provide care to an older person(s), May 2013.
The majority of the carers (72.4%, 1663/2296) reported that they lived with the older person for whom they provided care and received a carer’s allowance. Table 4.2 summarises the demographic profile of the family carers.

**Table 4.2 Carers’ Profile**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ethnic/cultural background</strong></td>
<td></td>
</tr>
<tr>
<td>White Irish</td>
<td>95.1 (2185)</td>
</tr>
<tr>
<td>Irish traveller</td>
<td>0.5 (11)</td>
</tr>
<tr>
<td>Other white background</td>
<td>4.0 (92)</td>
</tr>
<tr>
<td>Black/Black Irish/African/Black other</td>
<td>0.1 (2)</td>
</tr>
<tr>
<td>Asian/Chinese/Other Asian</td>
<td>0.2 (5)</td>
</tr>
<tr>
<td>Other/Mixed background</td>
<td>0.1 (3)</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
</tr>
<tr>
<td>Single (Never married)</td>
<td>25.2 (581)</td>
</tr>
<tr>
<td>Married/Civil partnership</td>
<td>62.5 (1441)</td>
</tr>
<tr>
<td>Living with a partner</td>
<td>2.8 (65)</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>6.4 (148)</td>
</tr>
<tr>
<td>Widowed</td>
<td>3.1 (69)</td>
</tr>
<tr>
<td><strong>Number of full-time dependants (other than the care recipient)</strong></td>
<td></td>
</tr>
<tr>
<td>No other dependants</td>
<td>62.3 (1248)</td>
</tr>
<tr>
<td>1 other dependant</td>
<td>22.5 (451)</td>
</tr>
<tr>
<td>2 other dependants</td>
<td>7.0 (141)</td>
</tr>
<tr>
<td>≥ 3 other dependants</td>
<td>8.2 (164)</td>
</tr>
<tr>
<td><strong>Highest educational qualification</strong></td>
<td></td>
</tr>
<tr>
<td>No formal education/primary education</td>
<td>24.0 (541)</td>
</tr>
<tr>
<td>Junior Certificate/Intermediate Certificate (or equivalent)</td>
<td>32.6 (734)</td>
</tr>
<tr>
<td>Leaving Certificate (or equivalent)</td>
<td>18.7 (422)</td>
</tr>
<tr>
<td>Vocational/Technical qualification (e.g. FETAC Level 5)</td>
<td>12.1 (273)</td>
</tr>
<tr>
<td>Third-level Non-Degree (e.g. University Certificate, Diploma)</td>
<td>9.2 (208)</td>
</tr>
<tr>
<td>Third-level Degree or Higher (e.g. Bachelor’s, Master’s, Doctoral Degree)</td>
<td>3.3 (73)</td>
</tr>
<tr>
<td><strong>Social class</strong></td>
<td></td>
</tr>
<tr>
<td>Professional/managerial</td>
<td>15.3 (302)</td>
</tr>
<tr>
<td>Non-manual</td>
<td>18.2 (359)</td>
</tr>
<tr>
<td>Skilled manual</td>
<td>21.6 (428)</td>
</tr>
<tr>
<td>Sems/unskilled</td>
<td>27.2 (538)</td>
</tr>
<tr>
<td>All others gainfully occupied</td>
<td>17.7 (351)</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td></td>
</tr>
<tr>
<td>Rural (a population of less than 1,500 people)</td>
<td>50.8 (1141)</td>
</tr>
<tr>
<td>Urban (a population of more than 1,500 people)</td>
<td>49.2 (1107)</td>
</tr>
<tr>
<td><strong>Living arrangements</strong></td>
<td></td>
</tr>
<tr>
<td>Co-residing with the care recipient</td>
<td>72.4 (1663)</td>
</tr>
<tr>
<td>Not residing with the care recipient</td>
<td>27.6 (633)</td>
</tr>
</tbody>
</table>
4.3 Carers’ health and wellbeing

The survey collected information on carers’ general health and wellbeing. A single item was used to measure respondents’ self-reported general health. In addition, the Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure the presence of depressive symptoms among carers and the Zarit Burden Interview (ZBI) was used to measure perceived burden and impact of caregiving on respondents.

4.3.1 Carers’ perceived general health

Respondents were asked to rate their health by responding to the following statement: ‘In general, would you say your health is poor (1), fair (2), good (3) or very good (4)?’ The majority of carers described their health as good or very good (68.9%, 1581/2295), with fewer than one third of respondents rating their health as poor or fair (31.1%, 714/2295) (Figure 4.1). There was little difference between male and female respondents’ overall rating of their self-perceived health.

4.3.2 Prevalence of depressive symptoms among carers

The prevalence of depressive symptoms was measured using the 20-item Center for Epidemiologic Studies Depression Scale (CES-D), which asked respondents to report the frequency with which they experienced depressive symptoms during the previous week. Respondents were asked to rate their responses on a three-point scale ranging from rarely or none of the time (0) to most or all of the time (3). Possible scores on the CES-D range from 0 to 60, with higher scores indicating a greater presence of depressive symptoms. A score of 16 or above is commonly used to identify caregivers who are at risk of clinical depression (Weissman et al. 1977; Beach et al. 2005).

Respondents’ scores ranged from 0 to 56, with an overall mean score of 15.8 (SD=11.5) (Table 4.3). In total, 43.7 per cent (769/1759) of respondents scored 16 or higher on the CES-D, indicating the presence of depressive symptoms. There was a statistically significant difference between male and female scores \( t(1755)=3.35, p<0.001 \), with female carers scoring higher on the CES-D (M=16.4, SD=11.7) than male carers (M=14.4, SD=10.7).

![Figure 4.1 Carers’ self-rated General Health by Gender](image)

![Table 4.3 Depressive Symptoms among Carers by Gender](table)

<table>
<thead>
<tr>
<th></th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Centre for Epidemiology Depression- Scale (CES-D)</td>
<td>16.4 (11.7)</td>
<td>14.4 (10.7)</td>
<td><strong>15.8 (11.5)</strong></td>
<td>3.35</td>
<td><strong>&lt; 0.001</strong>*</td>
</tr>
<tr>
<td>CES-D score &lt; 16</td>
<td>54.0 (680)</td>
<td>61.8 (308)</td>
<td><strong>56.3 (990)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CES-D score ≥ 16</td>
<td>46.0 (579)</td>
<td>38.2 (190)</td>
<td><strong>43.7 (769)</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

***Significant at \( p < 0.001 \)
A one way ANOVA was conducted to examine if differences in the prevalence of depressive symptoms existed between three carer age groups; carers aged less than 46 years, carers aged 46 to 64 years and carers aged 65 years and older. Results showed that there was a statistically significant difference between the three carer age groups [F(2, 1726)= 4.59, p < 0.05] in relation to prevalence of depressive symptoms (Table 4.4).

Post hoc comparisons to evaluate pairwise differences among the means were conducted using Tukey HSD test and results showed that there was a significant difference between CES-D mean scores for carers aged 46 to 64 years (M=16.4, SD=11.7) and carers aged 65 years and older (M=14.5, SD=10.6) (p < 0.05). Carers aged less than 46 years did not significantly differ from the other two carer age groups on the CES-D (p ≥ 0.05).

### 4.3.3 Perceived carer burden

The Zarit Burden Interview (ZBI) was used to assess perceived burden among carers and the impact of caregiving on physical and emotional health, finances, social life and interpersonal relationships. Scores on the ZBI range from 0 to 88, with higher scores indicative of greater caregiver burden. Respondents’ scores ranged from 0 to 82, with a mean score of 33.2 (SD=16.8) (Table 4.5). There was an overall observed difference between male and female carers [t(2023)= 4.16, p < 0.001], with female carers scoring significantly higher on average on the ZBI scale (M=34.1, SD=17.2) than male carers (M=30.7, SD=15.7).

ZBI scores were grouped into four categories; scores of between 0 and 20 indicate little or no burden; 21 to 40 indicate mild to moderate burden; 41 to 60 indicate moderate to severe burden; and 61 to 88 indicate severe burden (Hebert et al. 2000). Overall, 26.5 per cent (536/2026) of respondents experienced little or no burden, 40.3 per cent experienced mild to moderate burden (818/2026), 26.6 per cent experienced moderate to severe burden (539/2026), and 6.6 per cent of respondents experienced severe burden (133/2026) (Figure 4.2).

### Table 4.4 Depressive Symptoms among Carers by Age

<table>
<thead>
<tr>
<th>Age Group</th>
<th>&lt; 46 years</th>
<th>46 to 64 years</th>
<th>≥ 65 years</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Centre for Epidemiology Depression Scale (CES-D)</td>
<td>16.2 (11.8)</td>
<td>16.4 (11.7)</td>
<td>14.5 (10.6)</td>
<td>4.59</td>
<td>0.01*</td>
</tr>
</tbody>
</table>

*significant at p < 0.05

### Table 4.5 Carer Burden Scores by Gender

<table>
<thead>
<tr>
<th></th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>ZBI</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td></td>
<td>34.1 (17.2)</td>
<td>30.7 (15.7)</td>
<td>33.2 (16.8)</td>
<td>4.16</td>
<td></td>
</tr>
</tbody>
</table>

***Significant at p < 0.001

* Scores on the ZBI range from 0 to 88 with higher scores indicating greater burden
In order to examine differences between carer age groups in ZBI mean scores, a one way ANOVA was carried out (Table 4.6). Post hoc comparisons to evaluate pairwise differences among the means were also conducted using Tukey HSD test. Results showed that there was, on average, a significant difference between carer age groups ($F(2, 1991)= 5.60, p< 0.01$), with carers aged 46 to 64 years scoring significantly higher ($M=34.3, SD=16.7$) than carers aged 65 years and older ($M=31.3, SD=16.5$). There was no significant difference in ZBI mean scores between carers aged less than 46 years and the other two carer age groups ($p > 0.05$).

### 4.4 Caregiving and caregiving activities

Information about the carers’ role and caregiving activities was also collected. Respondents were asked about the type of carer’s allowance they received and whether they worked and/or studied outside of the home. Information relating to the frequency and type of care provided, the length of time respondents have been providing care and the training received to support them in their caregiving role were collected. Carers were also asked about the nature of the relationship to the care recipient and the perceived quality of the caregiving relationship.

#### 4.4.1 Carer’s allowance

The type of carer’s allowance received by carers and the proportion of carers who undertook study and/or work outside of the home are summarised in Table 4.7. The majority of respondents indicated that they received a full-rate carer’s allowance (56.8%, 1296/2282), a payment for carers who care for a person in need of full-time care and attention. The remaining respondents (43.2%, 986/2282) received a half-rate carer’s allowance, a payment for carers who care for a person in need of full-time care and attention and who also receive another social welfare payment, such as a state pension or a one-parent family payment.

Carers in receipt of a carer’s allowance are permitted to work and/or study outside of the home for up to 15 hours per week. In addition to their caregiving activities, approximately 11.6 per cent (260/2244) of carers reported that they engaged in study and/or work outside of the home; however, the vast majority of respondents did not work or study outside of the home.

### Table 4.7 Carer’s Allowance and Study/Work

<table>
<thead>
<tr>
<th>Carer’s allowance</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-rate Carer’s Allowance</td>
<td>56.8 (1296)</td>
</tr>
<tr>
<td>Half-rate Carer’s Allowance</td>
<td>43.2 (986)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study or paid work (up to 15 hours a week)</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid work up to 15 hours per week</td>
<td>10.4 (234)</td>
</tr>
<tr>
<td>Study up to 15 hours per week</td>
<td>0.7 (16)</td>
</tr>
<tr>
<td>Paid work and study up to 15 hours per week</td>
<td>0.4 (10)</td>
</tr>
<tr>
<td>None of the above</td>
<td>88.4 (1984)</td>
</tr>
</tbody>
</table>

#### 4.4.2 Caregiving activities

Respondents indicated that they had been providing care for an average of 6.8 years (SD=6.0). The length of time they had been providing care ranged from 1 month to 52 years (median = 5 years, IQR = 6 years). Figure 4.3 illustrates the number of hours of care provided by respondents in an average week. Approximately half of the respondents (48.2%, 1098/2276) reported that they provided 80 hours or more of care in an average week. A third of respondents (33.9%, 772/2276) reported that they provided care for between 40 and 80 hours and 17.8 per cent (406/2276) of respondents provided less than 40 hours in an average week.
Respondents were asked to indicate the frequency with which they provided support with activities of daily living to the care recipient (Table 4.8). The vast majority of carers reported that they provided help ‘sometimes or all of the time’ with housework (97.0%, 1938/1998), walking (85.8%, 1687/1967), dressing and undressing (81.4%, 1614/1982), and taking a bath or shower (80.6%, 1616/2005). A total of 69 per cent of carers indicated that they provided help with cutting and eating food (1355/1964) and over half of the carers indicated that they helped the care recipient with using the toilet (58.0%, 1148/1979). Responses to each of the six items were dichotomised into (0) ‘no help provided’ and (1) ‘help provided’ (sometimes/all of the time) and scores were then summated to create a scale that measured the overall level of help provided. Respondents’ scores ranged from 0 to 6 with a mean helping score of 4.7 (SD=1.5), indicating a high overall level of care provided.

Table 4.8 Frequency with which Carers provided Help with Activities of Daily Living

<table>
<thead>
<tr>
<th>Care provided</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never % (n)</td>
</tr>
<tr>
<td>Housework</td>
<td>3.0 (60)</td>
</tr>
<tr>
<td>Taking a bath or shower</td>
<td>19.4 (389)</td>
</tr>
<tr>
<td>Walking</td>
<td>14.2 (280)</td>
</tr>
<tr>
<td>Dressing and undressing</td>
<td>18.6 (368)</td>
</tr>
<tr>
<td>Cutting and eating food</td>
<td>31.0 (609)</td>
</tr>
<tr>
<td>Using toilet</td>
<td>42.0 (831)</td>
</tr>
</tbody>
</table>

Respondents were also asked whether they had received support to help them with their caregiving role. A quarter of the respondents (25.6%, 583/2281) indicated that they received some form of training to support them in their role. The most frequently reported training received was ‘manual handling’ (62.6%, 365/583), followed by ‘first aid’ (56.3%, 328/583); in addition, over one third of carers indicated that they received ‘other’ forms of training (e.g. training in PEG feeding, palliative care) to support them in their caregiving role (36.9%, 215/583).

4.4.3 Caregiving relationship

As illustrated in Figure 4.4, the majority of carers were adult children (51.5%, 1175/2281) of the care recipient. The remaining respondents were spouses (31.1%, 709/2281), other relatives (15.0%, 343/2281) and non-relatives (2.4%, 54/2281) of the older person to whom they were providing care.
Figure 4.4 Relationship to the Care recipient

Respondents were asked to rate the quality of their current relationship with the care recipient. The vast majority of respondents indicated that they perceived the quality of the current relationship as ‘good’ or ‘excellent’ (87.6%, 1991/2272). The remainder reported that they perceived the quality of the caregiving relationship as ‘poor’ or ‘fair’ (12.4%, 281/2272).

The rewarding aspects of caregiving were assessed using four questions. Carers were asked to indicate on a scale of 1 (never) to 4 (always), the frequency with which: they experienced feelings of happiness with the relationship; the care recipient made them feel good about themselves; they felt emotionally close to the care recipient; and they felt bored or in a rut being with the care recipient. Respondents were asked to relate the four questions to the relationship before caregiving commenced and again since caregiving commenced.

Scores range from 4 to 16, with higher scores indicating greater relationship rewards. The overall mean pre-caregiving rewards score was 13.4 (SD=2.3), while the rewards score since becoming a full-time carer was 12.4 (SD=2.7) (Table 4.9). The difference between perceived quality of the relationship before and after caregiving had commenced was found to be statistically significant [t(2019)= 21.82, p < 0.001***], with respondents on average reporting lower relationship reward scores since caregiving commenced.

Table 4.9 Comparison of Relationship Rewards Scores before Caregiving and since Caregiving

<table>
<thead>
<tr>
<th></th>
<th>Before-caregiving</th>
<th>Since-caregiving</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship reward scores</td>
<td>13.4 (2.3)</td>
<td>12.4 (2.7)</td>
<td>21.82</td>
<td>&lt; 0.001***</td>
</tr>
</tbody>
</table>

**significant at p < 0.001

4.5 Profile of care recipients

Demographic, dependency and mental health details were collected about the care recipients, for whom respondents were paid a carer’s allowance for the care they provided. This data was collected from the carer. Respondents reported the age, gender and dependency level of the care recipient and indicated whether the care recipient had a diagnosis of dementia provided by a medical practitioner.

4.5.1 Age and gender

Table 4.10 presents a summary of the care recipient profile by age and gender. The majority of the care recipients were female (59%, 1339/2263) and their mean age was 80 years (SD=8.2), with ages ranging from 65 to 103 years. The largest age group of care recipients was in the age category 75 to 84 years (39.7%, 899/2263). Just over a quarter of care recipients were aged 65 to 74 years (26.7%, 604/2263) and a third of care recipients were aged 85 years and older (33.6%, 760/2263).

Table 4.10 Age and Gender of Care Recipients

<table>
<thead>
<tr>
<th>Age</th>
<th>Female % (n)</th>
<th>Male % (n)</th>
<th>Total % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>65 to 74 years</td>
<td>21.2 (284)</td>
<td>34.6 (320)</td>
<td>26.7 (604)</td>
</tr>
<tr>
<td>75 to 84 years</td>
<td>38.0 (509)</td>
<td>42.2 (390)</td>
<td>39.7 (899)</td>
</tr>
<tr>
<td>≥ 85 years</td>
<td>40.8 (546)</td>
<td>23.2 (214)</td>
<td>33.6 (760)</td>
</tr>
<tr>
<td>Total</td>
<td>100 (1339)</td>
<td>100 (924)</td>
<td>(2263)</td>
</tr>
</tbody>
</table>

4.5.2 Dependency levels and diagnosis of dementia

Respondents were asked to indicate the level of help required by the care recipient with six activities of daily living. Response options included ‘can do with no help’ (1), ‘can do with some help’ (2), and ‘cannot do at all’ (3). Scores were summed to create a care recipient dependency scale; higher scores indicate a greater level of assistance needed with activities of daily living. Respondents’ scores ranged from 6 to 18 with a mean dependency score of 12.2 (SD=3.0), indicating an overall high level of care recipient dependency.

Family Carers of Older People: Results of a National Survey of Stress, Conflict and Coping
Table 4.11 summarises the level of help required by the care recipients and shows that care recipients required most care with activities such as housework (e.g. cleaning floors) (92.6%, 1986/2145), taking a bath or shower (82.7%, 1795/2171), walking (79.1%, 1716/2169), dressing and undressing (72.0%, 1559/2166), and cutting and eating food (55.3%, 1186/2147). Almost half of the care recipients required help with using the toilet (47.5%, 1024/2156). Respondents indicated that a fifth of the care recipients (21.5%, 485/2261) were diagnosed with a dementia by a doctor.

4.6 Carers’ experiences of support and coping

Respondents’ experiences of coping with providing care to an older person in their home were measured using two subscales from the Carers of Older People in Europe (COPE) Index (McKee et al. 2003). Respondents were asked to appraise the caregiving experience and indicate the perceived adequacy of quality of social and professional support on a four point scale with responses ranging from never (1), sometimes (2), often (3), to always (4). Scores for each subscale were summed to give a range of 4 to 16; higher scores indicate high positive value of caregiving and high quality support received.

4.6.1 Positive appraisal of caregiving

The respondents were asked to appraise the value of the caregiving role using the four-item ‘Positive Value’ subscale of the Carers of Older People in Europe (COPE) Index. The positive appraisal scale examines aspects of caregiving which are often valued by caregivers. Overall, respondents reported that they found caregiving to be a positive experience. Respondents’ scores ranged from 4 to 16 with a mean score of 13.17 (SD=2.5), indicating an overall positive appraisal of caregiving. The majority of carers reported that they felt that they ‘often or always’ coped well as a caregiver (84.6%, 1929/2281) and over three quarters indicated that they ‘often or always’ found caregiving worthwhile (78.8%, 1784/2264) (Table 4.12). Furthermore, the vast majority of respondents (91.5%, 2081/2274) reported that they ‘often or always’ had a good relationship with the care recipient. Just over half of the respondents (56.6%, 1284/2272) reported that they

<table>
<thead>
<tr>
<th>Level of help required with…</th>
<th>Can do with no help % (n)</th>
<th>Can do with some help % (n)</th>
<th>Cannot do at all % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housework</td>
<td>7.4 (159)</td>
<td>19.0 (407)</td>
<td>73.6 (1579)</td>
</tr>
<tr>
<td>Taking a bath or shower</td>
<td>17.3 (376)</td>
<td>36.9 (801)</td>
<td>45.8 (994)</td>
</tr>
<tr>
<td>Walking</td>
<td>20.9 (453)</td>
<td>58.7 (1274)</td>
<td>20.4 (442)</td>
</tr>
<tr>
<td>Dressing and undressing</td>
<td>28.0 (607)</td>
<td>50.4 (1092)</td>
<td>21.6 (467)</td>
</tr>
<tr>
<td>Cutting and eating food</td>
<td>44.8 (961)</td>
<td>42.4 (910)</td>
<td>12.9 (276)</td>
</tr>
<tr>
<td>Using the toilet</td>
<td>52.5 (1132)</td>
<td>33.5 (722)</td>
<td>14.0 (302)</td>
</tr>
</tbody>
</table>

Table 4.12 Positive Appraisal of Caregiving

<table>
<thead>
<tr>
<th>Coping appraisal</th>
<th>Never % (n)</th>
<th>Sometimes % (n)</th>
<th>Often % (n)</th>
<th>Always % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel you cope well as a caregiver?</td>
<td>0.5 (12)</td>
<td>14.9 (340)</td>
<td>29.5 (673)</td>
<td>55.1 (1256)</td>
</tr>
<tr>
<td>Do you find caregiving worthwhile?</td>
<td>2.9 (65)</td>
<td>18.3 (415)</td>
<td>21.6 (489)</td>
<td>57.2 (1295)</td>
</tr>
<tr>
<td>Do you have a good relationship with the person you care for?</td>
<td>1.1 (24)</td>
<td>7.4 (169)</td>
<td>16.6 (378)</td>
<td>74.9 (1703)</td>
</tr>
<tr>
<td>Do you feel that anyone appreciates you as a caregiver?</td>
<td>12.4 (283)</td>
<td>31.0 (705)</td>
<td>22.4 (508)</td>
<td>34.2 (776)</td>
</tr>
</tbody>
</table>
‘often or always’ felt appreciated as a caregiver; however, a substantial proportion of the carers (43.4%) reported that they never or only sometimes felt appreciated as a caregiver.

4.6.2 Perceived quality of support in caregiving

The respondents’ perceived adequacy of social and professional support was measured using the Quality of Support subscale of the Carers of Older People in Europe (COPE) Index. Scores ranged from 4 to 16 and the overall mean was 11.1 (SD=3.5), indicating a high level of perceived quality of support. Table 4.13 summarises carers’ responses to the four questions asked on the Quality of Support subscale. The majority of carers (63.8%, 1435/2251) reported that they ‘often or always’ felt well supported by their family and just over half of the respondents indicated that they ‘often or always’ felt well supported by friends and/or neighbours (54.1%, 1230/2272). In contrast, half of the respondents (50.4%, 1145/2282) indicated that they never or only sometimes felt well supported by health and social services. Overall, 56.7 per cent of respondents (1294/2285) indicated that they ‘often or always’ felt well supported in their role of caregiver, with 43.3 per cent of respondents reporting that they never or only sometimes felt well supported.

### Table 4.13 Carers’ perceived Quality of Support

<table>
<thead>
<tr>
<th>Perceived quality of support</th>
<th>Never % (n)</th>
<th>Sometimes % (n)</th>
<th>Often % (n)</th>
<th>Always % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel well supported by your friends and/or neighbours?</td>
<td>15.7 (357)</td>
<td>30.1 (685)</td>
<td>20.1 (457)</td>
<td>34.0 (773)</td>
</tr>
<tr>
<td>Do you feel well supported by your family?</td>
<td>11.7 (263)</td>
<td>24.6 (553)</td>
<td>17.4 (391)</td>
<td>46.4 (1044)</td>
</tr>
<tr>
<td>Do you feel well supported by health and social services?</td>
<td>18.3 (415)</td>
<td>32.1 (730)</td>
<td>19.9 (451)</td>
<td>29.8 (676)</td>
</tr>
<tr>
<td>Overall, do you feel well supported in your role of caregiver?</td>
<td>11.9 (273)</td>
<td>31.4 (718)</td>
<td>22.1 (503)</td>
<td>34.6 (791)</td>
</tr>
</tbody>
</table>

4.7 Carers’ experiences of mistreatment

This section presents findings relating to the psychological and physical mistreatment experienced by carers when providing care to an older person. Respondents were asked to report on the extent to which they experienced psychological and physical mistreatment. Response options were never (0), almost never (1), sometimes (2), most of the time (3), and all of the time (4). Overall, more than half of respondents (56.3%, 1255/2231) experienced some form of mistreatment by the care recipient in the previous three months, and just over a third (37.1%, 827/2231) reported that the mistreatment occurred sometimes or more frequently. Results are presented separately for psychological mistreatment and physical mistreatment experienced by carers.

4.7.1 Carers’ experiences of being psychologically mistreated by care recipients

Overall, half of respondents (56.3%, 1263/2244) reported that they experienced some form of psychological mistreatment by the care recipient in the previous three months, with over a third of carers (37.2%, 834/2244) reporting that the mistreatment occurred at least sometimes. The most frequently reported form of psychological mistreatment reported was the care recipient using a harsh tone of voice, insulting or...
swearing at the carer. As illustrated in Table 4.14, this was reported by over a quarter of respondents as occurring at least sometimes in the previous three months (28.5%, 645/2269); other forms of psychological mistreatment experienced by the carer were being screamed or yelled at (27.7%, 631/2275) and/or shouted at in anger (27.2%, 616/2263) by the care recipient. A smaller proportion of carers reported being threatened with physical force; this was reported by 5.0 per cent (114/2273) of respondents as occurring at least sometimes in the previous three months. In addition, a small proportion of respondents (3.8%, 86/2274) reported that the care recipient threatened to hit or throw something at them at least sometimes in the previous three months.

### 4.7.2 Carers’ experiences of being physically mistreated by care recipients

Five questions were used to measure carers’ experiences of physical mistreatment by their care recipient. In total, one in seven (13.4%, 302/2262) carers reported being physically mistreated by the care recipient, with a smaller number (5.6%, 126/2262) reporting that the behaviours occurred ‘at least sometimes’ in the previous three months. The most frequently reported form of physical mistreatment was being made to feel afraid that the care recipient might hit or hurt them (Table 4.15). This was reported by 4.4 per cent of respondents (99/2271) as occurring ‘at least sometimes’ in the previous three months. The second most frequently reported physical mistreatment experienced by carers was being pushed,
grabs, shoved or pinched by their care recipient. This was reported by 3.6 per cent of respondents (82/2278) as occurring at least sometimes in the previous three months. Other physical mistreatments experienced by carers included having something thrown at them (2.8%, 64/2270) and being hit or slapped by the care recipient (2.2%, 50/2275). A small proportion of respondents also reported being kicked by a care recipient or hit with a fist (1.5%, 35/2275).

### 4.8 Summary

Over two thousand carers in receipt of a carer’s allowance for care provided to an older person responded to a national survey. The sample profile matched that of the population of carers in receipt of a carer’s allowance for care provided to an older person. Findings relating to carers’ demographic and social profile were presented. The majority of respondents were female, aged 46 to 64 years, white Irish, married/civil partnership and had no other dependants. A third of the respondents reported that their highest qualification was the Junior or Leaving Certificate, and the largest social class group was the semi/unskilled group. The majority of carers lived in a rural location and resided with the care recipient for whom they received a carer’s allowance.

Information was also collected on carers’ health and wellbeing. The majority of respondents described their health as good or very good; however, over two fifths of respondents scored above the threshold for risk of clinical depression, with female respondents scoring higher than male respondents. In addition, the middle carer age group (aged 46 to 64 years) scored higher on the Zarit Burden Index than the younger carers (aged less than 46 years) or the older carers (aged 65 years and older). A third of respondents reported that they experienced moderate to severe burden, with higher burden scores found among female carers and carers aged 46 to 64 years.

The majority of respondents received a full-rate carer’s allowance and just over one in ten carers worked and/or studied outside of the home for up to 15 hours a week. Carers indicated that they have been providing care for an average of seven years and nearly half of the carers reported that they provided 80 hours or more of care in an average week. Carers reported that they provide most care with housework and with helping the care recipient to walk, dress and take a bath. The vast majority of respondents indicated that they received no form of training to support them in their caregiving role. Scores on the perceived relationship rewards scale were higher before caregiving commenced when compared to scores since the caregiving commenced.

Based on carer reports, care recipients’ age ranged from 65 to 103 years with a mean age of 80 years. The vast majority of care recipients were female and aged in the 75 to 84 year age group and had generally high levels of dependency, requiring most help with housework, taking a bath or shower and with walking. A fifth of respondents indicated that the care recipients were diagnosed with a dementia by a doctor.

The vast majority of respondents found caregiving to be a positive and worthwhile experience. The majority of carers also reported that they felt that they coped well with caregiving and that they had a good relationship with the care recipient. Just over half of carers felt appreciated as a caregiver, just over half reported that they felt well supported by friends and neighbours, and almost two thirds felt well supported by family. Half of the respondents indicated that they felt well supported by health and social services. Over two fifths of carers reported that they never or only sometimes felt well supported in their role of caregiver.

Information collected on carers’ experiences of being mistreated by the care recipient showed that over half of carers reported experiencing some form of mistreatment, with a third of carers reporting that they had experienced at least one psychological and/or physical act of mistreatment by their care recipient ‘at least sometimes’ in the previous three months. Over half of respondents reported that they experienced some form of psychological mistreatment by the care recipient in the previous three months, with over a third reporting that they were psychologically mistreated by the care recipient sometimes or more frequently; the most commonly-reported form of psychological mistreatment experienced by carers was being spoken to in a harsh tone of voice and being insulted or sworn at by the care recipient. Reports of being physically mistreated by the care recipient were much lower. In total, one in seven carers reported experiencing some form of physical mistreatment by the care recipient, with 5.6 per cent of carers indicating that such mistreatment occurred at least sometimes in the previous three months. The most frequently reported form of physical mistreatment was being made to feel afraid that the care recipient might hit or hurt them.
Chapter 5: Results Part II: Prevalence of Potentially Harmful Carer Behaviours and Factors Associated with Carer Behaviours

5.1 Introduction

This chapter presents the results pertaining to the prevalence of self-reported potentially harmful behaviours engaged in by carers. Associations between factors such as carer characteristics, caregiving factors, care recipient characteristics, positive appraisal of caregiving, perceived quality of support and potentially harmful carer behaviour are also presented. The prevalence of overall potentially harmful carer behaviour is presented first, followed by the prevalence of potentially harmful psychological and physical carer behaviours.

5.2 Prevalence of potentially harmful carer behaviour

Carers respond differently to the demands of caregiving and some may engage in potentially harmful behaviours when providing care to an older person. Potentially harmful behaviours refer to the behaviours engaged in by carers that may not be considered serious enough for formal service intervention, but that may still negatively impact on the quality of care provided to an older person (Beach et al. 2005). Potentially harmful carer behaviours, which occur sometimes or more frequently, indicate a greater risk for elder abuse (Beach et al. 2005; Cooper et al. 2009).

This section presents results from the survey pertaining to carers’ self-reports of potentially harmful psychological and physical carer behaviour. Respondents were asked to rate the frequency with which they engaged in each behaviour using the following response options: never (0), almost never (1), sometimes (2), most of the time (3), and all of the time (4). Previous research has demonstrated that behaviours that occur sometimes or more frequently indicate greater risk for elder abuse (Beach et al. 2005; Cooper et al. 2009). For this reason, respondents who indicated that they engaged in a potentially harmful behaviour ‘sometimes’, ‘most of the time’, or ‘all of the time’, are referred to as having engaged in potentially harmful behaviour ‘at least sometimes’.

The survey results showed that overall, a total of 36.8 per cent (829/2253) of respondents reported engaging in any potentially harmful behaviour in the previous three months, with 17.0 per cent (382/2253) reporting that they did so at least sometimes. The next sections report the extent to which respondents engaged in potentially harmful physical and psychological carer behaviours.

5.2.1 Prevalence of potentially harmful psychological carer behaviour

In total, 35.9 per cent of respondents (811/2258) reported engaging in any potentially harmful psychological behaviour in the previous three months, with 16.6 per cent of respondents (375/2258) indicating that they engaged in these behaviours at least sometimes in the previous three months. Table 5.1 summarises the frequency with which respondents engaged in potentially harmful psychological behaviours. The most frequently reported behaviour by carers was using a harsh tone of voice towards the care recipient, insulting or swearing at or calling the care recipient names; this was reported by

<table>
<thead>
<tr>
<th>Psychological Mistreatment</th>
<th>Never</th>
<th>Almost never</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>All the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the past three months, have you…</td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>Used a harsh tone of voice, insulted or sworn at or called</td>
<td>70.8 (1609)</td>
<td>16.6 (378)</td>
<td>12.1 (272)</td>
<td>0.4 (10)</td>
<td>0.1 (3)</td>
</tr>
<tr>
<td>the person you care for names?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screamed or yelled at the person you care for?</td>
<td>80.2 (1823)</td>
<td>11.6 (264)</td>
<td>7.7 (175)</td>
<td>0.3 (7)</td>
<td>0.2 (4)</td>
</tr>
<tr>
<td>Threatened to send the person you care for to a nursing home?</td>
<td>89.6 (2037)</td>
<td>5.6 (127)</td>
<td>4.5 (102)</td>
<td>0.2 (4)</td>
<td>0.1 (3)</td>
</tr>
<tr>
<td>Threatened to stop taking care of or abandon the person you</td>
<td>89.8 (2043)</td>
<td>6.2 (141)</td>
<td>3.8 (86)</td>
<td>0.1 (2)</td>
<td>0.1 (3)</td>
</tr>
<tr>
<td>care for?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Threatened to use physical force against the person you care</td>
<td>97.5 (2221)</td>
<td>1.8 (42)</td>
<td>0.6 (14)</td>
<td>0.1 (1)</td>
<td>0.0 (0)</td>
</tr>
</tbody>
</table>
12.6 per cent of respondents (285/2272) as having occurred at least sometimes in the preceding three months. The second most frequently reported psychological behaviour engaged in by carers was screaming or yelling at the care recipient; 8.2 per cent of respondents (186/2273) reported that they had engaged in this behaviour. A smaller proportion of carers reported that they threatened to send the care recipient to a nursing home (4.8%, 109/2273). A small minority of respondents reported that they engaged in other potentially harmful psychological behaviours; 4.0 per cent of respondents (91/2275) reported that they threatened to stop taking care of or abandon the care recipient and 0.7 per cent (15/2278) reported that they threatened to use physical force against the care recipient at least sometimes in the previous three months.

5.2.2 Prevalence of potentially harmful physical carer behaviour
Overall, a total of 8.0 per cent of respondents (182/2271) reported engaging in any potentially harmful physical behaviour, with 2.7 per cent of respondents (61/2271) reporting that they engaged in such behaviours towards the care recipient at least sometimes in the previous three months. A very small proportion of respondents indicated that these behaviours occurred regularly (Table 5.2). The most frequently reported physical behaviour was feeling afraid that they might hit or hurt the care recipient. This was reported by 2.2 per cent (49/2278) of respondents as occurring at least sometimes in the previous three months. A total of 3.9 per cent of carers (89/2273) reported engaging in actual physically harmful behaviours, i.e. roughly handling, hitting or slapping, or shaking the care recipient, in the previous three months, with 1.0 per cent (23/2273) reporting that these behaviours occurred at least sometimes. Overall, 0.9 per cent (21/2276) of respondents reported that they roughly handled the care recipient in other ways and 0.5 per cent (10/2278) reported that they hit or slapped the care recipient at least sometimes in the previous three months. A very small proportion of respondents reported that they shook (0.4%, 8/2249) or withheld food from the care recipient (0.1%, 3/2278) at least sometimes in the previous three months.

5.3 Factors associated with potentially harmful carer behaviour
The analysis of the survey data included several caregiver, care recipient and caregiving factors associated with potentially harmful carer behaviour. This section reports the results pertaining to factors associated with potentially harmful carer behaviour. Associations between carer characteristics, including gender, age, marital status, number of dependants, ethnic/cultural background, educational level, social class, area of residence, living arrangements, health and wellbeing factors and potentially harmful carer behaviours were examined. In addition, caregiving factors associated with potentially harmful carer behaviours were also explored. These included type of carer’s allowance, paid work/study, training received to support the caregiving role, hours of care per week, duration of caregiving, level of care provided, relationship to the care recipient, and the quality of the caregiving relationship. The associations
between care recipient characteristics, including gender, age, dementia diagnosis, dependency level, and potentially harmful carer behaviour are presented. Caregivers’ appraisal of the caregiving experience and perceived adequacy of social and professional support and their association with potentially harmful carer behaviour are also reported.

Potentially harmful carer behaviours were dichotomised for the purpose of analysis; carers who scored less than 2, equating to ‘never’ or ‘almost never’ engaging in a behaviour, were categorised as having ‘not engaged in potentially harmful behaviour’, while carers who scored 2 or more, equating to behaviours occurring ‘sometimes’, ‘most of the time’ or ‘all of the time’, were categorised as having ‘engaged in potentially harmful behaviour’.

5.3.1 Carer characteristics associated with potentially harmful carer behaviour

Several carer characteristics were found to be associated with potentially harmful carer behaviour. Table 5.3 presents comparisons between carers who reported that they engaged in potentially harmful behaviours and those who did not. Findings show a statistically significant association between gender and reports of potentially harmful carer behaviour, with a greater proportion of male carers (20.0%, 127/636) reporting that they engaged in potentially harmful behaviours in the previous three months than the proportion of female carers (15.8%, 102/664). An association was also found between the presence of depressive symptoms and potentially harmful carer behaviour. Carers who rated their general health as good or very good (16.5%, 322/1954) were significantly more likely to report that they engaged in potentially harmful behaviours (24.1%, 26/101) than Irish carers (16.5%, 353/2141).

Social class and education were also measured as possible correlates of potentially harmful behaviours. Social class was found to be significantly associated with potentially harmful behaviours engaged in by respondents in the previous three months. A higher proportion of respondents who were in the professional/managerial group (24.1%, 72/299) reported engaging in potentially harmful behaviours when compared to other occupational groups: non-manual (20.9%, 74/354), skilled manual (14.5%, 61/420), semi/unskilled (15.9%, 83/521), and all others gainfully occupied (16.3%, 56/343). No association was found between education levels and potentially harmful carer behaviour.

Carers’ place of residence, i.e. whether carers lived in a rural or an urban area, was found to be significantly associated with potentially harmful carer behaviour. A greater proportion of carers who lived in an urban area reported that they engaged in potentially harmful behaviours (18.8%, 203/1079) in the previous three months when compared to carers who lived in a rural area (15.5%, 173/1114). An association was also found between co-residence with the care recipient and potentially harmful carer behaviour. Respondents who indicated that they resided with the care recipient were significantly more likely to report that they engaged in potentially harmful behaviours (19.9%, 322/1616) than respondents who reported that they did not live with the care recipient (9.3%, 58/625).

Carer health and wellbeing factors were also measured as possible correlates of potentially harmful behaviours engaged in by carers. Table 5.4 summarises the carer health and wellbeing factors found to be significantly associated with potentially harmful carer behaviour. Carers who rated their general health as poor or fair were statistically more likely to report that they engaged in potentially harmful behaviours (24.1%, 166/688), than carers who rated their general health as good or very good (13.8%, 214/1550). An association was also found between co-residence with the care recipient and potentially harmful carer behaviour. Respondents who indicated that they resided with the care recipient were significantly more likely to report that they engaged in potentially harmful behaviours (19.9%, 322/1616) than respondents who reported that they did not live with the care recipient (9.3%, 58/625).

Carer health and wellbeing factors were also measured as possible correlates of potentially harmful behaviours. Carers who rated their general health as poor or fair were statistically more likely to report that they engaged in potentially harmful behaviours (24.1%, 166/688), than carers who rated their general health as good or very good (13.8%, 214/1550). An association was also found between the presence of depressive symptoms and potentially harmful carer behaviour. Carers with CES-D scores of 16 or greater, indicating depressive symptoms, were significantly more likely to report engaging in potentially harmful behaviours (27.2%, 205/755), than carers who scored less than 16 on the CES-D (10.4%, 102/978).
# Chapter 5: Results Part II: Prevalence of Potentially Harmful Carer Behaviours and Factors Associated with Carer Behaviours

## Table 5.3 Carer Characteristics associated with Potentially Harmful Carer Behaviour

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs % (n)</th>
<th>PHBs % (n)</th>
<th>$\chi^2$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>84.2 (1358)</td>
<td>15.8 (255)</td>
<td>5.60</td>
<td>0.02*</td>
</tr>
<tr>
<td>Male</td>
<td>80.0 (509)</td>
<td>20.0 (127)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 46 years</td>
<td>83.0 (367)</td>
<td>17.0 (75)</td>
<td>9.79</td>
<td>0.007**</td>
</tr>
<tr>
<td>46 to 64 years</td>
<td>85.2 (912)</td>
<td>14.8 (158)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 65 years</td>
<td>79.5 (555)</td>
<td>20.5 (143)</td>
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<td></td>
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<tr>
<td><strong>Marital Status</strong></td>
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<tr>
<td>Married</td>
<td>83.7 (1177)</td>
<td>16.3 (229)</td>
<td>1.35</td>
<td>0.25 ns</td>
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<tr>
<td>Not married</td>
<td>81.8 (688)</td>
<td>18.2 (153)</td>
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<tr>
<td><strong>Other Dependants</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>No other dependants</td>
<td>81.8 (996)</td>
<td>18.2 (221)</td>
<td>2.26</td>
<td>0.13 ns</td>
</tr>
<tr>
<td>Other dependants</td>
<td>84.5 (626)</td>
<td>15.5 (115)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ethnic/cultural Background</strong></td>
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</tr>
<tr>
<td>Irish</td>
<td>83.5 (1788)</td>
<td>16.5 (353)</td>
<td>5.88</td>
<td>0.02*</td>
</tr>
<tr>
<td>Non-Irish</td>
<td>74.3 (75)</td>
<td>25.7 (26)</td>
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<tr>
<td><strong>Education Level</strong></td>
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<td></td>
</tr>
<tr>
<td>No formal education/junior cert</td>
<td>83.6 (1037)</td>
<td>16.4 (203)</td>
<td>2.65</td>
<td>0.27 ns</td>
</tr>
<tr>
<td>Leaving cert/vocational</td>
<td>82.6 (562)</td>
<td>17.4 (118)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Third-level education</td>
<td>79.6 (222)</td>
<td>20.4 (57)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social Class</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional/managerial</td>
<td>75.9 (227)</td>
<td>24.1 (72)</td>
<td>15.18</td>
<td>0.004**</td>
</tr>
<tr>
<td>Non-manual</td>
<td>79.1 (280)</td>
<td>20.9 (74)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skilled manual</td>
<td>85.5 (359)</td>
<td>14.5 (61)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Semi/unskilled</td>
<td>84.1 (438)</td>
<td>15.9 (83)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All others gainfully occupied</td>
<td>83.7 (287)</td>
<td>16.3 (56)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Rural Vs. Urban</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural area</td>
<td>84.5 (941)</td>
<td>15.5 (173)</td>
<td>4.16</td>
<td>0.04*</td>
</tr>
<tr>
<td>Urban area</td>
<td>81.2 (876)</td>
<td>18.8 (203)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Co-residence with the Care recipient</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-residing with care recipient</td>
<td>80.1 (1294)</td>
<td>19.9 (322)</td>
<td>36.27</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Not co-residing with care recipient</td>
<td>90.7 (567)</td>
<td>9.3 (58)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*ns not significant    *significant at $p < 0.05$    **significant at $p < 0.01$    ***significant at $p < 0.001$

## Table 5.4 Carer Health and Wellbeing Factors associated with Potentially Harmful Carer Behaviour

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs % (n)</th>
<th>PHBs % (n)</th>
<th>$\chi^2$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Carer’s General Health</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor/fair</td>
<td>75.9 (522)</td>
<td>24.1 (166)</td>
<td>36.01</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Good/very good</td>
<td>86.2 (1336)</td>
<td>13.8 (214)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Carer Depressive Symptoms</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CES-D Score &lt; 16</td>
<td>89.6 (876)</td>
<td>10.4 (102)</td>
<td>81.74</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>CES-D Score ≥ 16</td>
<td>72.8 (550)</td>
<td>27.2 (205)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**significant at $p < 0.001$
Chapter 5: Results Part II: Prevalence of Potentially Harmful Carer Behaviours and Factors Associated with Carer Behaviours

Table 5.5 Comparison of Mean Carer Burden Scores between Potentially Harmful Carer Behaviour Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>No PHBs</th>
<th>PHBs</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Burden Score a</td>
<td>33.2 (16.8)</td>
<td>30.1 (15.6)</td>
<td>47.1 (15.3)</td>
<td>18.539</td>
<td>&lt; 0.001***</td>
</tr>
</tbody>
</table>

** significant at p < 0.001

*Scores on the Zarit Burden Interview range from 0 to 88

In addition, results showed a statistically significant association between carer burden and potentially harmful carer behaviour ($t(1997)= 18.539, p < .001$), with carers who reported no potentially harmful behaviours having significantly lower mean scores on the ZBI ($M=30.1, SD=15.6$) than those who reported potentially harmful behaviours ($M=47.1, SD=15.3$). Thus, increased levels of burden experienced by carers were related to an increased likelihood of engaging in potentially harmful behaviours (Table 5.5).

5.3.2 Caregiving factors associated with potentially harmful carer behaviour

Table 5.6 summarises the caregiving factors associated with potentially harmful behaviours engaged in by carers. Factors such as type of carer’s allowance, undertaking paid work and/or study outside of the home or receiving training to support carers in their caregiving role were not found to be associated with potentially harmful carer behaviour. However, the number of hours of care provided each week was found to be statistically

Table 5.6 Caregiving Characteristics associated with Potentially Harmful Carer Behaviour

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs</th>
<th>PHBs</th>
<th>$\chi^2$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Carer’s Allowance</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-rate</td>
<td>84.4 (1074)</td>
<td>15.6 (199)</td>
<td>3.84</td>
<td>0.05ns</td>
</tr>
<tr>
<td>Hal-rate</td>
<td>81.2 (774)</td>
<td>18.8 (179)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Paid Work/Study</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid work and/or study</td>
<td>80.6 (208)</td>
<td>19.4 (50)</td>
<td>1.21</td>
<td>0.27ns</td>
</tr>
<tr>
<td>No paid work or study</td>
<td>83.4 (1613)</td>
<td>16.6 (322)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Training to Support Caregiving Role</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training received</td>
<td>84.4 (482)</td>
<td>15.6 (89)</td>
<td>1.14</td>
<td>0.29ns</td>
</tr>
<tr>
<td>No training received</td>
<td>82.5 (1364)</td>
<td>17.5 (290)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hours of Care (per week)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$\leq 39$ hours</td>
<td>89.4 (353)</td>
<td>10.6 (42)</td>
<td>20.02</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>40 to 59 hours</td>
<td>84.5 (332)</td>
<td>15.5 (61)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60 to 80 hours</td>
<td>83.9 (307)</td>
<td>16.1 (59)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$&gt; 80$ hours</td>
<td>79.8 (852)</td>
<td>20.2 (216)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Duration of Care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$&lt; 3$ years</td>
<td>89.2 (357)</td>
<td>10.8 (43)</td>
<td>15.23</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>3 to 5 years</td>
<td>83.2 (632)</td>
<td>16.8 (128)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>$&gt; 5$ years</td>
<td>80.7 (882)</td>
<td>19.3 (211)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relationship to the Care recipient</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>78.2 (535)</td>
<td>21.8 (149)</td>
<td>16.66</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Adult child</td>
<td>84.5 (974)</td>
<td>15.5 (178)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>86.6 (337)</td>
<td>13.4 (52)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceived Quality of Caregiving Relationship</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor/Fair</td>
<td>56.9 (156)</td>
<td>43.1 (118)</td>
<td>147.40</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Good/Excellent</td>
<td>86.5 (1682)</td>
<td>13.5 (263)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ns not significant  * significant at p < 0.05  *** significant at p < 0.001
significantly associated with potentially harmful behaviours. Carers who reported that they provided more than 80 hours of care a week were significantly more likely to report that they engaged in potentially harmful behaviours (20.2%, 216/1068) than carers who provided fewer hours of care. The duration of care provided was also found to be significantly associated with potentially harmful carer behaviour. A larger proportion of carers who have been providing care for more than five years reported that they engaged in potentially harmful behaviours (19.3%, 211/1093), than carers who reported providing care for between three and five years (16.8%, 128/760) and those who provided care for less than three years (10.8%, 43/400). A direct relationship was found between hours of care provided per week and duration of care and potentially harmful carer behaviours, that is, as the number of hours of care and years of care provided increased, so too did the number of respondents who reported that they engaged in potentially harmful behaviours.

Spousal carers were statistically significantly more likely to report that they engaged in potentially harmful behaviours than adult children or other carers. Just over a fifth of spousal carers reported that they engaged in potentially harmful behaviours (21.8%, 149/684) compared to adult child carers (15.5%, 178/1152) or carers in other caregiving relationships (13.4%, 52/389). Results showed a statistically significant association between perceived quality of the caregiving relationship and potentially harmful carer behaviour. Respondents who perceived the quality of the caregiving relationship as poor or fair were significantly more likely to report that they engaged in potentially harmful behaviours (43.1%, 118/274) than respondents who rated their relationship as good or excellent (13.5%, 263/1945).

Respondents were asked to indicate the extent to which they provided help with activities of daily living (ADLs). Respondents who reported that they engaged in potentially harmful behaviours scored higher on the helping scale, and thus provided more help on average to the care recipient (M = 4.9, SD = 1.4), than respondents who indicated that they did not engage in potentially harmful carer behaviour (M = 4.7, SD = 1.5) (Table 5.7). There was a statistically significant difference in the level of help provided between the two groups [t(1787) = 2.66, p < 0.01] (Table 5.7).

5.3.3 Care recipient characteristics associated with potentially harmful carer behaviour

A number of care recipient characteristics were found to be associated with potentially harmful physical and psychological carer behaviour (Table 5.8). An association was found between the age of care recipients and potentially harmful carer behaviour. Respondents who indicated that they provided care to care recipients aged...
65 to 74 years were significantly more likely to report that they engaged in potentially harmful carer behaviour (21.2%, 124/586) than respondents who cared for care recipients aged 75 and 84 years (17.8%, 157/882) and 85 years and older (12.9%, 101/785). Respondents who indicated that they provided care to an older person with a dementia diagnosis were also significantly more likely to report potentially harmful carer behaviour (23.6%, 111/471) than respondents who provided care to care recipients without a diagnosis of dementia (15.1%, 263/1736). No statistically significant difference was found between the gender of the care recipient and the likelihood of reporting potentially harmful carer behaviour.

There was a statistically significant difference in mean scores on the care recipient dependency scale between carers who reported that they engaged in potentially harmful behaviours and those who reported that they did not [(1963) = 4.62, p < 0.001] (Table 5.9). On average, respondents who reported that they engaged in potentially harmful carer behaviour provided care to care recipients with significantly higher dependency needs (M=12.9, SD=3.0) than carers who reported no potentially harmful carer behaviours (M=12.1, SD=3.0).

### 5.3.4 Positive appraisal and quality of support associated with potentially harmful carer behaviour

The positive appraisal scale measures the positive value of caregiving and the quality of support scale measures perceived adequacy of social and professional support. Respondents were asked to answer four questions using responses ranging from 1 (never) to 4 (always). Scores were summed for each scale to give an overall sum ranging from 4 to 16, with higher values indicating a higher positive appraisal of the caregiving experience and higher perceived adequacy of quality of support.

Table 5.10 presents a comparison of the mean scores on the scales between two carer groups, namely carers who reported that they engaged in potentially harmful behaviours and carers who did not report engaging in potentially harmful behaviours. Results showed a statistically significant difference between the two groups on the positive appraisal scale [(2165) = 15.28, p < 0.001]. Carers who reported engaging in potentially harmful behaviours scored significantly lower on positive appraisal (M=11.4, SD=2.6) when compared to carers who reported no potentially harmful behaviours (M=13.5, SD=2.4). This suggests that carers who engaged in potentially harmful behaviours were less likely to positively value their caregiving experience when compared to those carers who did not engage in potentially harmful behaviours.

There was also a statistically significant difference between scores on the perceived quality of support scale [(2159) = 9.09, p < 0.001]. The mean score for carers who reported that they engaged in potentially harmful behaviours was, on average, significantly lower on the quality of support scale (M=9.6, SD=3.3) than carers who reported that they did not engage in potentially harmful behaviours (M=11.4, SD=3.4) (Table 5.10). This finding suggests an association between perceived adequacy of the support received by carers and potentially harmful behaviours, with carers who reported engaging in potentially harmful behaviours perceiving social and professional services to be less adequate than those who reported no potentially harmful behaviours.

### Table 5.9 Comparison of Care Recipient Dependency Mean Scores between Potentially Harmful Carer Behaviour Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>No PHBs</th>
<th>PHBs</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care recipient Dependency Score a</td>
<td>12.2 (3.0)</td>
<td>12.1 (3.0)</td>
<td>12.9 (3.0)</td>
<td>4.62</td>
<td>&lt; 0.001***</td>
</tr>
</tbody>
</table>

*Significant at p < 0.001  a Scores on the dependency scale range from 6 to 18

### Table 5.10 Comparison of Positive Appraisal and Quality of Support Mean Scores Between Potentially Harmful Carer Behaviour Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>No PHBs</th>
<th>PHBs</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Appraisal Score a</td>
<td>13.2 (2.5)</td>
<td>13.5 (2.4)</td>
<td>11.4 (2.6)</td>
<td>15.28</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Quality of Support Score b</td>
<td>11.1 (3.5)</td>
<td>11.4 (3.4)</td>
<td>9.6 (3.3)</td>
<td>9.09</td>
<td>&lt; 0.001***</td>
</tr>
</tbody>
</table>

*Significant at p < 0.001  a Scores on the positive appraisal scale range from 4 to 16  b Scores on the quality of support scale range from 4 to 16
5.4 Factors associated with potentially harmful psychological carer behaviour

This section of the report presents the factors associated with potentially harmful psychological carer behaviour. Carer characteristics, caregiving factors, care recipient characteristics, quality of support and coping factors associated with potentially harmful psychological behaviours engaged in by carers are reported.

5.4.1 Carer characteristics associated with potentially harmful psychological carer behaviour

Table 5.11 summarises the carer characteristics associated with potentially harmful psychological behaviour engaged in by the carer. Several carer characteristics were found to be associated with potentially harmful psychological behaviours. There was a statistically significant association between gender and potentially harmful psychological behaviour, with a greater proportion of male carers reporting that they engaged in potentially harmful psychological behaviours (19.2%, 122/636) than female carers (15.6%, 253/1618).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs % (n)</th>
<th>PHBs % (n)</th>
<th>$\chi^2$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>84.4 (1365)</td>
<td>15.6 (253)</td>
<td>4.14</td>
<td>0.04*</td>
</tr>
<tr>
<td>Male</td>
<td>80.8 (514)</td>
<td>19.2 (122)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 46 years</td>
<td>83.3 (369)</td>
<td>16.7 (74)</td>
<td>9.23</td>
<td>0.01**</td>
</tr>
<tr>
<td>46 to 64 years</td>
<td>85.5 (916)</td>
<td>14.5 (155)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 65 years</td>
<td>80.0 (561)</td>
<td>20.0 (140)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>84.0 (1184)</td>
<td>16.0 (225)</td>
<td>1.27</td>
<td>0.26ns</td>
</tr>
<tr>
<td>Not married</td>
<td>82.2 (693)</td>
<td>17.8 (150)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Dependants</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No other dependants</td>
<td>82.3 (1003)</td>
<td>17.7 (215)</td>
<td>1.98</td>
<td>0.16ns</td>
</tr>
<tr>
<td>Other dependants</td>
<td>84.8 (630)</td>
<td>15.2 (113)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnic/cultural Background</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irish</td>
<td>83.9 (1800)</td>
<td>16.1 (346)</td>
<td>6.46</td>
<td>0.01**</td>
</tr>
<tr>
<td>Non-Irish</td>
<td>74.3 (75)</td>
<td>25.7 (26)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education Level</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal education/Junior cert</td>
<td>84.0 (1042)</td>
<td>16.0 (199)</td>
<td>2.07</td>
<td>0.35ns</td>
</tr>
<tr>
<td>Leaving cert/vocational</td>
<td>83.1 (565)</td>
<td>16.9 (115)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Third-level education</td>
<td>80.4 (226)</td>
<td>19.6 (55)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Class</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional/managerial</td>
<td>76.6 (229)</td>
<td>23.4 (70)</td>
<td>15.76</td>
<td>0.003**</td>
</tr>
<tr>
<td>Non-manual</td>
<td>79.2 (281)</td>
<td>20.8 (74)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skilled manual</td>
<td>86.2 (362)</td>
<td>13.8 (58)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Semi/unskilled</td>
<td>84.1 (440)</td>
<td>15.9 (83)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All others gainfully occupied</td>
<td>84.3 (291)</td>
<td>15.7 (54)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural Vs. Urban</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural area</td>
<td>84.8 (948)</td>
<td>15.2 (170)</td>
<td>3.89</td>
<td>0.05ns</td>
</tr>
<tr>
<td>Urban area</td>
<td>81.6 (881)</td>
<td>18.4 (198)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-residence with the Care recipient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-residing with care recipient</td>
<td>80.4 (1303)</td>
<td>19.6 (317)</td>
<td>36.79</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Not co-residing with care recipient</td>
<td>91.1 (570)</td>
<td>8.9 (56)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*ns not significant    *significant at $p < 0.05$    **significant at $p < 0.01$    ***significant at $p < 0.001$
The association between carers’ age and potentially harmful psychological behaviour was statistically significant, with a greater tendency for carers aged 65 years and older to report that they engaged in potentially harmful psychological behaviours (20.0%, 140/701) than carers aged 46 to 64 years or aged less than 46 years. A statistically significant association was found between ethnic/cultural background and potentially harmful psychological carer behaviour; a quarter of respondents who were non-Irish reported that they engaged in psychologically harmful behaviours (25.7%, 26/101) compared to 16.1 per cent (346/2146) of Irish respondents. Marital status, education levels and whether respondents had other dependants were not associated with self-reported potentially harmful psychological behaviour. Similarly, there was no statistically significant association between whether respondents were living in urban or rural areas and whether they reported engaging in potentially harmful psychological behaviours towards the care recipient.

Social class was found to be associated with potentially harmful psychological carer behaviour that occurred at least sometimes in the previous three months. A larger proportion of respondents who were in the professional/managerial group reported engaging in potentially harmful psychological behaviour (23.4%, 70/299), when compared to the proportion of potentially harmful psychological behaviours engaged in by respondents in the other occupational groups: non-manual (20.8%, 74/355), skilled manual (13.8%, 58/420), semi/unskilled (15.9%, 83/523), and all others gainfully occupied (15.7%, 54/345).

Whether the respondent resided with the care recipient was also found to be significantly associated with potentially harmful psychological carer behaviour. Respondents who reported that they lived with the care recipient were statistically significantly more likely to report that they engaged in potentially harmful psychological carer behaviour (19.6%, 317/1620) than carers who reported that they did not reside with the care recipient (8.9%, 56/626).

Associations between respondents’ self-reported health and wellbeing and potentially harmful psychological behaviours were also explored (Table 5.12). Self-reported general health was significantly associated with reports of potentially harmful psychological behaviour. Respondents who self-reported their health as either poor or fair were significantly more likely to report engaging in potentially harmful psychological behaviour (23.4%, 161/689) than respondents who reported their health as good or very good (13.7%, 213/1554). A statistically significant association between carer depressive symptoms and potentially harmful psychological carer behaviour was also found, with 26.8 per cent (203/758) of respondents who scored 16 and above (indicative of depressive symptoms) reporting potentially harmful psychological behaviours, compared with 10 per cent of respondents who scored less than 16 reporting potentially harmful psychological behaviours.

Carer burden was also statistically significantly associated with potentially harmful psychological carer behaviour \( t(2002) = 18.436, \ p < .001 \), with carers who reported potentially harmful psychological behaviour having significantly higher mean burden scores (M=47.2, SD=15.3) than carers who did not report such behaviours (M=30.2, SD=15.6). Thus, respondents who experienced higher levels of burden as measured by the ZBI were significantly more likely to report engaging in potentially harmful psychological carer behaviour (Table 5.13).

### Table 5.12 Carer Health and Wellbeing Factors associated with Potentially Harmful Psychological Carer Behaviour

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs % (n)</th>
<th>PHBs % (n)</th>
<th>( \chi^2 )</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer’s General Health</td>
<td></td>
<td></td>
<td>32.07</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Poor/fair</td>
<td>76.6 (528)</td>
<td>23.4 (161)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good/very good</td>
<td>86.3 (1341)</td>
<td>13.7 (213)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Depressive Symptoms</td>
<td></td>
<td></td>
<td>83.88</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>CES-D Score &lt; 16</td>
<td>90.0 (881)</td>
<td>10.0 (98)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CES-D Score ≥ 16</td>
<td>73.2 (555)</td>
<td>26.8 (203)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

***significant at \( p < 0.001 \)
5.4.2 Caregiving factors associated with potentially harmful psychological carer behaviour

Table 5.14 summarises the association between caregiving factors and reports of potentially harmful psychological carer behaviour. A statistically significant association was found between the number of hours of care provided by respondents in an average week and potentially harmful psychological carer behaviour. Respondents who reported that they provided more than 80 hours of care a week were significantly more likely to report engaging in potentially harmful psychological behaviour at least sometimes in the previous three months (19.9%, 213/1071), when compared to respondents who reported that they provided 60 to 80 hours of care (16.3%, 60/367); 40 to 59 hours of care a week (14.2%, 56/393); and less than 40 hours of care a week (10.6%, 42/396). Thus, as the number of hours of care provided by the carer increased, so too did the number of reports of potentially harmful psychological carer behaviour.

### Chapter 5: Results Part II: Prevalence of Potentially Harmful Carer Behaviours and Factors Associated with Carer Behaviours

#### Table 5.13 Comparison of Mean Carer Burden Scores Between Potentially Harmful Psychological Carer Behaviour Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>No PHBs</th>
<th>PHBs</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Burden Score a</td>
<td>33.2 (16.8)</td>
<td>30.2 (15.6)</td>
<td>47.2 (15.3)</td>
<td>18.436</td>
<td>&lt; 0.001***</td>
</tr>
</tbody>
</table>

**a** Scores on the Zarit Burden Interview range from 0 to 88

#### Table 5.14 Caregiving Characteristics associated with Potentially Harmful Psychological Carer Behaviour

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs % (n)</th>
<th>PHBs % (n)</th>
<th>χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Carer’s Allowance</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-rate</td>
<td>84.6 (1079)</td>
<td>15.4 (197)</td>
<td>3.05</td>
<td>0.08ns</td>
</tr>
<tr>
<td>Half-rate</td>
<td>81.8 (781)</td>
<td>18.2 (174)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Paid Work/Study</strong></td>
<td></td>
<td></td>
<td>1.24</td>
<td>0.27ns</td>
</tr>
<tr>
<td>Paid work and/or study</td>
<td>81.0 (209)</td>
<td>19.0 (49)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No paid work or study</td>
<td>83.8 (1624)</td>
<td>16.2 (315)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Training to Support Caregiving Role</strong></td>
<td></td>
<td></td>
<td>0.93</td>
<td>0.34ns</td>
</tr>
<tr>
<td>Training received</td>
<td>84.6 (484)</td>
<td>15.4 (88)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No training received</td>
<td>82.9 (1374)</td>
<td>17.1 (284)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hours of Care (per week)</strong></td>
<td></td>
<td></td>
<td>20.16</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>≤ 39 hours</td>
<td>89.4 (354)</td>
<td>10.6 (42)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40 to 59 hours</td>
<td>85.8 (337)</td>
<td>14.2 (56)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60 to 80 hours</td>
<td>83.7 (307)</td>
<td>16.3 (60)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 80 hours</td>
<td>80.1 (858)</td>
<td>19.9 (213)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Duration of Care</strong></td>
<td></td>
<td></td>
<td>16.16</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>&lt; 3 years</td>
<td>89.5 (359)</td>
<td>10.5 (42)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 to 5 years</td>
<td>83.8 (638)</td>
<td>16.2 (123)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 5 years</td>
<td>80.8 (886)</td>
<td>19.2 (210)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relationship to the Care recipient</strong></td>
<td></td>
<td></td>
<td>16.33</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Spouse</td>
<td>78.7 (540)</td>
<td>21.3 (146)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult child</td>
<td>84.7 (978)</td>
<td>15.3 (176)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>87.2 (340)</td>
<td>12.8 (50)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceived Quality of Caregiving Relationship</strong></td>
<td></td>
<td></td>
<td>148.50</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Poor/Fair</td>
<td>57.5 (158)</td>
<td>42.5 (117)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good/Excellent</td>
<td>86.8 (1692)</td>
<td>13.2 (257)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ns not significant ***significant at p < 0.001
Chapter 5: Results Part II: Prevalence of Potentially Harmful Carer Behaviours and Factors Associated with Carer Behaviours

Table 5.15 Comparison of Helping Mean Scores between Potentially Harmful Psychological Carer Behaviour Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>No PHBs</th>
<th>PHBs</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of help provided score a</td>
<td>4.7 (1.5)</td>
<td>4.7 (1.5)</td>
<td>4.9 (1.5)</td>
<td>2.42</td>
<td>0.02*</td>
</tr>
</tbody>
</table>

a Scores on the helping scale range from 0 to 6

There were no associations between training received by carers to support them in their caregiving role, type of carer’s allowance received, or work or study undertaken outside the home and potentially harmful psychological carer behaviours.

The number of years of care provided to the care recipient was found to be statistically significantly associated with reports of potentially harmful psychological carer behaviour. A greater proportion of respondents who reported that they provided care for more than five years reported engaging in potentially harmful psychological carer behaviour at least sometimes in the previous three months (19.2%, 210/1096), than respondents who indicated that they have been providing care for between three and five years (16.2%, 123/761) or less than three years (10.5%, 42/401). There was a direct positive relationship between the number of years of care provided and potentially harmful psychological carer behaviours; that is, as the number of years of care provided increased, so too did the number of reports of potentially harmful psychological carer behaviour.

A statistically significant association was found between the respondent’s relationship to the care recipient and potentially harmful psychological carer behaviour. Spousal carers were significantly more likely to report engaging in potentially harmful psychological carer behaviours (21.3%, 146/686), than adult child carers (15.3%, 176/1154) or other carers (12.8%, 50/390).

The perceived quality of the caregiving relationship was also statistically significantly associated with potentially harmful psychological carer behaviour. A greater proportion of respondents who perceived the quality of the caregiving relationship as poor or fair, reported that they engaged in potentially harmful psychological behaviour at least sometimes in the previous three months (42.5%, 117/275) than respondents who reported that they perceived the relationship with the care recipient as good or excellent (13.2%, 257/1949).

The survey results indicated that there was a significant difference in the level of help provided between respondents who engaged in potentially harmful psychological behaviours and those who reported that they did not (t(1792) = 2.42, p < 0.05) (Table 5.15). On average, respondents who reported that they engaged in potentially harmful psychological behaviours scored significantly higher on the helping scale (M=4.9, SD=1.5) than respondents who indicated that they engaged in no potentially harmful psychological behaviours (M=4.7, SD=1.5), indicating that as the amount of help provided by carers increased, so too did the incidence of potentially harmful psychological carer behaviours.

5.4.3 Care recipient characteristics associated with potentially harmful psychological carer behaviour

Table 5.16 summarises the associations between care recipient characteristics and potentially harmful psychological behaviours engaged in by the carer. No significant difference was found between the gender of the care recipient and respondents’ self-reports of engaging in potentially harmful psychological behaviours at least sometimes in the previous three months.

The care recipients’ age and whether they had a diagnosis of dementia were found to be statistically associated with potentially harmful psychological carer behaviour. As the age of the care recipient increased, the number of self-reports of potentially harmful psychological carer behaviours decreased, indicating an inverse relationship between age of care recipient and self-reported potentially harmful psychological carer behaviour. Respondents who cared for care recipients aged 65 to 74 years were significantly more likely to report engaging in potentially harmful psychological carer behaviour (20.4%, 120/587) than respondents who reported that they provided care to care recipients aged 75 to 84 years (17.1%, 151/882) or aged 85 years and older (13%, 95/730). A diagnosis of dementia in the care recipient was also significantly associated with self-reports of potentially harmful psychological carer behaviour. Respondents who provided care to an older person with a diagnosis of dementia were significantly more likely to report engaging in potentially harmful psychological carer behaviour (22.9%, 108/472) than respondents who provided care to an older person without a dementia diagnosis (20.4%, 120/587) or other carers (12.8%, 50/390).

The care recipients’ age and whether they had a diagnosis of dementia were found to be statistically associated with potentially harmful psychological carer behaviour. As the age of the care recipient increased, the number of self-reports of potentially harmful psychological carer behaviours decreased, indicating an inverse relationship between age of care recipient and self-reported potentially harmful psychological carer behaviour. Respondents who cared for care recipients aged 65 to 74 years were significantly more likely to report engaging in potentially harmful psychological carer behaviour (20.4%, 120/587) than respondents who reported that they provided care to care recipients aged 75 to 84 years (17.1%, 151/882) or aged 85 years and older (13%, 95/730). A diagnosis of dementia in the care recipient was also significantly associated with self-reports of potentially harmful psychological carer behaviour. Respondents who provided care to an older person with a diagnosis of dementia were significantly more likely to report engaging in potentially harmful psychological carer behaviour (22.9%, 108/472) than respondents who cared for an older person without a dementia diagnosis (14.9%, 259/1740).
Differences in the dependency levels of the care recipient and whether carers engaged in potentially harmful psychological behaviour were also explored. A comparison of the mean scores on the care recipient dependency scale indicated a statistically significant difference between those who reported engaging in potentially harmful psychological behaviours and those who did not \( t(1967)=4.41, p<0.001 \) (Table 5.17). The mean dependency score of recipients cared for by respondents who reported potentially harmful psychological behaviours \( (M=12.9, SD=3.0) \) was significantly higher than the mean score of care recipients cared for by respondents who indicated that they did not engage in potentially harmful psychological behaviour \( (M=12.1, SD=3.0) \), suggesting that higher levels of care recipient dependency were associated with increased risk of potentially harmful psychological behaviours.

While this difference was statistically significant, the actual difference in mean scores between the two groups was quite small.

### 5.4.4 Positive appraisal and quality of support associated with potentially harmful psychological carer behaviour

Comparisons were conducted between carers who reported engaging in potentially harmful psychological behaviours and carers who reported that they did not and the extent to which the caregiving experience was positively valued. As illustrated by Table 5.18, the results indicate a statistically significant difference between the two groups \( t(2168)=15.22, p<0.001 \); respondents who reported engaging in potentially harmful psychological behaviour scored significantly lower on positive appraisal \( (M=11.4, SD=2.6) \) of the caregiving experience than...
respondents who reported no potentially harmful psychological behaviours ($M=13.5$, $SD=2.4$). This suggests that carers who reported engaging in potentially harmful psychological behaviours attached less positive value to the caregiving experience than those who did not report potentially harmful psychological behaviours.

Respondents’ scores on the perceived quality of support scale were compared between carers who reported engaging in potentially harmful psychological behaviour and those who did not (Table 5.18). Respondents who reported that they engaged in potentially harmful psychological behaviour had a lower overall mean score on the scale ($M=9.6$, $SD=3.3$) than carers who reported that they did not engage in potentially harmful psychological behaviour ($M=11.4$, $SD=3.4$). The mean scores for the two carer groups were found to be statistically significantly different ($t(2164)=9.01$, $p<0.001$), indicating that carers who reported engaging in potentially harmful psychological behaviours perceived social and professional services to be less adequate than those who did not report potentially harmful psychological behaviours.

### 5.5 Factors associated with potentially harmful physical carer behaviour

The carer characteristics, caregiving factors, care recipient characteristics, positive appraisal of the caregiving experience and quality of support factors associated with potentially harmful physical carer behaviour are reported in this section.

#### 5.5.1 Carer characteristics associated with potentially harmful physical carer behaviour

Several carer characteristics were found to be significantly associated with potentially harmful physical carer behaviour (Table 5.19). A statistically significant association was found between carers’ gender and potentially harmful physical carer behaviour. A greater proportion of male carers reported engaging in potentially harmful physical behaviour (4.5%, 29/641) compared to female carers (2.0%, 32/1626). There was no association between carer’s age, marital status or number of dependants and potentially harmful physical carer behaviour.

No relationship was found between education level, social class or whether respondents lived in an urban or rural area and self-reported potentially harmful physical carer behaviour. However, living with the care recipient was found to be significantly associated with potentially harmful physical carer behaviour, with respondents who indicated that they lived with the care recipient significantly more likely to report engaging in potentially harmful physical behaviours (3.4%, 56/1632), than respondents who indicated that they did not live with the care recipient (0.8%, 5/627). The number of respondents of non-Irish ethnic/cultural background was too small to permit analysis of the relationship between this factor and potentially harmful physical carer behaviour.

Table 5.20 summarises the association between carers’ reports of their health and wellbeing and potentially harmful physical carer behaviour towards the care recipient. Respondents who self-reported poor or fair general health were significantly more likely to report engaging in potentially harmful physical carer behaviour (4.2%, 29/694) than carers who reported good or very good general health (1.9%, 30/1561). The extent to which respondents self-reported depressive symptoms was also found to be statistically related to reports of potentially harmful physical carer behaviour. Respondents with elevated depressive symptoms, i.e. who scored 16 and above on the Center for Epidemiologic Studies Depression Scale (CES-D), were significantly more likely to self-report potentially harmful physical carer behaviour (4.4%, 33/758) than respondents who scored less than 16 on the CES-D (1.1%, 11/983).

The experience of higher carer burden was related to reports of potentially harmful physical behaviour. There was a statistically significant difference in the mean ZBI scores between carers who reported engaging in potentially harmful physical behaviour ($M=51.9$, $SD=15.4$) and those who did not ($M=32.6$, $SD=16.4$) ($t(2008)=8.783$, $p<.001$), suggesting that carers who reported engaging in potentially harmful physical behaviours experienced significantly higher levels of burden than those who did not report such behaviours (Table 5.21).
### Table 5.19 Carer Characteristics associated with Potentially Harmful Physical Carer Behaviour

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs % (n)</th>
<th>PHBs % (n)</th>
<th>$\chi^2$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td>11.47</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Female</td>
<td>98.0 (1594)</td>
<td>2.0 (32)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>95.5 (612)</td>
<td>4.5 (29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td>3.27</td>
<td>0.20ns</td>
</tr>
<tr>
<td>&lt; 46 years</td>
<td>97.5 (434)</td>
<td>2.5 (11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>46 to 64 years</td>
<td>97.9 (1052)</td>
<td>2.1 (23)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥ 65 years</td>
<td>96.5 (683)</td>
<td>3.5 (25)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
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<td>0.56ns</td>
</tr>
<tr>
<td>Married</td>
<td>97.5 (1382)</td>
<td>2.5 (36)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not married</td>
<td>97.0 (822)</td>
<td>3.0 (25)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Dependants</td>
<td></td>
<td></td>
<td>3.04</td>
<td>0.08ns</td>
</tr>
<tr>
<td>No other dependants</td>
<td>96.8 (1186)</td>
<td>3.2 (39)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other dependants</td>
<td>98.1 (733)</td>
<td>1.9 (14)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnic/cultural Background</td>
<td></td>
<td></td>
<td>- †</td>
<td></td>
</tr>
<tr>
<td>Irish</td>
<td>97.4 (2101)</td>
<td>2.6 (57)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Irish</td>
<td>97.1 (99)</td>
<td>2.9 (3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education Level</td>
<td></td>
<td></td>
<td>1.30</td>
<td>0.52ns</td>
</tr>
<tr>
<td>No formal education/junior cert</td>
<td>97.6 (1218)</td>
<td>2.4 (30)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leaving cert/vocational</td>
<td>96.8 (667)</td>
<td>3.2 (22)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Third-level education</td>
<td>96.8 (270)</td>
<td>3.2 (9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Class</td>
<td></td>
<td></td>
<td>4.02</td>
<td>0.40ns</td>
</tr>
<tr>
<td>Professional/managerial</td>
<td>96.0 (288)</td>
<td>4.0 (12)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-manual</td>
<td>97.5 (346)</td>
<td>2.5 (9)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skilled manual</td>
<td>98.1 (418)</td>
<td>1.9 (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sems/unskilled</td>
<td>96.6 (508)</td>
<td>3.4 (18)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All others gainfully occupied</td>
<td>97.7 (337)</td>
<td>2.3 (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural Vs. Urban</td>
<td></td>
<td></td>
<td>0.78</td>
<td>0.38ns</td>
</tr>
<tr>
<td>Rural area</td>
<td>97.6 (1092)</td>
<td>2.4 (27)</td>
<td></td>
<td></td>
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<tr>
<td>Urban area</td>
<td>97.0 (1059)</td>
<td>3.0 (33)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Co-residence with the Care recipient</td>
<td></td>
<td></td>
<td>11.96</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Co-residing with care recipient</td>
<td>96.6 (1576)</td>
<td>3.4 (56)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not co-residing with care recipient</td>
<td>99.2 (622)</td>
<td>0.8 (5)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**not significant  ***significant at $p < 0.001$

† Due to the small number of non-Irish respondents, significance testing was not possible.

### Table 5.20 Carer Health and Wellbeing Factors associated with Potentially Harmful Physical Carer Behaviour

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs % (n)</th>
<th>PHBs % (n)</th>
<th>$\chi^2$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer’s General Health</td>
<td></td>
<td></td>
<td>9.60</td>
<td>0.002**</td>
</tr>
<tr>
<td>Poor/fair</td>
<td>95.8 (665)</td>
<td>4.2 (29)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good/very good</td>
<td>98.1 (1531)</td>
<td>1.9 (30)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Depressive Symptoms</td>
<td></td>
<td></td>
<td>18.18</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>CES-D Score &lt; 16</td>
<td>98.9 (972)</td>
<td>1.1 (11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CES-D Score ≥ 16</td>
<td>95.6 (725)</td>
<td>4.4 (33)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**significant at $p < 0.01$  ***significant at $p < 0.001$
5.5.2 Caregiving factors associated with potentially harmful physical carer behaviour

A number of caregiving factors including type of carer’s allowance, paid work/study, training, hours of care, duration of care, relationship to care recipient and perceived quality of the caregiving relationship and their associations with potentially harmful physical carer behaviour were explored (Table 5.22). There was no association between the type of carer’s allowance paid to respondents, whether the respondent engaged in paid work and/or study outside of the home or whether training was received to support the respondent in their caregiving role and potentially harmful physical carer behaviour. A positive relationship was found between hours of care provided per week and reports of potentially harmful physical caregiver behaviour. As the reported number of hours of care provided each week increased, so too did the number of self-reported potentially harmful physical carer behaviours. As illustrated in Table 5.22, 3.8 per cent of respondents who reported providing care for more than 80 hours per week reported engaging in potentially harmful physical carer behaviour at least sometimes in the previous three months (41/1080); compared to 2.2 per cent of respondents who reported providing between 60 and 80 hours of care (8/360) and 1.5 per cent of respondents who reported providing care for less than 60 hours in an average week who engaged in potentially harmful physical behaviours (12/791).

Table 5.22

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs % (n)</th>
<th>PHBs % (n)</th>
<th>χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Carers Allowance</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-rate</td>
<td>97.7 (1250)</td>
<td>2.3 (30)</td>
<td>1.27</td>
<td>0.26</td>
</tr>
<tr>
<td>Half-rate</td>
<td>96.9 (932)</td>
<td>3.1 (30)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Paid Work/Study</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid work and/or study</td>
<td>95.8 (248)</td>
<td>4.2 (11)</td>
<td>2.41</td>
<td>0.12</td>
</tr>
<tr>
<td>No paid work or study</td>
<td>97.4 (1899)</td>
<td>2.6 (50)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Training to Support Caregiving Role</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training received</td>
<td>97.6 (562)</td>
<td>2.4 (14)</td>
<td>0.67</td>
<td>0.18</td>
</tr>
<tr>
<td>No training received</td>
<td>97.2 (1619)</td>
<td>2.8 (46)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hours of Care (per week)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 60 hours</td>
<td>98.5 (779)</td>
<td>1.5 (12)</td>
<td>9.45</td>
<td>0.01</td>
</tr>
<tr>
<td>60 to 80 hours</td>
<td>97.8 (360)</td>
<td>2.2 (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 80 hours</td>
<td>96.2 (1039)</td>
<td>3.8 (41)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Duration of Care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 3 years</td>
<td>98.3 (397)</td>
<td>1.7 (7)</td>
<td>1.77</td>
<td>0.41</td>
</tr>
<tr>
<td>3 to 5 years</td>
<td>97.0 (743)</td>
<td>3.0 (23)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 5 years</td>
<td>97.2 (1070)</td>
<td>2.8 (31)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relationship to the Care recipient</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>96.7 (671)</td>
<td>3.3 (23)</td>
<td>1.67</td>
<td>0.43</td>
</tr>
<tr>
<td>Adult child</td>
<td>97.4 (1128)</td>
<td>2.6 (30)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>98.0 (383)</td>
<td>2.0 (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Perceived Quality of Caregiving Relationship</strong></td>
<td></td>
<td></td>
<td>47.21</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Poor/Fair</td>
<td>91.0 (252)</td>
<td>9.0 (25)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good/Excellent</td>
<td>98.2 (1922)</td>
<td>1.8 (36)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

** denotes not significant ** significant at p < 0.01 *** significant at p < 0.001

Table 5.21

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>No PHBs</th>
<th>PHBs</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer Burden Score</td>
<td>33.2 (16.8)</td>
<td>32.6 (16.4)</td>
<td>51.9 (15.4)</td>
<td>8.783</td>
<td>&lt; 0.001***</td>
</tr>
</tbody>
</table>
An association was found between the quality of the caregiving relationship, as perceived by the respondent, and self-reports of potentially harmful physical carer behaviour. Respondents who perceived the relationship with the care recipient as poor or fair where significantly more likely to report engaging in potentially harmful physical behaviours (9.0%, 25/277), than respondents who perceived the caregiving relationship as good or excellent (1.8%, 36/1958).

The length of time respondents had been providing care to the care recipient was not statistically significantly related to reports of potentially harmful physical carer behaviour. Similarly, the carers’ relationship to the care recipient was also not associated with potentially harmful physical carer behaviour.

Respondents who reported that they engaged in potentially harmful physical behaviour scored significantly higher on the helping scale than respondents who reported that they did not engage in potentially harmful physical behaviours (t(1795) = 2.63, p < 0.01) (Table 5.23). The overall mean score for those in the potentially harmful physical behaviour group was 5.3 (SD = 1.2) while that of the carers who did not report potentially harmful physical behaviours was 4.7 (SD = 1.5). This suggests that as the level of help provided by carers increases, so too do self-reports of potentially harmful physical carer behaviour.

### 5.5.3 Care recipient characteristics associated with potentially harmful physical carer behaviour

Table 5.24 presents the associations between care recipient characteristics such as gender, age and whether or not the care recipient had a diagnosis of dementia, and potentially harmful physical carer behaviour. The gender of the care recipient was found to be significantly associated with reports of potentially harmful physical carer behaviour. Respondents who cared for female care recipients were significantly more likely to report engaging in potentially harmful physical carer behaviour (3.5%, 46/1320) than respondents who reported that they provided care to male care recipients (1.7%, 15/906). Age of the care recipient was not found to be associated with potentially harmful physical carer behaviour.

Whether or not care recipients had a diagnosis of dementia was significantly associated with potentially harmful physical carer behaviour. A larger proportion of respondents who cared for an older person with dementia reported engaging in potentially harmful physical behaviour (5.9%, 28/476) than respondents who cared for an older person without a diagnosis of dementia (1.9%, 33/1748).

#### Table 5.23 Comparison of Helping Mean Scores between Potentially Harmful Physical Carer Behaviour Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>No PHBs</th>
<th>PHBs</th>
<th>M (SD)</th>
<th>M (SD)</th>
<th>M (SD)</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of help provided score a</td>
<td>4.7 (1.5)</td>
<td>4.7 (1.5)</td>
<td>5.3 (1.2)</td>
<td>2.63</td>
<td>0.01**</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

** a Scores on the helping scale range from 0 to 6

#### Table 5.24 Care Recipient Characteristics associated with Potentially Harmful Physical Carer Behaviour

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No PHBs</th>
<th>PHBs</th>
<th>χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of Care recipient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>96.5 (1274)</td>
<td>3.5 (46)</td>
<td>6.75</td>
<td>0.01**</td>
</tr>
<tr>
<td>Male</td>
<td>98.3 (891)</td>
<td>1.7 (15)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Care recipient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>65 to 74 years</td>
<td>96.6 (575)</td>
<td>3.4 (20)</td>
<td>1.31</td>
<td>0.52**</td>
</tr>
<tr>
<td>75 to 84 years</td>
<td>97.3 (865)</td>
<td>2.7 (24)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>85 years and older</td>
<td>97.7 (712)</td>
<td>2.3 (17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia Diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosed with dementia</td>
<td>94.1 (448)</td>
<td>5.9 (28)</td>
<td>22.38</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>No diagnosis of dementia</td>
<td>98.1 (1715)</td>
<td>1.9 (33)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

** not significant **significant at p < 0.01 ***significant at p < 0.001
Table 5.25 Comparison of Care Recipient Dependency Scores between Potentially Harmful Physical Carer Behaviour Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>No PHBs</th>
<th>PHBs</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care recipient Dependency Score a</td>
<td>12.2 (3.0)</td>
<td>12.2 (3.0)</td>
<td>14.1 (2.7)</td>
<td>4.86</td>
<td>&lt; 0.001***</td>
</tr>
</tbody>
</table>
| a Scores on the dependency scale range from 6 to 18

Table 5.25 compares scores on the care recipient dependency scale between respondents who reported that they engaged in potentially harmful physical behaviours and those who did not. The results showed that the scores between the two groups were statistically significantly different \([t(1972)= 4.86, p < 0.001]\); on average, respondents who engaged in potentially harmful physical behaviours reported higher levels of care recipient dependency (M=14.1, SD=2.7) than carers who reported that they did not engage in potentially harmful physical behaviours (M=12.2, SD=3.0).

5.5.4 Positive appraisal and quality of support associated with potentially harmful physical carer behaviour

Subscales from the Carers of Older People in Europe (COPE) Index were employed to measure the positive value of caregiving and the quality of support as perceived by the respondents. Table 5.26 presents comparisons between respondents who reported engaging in potentially harmful physical behaviour and respondents who reported that they did not engage in potentially harmful physical behaviour.

The results suggest a statistically significant difference between the two groups on the positive appraisal scale \([t(2179)= 7.54, p < 0.001]\); carers who indicated that they engaged in potentially harmful physical behaviour scored significantly lower on the positive appraisal scale than carers who reported that they did not engage in potentially harmful physical behaviour (M=10.8, SD=2.8) than carers who reported that they did not engage in potentially harmful physical behaviour (M=13.2, SD=2.5). This indicates that carers who engaged in potentially harmful physical behaviours valued the caregiving experience significantly less positively than carers who did not engage in potentially harmful physical behaviours.

Also outlined in Table 5.26 is a comparison of the mean scores on the quality of support scale for carers who engaged in potentially harmful physical behaviours and those who did not. The results show that carers who reported engaging in potentially harmful physical behaviours scored significantly lower (M=9.2, SD=3.3) on the quality of support scale than carers who reported that they did not engage in potentially harmful physical behaviour (M=11.2, SD=2.5). The difference in the mean scores between the two carer groups was found to be statistically significantly different \([t(2172)= 4.26, p < 0.001]\), indicating that carers who engaged in potentially harmful physical behaviours perceived the adequacy of the support received as lower than carers who did not.

Table 5.26 Comparison of Positive Appraisal and Quality of Support Mean Scores between Potentially Harmful Physical Carer Behaviour Groups

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total sample</th>
<th>No PHB</th>
<th>PHBs</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Appraisal Score a</td>
<td>13.2 (2.5)</td>
<td>13.2 (2.5)</td>
<td>10.8 (2.8)</td>
<td>7.54</td>
<td>&lt; 0.001***</td>
</tr>
</tbody>
</table>
| a Scores on the positive appraisal scale range from 4 to 16
| Quality of Support Score b         | 11.1 (3.5) | 11.2 (3.5) | 9.2 (3.3) | 4.26 | < 0.001*** |
| b Scores on the quality of support scale range from 4 to 16

5.6 Predictors of potentially harmful carer behaviour

A number of logistic regression models were computed to identify independent factors associated with potentially harmful behaviours overall and covariates of potentially harmful physical and psychological carer behaviours.
Carer burden was found to be a major predictor of potentially harmful physical carer behaviour. In particular, severe burden experienced by carers significantly predicted potentially harmful physical behaviours, with respondents who experienced severe burden 17 times more likely to report potentially harmful physical behaviours than those who experienced little or no burden (OR 17.55, CI 3.07 to 100.20) (Table 5.27). Similarly, moderate to severe burden was also a significant predictor of potentially harmful physical carer behaviour, with respondents in this category over five times more likely to report potentially harmful physical behaviour than carers who experienced little or no burden (OR 5.50, CI 1.11 to 27.31). Mild to moderate burden was not identified as a significant predictor in this model. Other significant predictors of potentially harmful physical carer behaviours were gender, with male carers being nearly four times more likely than female carers to report engaging in potentially harmful physical behaviours (OR 3.89, CI 1.99 to 7.58), and the carer having a poor/fair relationship with the care recipient (OR 2.76, CI 1.35 to 7.61).

Similarly, the gender of the carer, quality of the caregiving relationship and carer burden were identified as independent predictors of potentially harmful psychological behaviours. Carer burden was the strongest predictor of potentially harmful psychological behaviours; mild to moderate burden (OR 4.23, CI 2.14 to 8.64), moderate to severe burden (OR 9.87, CI 4.76 to 20.44) and severe burden (OR 32.08, CI 13.53 to 76.05) were significant predictors of potentially harmful psychological behaviours when compared to respondents who reported little or no burden in caregiving. Indeed, respondents experiencing severe burden were 32 times more likely to report potentially harmful psychological behaviours than those experiencing little or no burden. Being a male carer was also a predictor for engaging in potentially harmful psychological carer behaviour (OR 1.76, CI 1.23 to 2.59), as was a poor or fair relationship with the care recipient (OR 1.90, CI 1.29 to 2.83) (Table 5.28).

### Table 5.27 Predictors of Potentially Harmful Physical Carer Behaviour

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>B (SE)</th>
<th>Odds Ratio</th>
<th>95% CI for Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>3.58 (0.15)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender of Carer (Reference - Female)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.36 (0.34)***</td>
<td>3.89</td>
<td>1.99 7.58</td>
</tr>
<tr>
<td>Quality of Caregiving Relationship</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor/Fair (Reference – Good/excellent)</td>
<td>1.01(0.37)**</td>
<td>2.76</td>
<td>1.35 7.61</td>
</tr>
<tr>
<td>Carer Burden (Reference – Little or no burden)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild to moderate burden</td>
<td>0.90 (0.80)</td>
<td>2.45</td>
<td>0.51 11.06</td>
</tr>
<tr>
<td>Moderate to severe burden</td>
<td>1.70 (0.82)*</td>
<td>5.50</td>
<td>1.11 27.31</td>
</tr>
<tr>
<td>Severe burden</td>
<td>2.87 (0.89)***</td>
<td>17.55</td>
<td>3.07 100.20</td>
</tr>
</tbody>
</table>

Note: R² = .05 (Cox & Snell), .24 (Nagelkerke). Model χ² = 85.63, p < .001.
*p < .05, **p < .01, ***p < .001.
Carer gender, quality of the caregiving relationship and carer burden were also significant predictors of total potentially harmful carer behaviours. The most significant predictors of overall potentially harmful carer behaviours were carer burden followed by gender, i.e. being a male carer, and the perceived quality of the caregiving relationship (Table 5.29).

In summary, carer burden was the strongest predictor of potentially harmful physical and psychological carer behaviours. In particular, the more severe the carer burden experienced by carers, the higher the likelihood of carers engaging in potentially harmful behaviours. Other factors identified as significant predictors of potentially harmful carer behaviour included being a male carer and having a poor relationship with the care recipient. The same predictors were identified for both potentially harmful physical and psychological carer behaviours.
5.7 Summary

In total, over a third of respondents indicated that they engaged in some form of potentially harmful psychological or physical behaviour in the previous three months, with 17 per cent of respondents reporting that they engaged in such behaviours sometimes or more frequently. Potentially harmful psychological behaviours occurring at least sometimes were reported by 16.6 per cent of carers; the most frequently reported psychological behaviour was using a harsh tone of voice towards the care recipient, insulting, swearing at or calling the care recipient names. Potentially harmful physical behaviours were reported as occurring at least sometimes by 2.7 per cent of carers and feeling afraid that they might hit or hurt the care recipient was the most commonly reported form of potentially harmful physical behaviour.

A number of carer characteristics were significantly associated with reports of potentially harmful carer behaviour, including the carer’s gender (being male), the carer’s age (being an older carer), ethnic/cultural background (being non-Irish), social class (in the professional/managerial group), living in an urban area and co-residing with the care recipient. Poorer health among carers, higher levels of depressive symptoms and higher levels of burden were similarly found to be significantly related to potentially harmful carer behaviours.

The caregiving factors found to be associated with potentially harmful carer behaviours included a greater number of hours of care provided a week, a greater number of years providing care, relationship to the care recipient (spousal relationship), quality of the relationship (poor quality of caregiving relationship) and higher levels of help provided by the carer.

Among the care recipient factors associated with potentially harmful carer behaviours were the age of the care recipient (65 to 74 years), a diagnosis of dementia and higher levels of dependency. Other factors associated with potentially harmful carer behaviours were lower appraisal of the caregiving experience and lower perceived levels of the adequacy of professional and social support.

Carer factors associated with potentially harmful psychological carer behaviour were similar to those for overall potentially harmful carer behaviours with one exception: while carers who reported engaging in potentially harmful psychological behaviours were more likely to report that they lived in an urban area, this association was not found to be significant. The caregiving factors associated with potentially harmful psychological carer behaviour were similar to those associated with overall potentially harmful carer behaviour, with the exception of type of carer’s allowance, which was found not to be statistically associated with potentially harmful psychological carer behaviour. The care recipient factors associated with potentially harmful psychological carer behaviour were the same as those associated with overall potentially harmful carer behaviours.

Being a male carer and co-residing with the care recipient were factors that were significantly associated with potentially harmful physical carer behaviour. Similar to both overall and potentially harmful psychological carer behaviour, poorer health among carers, higher levels of depressive symptoms and higher levels of burden were found to be significantly related to potentially harmful physical carer behaviours.

A greater number of hours of care provided per week, the quality of the relationship (poor quality of caregiving relationship) and higher levels of help provided by the carer were caregiving factors associated with potentially harmful physical carer behaviour. Care recipient factors found to be associated with potentially harmful physical carer behaviour included gender (being female), having a diagnosis of dementia and having higher dependency needs. Similar to overall potentially harmful carer behaviour, lower appraisal of the caregiving experience and lower perceived levels of adequacy of professional and social support were also found to be significantly associated with potentially harmful physical carer behaviours.

Overall, carer burden was found to be the strongest predictor of potentially harmful carer behaviour, including both psychological and physical behaviours. Other predictors included being a male carer and perceiving a poor overall quality of relationship with the care recipient.
6.1 Introduction

With the anticipated rise in the population of older people both in Ireland and worldwide, it is likely that the need for provision of family caregiving will increase. Family carers of older people face significant challenges, not only with the daily stresses of caregiving, but also because of changing family structures and ongoing threats to services and income supports. Furthermore, these challenges often intensify for many who struggle to provide care for older people with dementia, who frequently exhibit disruptive behaviours.

While the majority of older people are cared for at home by loving family members and are in receipt of good quality care, family carers who find themselves under increasing pressures may experience carer burden and conflicts within the caregiving relationship. The vast majority of previous studies undertaken in this field have focused predominantly on family carers of older people with dementia. To date, no systematic study has been conducted with family carers of older people in Ireland to examine their experiences of caring and measure the extent to which they experience conflict in their caregiving role.

This study was the first large-scale national study to survey family carers of older people in Ireland. The survey comprised a random sample of over two thousand carers of older people in Ireland in receipt of a state-funded carer’s allowance. With a relatively high response rate of 58 per cent, the survey population provided a representative cross-sectional sample of carers. The survey is one of the largest ever undertaken internationally to measure the prevalence of potentially harmful behaviours among carers and is the only study to measure such carer behaviour in a nationally representative sample of family carers of older people (Cooper et al. 2009).

This chapter discusses the main results from the study in the context of Irish and international literature. This will include discussion of carers’ experiences of mistreatment, potentially harmful behaviours engaged in by carers and the factors associated with potentially harmful carer behaviours. While the prevalence of potentially harmful carer behaviours reported in this study will be compared with prevalence rates reported in the international literature, the comparisons should be interpreted with some caution. Few studies have used similar measurement scales, with most reporting the use of face-to-face methods to collect data from family carers of older people with dementia.

6.2 Carers’ experiences of mistreatment

More than half of carers (56.3%) in the study experienced some form of mistreatment by the care recipient in the previous three months and just over a third (37.1%) reported that the mistreatment occurred sometimes or more frequently. Cooper et al. (2010c), who were the first to investigate the prevalence of abuse experienced by family carers of older people, similarly found care recipient mistreatment of the carer; nearly half of the carers (47.3%) in their study reported abuse by the care recipient in the previous three months and just over a third (37.3%) reported that these behaviours occurred at least sometimes. While there is a dearth of research on family carer reports of being mistreated by older family care recipients, serious abusive behaviours directed towards family carers by older care recipients are not rare (Paveza et al. 1992), particularly among family carers of older people with dementia (Cooper et al. 2010c).

The most commonly reported form of mistreatment of carers by their care recipients was psychological mistreatment. Reports of being physically mistreated by the care recipient were much lower; one in seven carers (13.4%) reported being physically mistreated by the care recipient in the previous three months, with a smaller number (5.6%) reporting that the behaviours occurred at least sometimes in the previous three months. The most frequently reported form of physical mistreatment experienced by carers was feeling afraid that the care recipient might hit or hurt them. While this was also the most common form of physical mistreatment reported by Cooper et al. (2010c), the overall prevalence rate of 5.9 per cent for physical mistreatment in that study was lower when compared with respondents in the present study. Although these findings suggest higher prevalence rates of abuse experienced by carers in Ireland compared to the UK, the differences may be attributable to the use of different instruments, including different versions of the Modified Conflict Tactics Scale, and different data collection methods. Cooper et al. (2010c) collected data through face-to-face methods; therefore carers may have been reluctant to report abusive behaviours by carer recipients directly to the interviewer.

Reports of carer mistreatment by the care recipient in the present study are much lower than those reported by a US study of 236 carers of older people which found that one in every four family carers reported that the older person had hit or tried to hurt them physically in any way (Pillemer and Suitor 1992). However, the higher levels of
physical mistreatment experienced by carers in this US study may be attributable to the fact that all care recipients were diagnosed with Alzheimer’s disease.

6.3 The prevalence of potentially harmful carer behaviour

Early studies of family carers and abusive behaviours mainly reported the prevalence of violent behaviours by family carers towards older family relatives. More recently, attention has turned to carer behaviours that may be considered less violent, but that may still be harmful to and compromise the quality of care received by the care recipient. Such potentially harmful behaviours may serve as a precursor to more serious elder abuse and may be amenable to early prevention and intervention efforts (Beach et al. 2005).

In the present study, over a third of respondents reported engaging in potentially harmful behaviours (36.8%) in the previous three months, with almost one in six carers (17.0%) reporting that they had engaged in such behaviours sometimes or more frequently, the threshold used to indicate greater risk for elder abuse. This finding is consistent with the prevalence range reported in a systematic review which found that the prevalence of abusive behaviours by family carers ranged from 11 to 55 per cent (Cooper et al. 2009). However, due to methodological differences between the present study and other prevalence studies, the current findings are directly comparable to just a small number of studies. The most similar study is that by Cooper et al. (2009), who used the same ten-item Modified Conflict Tactics Scale (M-CTS) to collect data from 220 family carers of older people with dementia in the UK. Cooper et al. (2009) found that just over half of the carers (52%) reported potentially harmful behaviours, with a third reporting that the behaviours occurred sometimes or more frequently. This higher prevalence in the Cooper et al. (2009) study may be explained, in part, by the fact that care recipients with dementia are considered at greater risk of abuse (Owens and Cooper 2010).

In addition, the present study found that just over a third of carers engaged in potentially harmful psychological behaviours (35.9%). One in six carers indicated that these behaviours occurred at least sometimes, which is substantially lower when compared with Cooper et al. (2009), who found that one third of carers engaged in potentially harmful psychological behaviours at least sometimes.

Verbal abuse was the most commonly reported form of potentially harmful psychological behaviour reported in both the present study and the Cooper et al. (2009) study. Verbal abuse is often difficult to detect as there is no visible evidence. In practice, community nursing services and homecare staff may need to ask family carers or older people themselves about abuse, rather than relying solely on observations during home visits (Sasaki et al. 2007). While family carers do report such behaviours, they often may not recognise them as potentially abusive, or may not know how else to manage certain situations which they are faced with in their caregiving role (Cooper et al. 2009; Beach et al. 2005).

In this study, eight per cent of carers indicated that they engaged in any potentially harmful physical behaviour. Respondents’ reports of potentially harmful physical behaviours were substantially lower than those reported in the aforementioned UK study, with just 2.7 per cent reporting that they engaged in such behaviours sometimes or more frequently in the previous three months, compared with four per cent reported by Cooper et al. (2009). Both the present study and the Cooper et al. (2009) study reported a prevalence of just 1.0 per cent for actual physical abuse, i.e. roughly handling, hitting or slapping, or shaking the care recipient, occurring at least sometimes in the previous three months.

The overall higher prevalence rates of potentially harmful carer behaviour reported by Cooper et al. (2009) may be attributable to the fact that all the family carers were caring for an older person with dementia, whereas just a fifth of carers in the present study indicated that they were caring for a person with a diagnosis of dementia. Caring for an older person with a cognitive impairment such as dementia can be stressful and may contribute to increased reports of potentially harmful behaviours by carers (Paveza et al. 1992).

Using the M-CTS measurement with a sample of 123 family carers, a Japanese study reported a slightly lower overall prevalence rate of 30 per cent and a rate of 15.4 per cent of potentially harmful behaviours occurring ‘at least sometimes’ (Kishimoto et al. 2013), as compared to the present study. This finding may be attributable to cultural differences associated with attitudes towards older people; Japan has a tradition of the Confucian principle of filial piety, whereby older people are assured of power, status and care within the family and are
respected members within communities (Tsukada et al. 2001).

Other studies using different instruments, definitions and data collection methods have reported higher levels of abuse by family carers. For example, in a study of 56 family carers in the UK, 45 per cent admitted to engaging in some form of abuse (Homer and Gilleard 1990). The prevalence of abusive behaviours reported by a Chinese study of 122 family carers of older people was substantially higher than that of the present study, with nearly two thirds (62.3%) of carers reporting that they engaged in abusive behaviours in the previous month (Yan and Kwok 2011).

The prevalence of abusive behaviours reported by carers in this study was substantially higher than the prevalence rate for all forms of elder abuse reported by community-dwelling older people in Ireland in 2010; in that study Naughton et al. (2010) reported a national prevalence rate of just 2.2 per cent of abuse experienced by older people in the previous year. This difference in prevalence rates may be explained, in part, by the fact that the respondents in the present study were carers who provided full-time care to an older person, a circumstance in which stress, burden and associated conflict and abuse are more likely to occur (Anetzberger 1987; Steinmetz 1988). Caregiver burnout, in particular, is associated with conflict in the caregiving relationship (Kishimoto et al. 2013) and is a predictor of abuse by family caregivers (Yan and Kwok 2011), including family carers of older people with dementia (Cooper et al. 2010).

In summary, the findings of this study demonstrate that family carers of older people are willing to report potentially harmful behaviours. The overall prevalence rate for potentially harmful behaviours was generally lower when compared to referent studies, most notably that conducted in the UK by Cooper et al. (2009). Few other studies have used similar methods to this study, with most comparable studies having substantially smaller sample sizes and including data collected from carers of older people with a cognitive impairment only, thus making comparisons difficult.

6.4 Factors associated with potentially harmful carer behaviour

There are several known risk factors leading to family carers engaging in abusive behaviours towards older care recipients. Recognising these risk factors can assist in preventing such behaviours. As this survey involved a large sample of family carers of older people, it was possible to identify several carer factors, care recipient factors and caregiving factors that were associated with potentially harmful carer behaviours. While a number of factors were found to be associated with potentially harmful carer behaviours, it is not possible to infer a causal direction of the observed associations.

6.4.1 Carer factors associated with potentially harmful carer behaviour

This study collected a range of descriptive variables in the sample of carers and explored whether a number of these variables, acting as carer factors, were related to potentially harmful carer behaviours. Several factors were identified as significantly related to potentially harmful behaviours by carers; the main factors were being a male carer, being an older carer and co-residing with the care recipient. Self-reported poor health, high levels of depressive symptoms and high levels of carer burden were also found to be associated with potentially harmful carer behaviour.

Being a male carer was found to be one of the strongest predictors for potentially harmful behaviours engaged in by family carers towards older people. Male carers were found to be nearly twice as likely to engage in potentially harmful behaviours towards the care recipient and nearly four times as likely to engage in potentially harmful physical behaviours, than female carers. There is some evidence in the literature that supports this finding. Kishimoto et al. (2013) also found that male family carers were more likely to report abusive behaviours and suggested that this might be because male carers were less likely to avail of social support than female carers. Male carers in the present study perceived the adequacy of social and professional support as lower than female carers; this perception may, in turn, leave them feeling less supported and thereby increase the likelihood of them engaging in potentially harmful behaviours towards the care recipient. This finding is also consistent with that reported by Drennan et al. (2012), who investigated neglect and abuse among paid carers in residential care settings for older people in Ireland; in that study male
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carers were significantly more likely to be neglectful towards older people (Drennan et al. 2012). While some studies have found that a female carer is more likely to engage in potentially harmful behaviours (Wang et al. 2006), others have failed to find any relationship between the gender of the carer and abusive behaviours (Pot et al. 1996; Sasaki et al. 2007; Cooper et al. 2010b). This suggests that observed associations between carer gender and potentially harmful behaviours may in fact be attributable to a range of cultural, social, or other factors not controlled for by these studies, and therefore warranting further investigation.

Being an older carer was also found to be significantly associated with potentially harmful carer behaviours towards older care recipients; however, while this factor was associated with potentially harmful psychological behaviours, the carers’ age was not related to potentially harmful physical carer behaviour. This is a noteworthy finding since the National Census data have shown a large increase in the number of older carers in Ireland (CSO 2012b). One reason for the association may be due to the likelihood of older carers being the spouse of the care recipient; in spousal relationships conflict and discord may be a normal part of the relationship. Moreover, an older carer may be trying to cope with his/her own health problems, which are likely to increase with advancing age. Pillemer and Suitor (1992) found age to be a predictor of acts of violence, with older carers more likely to report acts of violence than any other carers, and even more than carers who were fearful of becoming violent; however this finding was attributed to the higher numbers of spouses in the violent caregiver group. In contrast, several studies have found no association between carer age and harmful behaviours (Sasaki et al. 2007; Cooper et al. 2010b; Yan and Kwok 2011; Kishimoto et al. 2013).

This study found that living with the care recipient was significantly associated with potentially harmful psychological and physical carer behaviour. There is strong evidence for this relationship in the published literature (Pillemer and Suitor 1992; Paveza et al. 1992; Cooper et al. 2010b). Due to the pressures that may arise within a caregiving relationship, conflict is more prevalent in situations where the carer and care recipient share a living environment (Pillemer and Suitor 1992). Paveza et al. (1992) found that care recipients who lived with family, but without a spouse, were almost three times at greater risk for violence than those with alternative living circumstances. Pillemer and Suitor (1992) also found cohabitation with the care recipient to be associated with abusive behaviours. The findings of the present study are consistent with those of the national prevalence study on elder abuse in Ireland, which found that mistreatment of community-dwelling older people was most strongly related to living arrangements (Naughton et al. 2010). Accordingly, it appears that a shared living arrangement provides increased opportunities for tensions and conflicts in the caregiving relationship, which can, in turn, give rise to incidents of elder abuse (Yan and Kwok 2011).

Potentially harmful behaviours may be engaged in when carers themselves suffer ill health (Beach et al. 2005). This association was found in the present study, with self-reports of poor caregiver health associated with a higher self-reported frequency of potentially harmful carer behaviours. In addition, the presence of depressive symptoms among carers has been reported in the literature as a risk factor for abuse (Homer and Gilleard 1990; Coyne et al. 1993; Paveza et al. 1992). Just over two fifths of carers in the present study were at risk for clinical depression and, consistent with previous studies, respondents who experienced higher levels of depressive symptoms were more likely to report engaging in potentially harmful behaviours. Several previous studies provide evidence for this relationship and have reported an association between carers who are at risk for clinical depression and reports of a higher incidence of potentially harmful carer behaviours (Homer and Gilleard 1990; Pot et al. 1996; Beach et al. 2005; Cooper et al. 2010b). Paveza et al. (1992) found that violence in the caregiving relationship was three times more likely to occur when carers scored above the threshold for the risk of developing clinical depression on the CES-D than carers who scored below the cut-off score for risk of developing depression.

Family carers who are at risk of depression may struggle to cope with the everyday demands of caregiving more than non-depressed carers, and therefore may resort to engaging in potentially harmful behaviours. Carers in this situation require further support in dealing with the psychological distress associated with caregiving in order to enable them to avoid conflict and potentially harmful behaviours and thereby provide good quality care to the older care recipient. Sasaki et al. (2007) emphasised the need to examine the efficacy of pharmacological interventions, not only for the care recipient, but also for the carer. According to Paveza et al. (1992), whenever carers show signs of clinical depression, investigation by
professionals for evidence of care recipient abuse is warranted.

The overall strongest predictor of potentially harmful carer behaviour in this study was carer burden. More than one in four carers reported that they experienced moderate to severe burden. A logistic regression analysis showed that these carers were 13 times more likely to report engaging in potentially harmful behaviours, almost 10 times more likely to report engaging in potentially harmful psychological behaviours and over 5 times more likely to report potentially harmful physical behaviours than those who experienced little or no burden. There is strong corroborating evidence for this relationship in the literature (Wang et al. 2006; Sasaki et al. 2007; Cooper et al. 2010b; Yan and Kwok 2011). For example, Yan and Kwok (2011) found that carer burden was a significant predictor of verbal abuse by family carers towards older care recipients. Kishimoto et al. (2013) similarly reported that carer burden had significant effects on the carers’ behaviour and found that levels of carer burden vary according to the older care recipient’s needs and health problems. Efforts to reduce carer burden in practice can be challenging, as carer burden relates to the carer’s subjective perceptions of the caregiving experiences (Selwood et al. 2007; Cooper et al. 2010b). Cooper et al. (2010b) suggest that focusing preventive interventions on carers’ dysfunctional coping strategies and psychological difficulties, rather than attempting to address carer burden directly, may be more successful, which in turn may help to alleviate the level of burden experienced.

6.4.2 Care recipient factors associated with potentially harmful carer behaviour

As older people experience increasing frailty and infirmity, they become increasingly reliant on family carers and this, in turn, increases their likelihood of experiencing mistreatment from their caregiver. Several care recipient factors have been identified as being associated with higher levels of caregiver abusive behaviour. This study found that several care recipient factors were associated with potentially harmful carer behaviours. These included the age of the care recipient, having a dementia diagnosis, and higher dependency levels. All three factors were associated with carer self-reports of potentially harmful psychological behaviours; however having a dementia diagnosis and higher dependency levels were the only care recipient factors associated with potentially harmful physical behaviours.

This study found that the age of the care recipient was significantly associated with potentially harmful carer behaviours. Study respondents were more likely to report engaging in potentially harmful behaviours if they provided care to a person in the ‘younger old’ age category (65–74 years), than to someone aged 75 years and over; however, while care recipient age was associated with potentially harmful psychological behaviours, it was not associated with potentially harmful physical behaviours. These findings are consistent with those of a Japanese study, which reported that younger care recipient age was associated with verbal abuse by family carers, but not physical abuse (Yan and Kwok 2011). However, the national elder abuse prevalence study in Ireland found that those aged 70 years and older were twice as likely to report elder abuse as those aged 65 to 69 years (Naughton et al. 2010). The difference between the national prevalence study and the present study may be attributable to the fact that older people in the national prevalence study were asked about all forms of elder abuse, that is physical, psychological, financial, sexual and neglect, with financial abuse being the most prevalent type; this form of abuse was not included in the present study.

Another care recipient factor associated with both potentially harmful physical and psychological carer behaviours in the present study was higher levels of care recipient dependency. Respondents who reported that they engaged in potentially harmful carer behaviour provided care to those with significantly greater dependency needs and greater levels of help required with activities of daily living. This finding is consistent with that of several other studies that examined the relationship between care recipient factors and abusive behaviours (Pillemer and Suitor, 1992; Coyne et al. 1993; Sasaki et al. 2007; Cooper et al. 2010b). Based on care recipient reports, Beach et al. (2005) also found that older people with greater care needs were more likely to report potentially harmful behaviours by family carers. Greater care recipient dependency needs may result in an imbalance in the carer-care recipient relationship, with the care recipient highly reliant on the carer, who may have reluctantly assumed the role of caregiver. However, a number of the early studies of caregiver abuse failed to find evidence of an association between the level of functional impairment in the older person and abuse by the carer (Homer and Gillesrd 1990; Paveza et al. 1992; Pot et al. 1996). The observed differences between earlier and more recent studies, including the present study, may
be attributable to methodological differences across studies, including differences in sample size and in the methods used to measure abuse and its covariates.

A fifth of the respondents in the present study cared for an older person with dementia. These carers were more likely to report engaging in potentially harmful behaviours than carers whose care recipients were not diagnosed with dementia. The majority of studies undertaken with family carers have been conducted with family carers of older people with dementia; therefore, only a small number of studies have explored dementia as an independent risk factor for potentially harmful behaviours. One US study found that care recipients’ cognitive impairment was not a factor associated with potential abuse by family carers (Paveza et al. 1992). Similarly, a Japanese study of family carers of older people with a mild cognitive impairment reported no association with abusive carer behaviours (Kishimoto et al. 2013).

Most studies have tended to focus on the relationship between disruptive behaviours, often exhibited by older people with dementia, and abusive carer behaviours (Pillemer and Suitor 1992). Several studies have reported a relationship between abusive carer behaviours and behavioural disturbances in care recipients (Compton et al. 1997; Sasaki et al. 2007; Kishimoto et al. 2013). Reported by Cooney et al. (2006), a study among carers of older people with dementia in the UK found that abusive behaviours were engaged in by carers who were more likely to care for a person with higher levels of behavioural disturbances. Yan and Kwok (2011) found that agitated behaviour in the care recipient was associated with abusive carer behaviour. Pillemer and Suitor (1992) attributed violent feelings experienced by carers to the disruptive behaviours of their care recipients and to their own frustrations related to their inability to communicate.

While caring for an older relative, family carers may not be aware of the signs associated with dementia, which may, in turn, lead to conflicts within the caregiving relationship (Thobaben 2001; Bruce et al. 2008). Family carers may struggle to understand the disease and the challenging aspects of caring for a person with dementia, and may often receive little if any training to support them in their caregiving for an older person with dementia (Owens and Cooper 2010). This suggests the need for greater support and education, particularly for carers of persons with dementia.

### 6.4.3 Caregiving factors associated with potentially harmful carer behaviour

Aspects of caregiving, including the nature of the caregiving relationship, can play a role in engendering conflict in the relationship and give rise to potentially harmful carer behaviours. Several caregiving factors were identified as associated with potentially harmful carer behaviour. These included: the number of care hours per week, the number of years providing care, the relationship to the care recipient and the perceived quality of the caregiving relationship. The level of help provided by the carer, appraisal of the caregiving relationship and perceived adequacy of social and professional support were also found to be associated with potentially harmful carer behaviours.

The study findings showed that carers who reported engaging in potentially harmful behaviours were more likely to report providing a greater number of hours of care per week and higher levels of help than carers who did not report potentially harmful behaviours. Carers who reported engaging in potentially harmful behaviours were also more likely to report a greater number of years spent caregiving. Caregiving factors, such as increased number of caregiving hours and providing care for a longer number of years are well established as risk factors for abuse in the literature (Coyne et al. 1993; Cooney and Mortimer 1995; Cooper et al. 2010b). Carers who dedicate more time to caregiving are less likely to have personal time away from the care recipient to be able to relax or socialise, leaving them vulnerable to stress and to developing mental health problems, which may impact on the quality of care they provide (Beach et al. 2005). Cooper et al. (2010b) found that hours of care predicted abuse by family carers and noted that it is likely that carers who experience higher levels of stress are more likely to perceive that they provide more hours of care.

This study also found that the nature of the kinship relationship was associated with potentially abusive behaviours by carers. The findings showed that spousal carers were significantly more likely to report engaging in potentially harmful behaviours than carers who were adult children or other relatives. Consistent with this finding, Beach et al. (2005) found that care recipients were three to four times more likely to report potentially harmful behaviours when the carer was a spouse when compared to any other type of relationship. Conflict within a spousal relationship tends to be more tolerated than conflict within a parent-adult child relationship and
therefore, it may be deemed more socially acceptable for spousal carers to respond to the care recipient in potentially harmful ways that would otherwise be deemed unacceptable for adult children (Pillemer and Suitor 1992). Additionally, spouses who experience discord early on in their marriage may continue to experience it in later life (Pillemer and Wolfe 1986). There is also evidence in the family violence literature to suggest that caregiving can produce greater distress for spousal carers than for adult children (Montgomery 1989). This may be particularly salient for older spousal carers who may experience difficulties with caregiving while also trying to cope with their own declining health.

The risk of abusive carer behaviour may be associated with the perceived quality of the relationship between the carer and the care recipient; this can include the extent to which the carer feels appreciated and rewarded in caregiving (Williamson and Shaffer 2001). Perceived quality of the caregiving relationship was found to be a predictor for potentially harmful carer behaviours. Carers who perceived their relationship with the care recipient as poor or fair were almost twice as likely to report engaging in potentially harmful psychological behaviours than carers who perceived the relationship as good or excellent. In addition, carers who reported potentially harmful behaviours were more likely to value the caregiving experience less than carers who did not report potentially harmful behaviours.

The study also showed that there was a significant decline in perceived relationship rewards between the pre-caregiving period and the period since caregiving had commenced. This suggests that the act of caregiving had impacted the quality of the relationship between the carer and the older family member. The perceived quality of the caregiving relationship has been identified by other studies as a factor that influences the quality of care delivered by family carers (Williamson and Shaffer 2001) and some studies have shown a relationship between poor premorbid relationships and abuse by family carers (Williamson and Shaffer 2001; Homer and Gillear 1992; Paveza et al. 1992). Regardless of their relationship with the care recipient, carers may feel obliged to provide care, but may be reluctant to take on the caregiving role and may not provide the best quality of care because of a poor pre-caregiving relationship (Williamson and Shaffer 2001).

Social support and the availability of respite or other forms of assistance with caregiving may act to moderate and prevent carer abusive behaviours (Beach et al. 2005). Limited or absent social support can be associated with increased abusive behaviours by family carers (Cooper et al. 2010c). In this study, the majority of carers indicated that they felt well supported by family, friends and/or neighbours; however, just half of the respondents felt well supported by health and social services. In addition, respondents who reported engaging in potentially harmful behaviours were significantly more likely to perceive social and professional supports as less adequate than carers who did not report potentially harmful behaviours. Those caregivers who did not report feeling well supported by social services may have directly experienced reduced social support associated with budgetary cuts which were implemented by the Irish Government as part of austerity measures in the wake of the Irish economic crisis of 2008. Alternatively, as Cooper et al. (2010b) found, carers may not be using available support services, suggesting that carers may simply lack knowledge of existing services or may not be encouraged to utilise them (Paveza et al. 1992).

**6.5 Study limitations**

While this study provides self-report evidence of carer experiences from a large national sample of family carers, it has a number of limitations associated with the overall design. The study data relied on carer self-reports, which may be subject to self-report biases, a common concern when using the survey method. While family carers are willing to report abusive and potentially harmful behaviours, there is an inherent risk that they will self-report underestimations of the frequency and severity of their behaviours, and there is a risk that carers who engage in more severe and frequent abusive behaviours may be reluctant to report those behaviours (Cooper et al. 2008b, 2009). Referring to studies in the field of caregiver abuse, Cooney et al. (2006, p.569) highlighted the concern that study findings may represent: ‘an underestimation of the occurrence of the less common but more severe types of abuse by “pathological carers” who would be unlikely to participate in such a study’.
This study surveyed a random sample of carers who were in receipt of a state-funded carer’s allowance and hence it is only possible to make generalisations about the findings to the population from which the sample was drawn. It is therefore not possible to make generalisations to the wider population of carers of community-dwelling older people, including family carers who are not in receipt of the carer’s allowance and/or who are in full time employment. Additionally, the findings cannot be applied to non-kinship carers, such as paid carers who are employed by state or private agencies.

This study focused on potentially harmful psychological and physical carer behaviours and other forms of abusive behaviours, such as neglect and financial abuse, were not examined. Since financial abuse is reported to be the most common form of elder abuse experienced by older people in Ireland (Naughton et al. 2010), it is recognised that its omission is a limitation of the present study. While family carers may engage in neglectful and financially abusive behaviours, few other studies have measured neglect and financial abuse as family carers find it difficult to respond to questions relating to these forms of abuse (Lee and Kolomer 2005).

A number of other factors, which may be associated with potentially harmful carer behaviours, were not examined in this study. These include, *inter alia*, carer factors such as cognitive impairment, self-esteem, resentment, alcohol abuse, and physical and mental health problems, and care recipient factors such as mood and disruptive behaviours. While outside the scope of the present study, it is acknowledged that these factors are nonetheless important as possible correlates of potentially abusive behaviours by carers.
7.1 Introduction
The findings from this national study provide important new evidence about family caregiving in Ireland, including profiles of carers and their care recipients and insights into the carer-care recipient relationship in family caregiving. The study findings indicate the extent to which carers of older people experience conflict within the caregiving role, and identify a number of carer, care recipient and caregiving factors that are associated with potentially harmful carer behaviours. These same factors can be used to identify family carers who are at greatest risk for engaging in behaviours that may be harmful to the older person and that may compromise the quality of the care provided. Accordingly, the findings from this study offer important evidence that may inform health and social policy and professional practice in the field of family caregiving, and highlight the need for further research in this area.

7.2 Implications for practice and policy
The study findings can be used to inform policy and practice in relation to the development of early preventive interventions that can avert carer-care recipient conflict and associated harmful carer behaviours, and thereby prevent the escalation of these behaviours into more serious abusive behaviours. Such interventions can, in turn, result in an improved quality of care and improved quality of life for both the carer and the care recipient.

Provision of support services
Carer burden was the main predictor for potentially harmful carer behaviours identified by this study. Therefore, efforts need to be directed at interventions that can alleviate the level of burden experienced by family carers of older people. Carer organisations such as the Carers Association, Caring for Carers, Alzheimer Society of Ireland, and community primary care teams offer a range of advice, information and supports to family carers throughout Ireland. In line with the National Carers’ Strategy (Department of Health 2012b), national organisations representing the interests of carers need to continue to be supported in their respective roles in supporting carers. Consistent with the extant national health policy, as expressed in the policy document Future Health: A Strategic Framework for Reform of the Health Service 2012–2015 (Department of Health 2012c, p.7), services need to be able to ‘treat patients at the lowest level of complexity that is safe, timely, efficient, and as close to home as possible’. Therefore services that are localised, easily accessible and community-based can help to reduce the level of burden for family carers who are often required to accompany the older person to hospital appointments, GP visits, the chemist and to other health and social care services. Family carers, male carers in particular, need to be made aware of and encouraged to participate in and to utilise the existing services that provide support to carers and older care recipients.

Respite services, in particular, are important not only to an older person, but are an essential service for those providing care to an older family member on a full-time basis. This study showed that carers who reported potentially harmful behaviours were more likely to live with the care recipient than those who reported no abusive behaviours. Therefore, it is important that carers are provided with the opportunity for protected time and physical space away from the caregiving situation, in order to reduce carer burden and stress; access to a respite service can provide such protected time. In general, it will become increasingly important that respite care services are available to family carers of older people, given the anticipated growth in the population of older people, particularly the population of oldest old, and the growing reliance by the State on family carers to provide care to older family members. Additionally, respite services are particularly important in view of the fact that family carers are providing care in contexts of complex needs. There is evidence that access to respite services in emergencies, in particular, can contribute greatly to reducing caregiver burden.

All family carers should be valued and recognised for the essential, difficult and demanding work they carry out, and they should be recompensed appropriately (Department of Health 2012b). As outlined in the National Carers’ Strategy, it is crucial that income support payments, such as the Carer’s Allowance and Carer’s Benefit and, in particular, the Respite Care Grant, continue to be made available to eligible carers, so that carers do not become further financially burdened (Department of Health 2012b).
Routine screening
While experiences of being mistreated by the care recipient cannot justify a family carer engaging in potentially harmful behaviours towards the care recipient, both the carer and care recipient behaviours should be considered in the development of primary prevention strategies (Paveza et al. 1992). Accordingly, healthcare professionals should be encouraged to ask family members not only about the potentially harmful behaviours that they engage in towards the older care recipient, but also the abusive behaviours they experience from the care recipient (Cooper et al. 2009; 2010c).

Professionals tend to be reluctant to ask family carers about the quality of care that they provide to their older relative. However, this study and previous studies have demonstrated that family carers are willing to report when they engage in potentially harmful behaviours. Therefore, when conducting routine assessments, health professionals should routinely screen both older care recipients and their carers for evidence of potentially harmful behaviours. This should include screening family carers for the risk factors for potentially harmful behaviours, such as greater care-recipient dependencies, and also for the precursors of such behaviours, notably poor carer health, stress and burden. Evidence of potentially harmful carer behaviours, such as those reported in this study, should be treated as red flags and a cause for concern (Beach et al. 2005), as they are a possible prelude to more serious abusive behaviour. In this way, potentially harmful carer behaviours can be identified at an early stage, and interventions can be put in place to prevent cases where caregiving behaviours are at risk of deteriorating into serious cases of elder abuse. Cooper et al. (2009) asserts that if professionals examined abuse on a spectrum of behaviours, and not just behaviours that are dichotomised as abusive or not abusive, then they might feel more comfortable in asking about such behaviours and therefore respond by providing the appropriate support.

Carers’ health and wellbeing
As well as accurately assessing the health and wellbeing of older people being cared for in the community, health care professionals also need to be aware of the health and wellbeing of their carers, who are often trying to deliver the best care they can within the means and resources that are available to them. Additionally, family carers should be supported in having their own physical and mental health assessed, so that they are best able to cope with the challenges of caregiving and avoid the physical and psychological risks associated with caregiving, such as stress, burden and depression. More than two in five family carers were found to be at risk for clinical depression in the present study, and such depressive symptoms were found to be associated with potentially harmful carer behaviours. In line with the goals of the National Carers’ Strategy, management of the psychological distress experienced by carers also needs to be prioritised. Both voluntary and state-supported carer support groups are one resource through which the health and wellbeing of carers can be promoted, as such groups can help to identify specific carer needs, facilitate peer support and reduce carer isolation (Department Health 2012b). Where health screening identifies risk factors for potentially harmful behaviours, further investigation and appropriate interventions may be warranted.

Education and training
Knowing and being able to recognise and address the range of factors associated with potentially harmful carer behaviours is the important first step in preventing such behaviours occurring in caregiving relationships. Education is therefore important for all those associated, either directly or indirectly, with family caregiving. Family carers and other family members, carer organisations and healthcare professionals who regularly interact with family carers and their care recipients should be the principal targets of education and training in this regard. Education and training should include reference to the factors associated with potentially harmful carer behaviours, including carer burden, a poor carer-care recipient relationship, spousal relationships, poor general and psychological health of the carer, shared living arrangements, care recipients with dementia and poorly perceived social and professional supports.

Many family members find themselves, often unexpectedly, caring for an older relative who may be frail with complex health and care needs. This study highlighted that the vast majority of family carers receive no training to support them in their caregiving role. Training supports need to continue to be made available to family carers, either through community primary care teams or carer support organisations, so that they can be better prepared and equipped to provide quality care to older family members, particularly to those with higher dependency needs and more complex health problems.
Furthermore, carers need to be educated about dementia and other cognitive impairments that are associated with later life. As the population of older people with dementia is also expected to rise, family carers need to have the knowledge and skills to enable them to recognise early symptoms of dementia, to avail of the most appropriate supports available and to have the behavioural management skills to deal appropriately with dementia-related behavioural problems. The National Carers’ Strategy has also pointed to the need for relevant and accessible training services for carers (Department of Health 2012b).

Promotion of a good carer-care recipient relationship

As a poor carer-care recipient relationship was found to be a main predictor of potentially harmful carer behaviour, efforts need to be directed at promoting a healthy relationship between the family carer and the older care recipient. A family systems approach attempts to identify and resolve stresses within families and build upon their own strengths in order to help them remain intact and function better (Nerenberg 2008). Individual, spousal or family caregiving counselling may be necessary in some cases to support the resolution of difficulties in family relationships and to enhance the relationship. Engaging in activities that both the carer and the care recipient enjoy may also help to promote a healthier relationship; greater social participation and engagement in recreational activities has also been found to ameliorate carer burden (Thompson et al. 1993). This form of coping was the most frequently mentioned coping strategy as reported by family carers in Ireland (O’Sullivan 2008).

Alternative interventions to alleviate carer burden

As a risk factor for potentially harmful behaviours, carer burden needs to be addressed and ameliorated. While there is an array of interventions to address and reduce carer burden, no single intervention has been found to be effective in supporting family carers with the care they provide to older people (Ploeg et al. 2009). Nevertheless, various interventions can be explored that may alleviate the burden experienced by carers, such as case management, telecare, or simply sourcing support from family and friends. Different interventions may be needed for physically abusive carers and psychologically abusive carers (Pot et al. 1996).

7.3 Implications for future research

The findings of this study point to the need for further research. While the present study was the first large-scale systematic study undertaken with family carers of older people in Ireland, the sample included only those carers in receipt of a State-funded allowance. Further research is needed to examine conflicts in the caregiving relationship with other cohorts of carers, particularly those in full-time employment who may experience considerable stress in trying to balance work and caregiving commitments.

As the majority of the research to date has been cross-sectional, longitudinal studies are needed to examine associations between carer, care recipient and caregiving factors and potentially harmful carer behaviours over time. Longitudinal studies are also needed to better establish the prevalence of potentially harmful carer behaviours in relationships over time, to examine risk factors for such behaviours and to determine the long-term effects of potentially harmful behaviours on both the carer and the care recipient.

Follow-up studies would permit examination of the long-term impact of potentially harmful carer behaviours, such as earlier institutionalisation of care recipient, or whether and to what extent these behaviours evolve into more serious abusive carer behaviours. Longitudinal prospective cohort studies would also allow measurement of the factors associated with conflict and how they impact on the quality of the caregiving relationship over time. Better understanding of these factors could inform interventions to prevent or minimise conflicts in the caregiving relationship and better support carers in continuing to provide high quality care to older family members in the community.

As this study assessed physical and psychological behaviours only, future studies are needed to determine the prevalence of other potentially harmful carer behaviours, such as financial abuse, sexual abuse and neglect. While the present study explored a sizeable number of factors and their relationship to potentially harmful carer behaviours, other factors, such as challenging or disruptive behaviours by the care recipient and the physical health of the carer, were beyond the scope of this study and should be explored in future research.
While the use of anonymous questionnaires and associated lower social desirability response biases was a major strength of this study, the use of in-depth qualitative interviews would provide complementary evidence about the nature of caregiving, in the form of rich, nuanced and context-specific data (Pillemer and Suitor 1992). Additionally, data collected from carer-care recipient dyads would enhance the quality of the evidence about aspects of caregiving, such as conflict and burden and would also add to the overall validity and reliability of the evidence about family caregiving.

7.4 Conclusions

The reliance on families in Ireland for care provision is likely to increase with the projected rise in the older population, together with an expressed desire by older people to remain living at home. While the majority of family carers experience caregiving as rewarding and worthwhile, many are challenged by the everyday stresses inherent in caregiving and by the task of balancing their role and duties with other personal, social and economic demands.

With changing family structures, smaller family sizes and ongoing threats to state-funded income supports for carers, family caregiving in Ireland faces significant challenges and much uncertainty.

This study was the first large-scale national survey to examine family carers’ experiences of caring for an older person, with a focus on the conflicts that may arise within the carer-care recipient relationship. The study examined carer behaviours that may be deemed potentially harmful to an older person, either psychologically or physically, but that may not be deemed serious enough to warrant formal intervention. Over two thousand family carers of older people participated in the anonymous postal survey, yielding a response rate of 58 per cent.

Results showed that family carers do report that they experience conflicts when providing care to an older person, with over half of carers reporting that they experienced some form of mistreatment directed at them by the care recipient and with just over a third of carers admitting that they themselves engaged in potentially harmful psychological and physical behaviours towards the older person in their care. Being verbally abusive towards the older person was the most common form of harmful behaviour engaged in by carers. The prevalence rate for potentially harmful carer behaviours was found to be similar to that reported in other studies and lower than that reported in a UK study of family carers of older people with dementia.

The study identified several carer and care recipient characteristics, as well as caregiving factors that were associated with potentially harmful behaviours reported by family carers. In particular, several factors were found to be predictors of potentially harmful carer behaviours; carer burden was the overall strongest predictor with more than one in four carers reporting moderate to severe burden, making them over 13 times more likely to report engaging in potentially harmful behaviours towards an older person. Other predictors were being a male carer and perceiving the carer-care recipient relationship as poor.

The findings from this national study provide important new information about family caregiving in Ireland, including detailed profiles of carers and their care recipients and a better understanding of the carer-care recipient relationship. The study findings indicate the extent to which carers experience conflict within their caregiving role, and identify a number of carer, care recipient and caregiving factors that are associated with potentially harmful carer behaviours. These same factors can be used to identify family carers who are at greatest risk for engaging in behaviours that may be harmful to the older person and that may compromise the quality of the care provided. Accordingly, the findings from this study offer important evidence that may inform health and social policy and professional practice in the area of family caregiving. The study findings can be used in the development of early preventive interventions that can avert caregiver-care recipient conflicts and potentially harmful carer behaviours from deteriorating into more serious abusive behaviours. Such interventions can, in turn, result in improved quality of care and improved quality of life for both the carer and the care recipient.

Family carers of older people need to be valued, respected and supported in their caregiving role. The study highlights the need for continued support for carers so they can be enabled to provide quality care to an older family member living at home, while also being able to balance personal and social aspects of their own lives. Reliance on family carers to provide good quality care to older family members living at home will need to be prioritised as part of national social policy and will require greater provision of physical, emotional, social and...
economic supports. Preventive intervention efforts need to target carer burden, in particular, in an effort to alleviate the pressures experienced by many carers as a result of the difficult and demanding work of caregiving. In doing so, cases of potentially harmful carer behaviour may be prevented from deteriorating into more serious cases of elder abuse, and consequently, both family carers and dependent older people can benefit from an improved quality of life.


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