Supporting family carers of people living with dementia through online education: a case study from an Irish NGO.

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor of Education is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

Signed: I.D. No. 18213561 Date: 9/12/2022

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List of Acronyms

ASI – The Alzheimer Society of Ireland the provider of HBC-HBE.

FuN - Flexible Education Norway a non-governmental organisation working to promote knowledge and development in the field of flexible education. They were a project partner with The Alzheimer Society of Ireland on a successful Erasmus+ project to develop the Home Based Care-Home Based Education course.

HBC-HBE – Home Based Care-Home Based Education online education course that is the case in this research project.

LSDC – Later Stage Dementia Care-Blended Learning for Families. Follow-on course from HBC-HBE, also provided by The Alzheimer Society of Ireland.

NDO – National Dementia Office, which manages the delivery of the National Dementia Strategy.

NDS – National Dementia Strategy. Irish Government's strategy to address challenges posed by dementia in Ireland. Published in 2014.

NGO – Non Government Organisation

OQR – Online Questionnaire Respondent. Those who responded to Part A of this research project the online questionnaire.

OSG – Online Support Group offered by ASI to dementia family carers.

QQI – Quality and Qualifications Ireland – the national agency responsible for qualifications in Ireland

Abstract

Title: Supporting family carers of people living with dementia through online education: a case study from an Irish NGO.

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The purpose of this research is to examine if and how an online education course offered by The Alzheimer Society of Ireland supports family carers of people living with dementia.

The incidence of dementia is rising in Ireland and around the world. Much of the care for people living with dementia is undertaken informally by close family members. Caring for someone living with dementia can be very demanding. Family carers of people living with dementia require training and support to prepare and sustain them for the complex and changing nature of their role. This thesis considers Home Based Care-Home Based Education one such online course. It is the first such Irish study of an online course aimed at supporting family carers of people living with dementia.

This thesis uses a case study methodology with the online course being ‘the case’. With a convenience sampling strategy, it used multiple methods, first in the form of an anonymous online questionnaire, followed by 12 one-to-one interviews. Quantitative data was analysed using simple descriptive statistics. Qualitative data was examined using template analysis which is a form of ‘codebook’ thematic analysis. It is presented as a series of themes to answer the two research questions: (1) how does the course support dementia family carers, and (2) how can the course better support dementia family carers?

Evidence suggests that the online course supports participants in a number of ways. Learners gained new knowledge and a range of practical skills through interactions with tutors, peers and course materials. However, participants offered suggestions on how to make the course more supportive to participants. Findings are presented which will be of assistance to The Alzheimer Society of Ireland as they continue to deliver online training for family carers of people living with dementia into the future.

Chapter 1: Introduction and Background

1.1 Introduction

This thesis will focus on if and how Home Based Care-Home Based Education (HBC-HBE), an online education and training course, supports family carers of people with dementia. Family carers provide vital and much needed support to their relatives. However, caring for a close relative can be difficult and challenging. Dementia family carers require support to allow them to continue this ongoing and challenging task. This research will investigate if and how HBC-HBE supports, and could better support, family carers of people with dementia.

The Manager of the HBC-HBE online learning programme offered to these dementia family carers in Ireland has written this thesis. It is important to me, and to my employer The Alzheimer Society of Ireland (ASI), that HBC-HBE supports those impacted by dementia. ASI is an Irish non-government organisation (NGO) with charitable status. This thesis will help ASI better understand and improve the supports to family carers of people with dementia. This knowledge will be essential for ASI as it endeavours to provide the best possible support to people with dementia and their carers.

A growing body of research has already investigated how online learning supports dementia family carers. To the best of my knowledge this is the first such study carried out in the Republic of Ireland. It will therefore add to the bank of knowledge around this topic and should be of interest to policy makers, educators, people with dementia and their family carers in Ireland and beyond.

1.2 Rationale for this research project

There are several complimentary reasons that justify the importance of this research. The first reason is the scale of the challenge dementia presents globally. Dementia is defined as:

> a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive

> function (i.e., the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement (World Health Organisation, 2017).

It is estimated that at present fifty-five million people have dementia, and there are approximately 10 million new cases every year (World Health Organisation, 2021). In an earlier publication, WHO estimate that by 2030 seventy-eight million people will have the disease, and by 2050 the figure will be 132 million (World Health Organisation, 2017).

The increasing incidence of dementia worldwide means that it is an important and challenging health and economic issue. Economically, the costs associated with caring for people with dementia are enormous. Alzheimer's Disease International estimate that by 2030 the worldwide costs of dementia care will be US$2 trillion (Alzheimer's Disease International, 2015), a figure equivalent to the 2019 nominal Gross Domestic Product of Italy – the world's eighth largest economy.

Gillespie et al. (2015) estimated the cost of dementia care in Ireland to be €1.69 billion per annum, 'and what is particularly striking is the fact that almost half (forty-eight per cent) of the overall costs of dementia in Ireland are borne by family and friends who provide the much needed care services required' (Cahill, O'Shea and Pierce, 2012, p. 14). It is also clear that there are no cheap options for dementia care as home-based care, state provided long term care, and private nursing home care are all expensive (Carter *et al.*, 2021).

In Ireland, it is the policy of the government to support family carers through a National Carers Strategy which states that family carers will be 'supported to …care with confidence [and] …empowered to participate as fully as possible in economic and social life' (2012, p. 2). Two important words in this statement are *confidence* and *empowered*. The HBC-HBE online course that is the case in this Doctoral study attempts to support family carers by providing information and knowledge so that they become more confident in their care and improve their overall well-being, as they look after their family members living with dementia. An overview of the HBC-HBE course is provided in 1.4 below.

The second reason why this research is important concerns how societies manage and support the growing number of people living with dementia, and those that provide care for them. The reality in many countries including Ireland is that people with dementia are cared for informally by members of their own families or friends (Department of Health, 2014; Bergström and Hanson, 2018; Wimo, 2018). Many family caregivers find caring difficult and challenging, partly because of the terminal nature of the illness, and also because of the unpredictability of the disease. Family carers can feel a range of negative emotions such as depression, stress and caregiver burden (Mahoney *et al.*, 2005; Etters, Goodall and Harrison, 2008; Lafferty *et al.*, 2014; Chiao, Wu and Hsiao, 2015).

To address these challenges, Ireland's National Dementia Strategy (NDS) aims to improve dementia care so that people with dementia can live well for as long as possible, can access appropriate services and supports delivered in the best way possible and can ultimately die with comfort and dignity (Department of Health, 2014, p. 8). The NDS sets out a series of guiding principles including a commitment, 'to caring for more people in their homes for as long as possible, rather than in residential care' (Department of Health, 2014, p. 12). The Strategy highlights and confirms the centrality of community care, whereby – 'The majority of people with dementia live in their own communities and carers are the cornerstone of care for these people' (Department of Health, 2014, p. 22). Thus, the NDS supports the concept of community care (Knapp *et al.*, 1997).

Included in the thirty-five actions of Ireland's NDS is an objective under training and education which is especially relevant to this thesis – that is to ensure 'informal carers (are) confident and competent to care for their family member at home' (Department of Health, 2014, p. 31). In many cases the informal family carer is not prepared for their care responsibility. While caring for a person living with dementia can be rewarding (Lloyd, Patterson and Muers, 2016), there is also strong evidence that it is a demanding role and can impact negatively on the mental and physical health of family carers in Ireland (Brennan, *et al.*, 2017). Education and training for dementia family carers can help sustain community care as a core component of health and social policy in Ireland.

The third reason concerns how different organisations can address and meet the needs of family carers. To this end ASI and other organisations have developed a range of education and training interventions (The Alzheimer Society of Ireland, 2018; Dementia Understand

Together, 2022). The intention is that these education and training courses will assist family carers to better care for their loved ones with dementia. This thesis will investigate if and how learners on the fully online HBC-HBE course have gained support from their participation on the course.

The fourth issue is around pedagogy and how participants learn on HBC-HBE. Mindful that this thesis is an educational research project, it will explore which aspects of learning - the so-called ‘instructional dynamic’ which encompasses engagement with content, tutors, fellow learners and the learning environment (Ball and Forzani, 2007) – have contributed to helping course participants. This is important as it will inform the teaching and learning approach of courses developed by ASI to further support as many dementia family carers as possible into the future.

1.3 The development of online learning at ASI

As an organisation ASI has grown and developed over the years (The Alzheimer Society of Ireland, 2017). ASI offers a wide range of services and supports to people with dementia and their carers including day care, home care, day care at home, social clubs, dementia cafés, dementia advisors, a national helpline, and much more (The Alzheimer Society of Ireland, 2022).

Since 2009, ASI has attempted to support family carers who look after people with dementia by providing specialist education and training. In this thesis the term ‘family carer’ will be used to describe those people who are providing informal, unpaid care to a family member who is living with dementia, and the term ‘dementia family carer’ will be used to describe family members caring for a fellow family member living with dementia.

The background to the development of family carer training came from ASI Day Care and Home Care staff recognising the stresses and strains that family carers were experiencing on an ongoing basis. Carer stress has been described in academic research on family carer burden, see for example Osaki *et al.*, (2016) and Svendsboe *et al.*, (2016). The education and training courses offered by ASI seek to improve knowledge about dementia, and confidence in approaches to caring. The main face-to-face course called *Insights into Dementia –*

Informing and Empowering Family Carers covers and describes the signs and symptoms of dementia, the importance of communication, changing family relationships, changes in behaviour of the person with dementia, safety in the home, the importance of staying active, accessing appropriate dementia care information, caregiving skills, and looking after the carer (The Alzheimer Society of Ireland, 2019).

In 2016 ASI began to deliver HBC-HBE which was, and is, a fully online version of the *Insights* course with the same subject topics. HBC-HBE was developed through funding from Erasmus+ (European Commission, No date) by ASI in partnership with two other organisations Flexible Education Norway https://fleksibelutdanning.no/about-us/ and Ic Dien https://www.icdien.be/opleiding/ a Further Education College in Belgium. Flexible Education Norway (FuN) brought expertise in the development of distance learning courses, while Ic Dien had a wealth of experience developing course for nurses including topics on dementia (Timmons, Olstad and Vansteenkiste, 2016).

The modules for HBC-HBE were based on the content of the *Insights* face to face course. However, they were reimagined and re-designed by learning and development staff at ASI as well as staff from FuN and Ic Dien as part of the Erasmus+ project described above (Timmons, 2018) taking account of online learning design principles and theories. These included Chickering and Gamson's seven principles of good practice in undergraduate education (Chickering and Gamson, 1999), Gagne's nine events of instruction (Gagné, 2005) and Salmon's five stage model of teaching and learning online (Salmon, 2013).

Up to the end of 2021, ASI have provided training to over 4,000 dementia family carers. HBE-HBE has been delivered to over 1100 family carers, as outlined in Table 1.1 below.

TABLE 1. 1: OVERVIEW OF INSIGHTS / HBC-HBE COURSES DELIVERED 2009-2021

2000s	**2009-2014**	**‘15**	**‘16**	**‘17**	**‘18**	**‘19**	**‘20**	**‘21**	**Total**
No. of courses	75	27	24	26	26	32	24	5	239
Total no. of participants	1264	394	356	380	344	443	**435**	467	4083
No. of online participants	0	0	57	71	87	89	**391**	467	1162
Online participants as % of total	0	0	16%	19%	25%	20%	90%	100%	28%

In March 2020 the COVID-19 pandemic caused the cancellation of all face-to-face teaching and learning interactions in Ireland. Consequently, ASI decided to deliver the online HBC-HBE course to as many family carers as possible. Table 1.1 shows a marked increase in numbers of dementia family carers participating on HBC-HBE in 2020 and 2021. However, Table 1.1 also shows that only a small fraction of Ireland’s 64,000 family carers has completed ASI’s education and training programmes. ASI is very keen to increase the reach and impact of this course, to contribute positively to the care of people with dementia. This thesis will provide an in-depth examination of one such course and investigate if and how it supports family carers of people with dementia, and how it can potentially better support them.

1.4 The Home Based Care-Home Based Education (HBC-HBE) course

As with all intellectual outputs of Erasmus+ projects, the HBC-HBE course is an open educational resource, and is available to view on Moodle Cloud at https://dementia-care-downloads.moodlecloud.com/course/view.php?id=8. The HBC-HBE course is hosted on ASI’s Moodle Workplace Learning Management System. A Learning Management System ‘provides teachers with a means to create and deliver content, monitor student participation and assess student performance. It may also allow students to use interactive features such as threaded discussions, video conferencing and discussion forums’ (Cheng and Yuen, 2018, p. 241).

The online course is open to any type of family carer, that is, primary or ‘principal’ carers (Etxeberria, Salaberria and Gorostiaga, 2021) or secondary carers. HBC-HBE is delivered over seven weeks and participants are invited to spend approximately two and a half hours per week on a range of course activities. These activities include:

- reading through course content contained in Books. Books contain titled pages of information presented as a mixture of text, graphics and embedded videos.
- taking part in tutor moderated Discussion Forums where participants are invited to answer pre-set questions encouraging them to explore and share their dementia care experiences.
- providing weekly feedback through a very short questionnaire.
- completing a short ‘choice’ activity in weeks two and three which explore their care situation and emotional state of mind.
- taking part in a one-hour weekly synchronous (‘live’) video meeting held using Moodle Workplace video conferencing software ‘BigBlueButton’.
- from week two, completing a Weekly Review where participants are encouraged to reflect on how the materials they read or viewed can be applied to their care situation. Tutors read and provide supportive feedback on each submitted Weekly Review.
- completing an end of course quiz in week seven.
- completing a final course reflection in week seven.

Learners continue to have access to their HBC-HBE course on Moodle Workplace for a period of five years.

The delivery of HBC-HBE is informed by a social constructivist pedagogical (Vygotsky, 1978) approach in which collaboration and participation are encouraged. It is hoped that this interactivity will promote ‘levels of understanding and performance that potentially exceed independent learning’ (Salvador, 2019, p. 333). A key element of HBC-HBE is the promotion of a person-centred care approach to support course participants informed by the work of Tom Kitwood (Kitwood, 1997). Person-centred care has several ‘elements’ including, valuing ‘all human lives regardless of age or cognitive ability…. an individualized approach, recognizing uniqueness…. understanding of the world from the perspective of the service user…providing a social environment that supports psychological needs' (Brooker, 2006, p. 13).

The HBC-HBE's facilitators job 'is not to instruct as such, but to support the construction process, mainly by creating an environment in which construction can take place' (Bellefeuille, Martin and Buck, 2005, p. 373). All activities are voluntary and there are no assessments. Learners are free to decide if, how, and to what extent they engage on the various course activities.

The course is delivered / facilitated by a team of tutors. All tutors have a training delivery qualification at least to Quality and Qualifications Ireland (QQI) Level Six. Many are qualified Registered General Nurses. Very often they themselves are providing or have provided care for a family member with dementia. Some have or are working towards a post-graduate qualification in dementia or related discipline, for example gerontology. Full details of tutor background and experience is available in Appendix A.

Participants on each HBC-HBE course are divided into cohorts of twenty learners. Each cohort is facilitated by one tutor who provides feedback on learner weekly reviews, and monitors and facilitates discussion forum posts. During live synchronous video meetings, the lead tutor is joined by a second tutor / technical support to try to make sure each learner is able to participate in the meetings. In addition, there is technical support available to learners via a dedicated email address, phone number and a range of 'how to' videos on the HBC-HBE course page. A short biography and contact details of all tutors and support staff is listed in the 'Introduction to the Course' book available to learners in week one of the course.

1.5 Research Aim and Research Questions

This thesis will examine if and how learners feel they are supported to better deliver care to a family member living with dementia. Learners' views on how the course provider can improve their course experience will also be explored.

The two central research questions are:

How does HBC-HBE support dementia family carers? This question seeks to better understand the learner experience on HBC-HBE, and if and how dementia family carers feel that the course has helped them in their care situation.

How can HBC-HBE better support dementia family carers? This question aims to find out what improvements ASI can make to HBC-HBE so that it better supports dementia family carers.

1.6 Research Process

This research will use case study as a methodology for doing research. The use of case study as a methodology / research approach has been espoused by several writers (Merriam, 1988; Stake, 1995; Yin, 2014). Robson and McCartan, (2016) see case study as ‘A strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real-life context using multiple sources of evidence’ (p. 150). Case studies have also been used for investigating online learning environments (Picciano, 2016).

This case study will allow for ‘thick descriptions that…catch and portray to the reader what it is to be involved in the situation’ (Lincoln and Guba 1985 quoted in Cohen, Manion and Morrison, 2011, p. 241). It will follow Stake’s ‘intrinsic case study model’ (Stake, 1995) where the case ‘is a specific, complex, functioning thing’ (Stake, 1995, p. 2) - the HBC-HBE online learning course. The case is intrinsically interesting to this researcher’s own professional context.

This case study used multiple methods to investigate the research questions. The first part of this empirical research, Part A consisted of an anonymous online questionnaire. The online questionnaire consisted mainly of closed questions. It also contained seven open-ended questions. The results of the responses to the closed questions were analysed using simple Descriptive Statistics with Qualtrics and SPSS software. The open-ended questions were imported from Qualtrics and analysed using NVivo software. A particular form of thematic analysis called Template Analysis (Brooks *et al.*, 2015; King and Brooks, 2018) was utilised to analyse the open-ended questions. Template analysis is a type of ‘Codebook’ analysis

(Braun and Clarke, 2021) that allows for the development of a thematic template, which was developed and refined throughout the research phases.

Part B of the research consisted of one-to-one interviews with twelve course participants who had already completed Part A (the online questionnaire). Interviews were analysed using the template analysis type of thematic analysis coding framework (Braun and Clarke, 2006, 2019, 2021). NVivo was used again to analyse the interview transcripts.

1.7 A worthwhile case

The increasing importance of supporting family members caring for a person living with dementia is also evidenced in the growing literature and research related to this subject. This includes studies investigating individual online interventions targeting carers of people living with dementia. The diversity and heterogeneity of individual studies has led to the publication of a considerable number of systematic reviews. Systematic reviews have been defined as ‘a review of existing research using explicit, accountable rigorous research methods’ (Gough, Oliver and Thomas, 2017, p. 5). These systematic reviews seek to contextualise, review and measure the usability, effectiveness and impact of individual programmes. These systematic reviews show that in general online learning supports have a positive impact on dementia family carers (Boots *et al.*, 2014; Christie *et al.*, 2018; Klimova *et al.*, 2019; Frias *et al.*, 2020).

However, they have also identified gaps in the research in relation to the provision of online training and education for dementia family carers. Klimova *et al.* (2019) and Boots *et al.* (2014) call for more research into what, at the time, they refer to as a relatively under-researched topic. Christie *et al.* (2018) would like research in this area ‘to encompass the wealth of information …at the level of the end-user’ (p. 57). Hopwood *et al*., (2018) ask that future research ‘focus on which aspects of the interventions are most beneficial for different groups’ (p. 7). Another systematic review has encouraged future research to explore the views of family carers participating in online learning beyond the initial trial period or pilot phase of the intervention (Christie *et al.*, 2018, p. 57). This thesis will seek to address some of the gaps mentioned in these systematic reviews.

1.8 The researcher in context

Mindful of the importance for the researcher 'to reveal fully his or her identity and background' (Cohen, Manion and Morrison, 2011, p. 103), this researcher has worked in the Learning and Development Department of ASI since 2013. This has meant having direct responsibility for the development and delivery of education and training programmes for any external stakeholder including dementia family carers.

Along with a team of tutors / subject matter experts, I have devised the content, structure, and delivery mechanisms of the HBC-HBE course. The term 'insider researcher' (Mercer, 2007) has been used to describe the positionality of such scholars. Mercer sought 'to explore the pros and cons of 'insiderness' in relation to access, intrusiveness, familiarity and rapport' (Mercer, 2007, p. 7). She argues that there are advantages and disadvantages for insiders carrying out research under these four areas. Being aware and mindful of my 'insiderness' aids my reflexive approach to this research. Reflexivity and bias are discussed in more detail in chapter three below. I am aware of my 'naturalistic' position, that is a researcher who 'is not a detached 'scientist' but a participant observer who acknowledges (and looks out for) their role in what they discover' (Gillham, 2000, p. 7).

As the person responsible for the management of HBC-HBE, I want and needs to know if and how it supports course participants. In addition, it is important to investigate if and how ASI can better support dementia family carers, so that participants gain more insights, knowledge, and skills. This will not only have direct benefits to the course participants, but also to those they care for, and potentially to the state, as people living with dementia remain in their homes for as long as possible.

1.9 Overview of thesis

This thesis is structured as follows. Chapter two contains the literature that was reviewed and that has shaped and contributed to my understanding of the topic. A review and analysis of individual interventions and studies and a range of systematic reviews in this field will be outlined for the reader. The chapter will also trace this researcher's thinking that led to the generation of the research questions in this thesis. Chapter three outlines the research design and approach used in this research project. The research methodology will be outlined and justified, and a description of data collection and analysis methods will be offered to the reader. Chapter four will present and discuss research findings in relation to research questions one and two. Finally, chapter five offers conclusions and recommendations arising from this research project.

1.10 Chapter Summary

This chapter has introduced the topic to be studied in this thesis. It has described the HBC-HBE online learning course and established the rationale for the research. The two research questions have been set out, and the case study methodology to be used has been introduced. Finally, the structure and plan for the remainder of the thesis has been stated.

Chapter 2: Literature Review

2.1 Introduction

One of the primary aims of a literature review is to explore and evaluate existing literature relating to the research questions, and in doing so 'set the context and rationale for current research' (Dziuban *et al.,* 2016, p. 29). This chapter presents, analyses, and reviews the literature that was used to inform this thesis. It will offer a broader and deeper understanding about various learning interventions that have sought to support dementia family carers. This literature review also contributed to my thinking about research methodology, methods and the data analysis techniques employed. Literature pertaining specifically to research methodology and methods will be presented in chapter three.

This chapter begins by outlining my literature search strategy. It is clear from the literature review that there are numerous online interventions that have attempted to support dementia family carers. Research has been carried out on many of these individual interventions. The number, importance, and diversity of these individual interventions has led scholars to carry out a range of systematic reviews in this area.

Having reviewed both individual interventions and a range of systematic reviews, this chapter will outline five themes related to the literature. These are: (1) defining dementia; (2) the multifaceted nature of dementia family caring; (3) the impact of caring for a person with dementia; (4) the growth of online education provision for dementia family carers; and (5) the important components of online interventions for dementia family carers.

Emerging from this analysis of the literature and taking cognisance of my motivation and professional goals, a **Summary of Supportive Elements in Online Dementia Family Carer Training** will be outlined toward the end of this chapter. This summary will then be used to inform the field work undertaken in this thesis.

2.2 Literature Review Strategy

The literature review journey for this thesis started during the taught years of the Doctor of Education programme when I was developing his research topic. It continued with a formal literature search in January 2021. This was supplemented by my existing and growing knowledge of dementia through exposure to grey literature in the form of reports and conference presentations. It progressed through further exploration of bibliographies and other references. The process was further deepened as drafts of the thesis were presented to, and feedback obtained, from my supervisors. It has been a continuing and iterative endeavour.

The formal literature review approach that I followed for this Doctoral thesis can be described as a systematized review (Grant and Booth, 2009). Systematized reviews contain some features of a systematic review. Systematic reviews have been defined as '…the application of strategies that limit bias in the assembly, critical appraisal and synthesis of all relevant studies on a given topic' (Chalmers, Hedges and Cooper, 2002, p. 17), where the reviewer must follow 'an explicit path' (Dempster, 2003, p. 312).

Systematic reviews follow a series of pre-defined 'processes' (Lewis-Beck, Bryman and Futing Liao, 2004, p. 1111) or 'stages' (Torgerson, Hall and Lewis-Light, 2017), which include (1) development of a research question, (2) development of a plan or protocol, (3) information retrieval and study selection, (4) coding the retrieved data, (5) quality appraisal of the retrieved data, (6) synthesis or combining the results of included studies, and (7) writing up a report or summary of the review (pp. 168–179).

However, systematic reviews involve 'exhaustive, comprehensive searching' (Grant and Booth, 2009, p. 95), and are usually undertaken by 'a research team' (Torgerson, Hall and Lewis-Light, 2017, p. 169). While it is important to carry out a methodical review of the pertinent research literature, it was not possible for me to carry out a full systematic review as described above. Therefore, I used elements from a systematic approach and allied these to pragmatic search for relevant, focussed literature on the topic. Systematized reviews are 'typically conducted as a postgraduate student assignment' (Grant and Booth, 2009, p. 103) as is the case in this research. The elements of the systematic review that I followed were (1) development of a research question, (2) development of a plan or protocol (3) information retrieval and study selection, (4) coding the retrieved data (6) synthesising or combining the results of included studies, and (7) writing up a report or summary of the literature review.

The first step in any literature review is to identify the focus of the research. This research is interested in investigating if and how dementia family carers feel an online course has supported them in their care situation, and how it can better support them. Notwithstanding the fact that the exact wording of the research questions evolved through the research process, the key concepts and terms associated with this research were *dementia*, *family carers*, *online learning* and *support*. Following guidance from Creswell (2014) these terms will be defined and outlined in the pages that follow.

The search strategy focussed on exploring academic literature in the following academic databases: Scopus, Academic Search Complete, Eric International and Education Research Complete. These databases were chosen because they provide a comprehensive collection of academic literature on the topic. The initial search was undertaken in January 2021 using Dublin City University Library for academic literature published between 2000 and 2021, using the search terms set out in Table 2.1 below.

TABLE 2. 1: LITERATURE REVIEW SEARCH ITEMS

Family carers	AND Online Education
OR Family caregivers	OR E-learning
OR Informal carers	OR Distance education
	OR Digital learning

The breakdown of search results is given in Table 2.2 below. Inclusion criteria were full text, scholarly, peer reviewed, in English and published between 1st January 2000 to 31st December 2020.

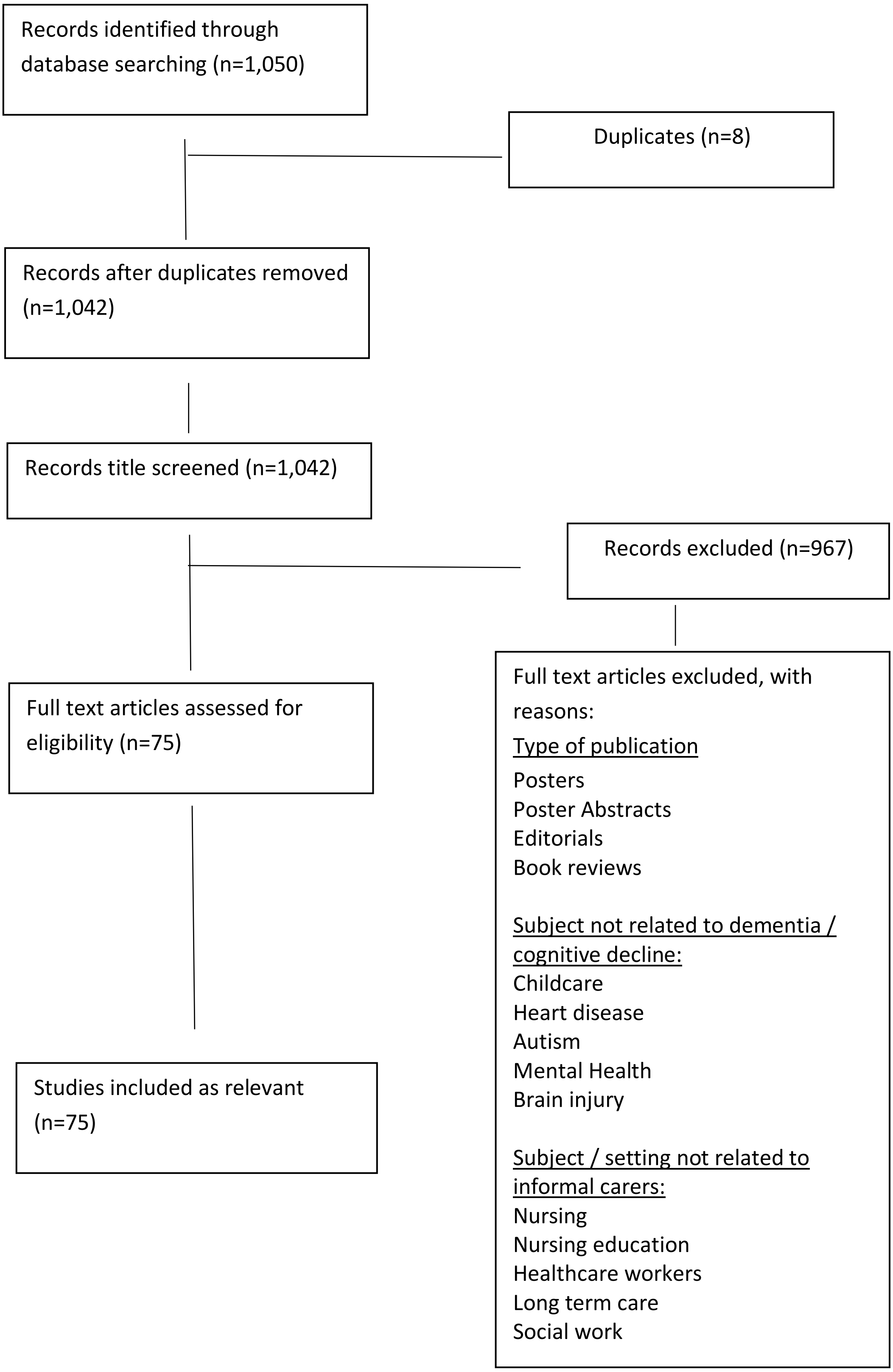
Relevant papers were those that met the inclusion criteria, and upon review contributed to my understanding of issues pertaining to the research questions in this study. Exclusion criteria included types of publication (for example posters or poster abstracts, book review and editorials); where the described intervention was not related to dementia care / cognitive decline (for example childcare, autism and brain injury), and where the subject or setting was not related to family carers (for example nurses / nursing education, long-term care and social work).

TABLE 2. 2: LITERATURE REVIEW RESULTS

Database / source	**No of papers**	**Excluded**	**Remaining / of relevance**
Eric International	55	47	8
Scopus	56	29	27
Academic Search Complete	699	667	32
Educational Research Complete	240	224	16
Totals	1,050	967	83
Duplicates			(8)
Total Number of Papers Remaining			75

Figure 2.1 below sets out the article search and selection process in a PRISMA flowchart which ‘depicts the number of papers that were dealt with during the Identification, Screening, Eligibility and Inclusion phases of the review process (Atalaia *et al.*, 2020, p. 8). It is important to emphasise that the search strategy was an iterative process. The use of backward snowballing search strategy of finding citations in a paper (Wee and Banister, 2016, p. 284) was used extensively, most especially to investigate further individual studies or cases of online interventions that were mentioned in other papers.

FIGURE 2. 1: PRISMA FLOWCHART ARTICLE SEARCH AND SELECTION PROCESS



2.3 Defining Dementia

There was a lot of background and descriptive information about dementia in the literature. Dementia has been described as an ‘umbrella term for a collection of symptoms that are caused by disorders affecting the brain and impact on memory, thinking behaviour and emotion’ (Alzheimer’s Disease International, no date). Dementia can affect people ‘severely enough to interfere with one’s activities of daily living and social autonomy’ (Gauthier *et al.*, 2021, p. 26). There are many different types of dementia with ‘some that will be very familiar to most people, such as Alzheimer’s disease and other forms that would be much rarer and therefore not widely known’ (McGowan *et al.*, 2019, p. 7).

It is generally accepted that dementia causes ‘a deterioration in cognitive functioning (that) affects memory, thinking, orientation, comprehension, learning capacity, language, and judgment, and is often accompanied by deterioration of emotional control, social behavior (sic), or motivation’ (Boots *et al.*, 2017, p. 2). Medical scientific definitions of dementia term the disease ‘a major neurocognitive disorder’ where the primary presenting symptom is not necessarily memory decline ‘but could be a speech problem or a change in personality, depending on the area of the brain that is initially affected’ (McGowan *et al.*, 2019, p. 7). Following the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) of the American Psychiatric Association, McGown (2019) lists six domains that may be impacted by a dementia, and these include ‘complex attention; executive function (e.g. planning, decision-making, mental flexibility); learning and memory; language (including fluency, word finding and the naming of objects); perceptual motor function (e.g. hand-eye coordination and visual tracking); and social cognition (including recognising emotions and insight)’ (McGowan *et al.*, 2019, p. 7).

Dementia is also a progressive condition often separated into ‘mild, moderate and severe corresponding to early, mid and late or advanced stages’ (Hanson *et al.*, 2019, p. 109). Currently, ‘there is no cure for most types of dementia’ (Alzheimer’s Disease International, no date). It is vitally important to support those with the condition as well as those who care for them (Department of Health, 2014). As outlined in chapter one the prevalence of dementia is increasing globally. In Ireland it is estimated that by 2025 65,077 people will be living with dementia (Alzheimer Europe, 2020) with this figure set to rise to 94,000 by 2031 (Pierce, Cahill and O’Shea, 2014).

2.4 The multifaceted nature of dementia family caring

Before beginning this section, a note on terminology is provided for the reader. In the American literature, the term 'caregiver' is often used to describe the delivery of informal unpaid care. In European literature the term family carer is more often used for the same purpose. For simplicity, the term dementia family carer will be used widely throughout this thesis, unless in directly quoted work in which case the preferred term of the original author will be used.

The literature defined family carers and described the diversity of types of carer. According to the 2012 Irish National Carers' Strategy, 'A carer is 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, 2012). The term 'family carer' or 'informal carer' seeks to distinguish members of the same family providing ongoing care and support to a close family member or relative, from other care providers including formal paid care workers. 'Caregivers can be spouses, partners, adult children, parents, other relatives (siblings, aunts, nieces/nephews, in-laws, and grandchildren), friends, or neighbors (sic)' (Whitlatch and Orsulic-Jeras, 2017, p. 59). The focus of this thesis is on dementia family carers, as they are the participants on HBC-HBE.

Dementia family carers are not a homogeneous group. In addition to 'spousal carers', who provide care to a partner / husband or wife (Brennan, , *et al.*, 2017), young carers provide support to a range of people with various illnesses (Elf *et al.*, 2012). The role can also depend on the carer's position within the family, for example spousal carers will usually undertake a wider range of care tasks than a son or daughter who may not live in the family home (Brennan, *et al.*, 2017).

Care tasks have been classified into three levels. 'Low level' consists mainly of companionship; 'medium level' involves cooking, driving, shopping or housework and care tasks such as washing, dressing and use of the toilet. Finally, 'high level' includes all of the preceding but at a more concentrated level given the person who needs care may be severely incapacitated (Care Alliance Ireland, 2015, p. 2).

Most of the 64,000 people living with dementia in Ireland have Alzheimer's disease. However, it is important to note that there are different sub-categories of dementia family carers because there are so many different types of dementia. The four most common dementias are Alzheimer's disease, frontotemporal dementia, Lewy-Body dementia and vascular dementia (Alzheimer's Disease International, no date). In addition, dementia family carers could be caring for people with younger onset dementia. In Ireland this presents additional challenges for the person with dementia and their families, as many state services and supports are not available to persons who are aged under sixty-five. There is also a lack of comprehensive information available across Europe (Jones *et al.,* 2018), to support people caring for persons with younger onset dementia. As such this group face particular needs including the need for social support and an acceptance of their role (Millenaar *et al.*, 2018).

Another sub-group are family carers of people with frontotemporal dementia. Frontotemporal dementia is associated with repetitive and difficult behavioural symptoms. Consequently those family members caring for someone with frontotemporal dementia are more prone to stress and burden (Gossink *et al.,* 2018). Caring for people with advanced dementia requires further skills. The provision of palliative care necessitates the ability to 'connect compassionately' with the person to whom they are providing care (Datta and Agrawal, 2017). Doing so without any formal preparation or training is a most difficult endeavour (Farrington, 2014; Hudson and Aranda, 2014; Harrop *et al.*, 2018).

As noted in chapter one, learners on HBC-HBE can be caring for a family member with any type of dementia. The implication of having so many different types of dementia, symptoms and therefore associated challenges for dementia family carers, makes the provision of an online intervention such as HBC-HBE challenging. This heterogeneity of complex and interlinked factors may help explain the variety of delivery interventions outlined in section 2.6.

One of the challenges for HBC-HBE is to provide information and learning materials relevant to a wide variety of dementia care situations, where symptoms can be mild, moderate or severe (Hanson et al., 2019), or where carers may be spouses (Brennan et al., 2017) or caring for someone with younger onset dementia (Millenaar et al., 2018). This is an ongoing challenge, which is partly addressed by having a heterogeneity of learners sharing their mixed backgrounds and experiences within each HBC-HBE cohort. As will be evident in later chapters, the findings in this research have contributed to a deeper understanding of how HBC-HBE supports dementia family carers and what ASI can do to better support them.

2.5 The impact of caring for a person with dementia

It became very clear in the literature that dementia family caring was a very demanding role. It should be acknowledged that caring for a family member with dementia can be rewarding and fulfilling. Positive aspects of caregiving can include role satisfaction, emotional rewards, personal growth, competence and mastery, faith and spiritual growth, relationship gains, sense of duty and reciprocity (Lloyd, Patterson and Muers, 2016, pp. 1550–1552).

However, there is a large body of research that demonstrates that dementia family carers experience negative effects of caregiving (Jütten, Mark and Sitskoorn, 2019). As one study notes, ‘Negative health effects for caregivers are widely documented in the literature and include higher levels of depression, compromised physical health, and decreased quality of life’ (Whitlatch and Orsulic-Jeras, 2017, p. 59). A further study supports this view stating that dementia ‘caregivers suffer from depression more often, perceive their workload as heavier and are in less good health, taking more medication than their peers’ (Schoenmakers, Buntinx and Delepeleire, 2010, p. 192).

Other negative impacts on carers include ‘stress, distress and psychological illness’ (Mahoney *et al.*, 2005). The concept of ‘caregiver burden’ has been described ‘as complex and multi-dimensional’, and includes ‘the overall physical, psychological, emotional and financial toll of providing care’ (Chiao, Wu and Hsiao, 2015, p. 341). The caregiver burden associated with informal dementia care has been divided into two dimensions. The first dimension is associated with the characteristics of the person with dementia, while the second dimension is linked to the characteristics of the caregiver (Etters, Goodall and Harrison, 2008). The characteristics of the person with dementia include the type of dementia, as well as the extent of any personality change which could also include psychiatric symptoms and behavioural disturbances. The second dimension, which focuses on family carer characteristics, could include ‘gender, cultural values, the relationship with the person with dementia, the amount of formal and informal care available and the caregivers’ physical and mental status, personality and coping strategy’ (Chiao, Wu and

Hsiao, 2015, p. 341). The family carer has to attempt to take cognisance of and balance these two domains in their role. Alleviating caregiver burden is one of the aims of many of the interventions described in section 2.6 below.

Symptoms of dementia can be associated with gradual and irreversible cognitive decline, changeable symptoms, distressing changes to personality and repetitive behavioural problems. These particular characteristics may influence research findings that have concluded that 'caring for a person with dementia can be more stressful than caring for a physically frail older adult' (Lloyd, Patterson and Muers, 2016, p. 1535).

An American study on caregiver stress has noted that caregiving responsibilities are 'complicated…are usually financially uncompensated, require the caregiver to juggle responsibilities [which can] leave the caregiver exhausted'(Hu *et al.*, 2015, p. 194). An Irish study of spousal carers of people with dementia found that '79% reported that they themselves provided 81% - 100% of the care to their spouse…that half of the participants [in the study] were sole carers, and almost half had been providing care for more than five years' (Brennan, *et al.*, 2017, p. 5).

Clearly, family carers need support to help them meet the challenges of caring for a relative living with dementia. In summary, these include coping with a gradual irreversible decline in the cognitive functioning of the person to whom they are providing care; trying to deal with a range of symptoms that have a complex trajectory and that become more challenging as time passes; psychologically knowing that dementia is a terminal disease; and dealing with the financial and physical challenges of providing care. In addition, they have to balance all of that with their own life challenges and commitments.

2.6 The growth of online education provision for family carers

There is a growing body of literature reporting on online interventions for dementia family carers. These studies were very useful in helping to inform this research project.

2.6.1: Part A Individual interventions

2.6.1.1: Overview of Studies of Individual Dementia Family Carer Interventions

The literature search described in section 2.2 above uncovered a wide range of interventions of interest to this research, and twenty-seven of them are listed in Table 2.3 below in chronological order. Research on these interventions have taken place around the world. The majority were from north America [USA and Canada] (twelve), and the Netherlands (five). Other countries where notable interventions or planned interventions were studied included, India (two), Hong Kong, Germany, France, Sweden, and four partnerships that involved joint delivery across various European Union countries.

Almost half of the reported interventions (thirteen out of twenty-six) were fully online courses: (note that one intervention the Internet Caregiver Support Service was reported on twice) *E-Care* (Finkel *et al.*, 2007)*, iCare* (Kajiyama *et al.*, 2013)*, Diapason* (Cristancho-Lacroix *et al.*, 2015)*, STAR Online Course* (Hattink *et al.*, 2015)*, Dementia E-Learning Programme* (Ho *et al.*, 2015)*, Mastery over Dementia* (Blom *et al.*, 2015)*, Tele-Savvy* (Griffiths *et al.*, 2016)*, UnderstAID* (Núñez-Naveira *et al.*, 2016)*, WeCareAdvisor* (Kales *et al.*, 2017)*, iSupport* (Mehta *et al.*, 2018)*, Online Cognitive Behavioural Therapy* (Meichsner, Theurer and Wilz, 2019)*, RHAPSODY* (Metcalfe *et al.*, 2019)*, Online Training and Support Programme* (Baruah *et al.*, 2020).

Additionally, there were two blended programmes *Partner in Balance* (Boots *et al.*, 2018) the education element of which was delivered online, and *Videophone Psychosocial Intervention* (Czaja *et al.*, 2013); three websites *Internet Caregiver Support Service (ICSS)* (Chiu *et al.*, 2009; Chiu and Eysenbach, 2011)*, Cuidate Cuidador 'Caregiver, take care of yourself'* targeting Spanish speaking carers (Pagán-Ortiz *et al.*, 2014)*, Virtual Healthcare Neighbourhood* (Fowler, Haney and Lemaster, 2016)*;* one ‘web portal’ STAR (note *STAR* is a web portal that contains an online course - Boyd examined usability of the full portal, and Hattink assessed usefulness and impact of the online course element of the portal) (Boyd *et al.*, 2014; Hattink *et al.*, 2015); two Apps the first named *Story-Call* (Davis *et al.*, 2014), and the second *CaFCa - Care of family carers of persons with dementia* (Kabir *et al.*, 2020) one digital hub called *Digital*

TABLE 2. 3: INDIVIDUAL INTERVENTIONS BY CHRONOLOGICAL ORDER AND TYPE

Author / Year / Country	**Name**	**Type**
Paul, Johnson and Cranston, (2000) USA	Alphabet Soup: The Power of Nutrition in Caregiving	Distance Education Teleconference programme
Finkel *et al.*, (2007) USA	E-Care Telecommunications Technology Psychosocial intervention	Online course
Chiu *et al.*, (2009) Canada	Internet-based Caregiver Support Service ICSS	Information website
Chiu and Eysenbach, (2011) Canada	Internet-based Caregiver Support Service ICSS	Information website
Czaja *et al.*, (2013) USA	Videophone Psychosocial intervention	Blended Delivery
Kajiyama *et al.*, (2013) USA	iCare Stress Management E-Training Programme	Online course
Boyd *et al.*, (2014) Europe	STAR	Web portal
Davis *et al.*, (2014) USA	Story-Call Mobile App for Dementia Caregivers	App
Pagán-Ortiz *et al.*, (2014) USA	Cuidate Cuidador 'Caregiver, take care of yourself'	Information Website
Cristancho-Lacroix *et al.*, (2015) France	Diapason Psychoeducation programme	Online Course
Hattink *et al.*, (2015) Netherlands / UK	STAR (European Skills training and Reskilling) for informal carers *plus* formal carers	Online Course
Ho *et al.*, (2015) Hong Kong	Dementia E-Learning Programme	Online course
Mierlo *et al.*, (2015) Netherlands	DEM-DISC (Dementia Digital Interactive Social Chart)	Internet based interactive tool
Blom *et al.*, (2015) Netherlands	Mastery over Dementia	Online course
Hattink *et al.*, (2016) Netherlands	Digital Alzheimer Centre (DAC)	Digital hub
Fowler, Haney and Lemaster, (2016) USA	Virtual Healthcare Neighbourhood	Information website
Gaugler, Reese and Tanler, (2016) USA	Care to Plan (CtP)	Online resource / tool
Griffiths *et al.*, (2016) USA	Tele-Savvy	Online course
Núñez-Naveira *et al.*, (2016) Den/Pol/Sw	UnderstAID ICT Platform	Online course
Kales *et al.*, (2017) USA	WeCareAdvisor	Online course

Author / Year / Country	**Name**	**Type**
Boots *et al.*, (2016), (2018) Netherlands	Partner in Balance	Blended course, but content delivered online
Gossink *et al.*, (2018) Netherlands	Intervention programme for frontal dementia carers	Not stated
Mehta *et al.*, (2018) India	iSupport	Online course
Meichsner, Theurer and Wilz, (2019) Germany	Online Cognitive Behavioural Therapy (CBT)	Online course
Metcalfe *et al.*, (2019) England /France/ Germany	RHAPSODY Online Information and Support	Online course
Baruah *et al.*, (2020) India	Online Training and Support Programme	Online course
Kabir *et al.*, (2020) Sweden	CaFCa - Care of family carers of persons with dementia	App

Alzheimer Centre (DAC) (Hattink *et al.*, 2016); two online resources / tools *Dementia Digital Interactive Social Chart) DEM-DISC* (Mierlo *et al.*, 2015), and *Care to Plan (CtP)* (Gaugler, Reese and Tanler, 2016); one videoconferencing / phone based intervention *Alphabet Soup* (Paul, Johnson and Cranston, 2000); and finally one where the intervention type was not stated (Gossink *et al.*, 2018).

2.6.1.2 Heterogeneity of interventions

The heterogeneity and diversity of interventions must also be noted and are described in detail in Appendix B. For example, the length of the interventions (where stated) was varied and ranged from the *RHAPSODY* intervention at six weeks (Metcalfe et al., 2019) to six months for the *Intervention programme for frontal dementia carers* (Gossink et al., 2018). Several interventions lasted between six to eight weeks for example *iCare* (Kajiyama *et al.*, 2013), *Mastery over Dementia* (Blom *et al.*, 2015), *Tele-Savvy* (Griffiths *et al.*, 2016), *Partner in Balance* (Boots *et al.*, 2018), *Online Cognitive Behavioural Therapy* (Meichsner, Theurer and Wilz, 2019), *RHAPSODY* (Metcalfe *et al.*, 2019) and the *CaFCa app* (Kabir *et al.*, 2020).

The content of the online courses was varied, in that no two interventions were identical. In an effort to detect common elements within interventions Figure 2.2 below shows a Word

Cloud visual representation of the most common words to appear under ‘Description / Content’ for the Online Courses in Appendix B.

FIGURE 2. 2: WORD CLOUD: COMPONENTS OF ONLINE INTERVENTION

Unsurprisingly many online courses covered the topic of dementia, including the provision of information about the disease, as well as managing or dealing with behavioural change caused by dementia *E-Care* (Finkel *et al.*, 2007), *iCare* (Kajiyama *et al.*, 2013) , *Cuidate Cuidador ‘Caregiver, take care of yourself’* (Pagán-Ortiz *et al.*, 2014), *Diapason* (Cristancho-Lacroix *et al.*, 2015), *WeCareAdvisor* (Kales *et al.*, 2017), *Intervention programme for frontal dementia carers* (Gossink *et al.*, 2018) and *iSupport* (Mehta *et al.*, 2018).

Many of these interventions sought to address the challenges of being a family carer. For example, twelve included the provision of information to participants: *Alphabet Soup* (Paul, Johnson and Cranston, 2000) *E-Care* (Finkel *et al.*, 2007), *Internet Caregiver Support Service (ICSS)* (Chiu *et al.*, 2009), *iCare* (Kajiyama *et al.*, 2013), *Story-Call* (Davis *et al.*, 2014), *Cuidate Cuidador ‘Caregiver, take care of yourself’* (Pagán-Ortiz *et al.*, 2014), *Mastery over Dementia* (Blom *et al.*, 2015), *Diapason* (Cristancho-Lacroix *et al.*, 2015), *DEM-DISC* (Mierlo *et al.*, 2015), *Virtual Healthcare Neighbourhood* (Fowler, Haney and Rutledge, 2014), *Digital Alzheimer Centre (DAC)* (Hattink *et al.*, 2016), *and RHAPSODY* (Metcalfe *et al.*, 2019).

This was mainly information about dementia *E-Care, ICSS* and *Cuidate Cuidador* (Finkel *et al.*, 2007; Chiu *et al.*, 2009; Chiu and Eysenbach, 2011; Pagán-Ortiz *et al.*, 2014), but also included information on services and supports available to dementia family carers, as in *Diapason* and *RHAPSODY* (Cristancho-Lacroix *et al.*, 2015; Metcalfe *et al.*, 2019). *DEM-DISC* had an interactive internet tool which provided information on health and social support services (Mierlo *et al.*, 2015). *Alphabet Soup* also concentrated on information and advice about food and nutrition for formal and informal carers of people with dementia in rural Montana (Paul, Johnson and Cranston, 2000).

Communication skills was another common component of many interventions including *E-Care*, (Finkel *et al.*, 2007), *iCare* (Kajiyama *et al.*, 2013) and *Mastery over Dementia* (Blom *et al.*, 2015). This ranged from the *Diapason* programme where better communication between the family carer and the person they were caring for was addressed by setting out a 'description of the most frequent language troubles and the strategies to modulate and adapt communication to the preserved skills of PWAD (person with Alzheimer's disease)' (Cristancho-Lacroix *et al.*, 2015, p. 3). For the *Partner in Balance* programme, communication covered 'communication changes due to memory problems and effective communications with adaptions' (Boots *et al.*, 2016, p. 6).

Stress management was a feature of a range of interventions including *iCare* (Kajiyama *et al.*, 2013), *Diapason* (Cristancho-Lacroix *et al.*, 2015), *Digital Alzheimer Centre (DAC)* (Hattink *et al.*, 2016), and *Online Cognitive Behavioural Therapy (CBT)* (Meichsner, Theurer and Wilz, 2019). Other interventions had content on teaching relaxation techniques as in *Mastery over Dementia* (Blom *et al.*, 2015), or addressing carer worry *Virtual Healthcare Neighbourhood* (Fowler, Haney and Lemaster, 2016).

The *Diapason* intervention had a section on planning for the future (Cristancho-Lacroix *et al.*, 2015), while relatedly the *Digital Alzheimer Centre (DAC)* addressed the issue of financial and legal matters (Hattink *et al.*, 2016). Some interventions focussed on the importance of staying active, namely *Diapason* (Cristancho-Lacroix *et al.*, 2015) and *UnderstAID* (Núñez-Naveira *et al.*, 2016); while other interventions covered care skills including *E-Care* which included the topic of safety (Finkel *et al.*, 2007), *Diapason* which covered avoiding falls (Cristancho-Lacroix *et al.*, 2015), *STAR* which examined practical difficulties in daily life (Hattink *et al.*, 2015), while *UnderstAID* looked at daily tasks (Núñez-Naveira *et al.*, 2016).

Self-care was the focus of several interventions. *E-Care* had a section on self-care (Finkel *et al.*, 2007). *STAR* had a section on looking after yourself (Hattink *et al.*, 2015), *Partner in Balance* emphasized the importance of stress, positivity and self-understanding (Boots *et al.*, 2016, 2018), and *RHAPSODY* had a section on self-care suggestions (Metcalfe *et al.*, 2019). This is consistent with an overall approach aimed at improving the wellbeing of dementia family carers and shows that many interventions went beyond just the provision of information.

Many interventions were action focussed. In describing these interventions researchers used words such as ‘management’ *E-Care* (Finkel *et al.*, 2007); ‘managing’ and ‘planning’ *iCare* (Kajiyama *et al.*, 2013); ‘understanding’ *STAR* (Hattink *et al.*, 2016); ‘dealing’ *iSupport* (Mehta *et al.*, 2018), and ‘strengthening’ and ‘coping’ *Online Cognitive Behavioural Therapy* (Meichsner, Theurer and Wilz, 2019). This demonstrates that these interventions sought to influence knowledge, understanding and behaviour of dementia family carers.

Five interventions sought to support dementia family carers through the provision of contact between participants. This contact between participants was facilitated by the affordances of online technology to provide and promote interactivity and social support. For example *Videophone Psychosocial Intervention* facilitated videophone contact between participants (Czaja *et al.*, 2013). The *Cuidate Cuidador 'Caregiver, take care of yourself'* course contained a comment section for interaction between caregivers (Pagán-Ortiz *et al.*, 2014). *Diapason* provided participants with access to private anonymous forums to enable contact (Cristancho-Lacroix *et al.*, 2015), while *UnderstAID* had a daily task section and a social networking feature allowing interaction between participants (Núñez-Naveira *et al.*, 2016). Peer blogging was a feature of *Virtual Healthcare Neighbourhood* (Fowler, Haney and Lemaster, 2016).

However, it should be noted that three interventions did not have any aspect of peer interaction. This was the case in the *Internet-based Caregiver Support Service ICSS* (Chiu *et al.*, 2009; Chiu and Eysenbach, 2011), *Mastery over Dementia* (Blom *et al.*, 2015), and *iSupport* (Mehta *et al.*, 2018). There seems to be an interesting tension between interventions with aspects of peer support, and those that are more individualised with no peer contact. This theme will be explored further in the chapter four below. Several studies provided access to ‘expert’ support in four interventions *Alphabet Soup* (Paul, Johnson and Cranston, 2000), *Cuidate Cuidador 'Caregiver, take care of yourself'*, (Pagán-Ortiz *et al.*, 2014), *Mastery over Dementia* (Blom *et al.*, 2015) and *Digital Alzheimer Centre* (Hattink *et al.*, 2016).

But did these various interventions assist dementia family carers, and if so, how? Findings from the research carried out in the papers above revealed a great deal. Appendix C below provides detail on aims, methodology, methods and findings of the individual studies outlined in Table 2.3 above. A commentary on Appendix C is now offered to the reader.

2.6.1.3 Studies of individual interventions

The studies in Table 2.3 above had two main aims. Some papers examined usability and user friendliness of the online intervention, for example the *Internet based Caregiver Support Service ICSS* (Chiu and Eysenbach, 2011), *STAR* (Boyd *et al.*, 2014) and the *Digital Alzheimer Centre* (Hattink *et al.*, 2016). A couple of studies were more descriptive and discussed the development of the intervention, for example *Story-Call* (Davis *et al.*, 2014) and *Cuidate Cuidador 'Caregiver, take care of yourself'* (Pagán-Ortiz *et al.*, 2014).

In addition, ten of the papers sought to measure the effectiveness of the intervention – *Alphabet Soup* (Paul, Johnson and Cranston, 2000), *E-Care* (Finkel *et al.*, 2007), *Internet-based Caregiver Support Service* (Chiu *et al.*, 2009), *Videophone Psychosocial Intervention* (Czaja *et al.*, 2013), *iCare* (Kajiyama *et al.*, 2013), *Diapason* (Cristancho-Lacroix *et al.*, 2015), *STAR* (Hattink *et al.*, 2015), *Mastery over Dementia* (Blom *et al.*, 2015), *Partner in Balance* (Boots *et al.*, 2016), and *Online Cognitive Behavioural Therapy* (Meichsner, Theurer and Wilz, 2019). Findings from these studies will be examined in 2.6.1.5 for effectiveness and 2.6.1.6 for usability.

2.6.1.4 Methodology and methods of studies on individual interventions

Ten of these papers were pilot studies on new or proposed interventions. This was the case for *E-Care* (Finkel *et al.*, 2007), *Videophone Psychosocial Intervention* (Czaja *et al.*, 2013), *Story-Call* (Davis *et al.*, 2014), *Diapason* (Cristancho-Lacroix *et al.*, 2015), *STAR* (Hattink *et al.*, 2015), *Care to Plan* (Gaugler, Reese and Tanler, 2016), *Tele-Savvy* (Griffiths *et al.*, 2016)*,* *UnderstAID* (Núñez-Naveira *et al.*, 2016)*, Intervention programme for frontal dementia carers* (Gossink *et al.*, 2018) and RHAPSODY (Metcalfe *et al.*, 2019).

There were two exploratory studies - *iCare* (Kajiyama *et al.*, 2013) and *WeCareAdvisor* (Kales *et al.*, 2017). That means that these interventions had not been delivered on an ongoing basis. Consequently, their efficacy has not been proven over time. It is unclear if the findings regarding these interventions would be replicated outside of a trial period and on an ongoing basis.

Nine of the research papers above reported on randomized control trials, as was the case for the following interventions *Diapason* (Cristancho-Lacroix *et al.*, 2015)*, STAR* (Hattink *et al.*, 2015)*, DEM-DISC* (Mierlo *et al.*, 2015)*, Mastery over Dementia* (Blom *et al.*, 2015)*, Partner in Balance* (Boots *et al.*, 2016, 2018)*, UnderstAID* (Núñez-Naveira *et al.*, 2016)*, Intervention programme for frontal dementia carers* (Gossink *et al.*, 2018)*, Online Cognitive Behavioural Therapy* (Meichsner, Theurer and Wilz, 2019) and *RHAPSODY* (Metcalfe *et al.*, 2019).

Four used purely qualitative methods. These included a usability study of a proposed programme *Internet-based Caregiver Support Service (ICSS)* (Chiu and Eysenbach, 2011)*;* an exploratory paper*, WeCareAdvisor* (Kales *et al.*, 2017) and a paper that sought to identify the components and acceptability of a proposed online course *Online Training Support Programme* (Baruah *et al.*, 2020). Purely qualitative methods were also used in a paper to describe the *Virtual Healthcare Neighbourhood* (Fowler, Haney and Lemaster, 2016) intervention.

Nine studies used mixed methods. These were the *Alphabet Soup* (Paul, Johnson and Cranston, 2000)*, Internet-based Caregiver Support Service (ICSS)* (Chiu *et al.*, 2009)*, Cuidate Cuidador 'Caregiver, take care of yourself'* (Pagán-Ortiz *et al.*, 2014)*, Diapason* (Cristancho-Lacroix *et al.*, 2015)*, Digital Alzheimer Centre (DAC)* (Hattink *et al.*, 2016)*, Care to Plan* (Gaugler, Reese and Tanler, 2016)*, Intervention programme for carers of dementia patients with frontal behaviour changes* (Gossink *et al.*, 2018)*, RHAPSODY* (Metcalfe *et al.*, 2019) and *CaFCa Care of Family Carers of Persons with Dementia* (Kabir *et al.*, 2020).

Twelve studies used purely quantitative methods, usually in an attempt to determine if and to what extent the interventions relieved stress, burden, depression, anxiety or if they improved carer knowledge or wellbeing – *E-Care* (Finkel *et al.*, 2007), *Videophone Psychosocial Intervention* (Czaja *et al.*, 2013), *iCare* (Kajiyama *et al.*, 2013), *Story-Call* (Davis *et al.*, 2014), *STAR* (Hattink *et al.*, 2015), *Dementia E-Learning Programme* (Ho *et al.*, 2015), *Mastery over Dementia* (Blom *et al.*, 2015), *Partner in Balance* (Boots *et al.*, 2016, 2018), *Tele-Savvy* (Griffiths *et al.*, 2016), *UnderstAID* (Núñez-Naveira *et al.*, 2016), *iSupport* (Mehta *et al.*, 2018) *and Online Cognitive Behavioural Therapy* (Meichsner, Theurer and Wilz, 2019). These quantitative studies mostly involved learners completing pre- and post-intervention questionnaires to measure a range of outcomes related to carer burden, depression, anxiety, wellbeing, knowledge about dementia, and sense of competence in care delivery.

2.6.1.5 Effectiveness findings from studies on individual interventions

Overall, findings on these online interventions were mostly positive – please see Appendix C for full details. In the purely quantitative studies, *E-Care* showed that those who participated in the intervention were less depressed thereafter and had increased confidence after the intervention. However, some of the positive findings were not statistically significant (Finkel *et al.*, 2007).

For the *Videophone Psychosocial* intervention results were mostly positive with those who received the intervention reporting a decrease in burden, an increase in perceived social support, and positive perceptions of caregiving experience. However, there were no differences in feelings of depression (Czaja *et al.*, 2013).

The experiment group in the *iCare* Stress management intervention reported a significant improvement in stress levels. Changes in other measures including depression, quality of life and caregiver bother were not significant. There was a concerning high dropout rate thirty-three percent during the intervention (Kajiyama *et al.*, 2013).

The *STAR* programme was well received by both formal and informal dementia carers, with ‘a significant improvement in the experimental group, indicating that they felt less distressed in tense situations, had more empathy and concern for the well-being of other people, and were better able to understand situations and the actions of other people’ (Hattink *et al.*, 2015, p. 5). Dementia family carers in the experimental group of the *Mastery over Dementia* programme showed statistically significant lower levels of depression and anxiety post intervention, though the extent of the effect sizes were moderate for anxiety and small for depression. There was also a sizable drop out in the experimental group (Blom *et al.*, 2015).

For *Partner in Balance* findings showed significant increases in favour of the intervention group for self-efficacy, mastery and quality of life. But there were no significant differences for depressive symptoms, anxiety or stress (Boots *et al.*, 2018). Research on the *Tele-Savvy* intervention found significant decreases in burden, anxiety and depressive symptoms, and participants agreed or strongly agreed with positive aspects of the programme (Griffiths *et al.*, 2016).

The *UnderstAID* programme showed poor to mixed results with only thirty-three percent of caregivers satisfied with the platform, and only fifty percent stating it was technically and pedagogically acceptable. But there was a decrease in depressive scale for the experimental group post intervention (Núñez-Naveira *et al.*, 2016). Finally, the '*Online Cognitive Behavioural Therapy*' programme showed statistically significant medium sized improvements for coping with grief; but no statistically significant improvements for burden or depression; emotional wellbeing improved as the intervention progressed, and overall satisfaction with the intervention was excellent (Meichsner, Theurer and Wilz, 2019).

There is a possibility that other factors outside of these interventions led to changes in reported family carer burden, stress, anxiety, and other scales that were measured in each particular study. The two domains of caregiver burden (Etters, Goodall and Harrison, 2008) which are related to the person to whom care is being provided and the person providing the care, illustrate that there are many variables involved in dementia care. Changes in either of these domains could also lead to alterations in stress, depression and anxiety experienced by the dementia family carer. Therefore, while measuring changes in the emotional state of dementia family carers is useful, it does not always explain what caused these changes to take place.

Perhaps for this reason the findings of mixed method and qualitative studies could prove more instructive, as they could include the perspectives and feelings of course participants. Findings from mixed methods studies were also mainly positive. Interestingly, participants in the videoconferencing intervention *Alphabet Soup* reported valuing the information provided, the interaction with others, the immediate response to questions from the panel of experts, and the convenience of saving time (Paul, Johnson and Cranston, 2000). Even though this intervention is dated in terms of the technology employed, the findings relating to information provision, interaction with others and access to experts are important and have been repeated in other and more recent studies, as will become clear later in this chapter.

Chiu (2009) found that participating on the *Internet Caregiver Support Service (ICSS)* reduced carer burden, and that dementia family carers could benefit from receiving professional support via asynchronous e-mails and a dedicated information web site. However, the '*Caregiver, take care of yourself*' intervention showed mixed results. The quantitative findings revealed a positive but not statistically significant increase in sense of self-mastery, sense of social support, caregiver burden and depressive symptomology for the experiment group. On the other hand, qualitative data from focus groups showed favourable views on caregivers' experiences of using the website (Pagán-Ortiz *et al.*, 2014).

The intervention programme for frontal dementia carers reported participants feeling a greater sense of competence, while burden, stress and depression decreased, but not significantly (Gossink *et al.*, 2018). Though the mode of delivery of this programme is unclear, it is included here due to its multi-component nature and social support pedagogical approach. These are themes that are repeated elsewhere in the literature, and as such this programme is of interest.

Purely qualitative studies tended to concentrate on usability of various interventions, as noted in section 2.6.1.3 above, and it is to usability studies that we now turn.

2.6.1.6 Usability findings from studies on individual interventions

The *Diapason* intervention was evaluated for efficacy and usability using mixed methods. Quantitative findings showed no significant differences in self-perceived stress between the control and experimental group. However, the experimental group improved their knowledge of dementia. It should also be noted that users did not use the website after the course finished. Qualitative findings showed that male caregivers were most disposed toward the programme. Interviews with participants found that dementia family carers wanted personalised support, extensive information, specific assistance, and more communication with professionals and peers (Cristancho-Lacroix *et al.*, 2015).

Hattink *et al.* (2016) also carried out a mixed methods study on the *Digital Alzheimer Centre* (DAC) to investigate the usability and usefulness of DAC. The study used a combination of participant observation, online surveys, and interviews. For usability the authors found eight categories of errors, three of which were critical, and that only about half the respondents used the hub. However, those who did use DAC found it useful especially for understanding dementia, with sixty-two percent of carers reporting a positive attitude towards the intervention.

Care to Plan (CtP) was examined for its utility and feasibility by Gaugler, Reese and Tanler (2016). They concluded that participants found the intervention easy to understand, especially in terms of the layout. They also found that the individualized recommendations could meet the needs of users. The *RHAPSODY* intervention was assessed for user acceptability and satisfaction. It was found that seventy-six percent of users described it as useful and easy to use, while eighty-five percent intended to use it in future. Additionally, it led to reductions in stress levels and in carers negative reaction to memory symptoms (Metcalfe *et al.*, 2019).

In a purely qualitative study Chiu and Eysenbach (2011) wanted to get a better understanding of factors influencing family carers use of *Internet Caregiver Support Service (ICSS)* a web-based intervention. They found that three factors influenced the use of the intervention: caregiver needs; ICT factors including accessibility barriers, and perceived efforts to use the technology; and individual preferences for using technology. Fowler (2016) also used qualitative methods to investigate dementia family carers' views on the of *Virtual Healthcare Neighbourhood* intervention. They viewed the intervention positively.

In an exploratory study the *WeCareAdvisor* intervention was investigated for the style and approach, 'look and feel' of the online course, and types of psychoeducation most needed by carers (Kales *et al.*, 2017). They found that participants expressed a need for advice, and to speak with someone, as well as contact through daily emails with words of encouragement, and tailored support to meet individual needs. Finally, Baruah (2020) sought to identify the components and acceptability of a proposed online course. Their paper provided a detailed outline of content including symptom management, dementia stages, food to be given, provision of information on care services, caring for the carer, family dynamics, connecting with other caregivers, and addressing stress and burden (p.523).

2.6.1.7 Conclusions on studies of individual interventions

What is clear is that there is a considerable body of international research on a range of online interventions designed to support dementia family carers. These interventions vary in terms of their length, aims and objectives, content, format and age. The studies reporting on these interventions also varied greatly in terms of their aims, methodology and methods. Many studies measured changes in depression, anxiety, sense of competency, and burden (among others). They showed positive results with some qualifications around statistical significance in some cases.

However, the existence of so many variables in relation to the interventions and research papers described earlier makes it difficult to reach firm conclusions regarding online learning for dementia family carers. Interventions are delivered using different technology modalities, they vary in length, content is not uniform, and the interventions follow various formats. The research papers use different methodologies and methods, and have produced different findings, many positive but usually with qualifications. Other studies examined usability and acceptance of interventions from the standpoint of the end user. They pointed out areas for improving the learner experience.

All these factors – conflicting or mixed results, pilot or evaluation studies, many quantitative based methodologies that did not explore the views of end users in any depth - motivated me to delve deeper into published research in this field and led to the discovery of a range of review types including systematic and meta reviews. The findings of the most relevant reviews are presented in the following section.

2.6.2 Part B: Systematic reviews

2.6.2.1 Heterogeneity of reviews

There is a growing number of systematic and meta reviews that have tried to methodically locate, describe, and synthesise the myriad of online interventions that have been delivered to dementia family carers. I found eighteen such reviews during the course of his research (Magnusson, Hanson and Borg, 2004; Godwin *et al.*, 2013; Boots *et al.*, 2014; McKechnie, Barker and Stott, 2014; Hu *et al.*, 2015; Huis in het Veld *et al.*, 2015; Lee, 2015; Jackson *et al.*, 2016; Waller *et al.*, 2017; Christie *et al.*, 2018; Hopwood *et al.*, 2018; Sherifali *et al.*, 2018; Klimova *et al.*, 2019; Cheng and Zhang, 2020; Frias *et al.*, 2020; Leng *et al.*, 2020; Etxeberria, Salaberria and Gorostiaga, 2021; Wallace *et al.*, 2021). A synopsis of these systematic review papers is presented in tabular form in Appendix D below.

Most of these papers were classified as systematic reviews, with the following exceptions - two systematic meta reviews (Huis in het Veld *et al.*, 2015; Leng *et al.*, 2020), two reviews (Magnusson, Hanson and Borg, 2004; Lee, 2015), two systematic reviews and meta-analysis (Sherifali *et al.*, 2018; Etxeberria, Salaberria and Gorostiaga, 2021) and one meta review (Cheng and Zhang, 2020), where ‘a meta-analysis is generally defined as the analysis of analyses’ (Given, 2008, p. 507).

2.6.2.2 Aims of reviews

Although not all of the reviews related to dementia specific family carers (Magnusson, Hanson and Borg, 2004; Hu *et al.*, 2015; Sherifali *et al.*, 2018; Wallace *et al.*, 2021), or did not focus exclusively on online interventions (Huis in het Veld *et al.*, 2015; Jackson *et al.*, 2016; Waller *et al.*, 2017), they were still of relevance and interest for this research project. For example, Magnusson, Hanson and Borg (2004) in their literature review on how ICT could be used to support frail older people living at home and their carers, found user-friendliness of the intervention to be very important. Put simply, if the learners cannot use or navigate the platform, they are not going to be able to access materials or activities and consequently it is unlikely that they will find the intervention supportive.

Systematic reviews focussed on a range of different issues. One looked at the very important task of reducing caregiver stress (including dementia family carers) through online interventions (Hu *et al.*, 2015). Similarly, Sherifali *et al.* (2018) reviewed the impact of internet-based interventions on caregivers' mental health. The majority of the studies (nine out of thirteen) that they examined in their review involved dementia family carers. This was also the case with Wallace *et al.* (2021) where most of the studies they selected (thirteen out of seventeen) focussed on dementia family carers and examined a question of strong interest do this research project - do carers who connect online have better outcomes?

Of the exclusively non-online interventions, Huis in het Veld *et al.* (2015) looked at the effectiveness of a range of interventions including online interventions in supporting self-management in dementia family carers. Their selected studies had to include 'direct or indirect (by phone / email) contact between the informal caregiver and the healthcare professional providing the intervention' (pp. 2-3). Similarly, Jackson *et al*. (2016) included studies of interventions provided by telephone, internet or combined formats to provide support to dementia family carers. Finally, Waller *et al.* (2016) also examined how telephone and internet-based interventions supported dementia family carers. Consequently, these reviews are included as they reported important findings for this thesis.

The focus of these reviews varied. The majority were interested in measuring the effectiveness or efficacy of various interventions (Magnusson, Hanson and Borg, 2004; Godwin *et al.*, 2013; Boots *et al.*, 2014; McKechnie, Barker and Stott, 2014; Hu *et al.*, 2015; Huis in het Veld *et al.*, 2015; Jackson *et al.*, 2016; Klimova *et al.*, 2019; Frias *et al.*, 2020; Leng *et al.*, 2020). An early study looked at the 'psychosocial effects (i.e. depression, burden, stress and strain) of technology-driven interventions targeted toward informal caregivers of people with dementia' (Godwin *et al.*, 2013, p. 217). Boots *et al.* (2014) provided an overview of the evidence for effectiveness, feasibility and quality of internet interventions for dementia family cares. Covering the time period up to 2012, a study from the United Kingdom analysed the question 'how effective are computer mediated psychosocial interventions for informal carers of people with dementia?' (McKechnie, Barker and Stott, 2014, p. 1620). Hu *et al.* (2014) assessed the effectiveness of internet-based interventions that aimed to decrease caregiver stress – they specifically reviewed open-label and randomised control trials. The effectiveness of interventions that supported self-management for dementia family carers was the focus of another study (Huis in het Veld *et al.*, 2015).

Telephone, internet or combined support for dementia family carers was the subject of the Jackson *et al*. (2016) systematic review. Klimova *et al.* (2019) provided a systematic review of E-learning as a valuable caregiver's support for people with dementia. A more recent systematic review assessed the effectiveness of psychoeducational interventions with respect to burden, anxiety and depression in family caregivers of people with dementia living at home (Frias *et al.*, 2020). Effectiveness was again the aim of the systematic review by Leng *et al.* (2020) which aimed to 'assess the efficacy of internet-based supportive interventions in ameliorating health outcomes for family caregivers of people with dementia and examine whether specific types of internet-based supportive interventions had a beneficial impact on family caregivers' health outcomes' (p. 2).

Other systematic reviews had slightly different objectives. The Huis in het Veld *et al.* (2015) systematic meta review assessed systematic reviews that had focussed on the effectiveness of interventions (a meta systematic review is itself a review of systematic reviews). But they were also interested in 'the effectiveness of various types of professional self-management support interventions' (Huis in het Veld *et al.*, 2015, p. 2), not all of which were delivered online. Waller *et al.* (2017) were interested in effectiveness, but also in the methodological quality of the included studies in their systematic review.

The objectives of a Dutch review covering the period 2007-2017 were '(1) to explore the evidence on the topic of implementing eHealth interventions for informal caregivers of people with dementia, and (2) to identify determinants that influenced whether the intervention was successfully implemented' (Christie *et al.*, 2018, p. 59). The Hopwood *et al.* (2018) systematic review had three objectives – to identify the key components of existing internet-based interventions designed to support dementia family carers; to develop an understanding of which components are most valued by caregivers and once again to consider the effectiveness of the interventions. The Hopwood systematic review is therefore very important for this research project as will become apparent.

2.6.2.3 Systematic review findings regarding effectiveness

In keeping with many of the individual intervention studies reported on earlier, many systematic reviews studies reported the benefits and promise of online interventions. Systematic reviews of online interventions targeting dementia family carers are not without limitations as ‘the included studies consisted of complex and inconsistent interventions and designs, making pooling of the data impossible’ (Boots *et al.*, 2014, p. 342).

Despite this limitation the same systematic review found that ‘multicomponent programs that combined information, tailored caregiving strategies, and contact with other caregivers resulted in positive effects on confidence, self-efficacy, stress, burden, and depression’ (p. 340). Recognising the diversity of intervention types Klimova *et al.* (2019) concluded that ‘the detected studies showed that eLearning portals / programs / courses helped caregivers feel more confident about dementia care, enhanced their knowledge and skills, reduced their perceived stress, and enhanced their feelings of empathy, understandings and concern’ (p. 4).

Christie *et al*. (2018) state that eHealth interventions for informal caregivers ‘are effective in improving a range of psychological outcomes in caregivers, such as the reduction in caregiver depression, anxiety, stress and burden, as well as increasing positive aspects of caregiving, caregiver self-efficacy, and confidence’ (p. 52). A meta-analysis study stated that ‘internet-based supportive interventions significantly ameliorated depressive symptoms, perceived stress, anxiety, and self-efficacy in dementia caregivers’ (Leng *et al.*, 2020, p. 2).

The systematic review by Frias *et al.* (2020) reported on psychoeducational interventions that were either delivered via technology or group-based methods. Both had advantages: ‘Technology-based Interventions significantly affect burden while Group-based Interventions affect anxiety, depression, insomnia and burden and quality of life and self-efficacy’ (Frias *et al.*, 2020, p. 787). Finally, Etxeberria, Salaberria and Gorostiaga (2021) concluded their study by saying that the ‘results revealed that online interventions may have positive effects on caregivers’ psychological wellbeing’ (p. 1175).

Other studies were more guarded in their assessment of the effectiveness of the interventions under review. Godwin *et al.* (2013) reported that although six of the eight studies in their review reported decreases in anxiety or depression, the contents of the programmes and methods of analysis varied considerably. Consequently, they concluded that ‘there was insufficient evidence to support or refute technology driven interventions’ (p. 221). In a balanced and convincing discussion in their study McKechnie, Barker and Stott (2014) write that because interventions were varied and multifaceted with a range of outcome measures, direct comparison between them is difficult. And although all studies found some ‘positive effects…..the lack of statistical power of many studies and the use of some non-standardized measures further complicates comparison of studies’ (p. 1634).

The systematic review by Sherifali *et al.* (2018) showed only ‘small to moderate beneficial effects of internet-based interventions on caregiver mental health including a reduction in symptoms of depression, stress or distress, and anxiety’ (p. 7). Moreover, another review concluded that ‘current evidence failed to support the efficacy of internet-based supportive interventions on caregiver burden, coping competence, caregiver reactions to behavioral (sic) symptoms, or quality of life’ (Leng *et al.*, 2020, p. 9).

The evidence is therefore mixed, but it does suggest that online interventions have at least the potential to be helpful to dementia family carers. They can, and often do, lead to psychological gains in terms of reduced stress and burden. But crucial questions remain to be answered if ASI is going to succeed in its quest to better support more dementia family carers into the future. How are courses going to be organised? What format are they going to take? How are they going to best meet the needs of dementia family carers?

2.7 The important components of online interventions for dementia family carers

The Boots *et al*. (2014) systematic review referred to above provided a robust evidence-based overview and analysis on the needs of family carers of people with dementia (Boots *et al.,* 2014). As reported earlier they found that ‘multicomponent programs’ that combined information, tailored caregiving strategies, and contact with other caregivers resulted in positive effects on confidence, self-efficacy, stress, burden, and depression (p. 340). Further, they state that guidance by a coach / expert, and online interactions between family carers are important elements of impactful interventions.

An important finding of the systematic review by Boots *et al.* (2014), which analysed interventions up to late 2013, was that the elements they found to be useful – multicomponent programmes combining information, tailored caregiving strategies, contact with and between peers, access to a coach / expert - have also been identified in other studies. For example, the analysis of individual studies above showed the importance of information provision, which was included in thirteen interventions *Alphabet Soup, E-Care, Internet Caregiver Support Service (ICSS), iCare, Story-Call, Cuidate Cuidador 'Caregiver, take care of yourself', Mastery over Dementia, Diapason, DEM-DISC, Virtual Healthcare Neighbourhood, Digital Alzheimer Centre (DAC), and RHAPSODY* – see Appendix B for author details and intervention content.

Whitlatch and Orsulic-Jeras (2017) also agree about the importance of information provision for dementia family carers. They found that information about dementia, signs and symptoms, and how the disease progresses, were important elements of support interventions for dementia family carers. In addition, the provision of information about the future care needs of the individual, especially in relation to legal and financial information, and information about how to access appropriate services are also vital to the wellbeing of the person with dementia and their care partner. They describe the educational and informational needs in some detail. However, their paper does not clearly delineate between educational and informational needs – these two domains seem to merge.

The action-oriented nature of interventions is mentioned in systematic reviews. For example, 'tailored caregiving strategies' (Boots *et al.,* 2014) involves the provision of individualized support for dementia caregivers, so that they can manage difficult challenges associated with behaviour changes in the person to whom they are providing care. In a similar vein, another systematic review describes the 'self-management' support needs of family carers of people with dementia (Huis in het Veld *et al.*, 2015). According to their systematic meta review, family carers take on the self-management tasks of the person with dementia as the disease progresses. Self-management refers to managing the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes essential in living with a chronic condition. Quoting Martin *et al.* (2013) they list five self-management targets for people with dementia as being: relationship with family; maintaining an active lifestyle; psychological wellbeing; techniques to cope with memory changes; and information about dementia (Huis in het Veld *et al.,* 2015, p. 2). Furthermore, Whitlatch and Orsulic-Jeras (2017) found that dementia family carer interventions needed an educational component to help with managing the behaviour of the person with dementia. Education elements should also address coping and stress management for both the person living with dementia and their carer (p. 59).

Contact with other caregivers (peers) is an important component of successful online interventions (Boots et al., 2014). This is evidenced by the five individual interventions examined earlier which included the facilitation of contact between course participants (see section 2.6.1.2 above). A more recent systematic review (Hopwood *et al.*, 2018) reveals further evidence about the need for contact with and between carers, and also access to an expert or professional. Hopwood *et al*. (2018) focussed on identifying the key components of successful internet-based interventions aimed at supporting dementia family carers. Their systematic review looked at qualitative as well as quantitative data in a total of forty articles addressing thirty-one interventions. All the interventions were primarily internet based, and in common with HBC-HBE included family carers who provide care to people with all stages and types of dementia.

Hopwood *et al.* (2018) outlined the key components of successful online interventions for dementia family carers as being: information, peer support, psychological support, contact with professionals and decision-making support. 'Information' included provision of information on dementia, practical aspects of caregiving, and available local and national services. These were especially valued as part of multicomponent interventions and when tailored to the individual needs of the caregiver. Peer support was provided through discussion forums or video conferencing software, and could entail, 'supportive messages, information seeking, discussing the emotional impact of caring and developing support networks' (p. 4). Peer support was a key component in twenty-five of the forty studies they examined.

Psychological support consisted of either therapeutic relaxation techniques or self-directed modules or homework, reflective diaries, assignments, or regular assessments with support from a professional coach, most often a psychologist. Contact with professionals entailed allowing course participants to contact either a social care or health professional including nurses, occupational therapists, or social workers. This resulted 'in personalized practical advice for caregivers at home on caring and dementia, as well as emotional support, and caregivers reported feeling less isolated as a result' (p. 5). Though listed as being important, most studies in the meta review did not provide details of what was entailed by decision-making support. In some interventions, decision making support came from other components of the intervention such as peer or contact with professionals.

Whitlatch and Orsulic-Jeras (2017) describe the types of supportive interventions offered to dementia family carers. These include support groups and technology-based interventions. During the middle stages of dementia care coordination programmes provide information, coaching, and emotional support to dementia family caregivers. They also stress the worthiness of online ‘multicomponent interventions’ - a phrase also used by Boots *et al*. (2014) - which they believe ‘have the potential to improve knowledge, skills, and coping, while enabling meaningful engagement and caring relationships and support for caregivers and individuals living with dementia’ (Whitlatch and Orsulic-Jeras, 2017, p. 66).

This section has examined and analysed the components of online interventions designed to support dementia family carers. A summary of the supportive elements in online dementia family carer training is now provided below.

2.8 Summary of Supportive Elements in Online Dementia Family Carer Training

A summary of supportive elements in online dementia family carer training is set out below.

The Learning Environment: The importance of the learning environment should not be understated. Many studies concentrated on assessing the usability and acceptability of various interventions including videoconferencing *Alphabet Soup* (Paul, Johnson and Cranston, 2000), websites *Internet Based Caregiver Support Service (ICSS)* (Chiu and Eysenbach, 2011), and hubs *STAR* (Boyd *et al.*, 2014), and *Digital Alzheimer Centre (DAC)* (Hattink *et al.*, 2016). Learning environments are how learners engage with course materials, and they should easily facilitate interaction between course participants and tutors / experts / professionals.

Peer Contact: I was informed by findings in two systematic reviews (Boots *et al.*, 2014; Hopwood *et al.*, 2018), which mentioned the importance of contact with other caregivers as being an important element of successful interventions. Five of the individual studies outlined in section 2.6.1.2 facilitated contact between course participants, *Videophone Psychosocial Intervention* (Czaja *et al.*, 2013), *Cuidate Cuidador 'Caregiver, take care of yourself'* (Pagán-Ortiz *et al.*, 2014), *Diapason* (Cristancho-Lacroix *et al.*, 2015), *UnderstAID*

(Núñez-Naveira *et al.*, 2016) *and Virtual Healthcare Neighbourhood* (Fowler, Haney and Rutledge, 2014).

Information: This was mentioned by a number of authors as being vital in supporting family carers (Paul, Johnson and Cranston, 2000; Boots *et al.*, 2014; Huis in het Veld *et al.*, 2015; Whitlatch and Orsulic-Jeras, 2017; Hopwood *et al.*, 2018). The literature review found thirteen individual interventions in which the provision of Information was an important component *Alphabet Soup* (Paul, Johnson and Cranston, 2000), *E-Care* (Finkel *et al.*, 2007), *Internet Caregiver Support Service (ICSS)* (Chiu *et al.*, 2009), *iCare* (Kajiyama *et al.*, 2013), *Story-Call* (Davis *et al.*, 2014), *Cuidate Cuidador 'Caregiver, take care of yourself'* (Pagán-Ortiz *et al.*, 2014), *Mastery over Dementia* (Blom *et al.*, 2015), *Diapason* (Cristancho-Lacroix *et al.*, 2015), *DEM-DISC* (Mierlo *et al.*, 2015), *Virtual Healthcare Neighbourhood* (Fowler, Haney and Rutledge, 2014), *Digital Alzheimer Centre (DAC)* (Hattink *et al.*, 2016), *and RHAPSODY* (Metcalfe *et al.*, 2019) – see Table 2.3 and Appendix B.

Information on the following topics were seen to be important: dementia, types, symptoms, progression, legal issues, financial planning and appropriate services (Whitlatch and Orsulic-Jeras, 2017); and practical aspects of caregiving, or available local and national services (Hopwood *et al.*, 2018).

Education: This was specifically included in the study by Whitlatch and Orsulic-Jeras, (2017) where they mention managing behaviours, family relationships, stress management and risk factors. The systematic meta review by Huis in het Veld *et al.* (2015) refers to the importance of educating participants about relationships between the person with dementia and the informal caregiver, maintaining an active lifestyle, psychological wellbeing and techniques to cope with memory changes, as all being important self-management techniques. Decision making support is mentioned by Hopwood *et al.* (2018). Communication was also listed in seven studies as an important educational component of online interventions (section 2.6.1.2). Improved communication in dementia care is inherent in how family members manage behaviours, family relations, and learned techniques to deal with memory changes.

Stress management was also a feature of individual interventions. These included *iCare, Diapason* (Cristancho-Lacroix *et al.*, 2015), *Digital Alzheimer Centre (DAC)* (Hattink *et al.*, 2016), and *Online Cognitive Behavioural Therapy (CBT)* (Meichsner, Theurer and Wilz, 2019). Relaxation techniques were included in *Mastery over Dementia* (Blom *et al.*, 2015), while the *Virtual Healthcare Neighbourhood* (Fowler, Haney and Rutledge, 2014) addressed carer worry. Activities was a component of the *Diapason* (Cristancho-Lacroix *et al.*, 2015) and *UnderstAID* (Núñez-Naveira *et al.*, 2016) interventions; while care skills formed part of the content of three interventions *Diapason* (Cristancho-Lacroix *et al.*, 2015), *UnderstAID* (Núñez-Naveira *et al.*, 2016) and *STAR* (Hattink *et al.*, 2015).

Professional / Tutor / Expert Advice: This was outlined by the Hopwood *et al.,* (2018) systematic review, as being one of the important components of successful online interventions for dementia family carers. In an exploratory study of the *WeCareAdvisor* programme, participants reported their need for advice and the importance of being able to speak with someone. They wanted contact through daily email with words of encouragement and tailored support to meet their own individual needs (Kales *et al.*, 2017). Many of the interventions had an element of professional contact and support. *Cuidate Cuidador ‘Caregiver, take care of yourself’* had an ‘ask the expert’ section (Pagán-Ortiz *et al.*, 2014). *Mastery over Dementia* featured guidance from a coach (Blom *et al.*, 2015), while the *Digital Alzheimer Centre (DAC)* provided learners with a forum moderated by a professional for the exchange of ideas and practice (Hattink *et al.*, 2016).

Psychological Care: As reported earlier, psychological well-being is one component of self-management targets for people with dementia (Huis in het Veld *et al.*, 2015). The Hopwood *et al.,* (2018) systematic review identified the important components of internet based interventions to support dementia family carers. These included psychological support delivered through self-directed modules and with support from a tutor expert.

2.9 Implications of literature review

What became clear to me following this literature review was that there is a huge variety of online learning interventions designed to support dementia family carers. Many of these interventions have been useful to family carers. They have supported them by increasing their dementia knowledge, reducing their stress and strain, and by making them feel more confident in their role.

But questions remain to be posed and answered. Primarily, it is not always clear how exactly family carers take benefit from these interventions. This relates to a conclusion in the systematic review by Waller *et al.,* (2017) who call for 'methodologically rigorous trials [….] to further identify the components of interventions effective in improving outcomes' (Waller *et al.*, 2017, p. 17).

This research project asks learners on HBC-HBE about if and how they have gained support from the intervention. In so doing, this research seeks to address other specific gaps mentioned in the literature on this topic. Boots *et al.* (2014) highlight the limited number of studies of high methodological quality and call for more research in this field. Another study laments the fact that eHealth intervention studies 'struggle to encompass the wealth of information …at the level of the end-user' (Christie *et al.*, 2018, p. 57).

In another systematic review McKechnie, Barker and Stott (2014) had earlier written that future research should include qualitative elements, especially interviews, to explore 'deeper insight into carers' experiences of using the interventions, and … to go beyond measurement of symptom reduction and tap into factors, such as feeling supported and less alone, that are of great importance to carers' (McKechnie, Barker and Stott, 2014, p. 1635). Finally, the systematic review by Christie *et al.* (2018) called for future research to study interventions beyond their initial or trial period.

As a Doctoral study, this research will be of high methodological quality and rigorous in its methods and analysis. It will examine the views of the end-user. This study will focus on an established intervention and will endeavour to go beyond simply measuring symptom reduction.

In conclusion, this literature review has provided direction for the rest of this thesis. It has described dementia and the complex tasks involved in dementia family caring. This has negative impacts on dementia family carers. Online interventions have supported many dementia family carers around the world. An analysis of these interventions has allowed me to summarise the most important components of successful interventions. This was presented as the Summary of Supportive Elements in Online Dementia Family Carer Training. This summary will be used as the basis for the field work in this thesis, and this will be described in more detail in chapter three.

2.10 Chapter Summary

This chapter has provided an insight into the literature reviewed to inform this thesis. It has outlined, described, and analysed the key terms in the research questions. Individual interventions were presented and analysed. To better understand the efficacy, impact and usability of various dementia family carer online interventions, systematic reviews and meta-analyses were presented as a form of triangulation of research typologies. Though complex, findings guardedly confirm that online interventions can be of benefit to dementia family carers.

Moreover, this literature review has illustrated the development of my thinking about how the research questions were moulded, developed, and finalized during the iterative process of reviewing the research literature. The gaps in the current literature in relation to a lack of high-quality studies, few studies of more established interventions, and that involve the end-user, were allied to my needs as the researcher in my professional context. What has emerged is the Summary of Supportive Elements in Online Dementia Family Carer Training. This summary will be used as the foundation of this research as will become clear in chapter three.

Chapter 3: Research Design and Methodology

3.1 Introduction

This chapter will present the research design and methodology used in this thesis. It will do so by first setting out my own research philosophy. It will then describe and justify my research methodology. Following on from a description of my research methodology will be an account of the data collection and data analysis methods that I used in this thesis. The chapter will also outline what steps have been taken to contribute to validity and reliability. Finally, the ethical challenges encountered in this research project will be described and a commentary provided on how I have attempted to overcome them.

The foundations for any research project must be clearly stated and coherent (Cohen, Manion and Morrison, 2011). These foundations allow me as the researcher to outline and explain what has variously been described as a worldview (Creswell, 2014), or paradigm (Guba and Lincoln, 1994, 2005; Picciano, 2016; Coe *et al.*, 2017). The term research philosophy, which 'refers to a system of beliefs and assumptions about the development of knowledge' (Saunders, Lewis and Thornhill, 2019, p. 130), will be used in this thesis. It is important for me as the researcher to explicitly state my research philosophy, as it underpins and influences the research methodology and the research methods that I used in this thesis, as outlined in Figure 3.1 below.

FIGURE 3. 1: STEPS IN RESEARCH DESIGN PROCESS

Research Philosophy	➡	Approach to theory development	➡	Research Methodology	➡	Research Methods

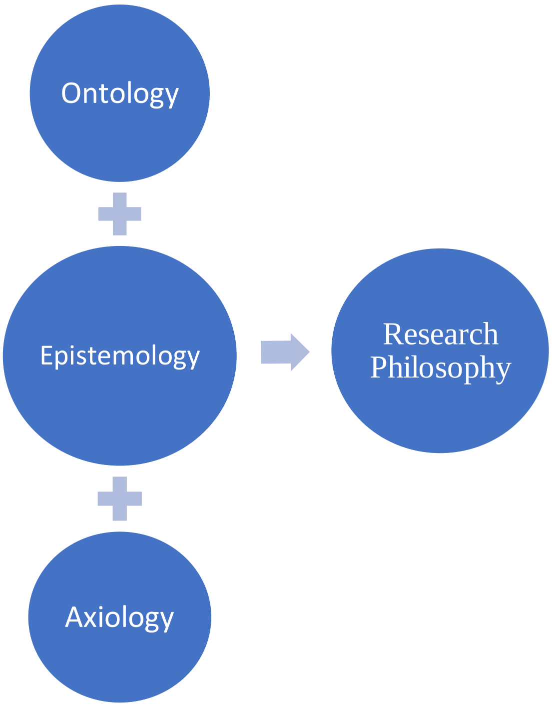
Adapted from 'Research Onion' as outlined in Saunders (2018) p. 130.

3.2 Research Philosophy

I intend to follow the process outlined by Saunders, Lewis and Thornhill, (2019) in setting out the underpinnings of my research philosophy. This is due to the clarity with which they set out to explain how one goes about deciding on their research philosophy. One's research philosophy is influenced by one's assumptions about the realities we encounter in our research (ontological assumptions), about human knowledge (epistemological assumptions), and about the extent and ways our values influence the research process (axiological assumptions) (Saunders, Lewis and Thornhill, 2019, p. 130), as set out in Figure 3.2.

I undertook the HARP (Heightening your Awareness of your Research Philosophy) Questionnaire (Saunders, Lewis and Thornhill, 2019) in March 2022 to further review and explore my research philosophy. The Questionnaire consisted of thirty statements related to beliefs and assumptions around ontology, epistemology and axiology. My highest scoring philosophical position was Interpretivism.

FIGURE 3. 2: COMPONENTS OF A RESEARCH PHILOSOPHY (SAUNDERS, LEWIS AND THORNHILL, 2019)



3.2.1 Ontology

Coe *et al*. (2017) define ontology as the 'assumptions which concern the very nature or essence of the social phenomena being investigated' (p. 5). Waring (2017) simply defines ontology as ‘the form and nature of the social world’ (p. 16). While for others, ontology refers to the attitudes a researcher may have ‘about the world around them on a spectrum ranging from realist, in which the world is entirely objective, to nominalist, in which the world exists only in one's interaction with it’ (Stewart, 2014, p. 147).

For Waring one’s ontology can be anywhere along a continuum ‘from realism to constructivism’, where a realist position would hold that ‘a singular objective reality (that) exists independently of people’s perceptions of it (while) under constructivism reality is neither objective nor singular, but multiple realities are constructed by individuals’ (Waring, 2017, p. 16). Other writers argue that the questions that inform one’s ontological position ‘spring directly from what philosophy terms the nominalist-realist debate’. Realists believe that ‘objects have an independent meaning and are not dependent on the knower’, whereas the nominalist view is that ‘objects of thought are merely words’ and consequently a person through their life experience, education and a myriad of other factors gives those objects meaning intrinsically (Coe *et al.*, 2017, p. 5).

My experience in teaching and learning makes me lean toward a nominalist / constructivist ontology where ‘subjective meanings are negotiated socially and historically. They are not simply imprinted on individuals but are formed through interaction with others …. and through historical and cultural norms that operate in individuals’ lives’ (Creswell, 2014, p. 37). My position is shaped by my own academic training, my professional work experience, and my life experience. For example, I completed a fully online M.A. in Online and Distance Education with the Open University. It was a very engaging educational experience, where ongoing deep interaction with peers was supported and encouraged. It is also evident in the pedagogical approach used in my own teaching and in how in the online course, that is the subject of this research, is organised and presented to learners, as will be seen later.

3.2.2 Epistemology

Epistemology has been defined as ‘the very basis of knowledge – its nature and forms (and), how it can be acquired, and how communicated to other human beings’ (Cohen, Manion and Morrison, 2011, p. 6). Epistemology concerns the researcher's ‘beliefs about the nature of knowledge, which ranges from positivist, in which researchers seek to explain and predict the social world's perspective, and anti-positivist, also known as interpretivist, in which the world is essentially relativistic’ (Stewart, 2014, p. 147). A positivist epistemology would be one where ‘knowledge is hard, objective and tangible’ while an anti-positivist / post-positivist position would believe that ‘knowledge is personal, subjective and unique’ (Coe *et al.*, 2017, p. 6). For Waring (2017), one’s epistemology is located somewhere along a continuum between the extreme positions of positivism and interpretivism.

My own epistemology leans toward an interpretive position, ‘where reality is socially constructed’ (Sefotho, 2015, p. 27). Therefore, I believe it necessary to ‘get inside the mind of the person and to understand from within’ (Cohen, Manion and Morrison, 2011, p. 17). In Waring’s (2017) terms my epistemological position would tend towards ‘subjectivist, transactional, interactive’, where ‘the investigator and the object of the investigation are assumed to be interactively linked so that the “findings” are literally created as the investigation proceeds’ (Waring, 2017, p. 18).

My own epistemology is also post-positivist in that it rejects a purely positivist scientific position on the nature of knowledge and knowing. Rather my post-positivism ‘adopts a pluralist view of multiple, coexisting realities rather than a single reality’ (Cohen, Manion and Morrison, 2011, p. 27). I identify with an interpretivist framework which mainly ‘focuses on understanding and meaning-making, as opposed to explanation, as the main purpose of research’ (Given, 2008, p. 465). This interpretivism is associated with a broadly social scientific perspective akin to my own academic background.

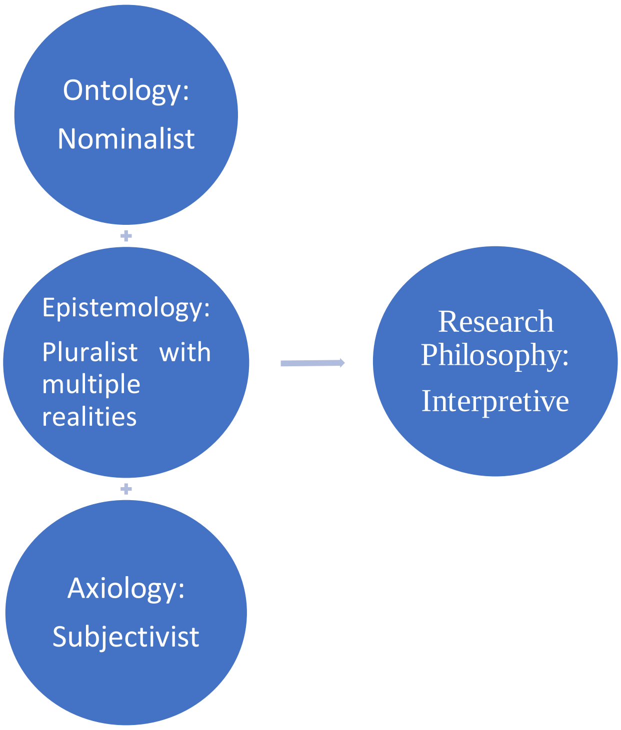
3.2.3 Axiology

Axiology can be defined as ‘the philosophy of values’ (Given, 2008, p. 53). My own values impacted on all decisions taken during the research project. For me, it is important to state that my values as an education professional are founded on a desire to support and empower learners on our HBC-HBE course.

As a novice researcher, my core set of values towards this research project are subjective in nature, with a commitment to respect and represent the knowledge and insight of the research participants. The methodology and methods chosen will provide dementia family carers with a platform to relate their experiences in participating on HBC-HBE. As a Doctoral researcher my commitment is to a rigorous and appropriate methodological approach to the research project.

In terms of my approach to research and my research participants, I recognise the reality of my position in relation to this research project, as being that of an insider researcher (Mercer, 2007). This will be discussed in more detail later in the section 3.9. Figure 3.3 below outlines my interpretive research philosophy as consisting of a nominalist ontology, a pluralist epistemology with multiple realities and a subjective axiology.

FIGURE 3. 3: MY RESEARCH PHILOSOPHY



3.3 Summary of the research objectives

The aims and objectives of this research and how they are to be achieved through the research questions also contribute to the framing of my methodological approach. As outlined earlier, this research will investigate if and how the online HBC-HBE course supports dementia family carers. The two specific research questions are:

How does HBC-HBE support dementia family carers?

How can HBC-HBE better support dementia family carers?

These research questions have been chosen partly because they fill a gap in the academic research literature as outlined in chapter 2. The questions are also important to my work where I manage the HBC-HBE online learning course, to ASI my employer, and to the 64,000 family carers in Ireland looking after a person living with dementia.

The research questions also reflect my own research philosophy. They are concerned with creating a better understanding of how learners are supported through an online education course, by giving research respondents the opportunity to describe their valuable and important learning experiences. Epistemologically, the questions lend themselves to 'getting inside the mind' of the respondents. Their views and experiences are very important and warrant detailed and rigorous exposure.

3.4 Research Methodology

Having set out my research philosophy, I will now outline the research methodology used in this thesis in more detail. 'Methodology connotes a set of rules and procedures to guide research against which its claims can be evaluated' (Daly, 2003, p. 192). This thesis will use case study as its research methodology.

3.4.1 Case Study as a Research Methodology

Yin (2014) offers a two-part definition of what constitutes a case study. He sees case study as 'an empirical inquiry that investigates a contemporary phenomenon (the "case") in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident'(Yin, 2014, p. 16). The 'case' in this case study is the HBC-HBE online course, and the context is the care environment of the participants on HBC-HBE. Case study has been used to examine a wide range of educational phenomena including 'an individual, such as a teacher or student; an institution such as a school; an event, project or programme within an institution (Day Ashley, 2017, p. 114). This case study will investigate a programme of study.

As Cohen, Manion and Morrison (2011) point out

> Case studies can establish cause and effect ('how' and 'why'); indeed one of their strengths is that they

> observe effects in real contexts, recognizing that context is a powerful determinant of both causes and effects, and that in-depth understanding is required to do justice to the case (p. 289).

Other scholars agree that ‘case study is a very flexible methodology (and) is particularly popular among researchers examining online or blended learning in a single course or program (sic)’ (Picciano, 2016, p. 17), as is the situation in this thesis.

3.4.2 Rationale for Case Study Methodology

Case study as a research methodology is suited to real-world situations, especially when ‘there are many variables in a single case, and hence, to catch the implications of these variables usually requires more than one tool for data collection and many sources of evidence’ (Cohen, Manion and Morrison, 2011, p. 289). Chapter two set out the array of variables involved in dementia care practice (section 2.4), and in online dementia family carer training courses (section 2.8). Put simply, there are too many variables to manage and isolate to conduct a purely quantitative method of enquiry, even if this was consistent with my own research philosophy. In addition, I agree with Chan *et al.'s* (2010) assertion that ‘qualitative research is a good approach to assess the particular experiences of a particular group of health consumers’ (dementia family carers in this case) (p. 167). And yet as the researcher I am mindful of the advantages too of a partly quantitative approach to specifically answer the two research questions in this thesis, as I will outline in section 3.6.

What is at the heart of this research is the aim to get a better understanding of if and how the HBC-HBE online course supports learners. This is a complex question and will require a study and a researcher that can probe ‘beneath the surface’ (Cohen, Manion and Morrison, 2011, p. 296) of the learner experience. Firstly, to try to understand if and how the course supported learners. Secondly, to try to understand which elements of the course they found supportive in terms of how they learned on the course. These elements are referred to as ‘the instructional dynamic’ that is learners’ engagement with content, tutors, fellow learners and the learning environment (Ball and Forzani, 2007). This is important as it will help the provider and researcher design future courses that meet the expressed needs and learning experience of this cohort of learners.

It is also the case that the boundary between phenomenon and context is blurred for learners on the HBC-HBE course. It is so in the sense that learners are engaged with materials and communications (educational phenomena) that are designed to influence and improve their life context – the aspect of caring for a family member with dementia. The participants are practicing care as they learn on the course, so it could be argued that for them learning and doing care are taking place simultaneously.

3.4.3 Case Study Design

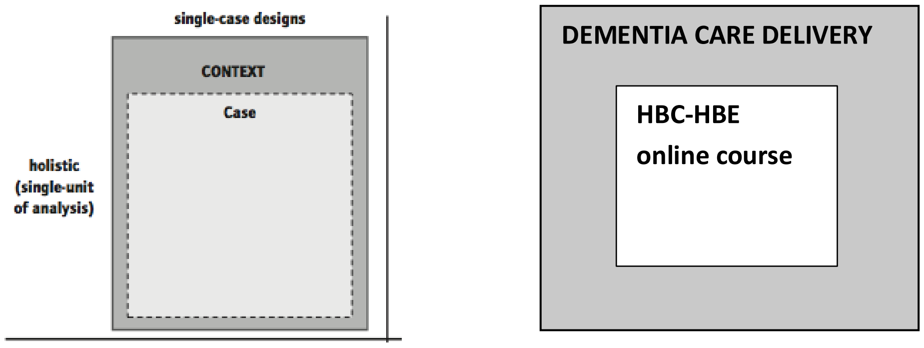
I will now set out and describe the elements in my Case Study design. Table 3.1 below provides a summary of the main components.

TABLE 3. 1: OVERVIEW OF CASE STUDY DESIGN

Methodology	**Research Subject**	**Method**	**Data Analysis**
Single Embedded Descriptive / (Explanatory) Case Study – to answer 'how' and 'why' questions	Home Based Care-Home Based Education - An Online Learning Course for family carers of people living with dementia. How does HBC-HBE support dementia family carers? How can HBC-HBE better support dementia family carers?	Multiple Methods • Online Questionnaire with closed and open questions • One-to-one interviews.	Yin (2014) Explanation Building

The case in question – the bounded system – is the online HBC-HBE course. It is a single specific course offered by ASI to dementia family carers. The context is dementia care as actively practiced by course participants. The course structure and content has been described in chapter one of this thesis. The course is unique in that it is only available to a specific cohort of learners. To that end, this case study will be a single embedded case study best represented in Figure 3.4 below (Yin, 2014, p. 50).

FIGURE 3. 4: SINGLE EMBEDDED CASE STUDY



Adapted from Yin (2014 p. 50)

There are several types of case study. In keeping with my research philosophy, and to answer the research questions, this case study will be primarily ‘descriptive’. Descriptive case studies ‘describe a phenomenon within its real-world context’ ((Yin, 2014, p. 238).

The case study will also be partly ‘explanatory’ that is, ‘a case study whose purpose is to explain why some condition came to be (e.g. how or why some sequence of events occurred or did not occur)’ (Yin, 2014, p. 238). The condition in question is ‘support’, in relation to if and how learners have felt supported on a particular learning programme, and how the course provider may better support learners as they care for a person living with dementia.

This case study will use multiple methods to find out the views and feelings of participants. The multiple methods consist of a detailed online questionnaire, followed by one-to-one semi-structured interviews with learners – these will be outlined in further detail in 3.6 Research Methods below. This research will seek to build a stronger understanding of how and why learners on HBC-HBE feel supported. To that end, I will use primarily narrative accounts ‘to encompass the wealth of information …at the level of the end-user’ (Christie *et al.*, 2018, p. 57). This will allow me to build my own knowledge so that I have a better understanding of the complexities - especially around the concept of support - of caring for somebody who has dementia within their family network. As we will see, the process of ‘explanation building’ (Yin, 2014) will be an iterative one in that my analysis will build on my initial literature review through a repeated process of data gathering and analysis.

3.5 Approach to Theory Development

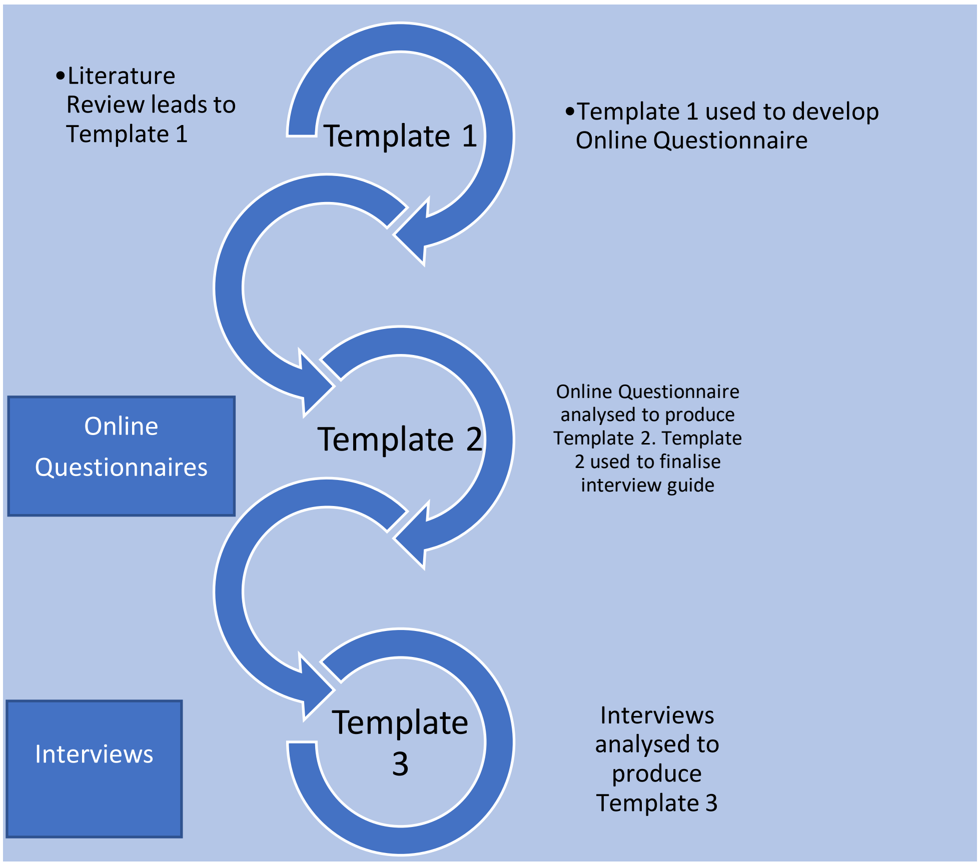
Approaches to theory development are important in any research project (Saunders, Lewis and Thornhill, 2019). While this research is not primarily motivated by developing new theories *per se*, it is looking at the issue of 'support' for a specific cohort of adult learners who are dementia family carers. The previous chapter contained an overview and analysis of the academic research literature on how online education can and does support family carers summarised in section 2.8 above.

This study used an abductive approach to theory development where I collected 'data to explore a phenomenon, identify themes and explain patterns, to generate a new or modify an existing theory which you subsequently test through additional data collection' (Saunders, Lewis and Thornhill, 2019, p. 153). The theory in question is related to how dementia family carers are supported through online interventions described in section 2.8 above. This consisted of the learning environment, peer contact, information, education and professional / tutor / expert advice and psychological support.

This abductive approach has parallels to Yin's (2014) 'iterative nature of explanation building….where the final explanation is likely to be a result of a series of iterations' (p. 149). In this thesis, the iterations are in relation to the templates developed to present the research findings. These templates have been developed and refined by analysing data at different points in time during the research project.

The abductive approach is outlined in Figure 3.5 below. It involved an initial review of the literature as outlined in chapter two. This led to the development of the Summary of Supportive Elements in Online Dementia Family Carer Training. The Summary of Supportive Elements in Online Dementia Family Carer Training was used to produce Template one. Template one was used to develop the questions in the online questionnaire. The online questionnaire was administered, and answers were analysed. This led to the development of Template two. Template two was used as the basis for interview questions. Interviews were carried out and analysed leading to the development of the final Template three.

FIGURE 3. 5: ABDUCTIVE APPROACH TO THEORY DEVELOPMENT



3.6 Research Methods

The research methods in this study consisted of, firstly, an anonymous online questionnaire and, secondly, a series of one-to-one interviews with participants on the HBC-HBE course. Online questionnaires have many advantages. For me as the researcher they include low administration costs and fast and easy distribution to the target audience. For the respondent there is the convenience of completing the questionnaire at a time that suits them (Cohen, Manion and Morrison, 2011, p. 280). These were important considerations in this research, and I believed that as the respondents had already taken part in an online course, they would be familiar with using the internet, and would therefore be able to navigate through the online questionnaire.

Interviews are a widely used instrument for data collection (Cohen, Manion and Morrison, 2011, p. 409). Semi-structured, in-depth interviews have been described as 'purposeful interactions' where the interviewer attempts to 'learn' 'discover' and 'record' 'what that person (the interviewee) thinks and feels (about the topic) and what significance or meaning it may have' (Mears, 2017, p. 183). Interviews allow the researcher to 'press not only for complete answers but for responses about complex or deep issues' (Cohen, Manion and Morrison, 2011, p. 409).

Interviews were chosen as a research method so that I could get a deeper understanding of the experiences of learners. Interviews can focus on the learner's story of a particular experience (the HBC-HBE online course), so as 'to gain insight into the processes or outcomes of the learning, as well as to track learners' perspective changes or developmental progression over time' (Drago-Severson, 2004 quoted in (Cranton and Hoggan, 2012, p. 524).

3.6.1 Sampling Strategy

This research is a case study of a particular online learning course. As such the sampling strategy is 'non-probability', where 'some members of the wider population definitely will be excluded and others definitely included' (Cohen, Manion and Morrison, 2011, p. 153). Furthermore, I used convenience sampling as I had a 'captive audience' (Cohen, Manion and Morrison, 2011, p. 154). Access to the research participants was straightforward, as all had taken part on the HBC-HBE course. Therefore, ASI had access to their names and email addresses, as these had been provided by learners on the application form when they applied to take the HBC-HBE course. Only those learners who, on their application form, had given ASI permission to contact them were invited to participate in this research study. This research was undertaken with the full permission of ASI (including in relation to data protection measures). The letter of permission from the Chief Executive Officer of ASI is attached in Appendix E below.

An email invitation to complete the online questionnaire was distributed in mid-November 2021 to 697 people. The text of the email contained a very short overview of the research, attached below as Appendix F. The email contained the Information Sheet as an attachment. The Information Sheet is attached below as Appendix G. The Information Sheet contained a link to the anonymous online questionnaire. Seventeen emails did not reach the intended recipient mostly because the email address was no longer in operation.

Of the 680 learners to which the email invitation was sent, 303 people accessed the questionnaire. However, seventy-eight people did not provide consent and therefore did not respond to any questions in the questionnaire. The majority of these did not consent to the statement ‘I understand that my data will only be used for analysis in this study and the production of academic outputs such as conference presentations, book chapters and academic articles’. In retrospect, perhaps I should have inserted the word ‘anonymous’ before the word ‘data’ in this question. This issue did not arise in the Pilot Questionnaire responses.

A note was placed at the end of the online questionnaire inviting those interested in being interviewed to email me at my student email address. Twelve people did so, and eight of them were interviewed for Part B of the research. When it became clear that other interview candidates were required, I emailed two cohorts of learners from 2021 (those taking HBC2/21 and HBC3/21) to invite people to express their interest in being interviewed. Those who expressed an interest were emailed (Appendix H) further information (Appendix I) and a consent form (Appendix J). Once consent forms were signed and returned to me interviews were arranged at a mutually suitable date and time. Four interviews were held with this cohort.

3.6.2 Piloting the Research Instruments

I piloted and distributed the online questionnaire to fourteen learners via Qualtrics in early November 2021. Responses were analysed using Qualtrics. Five of these learners were interviewed in relation to their experience of using the online questionnaire, with each interview lasting approximately thirty minutes. Based on learner feedback, I made changes to the wording and the running order of questions. Feedback was positive about the overall length of the questionnaire and how easy it was to understand the steps involved in going from providing Informed Consent to the actual questionnaire. I also sought feedback on the content and structure of the online questionnaire from the ASI Research Manager – an experienced Qualtrics user and PhD holder.

A ‘mock’ interview was held with one of my own family via Zoom to ensure the interview was recorded properly, and that there were no technical difficulties such as poor audio transcript. The first interview with Interviewee one took place on 6th May 2022 and was the pilot interview. Feedback from Interviewee one was used to further inform subsequent interviews. Interviewee one brought up the of issue of her lack of ‘emotional readiness’ to take part or benefit in HBC-HBE. Investigating Interviewee one’s lack of emotional readiness was important in helping ensure internal reliability in the case study, and this is further outlined in section 4.8.2 below. Thus, Interviewee one’s feelings about emotional readiness were explored with all other interviewees. This will be presented in further detail in chapter four.

3.6.3 Part A - The Online Questionnaire

Part A of this research consisted of an online questionnaire. The full online questionnaire is attached as Appendix K below. The online questionnaire contained thirty-two questions, of which twenty-five were closed and seven were open-ended. Table 3.2 below shows which questions in the online questionnaire of this research addressed elements of the **Summary of Supportive Elements in Online Dementia Family Carer Training** that was developed from the literature review in chapter two. The questionnaire was distributed via email on 15th November 2021. It remained open for two weeks, closing on 29th November 2021.

3.6.4 Part B – One-to-one Interviews

Interview questions were developed following analysis of responses to the online questionnaire. The interview guide is attached below as Appendix L. The interviews were semi-structured. They focussed on if and how HBC-HBE learners found the course supportive. Interviewees were also asked about obstacles to their participation on HBC-HBE, if they could suggest any improvements to the learning environment, and if they had anything else they would like to add that had not been covered in earlier questions.

The interview also sought their views on the various elements of the instructional dynamic, and the emerging theme of emotional readiness that was raised in the pilot interview. Interviewees were also asked about their views and experiences of the learning platform. Each interview was recorded on Zoom and the Zoom transcript was edited by the researcher. Zoom was chosen for its functionality, convenience, data management and security features and cost effectiveness (Archibald *et al.*, 2019).

TABLE 3. 2: PART A ONLINE QUESTIONNAIRE QUESTIONS RELATING TO 'SUPPORTIVE ELEMENTS'

Theme	Sub-theme	Part A Question
Learning Environment	Learning Platform	Q.45, Q.46, Q.47
	Course materials	Q.33a, Q.33d, Q.36a, Q.36b, Q.36c
Peer Contact	Peer support	Q.25b, Q.33c, Q.42a, Q.42b, Q.42c, Q.43
Information	Dementia	Q.26a, Q.26c, Q.31
	Dementia services	Q.26b, Q.26c, Q.31
	Dementia signs	Q.26a, Q.26c, Q.31
	Dementia symptoms	Q.26b, Q.26c, Q.31
	Dementia progression	Q.26b, Q.26c, Q.31
	Legal & financial planning	Q.31
Education	Communication	Q.31
	Family relations	Q.25a, Q.27d
	Managing behaviours	Q.27c
	Stress	Q.27b, Q.30c,
	Risks	Q.27a
	Decision making / change / new ideas	Q.29
	Care skills	Q.30e, 27d
Professional / Tutor / Expert Support	Expert support	Q.33b, Q.39a, Q.39b, Q.39c, Q.43
Psychological Support	Emotional support	Q.25, Q.30b, Q.30c.

3.7 Data Analysis

This thesis uses 'explanation building' as its analytical technique where 'the goal is to analyze (sic) the case study data by building an explanation about the case' (Yin, 2014, p. 147). I used narrative from qualitative data to describe how, and to what extent, learners felt the HBC-HBE course supports them as dementia family carers, as well as how and why various elements of the instructional dynamic led to them feeling supported.

Yin (2014) further states that such explanation building works best if ‘the explanations reflect some theoretically significant propositions’ (p. 147). The significant proposition in this thesis relates to the initial description of what the academic research literature reports about online education for dementia family carers. This is set out in the ‘Summary of Supportive Elements in Online Dementia Family Carer Training’ in chapter two above.

My analytical preference for explanation building allowed me to employ an iterative approach to construct a more refined explanation of ‘support’. This was done by using a form of thematic analysis (Braun and Clarke, 2006) called template analysis (Brooks *et al.*, 2015). Template analysis consists of analysing various sets of data to build a more compelling case, which I note may not end conclusively, but may lead to further research questions (see section 3.7.2 for full outline of template analysis).

3.7.1 Quantitative Data Analysis

Both the pilot and final online questionnaires were constructed using Qualtrics, a survey software instrument that allows the design, development, distribution, and analysis of online questionnaires. Closed questions in the online questionnaire were analysed using Qualtrics. This initial analysis was double checked through exportation of the dataset to SPSS with which I carried out further statistical analysis.

This thesis is not attempting to generalize about the population at large. Therefore, data analysis in this research project can be termed non-parametric (Cohen, Manion and Morrison, 2011, p. 606). Simple descriptive statistics were used to present the data in a meaningful way that helps to answer the research questions.

3.7.2 Qualitative Data Analysis

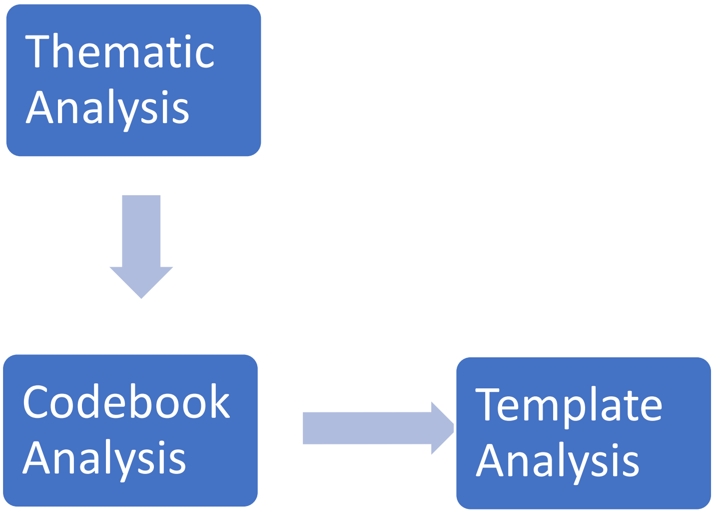
The open-ended questions in the online questionnaires and transcripts from one-to-one interviews were analysed using NVivo, a qualitative data analysis computer software package. For the online questionnaire, all responses to all the open-ended questions were imported from Qualtrics into NVivo. Several coding processes were trialled in early 2021, following background reading on the utility of various coding methods and frameworks (Saldaña, 2021).

Mindful too of the need for my coding methods to align with my research philosophy and the requirements of this research project, I was drawn to thematic analysis (Braun and Clarke, 2006) as a potential analytical method. Thematic analysis can be defined as ‘a method for identifying, analysing and reporting patterns (themes) within data’ (Braun and Clarke, 2006, p. 79). However, there are many variations of thematic analysis (Braun and Clarke, 2014, 2021). I agree with Saldaña’s description of coding as a dialectical activity involving both deductive (with some pre-determined codes) and inductive (coding with an open a mind as possible) techniques:

> As an inductive coding system is constructed and becomes solidified, it then becomes a deductive coding system for the data analyses that follow. One cannot help starting a project with some knowledge about what may be found. Yet, investigators must also remain open to new discoveries and constructions of knowledge about the human condition (Saldaña, 2021, p. 41).

In this thesis I used template analysis to examine my qualitative data. Template analysis is a form of codebook analysis. Codebook analysis is a ‘version’ of thematic analysis (Braun and Clarke, 2021, p. 333). Figure 3.6 locates the position of template analysis as a type of thematic analysis.

FIGURE 3. 6: LOCATION OF TEMPLATE ANALYSIS AS TYPE OF THEMATIC ANALYSIS



Braun and Clarke (2021) outline three 'versions' of thematic analysis, one of which is codebook analysis. I was drawn to codebook analysis for several reasons. Firstly, it sits broadly within a qualitative paradigm with some pragmatic compromises (p.333-334). This is consistent with my own interpretive research philosophy. Codebook thematic analysis uses a structured coding framework, sometimes called a template. Further, it employs the values of what Braun and Clarke call 'reflexive thematic analysis,' especially in terms of approaches to coding reliability (where reliability between coders is not necessarily required). Codebook thematic analysis also recognises and values the subjectivity of the researcher. This is an important point given my own positionality as an insider researcher.

Further, they state codebook thematic analysis can be undertaken by novice researchers and 'the required output can often be a descriptive or summative analysis of semantic meaning with results accessible to, and actionable by, practitioners and stakeholders' (Braun and Clarke, 2021, p. 335). This is consistent with the rationale behind this research project, where I want to find out more about how HBC-HBE can better support dementia family carers.

In developing my themes, I used template analysis as described by Brooks *et al.*, (2015), and outlined in Table 3.3 below. As stated earlier, template analysis is a form of codebook analysis (Braun and Clarke, 2021, p. 335), 'which emphasizes the use of hierarchical coding but balances a relatively high degree of structure in the process of analysing textual data with the flexibility to adapt it to the needs of a particular study' (Brooks *et al.*, 2015, p. 203).

TABLE 3. 3: FEATURES OF TEMPLATE ANALYSIS

Template Analysis
Compatible with range of research philosophies, including interpretive
Flexible coding guided by initial set of *a priori* codes
Development of a coding template that is applied to further data, revised and reapplied
Emphasis on reflexivity of researcher

Adapted from King, (2012), p. 427).

Template analysis lends itself well to an iterative approach where a coding template is developed following the analysis of a subset of data, 'which is then applied to further data, revised and refined' (King, 2012, p. 427). This is consistent with Saldaña's notion of coding as a dialectical activity that was outlined earlier in this section. As such it fits well with my approach, which is to use the Summary of Supportive Elements in Online Dementia Family Carer Training as my initial set of *a priori* themes in Template one (Table 3.4 below). Template one was used as a starting point to analyse further data namely via the online questionnaire and one-to-one interviews. This is consistent with my abductive approach to theory development outlined in Figure 3.5 in Section 3.5 above.

TABLE 3. 4: TEMPLATE 1 – SUMMARY OF SUPPORTIVE ELEMENTS IN ONLINE DEMENTIA FAMILY CARER TRAINING

1. Information on:
Dementia
Legal and Financial Planning
Progression
Services
Signs and Symptoms
2. Education on:
Activities and Lifestyle
Care Skills
Communication
Decision Making
Family Relations
Managing Behaviours
Risks
Stress
3. Support From
Expert / Professional / Tutor
External Services
Peers on the Course
4. Learning Environment
5. Psychological Support

The steps involved in template analysis are set out in Table 3.5 below, together with a timeframe to show when I carried out each step in this research project.

Step 1: Become familiar with the data. I copied responses to all open-ended questions into Word documents from Qualtrics. I read and re-read all these documents. I trialled a number of coding types (In Vivo and Process / Action coding as both were recommended by Saldaña for analysis of case studies) before deciding to use Template Analysis as my analytical strategy and Descriptive and Values Coding as my coding methods. Descriptive Coding uses short phrases to describe a passage of text, usually a noun and is suited to new or novice researchers. This was combined with Values Coding which is ‘the application of codes to qualitative data that reflect a participant’s values, attitudes, and beliefs, representing his or her perspectives or worldview’ (Saldaña, 2021, p. 167).

TABLE 3. 5: STEPS INVOLVED IN TEMPLATE ANALYSIS

Step	What is involved?	What did I do?	When did I do it?
Step 1	Become familiar with the data	Read and re-read all the responses to open ended questions in Online Questionnaire	March 2022
Step 2	Carry out preliminary coding	Using NVivo, I coded all data by using descriptive words to ascribe meaning to all the text, using Template 1 (*a priori* codes) as the basis for the template	April 2022
Step 3	Organise the emerging themes into meaningful clusters	Identification of potential emergent themes by grouping individual codes under parent codes	April 2022
Step 4	Define the initial coding template	Tidy up the codes and use researcher knowledge to recognise themes that tell the story of the data collected so far, which is a subset of all the data (Template 2)	May 2022
Step 5	Apply initial template to further data and modify as necessary	Data from interviews was analysed using Template 2.	July-August 2022
Step 6	Final interpretation stage leading to final Template 3	Finalise the template by applying it to the full data set	September – November 2022

Step 2: Carry out preliminary coding: Using Descriptive and Values Coding, I coded answers to all the open-ended questions in the online questionnaire, using and refining Template 1 (Table 3.4 above). Template one contained my initial themes which were Informational Support, Educational Support, Support Sources, Learning Environment and Psychological Support. These were extended to include new headings based on the number of codes under the headings of Emotions; Learning Environment was Good; Satisfaction with the Course; Suggestions and Person-centred Approach.

Step 3: Organise the emerging themes into meaningful clusters. Figure 3.7 below shows the start of the clustering process whereby I highlighted the codes with twenty or more references. These were:

FIGURE 3. 7: CLUSTERING OF CODES

Informational Support: Dementia	26
Tutor as Expert	53
Peer Support	107
Emotions: Re-assurance	38
Emotions: Confidence	24
Emotions: Connected	31
Course Materials	37
Video Meetings	20
Lack of engagement: Time	25
Satisfaction with the course	84
Gratitude from participants	26
Suggestions: No suggestions, happy	33
Moodle: User friendliness	33

Clustering provided the catalyst for theme development. For example, it became clear that Emotions were going to be an important focus in theme development. Other areas presented themselves as being important – tutor as expert and peer support. My focus then was to read through the codes and quotes from learners to try to assemble a more meaningful set of themes.

Step 4: Define the initial coding template. Once clustering was complete and reviewed, I themed the data ‘Categorically (a method that) provides descriptive detail about the patterns observed and constructed by the analyst’ (Saldaña, 2021, p. 259). This led to the production of Template two. Template two had eight themes:

Theme 1: Learners were mainly satisfied with the course and could articulate how it would continue to benefit them in the future.

Theme 2: Many learners gained a range of skills and practical tips from participating on the course.

Theme 3: The course helped to support learners psychologically in terms of meaningful connections with tutors and other carers, which caused increased levels of confidence and feelings of reassurance.

Theme 4: Learners valued each component of the ‘instructional dynamic’, though some found it difficult to distinguish their individual contribution to their learning experience.

Theme 5: Most agreed that the online learning environment allowed learners to interact meaningfully, but some felt challenged by it.

Theme 6: Participation and engagement with course activities and materials was impacted by Moodle usability issues and by characteristics of learners.

Theme 7: More needs to be done to support this cohort of learners in terms of wider supports and more education and training.

Theme 8: Moodle needs to be more user-friendly and easier to use.

As an example, the hierarchy of theme five is provided in Figure 3.8 below together with the number of references to each code.

FIGURE 3. 8: TEMPLATE 2 CODES RELATING TO THEME 5

Theme 5: Most agreed that the online learning environment allowed learners to interact meaningfully, but some felt challenged by it	
5.04 Video Meetings	20
5.04.1 'Video meetings provided real time answers'	2
5.04.2 Opportunity to ask your own specific Questions	1
5.04.3 Video meetings info enhanced other aspects of the course	1
5.03 Discussion Forums	7
5. Learning environment was good (Moodle)	14
5.01 Instructional Videos	6
3.5 Admin and IT Support	3
5.05 Course structure was logical	2
5.06 Learning 'at my own pace'	2
6.9 Interactive and easy to use	1
5.1.9 IT issues prevented further participation	2
5.1.9.2 Poor home internet quality	1
5.1.9.3 Poor laptop skills	2
7.2.5.2 Too much scrolling	1
7.2.5.3 Not suitable course for those with poor IT skills	4
7.2.6 Compared to F2F	6
7.2.7 Privacy	2

Step 5: Apply the initial template to further data and modify as necessary. Template two was used as the basis for developing questions for the one-to-one interviews, and as the starting point for analysing the transcripts from the one-to-one interviews.

A total of twelve one-to-one interviews were carried out between 6th May and 1st June 2022. Following analysis of interviews Template two was modified and adjusted. I added some new codes, especially in relation to emotional readiness. The themes were re-arranged to specifically answer the research questions. For example, theme seven was amended and codes relating to how ASI could provide general support to learners were omitted, as they did not answer the research questions.

I analysed the revised set of codes again, and this fresh analysis led to the development of a final set of themes in Template three. I became swamped in codes, so undertook an exercise to amalgamate and refine codes (Flick, 2018, p. 44). Secondary coding was also carried out, and final themes were re-formulated specifically to answer the research questions. They will be presented as Template three in chapter four Research Findings and Discussion.

3.8 Validity and Reliability of Data

It is important that the instruments to collect data used in this thesis are seen to be useful for the purposes of the research. This thesis collected quantitative data through closed questions in the online questionnaire. It also collected qualitative data through open ended questions in the online questionnaire and in the one-to-one interviews. There are two methods to determine such usefulness. They are validity and reliability. In the pages that follow steps taken to ensure validity and reliability in this thesis will be presented.

3.8.1 Quantitative Data Validity and Reliability

Content validity refers to whether the items in the online questionnaire are suited to measure the underlying variables. For this research study the variables that were deemed important for supporting dementia family carers were initially taken from previous literature and studies about this cohort of learners (literature review leading to Summary of Supportive Elements in Online Dementia Family Carer Training leading to Template one).

‘Face validity’ was achieved ‘by asking respondents whether the instrument or test looks valid to them’ (Muijs, 2004, p. 66). This validity criterion was measured during the pilot questionnaire phase of this research project where fourteen family carers completed the pilot questionnaire and six were interviewed for specific feedback.

Based on my own knowledge and from the conclusions in the literature review in this thesis, I did expect that HBC-HBE would support at least some learners, given that it was similar to several of the interventions examined in chapter two. This is in line with ‘*Predictive* *validity* [which] refers to whether or not the instrument you are using predicts the outcomes you would theoretically expect it too (sic)' (Muijs, 2004, p. 67).

To demonstrate concurrent validity 'data gathered from using one instrument must correlate highly with data gathered from using another instrument' (Cohen, Manion and Morrison, 2011, p. 189). This was achieved in this thesis in two ways. Firstly, data gathered from the pilot online questionnaires produced findings that were similar to data gathered from the actual online questionnaires. Secondly, there were many similarities and consistencies in the data collected using two different instruments as will be presented in chapter four.

Construct validity 'concerns the extent to which a particular measure or instrument for data collection conforms to the theoretical context in which it is located' (Cohen, Manion and Morrison, 2011, p. 188). Questions in the online questionnaire used in my research were developed following consultation of other relevant studies that were attempting to measure similar concepts (Lewis, Hobday and Hepburn, 2010), or in similar fields such as measuring learners' experiences of using information and communication technology (Torp, Bing-Jonsson and Hanson, 2013; Mierlo *et al.*, 2015).

Reliability in quantitative research has two main forms – *repeated measurement* and *internal consistency* (Muijs, 2004, p. 72). Repeated measurement means measuring the same audience twice to see if they provided the same scores. This was not consistent with the design for this study. However, it should be noted that the mean scores on the pilot questionnaire were broadly similar to those in the final questionnaire.

Internal consistency 'refers to how homogeneous the items of a test are or how well they measure a single construct' (Muijs, 2004, p. 73). In the online questionnaire used for Part A of the study, internal consistency of sub-scales was measured using a co-efficient alpha (Cronbach's alpha), and all of the internal subscales scored over 0.7 indicating a good measure of internal consistency, see Appendix M for full details.

However, two sub-scales had a low score, those for 'Emotional Support' and 'Overall Impact'. The Emotional Support scale in the online questionnaire only used two items. This is much smaller than other measures of emotion such as the twenty-four item Achievement Emotions Questionnaire (AEQ) (Pekrun *et al.*, 2011). Following feedback from the Pilot Questionnaire, the number of questions were kept to a minimum. To strengthen and support the data regarding emotional support, Part B of this research project explores in much more detail the issue of emotion, and emotional readiness.

The scale that attempted to measure Overall Impact also scored a low figure of 0.397 for internal consistency. As already mentioned, I was very mindful of not making the questionnaire too lengthy. While the measure of overall impact as a concept or scale may not have been internally consistent, nevertheless important trends may still be apparent from deriving simple descriptive statistics and combining this with qualitative data, as outlined in chapter four below. In addition, the issue of ‘overall impact’ was further addressed in Part B of the research – the one-to-one interviews.

3.8.2 Qualitative Data: Reliability

Some writers argue that reliability is not a useful concept in qualitative research, preferring the term ‘dependability’ (Lincoln and Guba 1985 quoted in Cohen, Manion and Morrison 2011). For them, dependability involves

> member checking (respondent validation), debriefing by peers, triangulation, prolonged engagement in the field, persistent observations in the field, reflexive journals, negative case analysis and independent audits (Cohen, Manion and Morrison, 2011, p. 202).

This thesis has used all of these indicators to aid reliability. Interviewees were sent transcripts of their interview for checking and accuracy. Several of them returned transcripts with additions and edits. In relation to debriefing by peers, I presented interim findings of my thesis at an international conference of researchers and practitioners working in dementia in June 2022 as a poster. The poster is attached as Appendix N below.

At its simplest, triangulation can be defined as ‘the use of two or more methods of data collection in the study of some aspect of human behaviour’ (Cohen, Manion and Morrison, 2011, p. 195). This study is characterised by what Denzin 1970 quoted in Cohen, Manion and Morrison (pp. 196) terms *methodological triangulation* – that is the use of different methods on the same object of the study. A form of triangulation was also attempted in chapter two, where literature on individual interventions was combined with literature from systematic reviews, to produce the Summary of Supportive Elements in Online Dementia Family Carer Training.

I would argue that regarding engagement in the field, my own location and practice have been important factors in planning and executing this research project. I have worked at ASI since 2013, and in online education since 2006. I have been thinking about this field of study for a long time, and have engaged in previous research and academic discourse in relation to this topic (Timmons, Olstad and Vansteenkiste, 2016; Timmons, 2018; McHale *et al.*, 2019; Casey *et al.*, 2020).

Research participants in this study were dementia family carers who had taken the HBC-HBE course in the years 2019, 2020 and 2021. I deliberately wanted to seek and obtain the views and range of voices of participants over a prolonged period of time – persistent observation – 'in order to establish the relevance of the characteristics for the focus' (of the study) (Cohen, Manion and Morrison, 2011, p. 185). Additionally, I conducted my field work from November 2021 to June 2022.

The concept and practice of reflexivity is an important feature of professional discretion and ethical practice (D'Cruz, Gillingham and Melendez, 2007). Reflexivity has been defined as 'a process that enables researchers to critically examine the nature of their work and how their assumptions, underlying values, and preconceptions affect the research produced' (Alley, Jackson and Shakya, 2015, p. 427). To aid my reflexivity I kept notes on meetings with my supervisors. These acted as a reflexive guide to my studies. An ongoing challenge was 'to stay in the moment' within my research journey and to acknowledge the tension and difficulty of this, while also embracing the subjectivity of my position. Achieving this balance remained an ongoing challenge throughout this research project. This was particularly acute when analysing the data and writing up chapter four. I had to ensure I was accurately interpreting and representing the data collected from research participants.

Moreover, my reflexivity allows me to acknowledge the potential of power imbalances and bias in my research endeavours. Floyd and Arthur (2012) provide a useful summary of what being an insider researcher means 'being emotionally connected to the research participants' while also understanding that 'the researcher's position…may also act as a constraint, limiting who is willing to participate and what is revealed' (Floyd and Arthur, 2012, p. 173).

The pilot interview with Interviewee one proved to be different from the majority of the rest of learner experiences, in that this person was quite negative about her course experience. I used her story as a segment in my interviews with all other candidates (Interviewees two to twelve) so that I could get their perspectives on the issues Interviewee one raised, particularly about emotional readiness to undertake and participate in HBC-HBE.

3.8.3 Enhancing Quality in Qualitative Research

Tracy (2010) sets out eight criteria that she believes provide a useful framework for quality in qualitative research. Some of these quality criteria are addressed elsewhere in my thesis, for example ‘worthy topic’ in section 1.7 above, ‘ethics’ in section 3.9 below, and ‘significant contribution’ in section 5.3 below.

Others can be difficult for the researcher themselves to judge or measure. For example, ‘resonance’ which is defined as ‘the researcher’s ability to meaningfully reverberate and affect an audience’ (Tracy, 2010, p. 844). I have endeavoured to show how online learning can and could better support dementia family carers, and hopefully my findings will have transferability value to a range of practitioners in dementia and related fields – see section 5.1 below.

Time will tell if my research provides a ‘significant contribution’ (another of Tracy’s (2010) quality criterion). For example, she mentions ‘theoretical significance’ and I am confident that my findings have improved our understanding of the processes by which how online learning can be a support to dementia family carers. The findings may also be practically significant in that this research has provided ASI with an action plan on how to make HBC-HBE more supportive. It has also provided a catalyst for strategic thinking within ASI with a commitment to seek additional state funding to increase the number of course participants as soon as possible.

I am hopeful that my thesis has what Tracy (2010) terms ‘meaningful coherence whereby ‘the study hangs together well. The reviewed literature situates the findings. The findings attend to the stated research questions or foci. Finally, the conclusions and implications meaningfully interconnect with the literature and data presented’ (p. 848). I have made every effort to achieve meaningful coherence, but I will leave it to the reader to judge if this is actually the case.

3.8.4 Quality in Case Study Design

As the natural setting for this research is the case, and as the methodology is a case study methodology, I will discuss further below how the quality of this case study addresses issues around qualitative data validity. Yin (2014) outlines four quality tests for Case Study design. I will very briefly look at these in turn below.

3.8.4.1 Construct Validity

This involves 'identifying correct operational measures for the concept being studied' (Yin, 2014, p. 46). I have used multiple sources of evidence including a detailed online questionnaire and in-depth interviews with twelve people who completed HBC-HBE at various times over the past three years. In addition, I have sought to establish a chain of evidence with an array of quantitative data presented using simple descriptive statistics. Qualitative data has been analysed using NVivo, which allows the researcher to enhance the validity of research findings by managing large amounts of data, and by offering facilities to retrieve data and codes related to specific topics (Flick, 2018, p. 44).

3.8.4.2 Internal Validity

This type of validity is used for explanatory case studies and involves seeking causal relationships 'whereby certain conditions are said to lead to other conditions' (Yin, 2014, p. 46). This case study is mainly descriptive with an element of explanation building through narrative accounts of how learners describe the extent to which they felt HBC-HCE supported them as family carers.

It used explanation building as described above as its analytical technique (see Table 3.1). Research Question one asks How does HBC-HBE support dementia family carers? Internal validity can also be addressed by focussing on rival explanations. This was of particular importance in Part B of the research where Interviewee one's experience around emotional readiness was discussed with all eleven other interviewees.

3.8.4.3 External Validity

External validity involves 'defining the domain to which a study's findings can be generalized' (Yin, 2014, p. 46). Based on my research questions, I am concerned with the experiences of learners on one course of study. While I do not seek to generalize their experiences to the general population, I do think this research will be of interest to educational researchers more broadly, and practitioners in the field of online education, especially those who are supporting family carers or other groups involved in emotional journeys.

3.8.4.4 Reliability

The goal here is to minimise errors and biases in the study (Yin, 2014, p. 49). I have endeavoured to be as transparent in the development and execution of this case study, and developed a case study protocol to assist me in this project. It is attached below as Appendix O. The protocol details the procedures that I followed and the rationale for so doing. This should allow other researchers to repeat this case study, thereby increasing reliability. To further increase reliability of my case study design, all my data is contained in Qualtrics and NVivo – my case study database.

3.9 Research Ethics

Floyd and Arthur (2012) 'put forward the notion of external and internal ethical engagement for insider researchers' (Floyd and Arthur, 2012, p. 172). The external relates to the activities external to the conducting of research activities, for example going through the ethical approval process. It is important to note that this research project was approved by the Research Ethics Committee at Dublin City University on 15th June 2021 (DCUREC/2021/139), which is attached as Appendix P below.

The internal 'relates to the ethical and moral dilemmas that insider researchers have to deal with once "in the field" linked to ongoing personal and professional relationships with participants, insider knowledge, conflicting professional and researcher roles, and anonymity' (Floyd and Arthur, 2012, p. 174). Utilising my reflexive approach, I must acknowledge the potential possibility that participants in my research took part with various motives that may have biased their contributions. For example, they may have wanted 'to give something back', to ASI who provided them with a free course, or other services in their time of need; or to say what they thought I wanted to hear.

My positionality as the researcher, especially in relation to my ‘insiderness’ (Mercer, 2007) was explored in section 1.8 above. It is important to acknowledge that as the manager of HBC-HBE I had access to course participants and their materials and the documentation they produced on HBC-HBE. At one point I did consider using course documentation as a source of data. However, I decided against this as I felt it would have blurred the ethical lines in that participants would not have provided consent for those materials to be used at the time they produced those materials. There were also potential issues in relation to data protection and the transfer of personal data between two institutions – The Alzheimer Society of Ireland where I work and Dublin City University where I am a student. It should also be noted that I formally requested and was granted permission from the CEO of ASI to undertake this research, and his letter of permission is set out in Appendix E below.

My positionality also meant that I had to be mindful of separating out my ongoing work and my role as a researcher. At times this was difficult. However, I have tried to separate both roles by closely following my case study methodology, by only reporting on my analysis of my research data, and by being reflexive at all times. In addition, from a work perspective, I did not talk about my research to work colleagues. I did not seek out any advice (except regarding the design of the online questionnaire – see 3.6.2 above).

During the data collection phase of my research, especially when I was conducting interviews I tried to practice ‘relational ethics’ by being emotionally connected to participants by displaying ‘compassion, nurturance, affection, promise keeping and intimacy’ (Tracy, 2010, p. 847). In short, I tried to make interviewees feel comfortable and to counter any feelings of a potential power imbalance they may have had in relation to my own positionality.

Simultaneously, I had to be mindful of the power relations between myself and research participants. Invitations to participate in this research was only sent to HBC-HBE course participants who had already provided consent to be contacted for initiatives that may be of interest to them. In addition, both Information Sheets for Part A and Part B of the research (Appendix G and I) had explicit statements that participation in the research was voluntary, and that withdrawal without penalty was allowed at any time. In addition, candidates were advised that participation or non-participation would have no implications for partaking in any other interventions offered by ASI. Consent Forms (Appendix J and K) also clearly stated that participation in the research would not bring direct benefits to candidates.

I was always conscious especially in interviews to be receptive to negative and positive comments made by research participants. I also had to be mindful of the potential negative emotions that might be experienced by interview candidates. I devised an Interview Candidates Support Plan which set out a series of steps to follow in case the interview candidate became upset during the interview. This was submitted with my Ethics Application Form and is attached below as Appendix Q.

However, against all of that is the reality that the data I gathered have helped me to meaningfully answer my research questions. As will be outlined in chapter four, there is enough evidence that participants provided real and useful information to significantly answer the research questions and to increase my own knowledge of how this course works (or doesn’t work) for family carers of people living with dementia.

3.10 Chapter Summary

This chapter has set out the case study research methodology that was used in this thesis. The methodology was derived from my research philosophy, which itself was comprised from my ontological, epistemological and axiological positions. Research methods were described in some detail and comprised both quantitative and qualitative approaches. Data analysis techniques were described. Finally, I described measures taken to ensure validity, reliability and quality of the approach taken in this thesis.

Chapter 4: Findings and Discussion

4.1 Introduction

The findings and analysis presented in this chapter are derived from the two research instruments used in this case study of the HBC-HBE online course for dementia family carers. For a fuller description of HBC-HBE please refer to 1.3 and 1.4 above. They are (a) the anonymous online questionnaire and (b) one-to-one semi-structured interviews. Data gathered will be used to answer the two research questions: How does HBC-HBE support dementia family carers? How can HBC-HBE better support dementia family carers?

The online questionnaire was distributed in mid-November 2021 to 697 family carers who had completed the HBC-HBE course in 2019, 2020 and 2021, and who had given their consent to be contacted. These family carers were sent an email which contained a brief introduction to the research topic and a link to the anonymous online questionnaire. A total of 303 people accessed the initial part of the questionnaire. However, seventy-eight people did not provide consent and therefore did not access the online questionnaire.

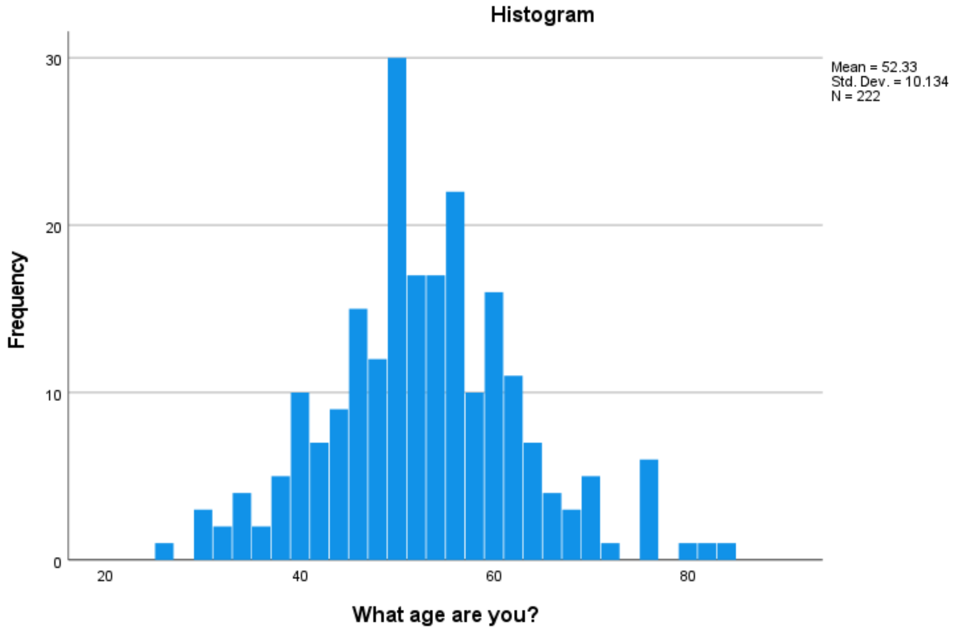
It is apparent that response rates to each section of the online questionnaire dropped slightly as respondents progressed through it, as follows: Section 1 Demographics 225 responses (thirty-three percent); Section 2 Support 209 responses (thirty-one percent); Section 3 Course Components 206 responses (thirty percent) and Section 4 Learning Platform 196 responses (twenty-nine percent).

The interviews took place in May and June 2022. Twelve HBC-HBE participants were interviewed. Interviews took place over Zoom and were recorded and transcribed. The average length of the interviews was just over fifty-two minutes.

4.2 Demographic Background of Respondents and Interviewees

Respondents to the online questionnaire were mostly female (84.89 percent or 191 people). The remainder were male (13.33 percent or thirty) or preferred not to say (1.33 per cent or three). One person described themselves as non-binary / third gender (0.44 percent). The frequency or spread of respondents’ ages is given in Figure 4.1. The youngest respondent was twenty-six, and the oldest respondent was eighty-four. The largest number of respondents (ninety-two) were aged between forty-six and fifty-six. The average age of respondents was 52.33 years of age.

FIGURE 4. 1: ONLINE QUESTIONNAIRE: AGE FREQUENCY OF RESPONDENTS



The overwhelming majority of respondents (ninety-seven percent) identified themselves as white Irish. Most respondents were experienced computer users, describing themselves as moderately (forty-three percent) and extremely (forty-one percent) confident using computers and IT equipment. Nobody described themselves as ‘not at all confident’, though three percent described themselves as ‘slightly confident’ or thirteen percent as ‘somewhat confident’.

Overall, thirty-one people (fourteen percent of total) completed the course in 2019, 106 (forty-seven percent) in 2020 and eighty-seven (thirty-nine percent) in 2021. The response rate per year, that is the number of responses divided by number of invitations was fifty-three percent for those who completed the course in 2019, thirty-nine percent in 2020 and twenty-five percent in 2021. There is an almost equal split between respondents who were participating in an online course for the first time (forty-five percent), as opposed to those who had already completed an online course (fifty-five percent). Most respondents (seventy-six percent) used a laptop computer to access the course. A further eight percent used a desktop computer, while the remainder used iPad or Tablet nine percent or smart device seven percent.

The majority of respondents were relatively new to caring for a family member with dementia. For example, fifty-six percent of respondents had been caring for up to two years. A further twenty-nine percent had been caring between two and four years, while only fifteen percent had been caring for over four years.

There was an even split between those who described themselves as 'primary' or 'secondary' carers. Primary carers provide 'the most care as opposed to secondary carers (carers who provide only some of the care and are ancillary to the primary carer)′ (Greenwood et al., 2009, p. 339). It is noteworthy that a small majority (fifty-three percent) of research participants identified themselves as secondary carers, as opposed to primary carers at forty-seven percent. This research is therefore somewhat novel, as according to one systematic review in this field, many other previous interventions were aimed at 'principal caregivers, and none…..included secondary caregivers (Etxeberria, Salaberria and Gorostiaga, 2021, p. 1178). For those describing themselves as primary carers, most were caring for a parent (fifty-nine percent), while a considerable number were caring for a spouse (twenty-eight percent). For those describing themselves as secondary carers, the majority were caring for a parent (fifty-seven percent).

Ten of the interview candidates were female and two were male. Two had completed the course in 2019, four in 2020 and six 2021. Six Interviewees were secondary carers. Five were primary or joint primary carers. One was both a primary and secondary carer – the latter 'Julia', Interviewee seven was caring for her neighbour (primary) and her father who lived overseas (secondary). Full details are provided in Table 4.1 below.

TABLE 4. 1: INTERVIEW CANDIDATES' DEMOGRAPHIC BACKGROUND

Interviewees by chronological order	Gender	HBC Year	Carer role
Interviewee 1: 'Jane'	Female	2020	Secondary carer for her mother
Interviewee 2: 'Frances'	Female	2019	Secondary carer for her mother
Interviewee 3: 'Mary'	Female	2021	Primary carer for her husband
Interviewee 4: 'Violet'	Female	2019	Secondary carer for her father
Interviewee 5: 'Margaret'	Female	2020	Secondary carer for her mother-in-law
Interviewee 6: 'Anne'	Female	2020	Secondary carer for her mother
Interviewee 7: 'Julia'	Female	2021	Secondary carer for her neighbour and Primary carer for her father
Interviewee 8: 'Louise'	Female	2020	Primary carer for her father
Interviewee 9: 'Emma'	Female	2021	Secondary carer for her mother
Interviewee 10: 'Jessica'	Female	2021	Primary carer for her father
Interviewee 11: 'Nathan'	Male	2021	Joint primary carer for his father
Interviewee 12: 'Conor'	Male	2021	Joint primary carer for his father

4.3 Reporting Research Findings

Chapter three of this thesis described how template analysis was used to analyse the responses from the online questionnaire and the one-to-one interviews. In addition, simple descriptive statistics have been used to analyse the closed questions in the online questionnaire. The qualitative dataset of completed online questionnaire returns were exported from Qualtrics into NVivo. NVivo assigned each respondent a number between 1 and 303. In what follows online questionnaire respondents will be referred to as OQR followed by their NVivo number. Interviewee respondents are numbered from 1 to 12 in the chronological order in which the interviews took place. The pseudonyms in Table 4.1 above will be used in the narrative that follows.

This is a descriptive case study. Key statistics or individual quotations will be used throughout the following sections to illuminate each theme and provide an authentic 'thick description' (Yin, 2014) of the experiences of dementia family carers on HBC-HBE. To aid 'thick description' and authenticity, the voice of family carers will be used extensively.

4.4 Theme 1: Many learners gained a range of skills and practical tips from participating on the course

Respondents agreed that participating on the HBC course provided them with a range of important information regarding dementia and available support services. In response to Q.26 of the online questionnaire, ninety-five percent agreed or strongly agreed with the statement 'The HBC-HBE course provided me with *important* information about dementia'; ninety-three percent agreed or strongly agreed with the statement 'The HBC-HBE course provided me with *new* information about dementia; while eighty-nine percent agreed or strongly agreed with the statement 'The HBC-HBE course provided me with *relevant* information about *other support services'* (my emphasis). Table 4.2 below contains the full figures.

TABLE 4. 2: HBC-HBE AS A PROVIDER OF INFORMATIONAL SUPPORT

Question	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**	**Total**
The HBC-HBE course provided me with *important* information about dementia	3%	0%	0%	32%	63%	n=208
The HBC-HBE course provided me with *new* information about dementia	2%	1%	3%	36%	57%	n=205
The HBC-HBE course provided me with *relevant* information about *other support services*	3%	1%	6%	43%	46%	n=207

Note: the % figures in some tables do not add up to 100% due to rounding up or down of decimal places.

Learner comments support these figures:

> *It thought me (sic) key nuggets of information that I never knew before [OQR: 54].*

Other comments included that HBC-HBE ‘provided a lot of information’ (OQR: 41), that was ‘really informative’ (OQR: 159). Learners also reported feeling that they had a better understanding of dementia:

> *It helped me to start to understand complexity of dementia and Alzheimer disease and give me a tools (sic) how to provide better care (OQR: 106).*

HBC-HBE participants pointed out that they had gained a lot of information and knowledge about dementia. Jessica summed up the feeling that knowledge leads to power and is a catalyst for better care practice:

> *So, I acquired some of the recommended reading for want of a better word ….um I found those really useful. Because I’m a great believer that knowledge is power, you know. If I understand how something works, I’ll be better able to manage it (Jessica, primary carer).*

Respondents linked this increased understanding to improvements in how they provided care, as evidenced by the comment above. Several commented that the course helped them understand dementia specifically (OQRs: 89, 182, 271), or what was happening to the person they were caring for (OQR: 36, 37). Others found that ‘new information re. stages of dementia was helpful’ (OQR: 72).

Mary felt that she now understands that dementia is ‘different for everybody’, and that family carers need to find ‘their own way into the jungle’. The same person also made the link between information leading to greater knowledge and understanding of dementia. Another comment was more specific, linking greater understanding of the disease to improved interactions and communication with this carer’s mother (OQR: 119).

For HBC-HBE, one respondent commented that the course gave them ‘the tools and information not only for me but my siblings’ (OQR: 23), denoting a sharing of materials with wider family members. This is similar to findings in the one of the interventions examined in chapter two the *Internet based Caregiver Support Service (ICSS)* where a participant noted that '*we* re-read the information' [my emphasis] (Chiu et al., 2009, p. 333).

HBC-HBE also provided information about what support services were available to dementia family carers. Many learners found this to be beneficial. In her interview Anne outlined how this was helpful to her:

> *the other thing I would say is definitely information about supports that are available. That was key as well. And the confidence to say no, 'I know that's available or should be', or whatever, and that was a huge help (Anne, secondary carer).*

This comment was backed up by Louise who said that the course 'pointed me in the right direction for where to go to instigate getting extra care ourselves'. This helped facilitate learners taking action as will be demonstrated in theme five below in section 4.8. HBC-HBE learners mentioned other useful types of informational support. For example, Jane found information about costs of different types of care available in her area helpful, 'Yes, financially, I was able to find out about different carers and stuff like that'.

Learners were keen to point out the educational value of participating in HBC-HBE. This entailed gaining knowledge (and sometimes information) on care skills, communication skills, managing behaviours and a host of practical ideas that were useful in their dementia care tasks. In response to Q.30 of the online questionnaire, an overwhelming majority of participants (ninety-two percent) agreed or strongly agreed with the statement 'I felt the HBC-HBE course improved the care I provided'; while eighty-five percent agreed or strongly agreed with the statement 'The HBC-HBE course improved my care skills'. The full set of figures are provided in Table 4.3 below.

TABLE 4. 3: HBC-HBE AS PROVIDER OF CARE SKILLS AND IMPROVED CARE

	Strongly disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree	Total
I feel the HBC-HBE course improved the care I provided	0%	2%	6%	49%	43%	n=208
The HBC-HBE course improved my care skills	0%	3%	12%	60%	25%	n=206

Moreover, respondents to the online questionnaire described a range of care skills in their responses to open ended questions. These included tips about ‘the importance of staying active’ (OQR: 279), and about ‘constipation, swallow, music therapy and not asking direct questions’ (OQR: 20). Another participant recognised how ‘even simple things like noise levels could be affecting her’ (OQR: 251).

Learners were keen to point out how their communication skills had improved:

> *I learned how to communicate better with the person with dementia. Learned what tone of voice works, learned what words are best to use. Learned how to agree rather than disagree with the person with dementia. Learned the art of distracting them if they become irritated. Learned how to be a support person to the primary carer and reminded them frequently of ideas we learned on the course, in order to help them through challenges (OQR: 195).*

The quote above gives a detailed descriptive insight into how this learner’s communication skills improved. The respondent above uses the word ‘learned’ in relation to these skills, showing the educational value of HBC-HBE. They also relay how they liaised with the primary carer in relation to communication skills, again demonstrating the added benefits of HBC-HBE to wider family members.

The course gave one participant ‘ideas how to communicate better and learn different ways of communication’ (OQR: 83). These included tips about ‘tone of voice and speaking more clearly’ (OQR: 119) or ‘body language’ (OQR: 33).

I-Care included a section on communication skills with a view to improving participants ability ‘to relate to the person with dementia’ (Kajiyama *et al.*, 2013, p. 549). The descriptive quote below shows how this participant now has a greater understanding of dementia and related behaviours, and that this understanding has had a significant impact on how the family provide care. In turn this has contributed to a ‘massive difference to her general mood and wellbeing’:

> *Understanding that her behaviour may be a result of something she can’t articulate. Like wetting herself. I learned that everything .... can effect (sic) her mood, behaviour or add to her confusion. The course totally changed the way we as a family interact with her, plus we made sure to implement a routine that we all follow and insure (sic) her medication and dietary requirements are met. It really made a big impact on my behaviour and how I speak to her. It has made a massive difference to her general mood and wellbeing. Plus, we understand what’s going on now, she was very good at hiding it (OQR: 251).*

One learner commented that the course ‘helped me understand dementia and the behaviours associated with it’ (OQR: 37). Moreover, some reported getting insights into why some behaviours occur and to ‘watch for triggers’ for such behaviour (OQR: 62). This knowledge and insight allowed one respondent ‘to cope better with my wife’s frustrating moments…to deal with her in a more calmer fashion’ (sic) (OQR: 121).

Respondents were also asked about how the course supported them in their care situation (Q.27 of the online questionnaire). A large number (eighty-four percent) agreed or strongly agreed that the course provided *useful* ideas on maintaining an active lifestyle for the person to whom they were providing care. The same figure (eighty-four percent) also agreed or strongly agreed that the course provided *useful* ideas about the provision of personal care. A slightly lower, but still significant seventy percent of respondents agreed or strongly agreed that the course provided *new* ideas about maintaining an active lifestyle for themselves. However, ninety-one percent of respondents agreed or strongly agreed that the course gave them *helpful ideas* about how to maintain a safe care environment. Table 4.4 below has the full details.

TABLE 4. 4: HBC-HBE AS PROVIDER OF PRACTICAL SUPPORTS

Statement	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Total
The HBC-HBE course provided useful ideas about how to maintain an active lifestyle for the person with dementia	2%	5%	9%	53%	31%	n=207
The HBC-HBE course provided new ideas about how to maintain an active lifestyle for myself	2%	5%	23%	46%	24%	n=207
The HBC-HBE course provided me with beneficial ideas about how to provide personal care	1%	2%	12%	50%	34%	n=206
The HBC-HBE course gave me helpful ideas about how to maintain a safe care environment	2%	2%	4%	48%	43%	n=207

Nathan elaborated on the benefits of practical tips on his care practice:

> *The biggest thing that benefited most on a practical level was the idea about having contrast in colours for him. Like, for example…. if you are giving him a plate to have it contrasting on the table...... And actually, began to see him (his father) benefitting from that little tip was yeah. The course was extremely beneficial and supportive in lots of ways (Nathan, joint primary carer).*

The issue and importance of contrasting colour schemes was taken up by two other research participants. Violet found the tips on decorating and 'making skirting boards have contrasting colours' useful. A respondent to the online questionnaire found a useful tip for dressing, 'before the course I laid out his clothes on the bedsheets…. I couldn't understand [why] he didn't see a white vest on a white bedsheet…. now I use coloured bedsheets and dressing him is easier every time' (OQR: 154).

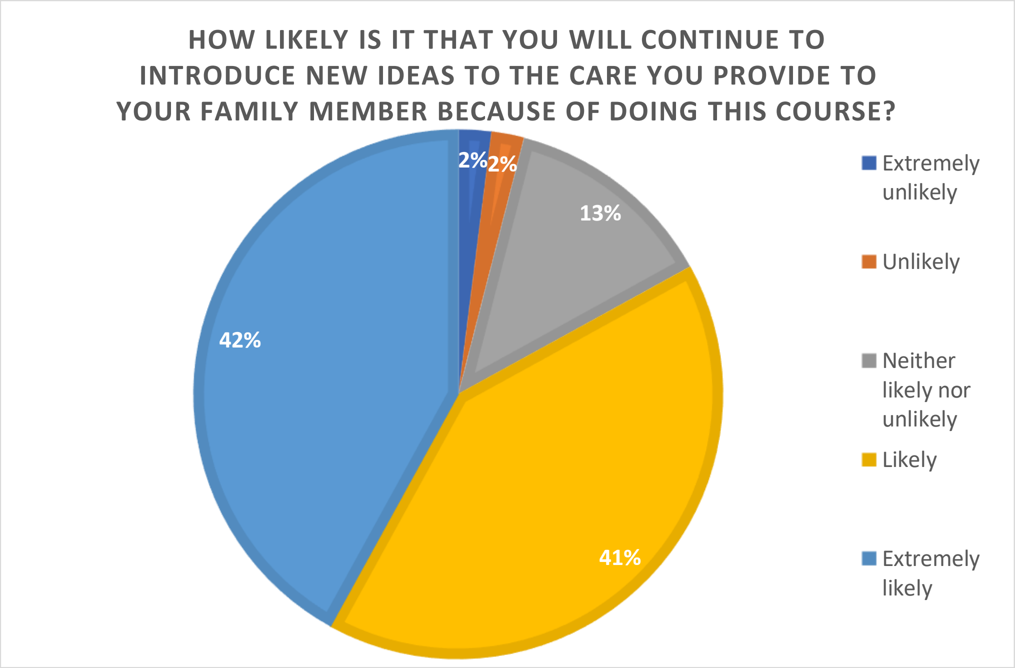
Another Interviewee, Julia, was grateful to learn about distraction techniques from a fellow course participant. These help to re-orientate the person with dementia to change conversations or repetitive behaviours, 'And the lady that I look after, I use that exact type of distraction technique all the time with her' (Julia, primary and secondary carer). Mary recognised the importance of ‘slowing everything down’, and ‘not bombarding somebody’ with a list of tasks or activities.

In addition, and importantly, the majority of learners were open to trying *new* ideas in their care practice. Figure 4.2 below shows that eighty-three percent of course participants said it was likely or extremely likely that they would *continue* to introduce *new* ideas to the care provided to their family member because of doing this course (my emphasis). These figures were supported by some individual comments, such as:

> *The information that I received from not just the tutor, but other participants meant I was able to come up with new ideas to help (OQR: 77).*

Learners commented on the importance of ‘new ideas’ (OQRs: 27 and 158), and one participant commented, ‘This course provided me with extra skills & fresh ideas to provide better care within my home’ (OQR: 256).

FIGURE 4. 2: HBC-HBE PARTICIPANTS LIKELIHOOD TO INTRODUCE NEW IDEAS TO CARE PRACTICE



Planning for the future is an important part of coping with dementia as reported in section 2.6.1.2. For example, the *Diapason* intervention had a section on planning for the future (Cristancho-Lacroix *et al.*, 2015), while relatedly the *Digital Alzheimer Centre (DAC)* addressed the issue of financial and legal matters (Hattink *et al.*, 2016). The provision of information as reported in Table 4.2 can help participants make plans. Louise mentions the importance of informational support and information imparted by other participants (or possibly the tutor) to help her cope with particular situations:

> *It [HBC-HBE] gave me and the tools (for) when particular situations arose, I could say to myself 'oh somebody spoke about that', or 'we got some information on that'. And I could go back then and look at stuff, or I would remember the stuff that had been spoken about, and I did find that helpful (Louise, primary carer).*

Other participants on HBC-HBE mentioned how they valued knowing what to expect going forward. One respondent commented that 'the interaction with course participants [was] helpful especially with regard to what to expect going forward' (OQR: 167). There was agreement among many that being in a cohort with other carers who had differing experiences and perspectives was valuable, and also helped prepare for the future (OQR: 184). In other words, the mix of experiences from dementia family carers, some of whom had been caring for a considerable period of time, was helpful to newer carers who did not have the same knowledge or experience.

4.4.2 Discussion

This theme has shown the importance of information leading to a better understanding of dementia as a 'complex disease' (Ma *et al.*, 2018), as well as providing links to appropriate services and supports. It has also shown that participants valued information that was new, useful and practical. This led to a greater understanding of dementia. It is interesting that participants felt inclined to share information within their families. This could be looked on as a kind of 'knock-on' indirect benefit of the course. It could imply that the 'reach' of the course is greater than that highlighted in Table 1.1, section 1.3 above.

This feedback strongly supports findings from earlier studies which showed that the provision of information about dementia was widely regarded as being an important component of twelve online interventions – see section 2.8 above – including *E-Care* (Finkel *et al.*, 2007), *Internet Caregiver Support Service (ICSS)* (Chiu *et al.*, 2009), *iCare* (Kajiyama *et al.*, 2013), *Story-Call* (Davis *et al.*, 2014), *Cuidate Cuidador 'Caregiver, take care of yourself'* (Pagán-Ortiz *et al.*, 2014), *Mastery over Dementia* (Blom *et al.*, 2015), *Diapason* (Cristancho-Lacroix *et al.*, 2015), *DEM-DISC* (Mierlo *et al.*, 2015), *Virtual Healthcare Neighbourhood* (Fowler, Haney and Lemaster, 2016), *Digital Alzheimer Centre (DAC)* (Hattink *et al.*, 2016), *and RHAPSODY* (Metcalfe *et al.*, 2019). This theme elaborates and describes in some detail how exactly information has supported dementia family carers participating on HBC-HBE.

Many learners also reported the benefits of gaining practical tips on how to cope with various situations (educational support). These include care skills where the figures reported in Table 4.3 compare favourably to other interventions such as *E-Care* where, 'The majority of caregivers (ninety-four percent) found the support groups valuable and sixty-five percent indicated that participation in the groups improved their caregiving skills' (Finkel et al., 2007, p. 447). The findings in this thesis add credence to the importance of educational support reported on earlier in chapter two. This thesis clearly outlines and describes the positive impact that HBC-HBE has had on dementia family carers' practical skills including managing constipation, food intake and staying active.

In chapter two it was noted that Communication was a feature of other interventions – see 2.6.1.2 and 2.8 above, most notably in *Diapason* (Cristancho-Lacroix et al., 2015) and *Partner in Balance* (Boots et al., 2016). This thesis has described exactly how dementia family carers feel their improved communication skills - such as in the tone of voice they use, distraction techniques employed, their body language - have enhanced their care practice.

Managing changing and challenging behaviours is one of the most difficult and stress-inducing parts of caring for someone living in dementia. Chiao, Wu and Hsiao (2015) report that 'the primary factor of caregiver burden was behavioural problems or psychological symptoms' (p.348). It was reported in section 2.6.1.2 that many interventions addressed this topic - *E-Care* (Finkel et al., 2007), *iCare* (Kajiyama et al., 2013), *Cuidate Cuidador 'Caregiver, take care of yourself'* (Pagán-Ortiz et al., 2014), *Diapason* (Cristancho-Lacroix et al., 2015), *WeCareAdvisor* (Kales et al., 2017), *Intervention programme for frontal* *dementia carers* (Gossink et al., 2018) and *iSupport* (Mehta et al., 2018). The self-reported ability of many HBC-HBE participants to manage behaviours is quite a significant finding of this study, as it should help to alleviate carer burden.

This theme has provided narrative accounts and direct evidence from dementia family carers about how HBC-HBE has been a support to them. In some cases, the distinction between information and education support is somewhat blurred. Just how information is turned into knowledge is not always clear. However, learners have expressed how communication skills, managing behaviours and a range of practical tips made a real and impactful difference to their care delivery practice. This contributes to our understanding and knowledge of how online interventions support dementia family carers.

4.5 Theme 2: Learners gained support through engagement with tutors, peers and course materials

This theme further explores the question of how HBC-HBE supported dementia family carers. In chapter two the Summary of Supportive Elements in Online Dementia Family Carer Training pointed to the importance of the 'instructional dynamic' (Ball and Forzani, 2007) – that is tutors, peers, materials and environment – as a potential support to dementia family carers. This theme explores if, and to what extent, this was actually the case (note the online learning environment will be examined in theme four below).

Table 4.5 below summarises responses to Q.33 of the online questionnaire and shows that the interactions with Tutors had the highest mean score of 4.29, with forty-five percent of respondents saying that interactions with tutors were 'extremely supportive' and forty-two percent saying they were 'very supportive'. The second most important component was 'interactions with your fellow course participants' (peer support) which had a mean score of 3.97. That is followed closely by 'reading the course materials' at 3.82, and finally 'completing the weekly reflective assignment' at 3.56. The 'Not at all supportive' scores for all elements are between zero and two per cent.

TABLE 4. 5: HOW SUPPORTIVE DID YOU FIND THE FOLLOWING LEARNING ACTIVITIES?

Question	**Not at all supportive**		**Slightly supportive**		**Moderately supportive**		**Very supportive**		**Extremely supportive**		**Total**	**Mean**
Reading course materials: e-books, factsheets	0%	1	6%	13	23%	48	50%	103	20%	40	205	3.82
Interactions with your Tutor	1%	2	1%	3	10%	21	42%	86	45%	93	205	4.29
Interactions with your fellow course participants	2%	5	6%	13	17%	34	41%	85	33%	68	205	3.97
Completing the Weekly Reflective Assignment	2%	4	16%	33	24%	49	39%	78	19%	38	202	3.56

Responses to Q.39 of the online questionnaire show that HBC-HBE participants found tutors supportive across different parts of the course, but mostly at video meetings, which had a mean score of 4.18. This is followed by interactions with tutor on discussion forums at 3.94 and finally feedback from tutors on weekly reflective assignments at 3.81. Full details are provided in Table 4.6 below.

TABLE 4. 6: IMPORTANCE OF TUTOR SUPPORT IN ASSISTING AND INFORMING CARE DELIVERY

Question	Not at all important		Slightly important		Moderately important		Very important		Extremely important		Total	Mean
Interactions with Tutors on Discussion Forums	3%	5	10%	19	14%	26	38%	72	36%	68	190	3.94
Interactions with Tutors at Video Meetings	2%	3	4%	7	13%	24	39%	74	43%	81	189	4.18
Feedback from tutors on Weekly Reflective Assignments	3%	6	8%	16	25%	48	31%	59	32%	62	191	3.81

Individual comments from learners’ support these finding as this representative quote shows:

> *I think interaction with the tutors was very important, their personal experience and willingness to share was very grounding. They actually knew what it was like, it wasn't just a textbook giving the perfect answers or ideal outcomes. This was real people giving real advice that works (OQR: 260).*

Tutors were seen by learners as experts – ‘the depth of knowledge of the tutor was exceptional’ (OQR: 54). Many learners felt that tutors had good facilitation skills and that they created ‘a wonderful space for all participants to share their experiences and concerns’ (OQR: 22). Another participant ‘found the facilitator very encouraging and helpful’ (OQR: 101). Participants appreciated the provision of feedback from tutors ‘that was particularly reassuring and supportive’ (OQR: 256). Also helpful was tutor advice ‘about positive actions to take’ (OQR: 36). Tutors showed other competencies. They ‘listened to everyone and what state they were at’ (OQR: 36), and showed compassion, ‘the tutor was knowledgeable, experienced and kind’ (OQR: 151).

Margaret a female, secondary carer commented that her tutor was ‘just beautiful’ in her approach to her work. This was in reference to tutor two, Table 1.2. Some tutors are clearly exhibiting kindness traits associated with a ‘pedagogy of care’ (Noddings, 2003; Adams and Rose, 2014; Cramp, 2015; Clouston, 2018), thereby going beyond the normal requirements ‘of timely feedback and positive personal comments’ (Adams and Rose, 2014, p. 6). Clearly the role of the tutor is very important. This resonates with findings in other reported interventions such as the *Internet based Caregiver Support Service (ICSS)*, ‘Caregivers felt the online therapists were professional, caring, and provided satisfactory advice’ (Chiu et al., 2009, p. 332).

However, not all participants on HBC-HBE shared this positive feeling about tutors, as this quote shows:

> *Often the tutors, while well meaning, didn't have facilitation skills, so I found that my learning was nearly in spite of them! (OQR: 34).*

Jessica thought the tutors could have been stronger and more conscientious about starting video meetings on time, instead of waiting and facilitating late arrivals who may have been having technical difficulties. She commented, ‘maybe that point [starting on time] …and being respectful of other people who are on the meeting could have been reiterated a couple of times [by the tutor]’ (Jessica, primary carer).

Evidence suggests that peer support is also an important component of the learner experience on HBC-HBE. Table 4.5 above has already demonstrated that seventy-four percent of survey respondents found interactions with peers to be either very supportive (forty-one percent) or extremely supportive (thirty-three percent). Participants on HBC-HBE gained support (defined as support / advice from other learners on the course) from their peers mostly via live video meetings and discussion forums, and to a lesser extent through private messaging on the Moodle course page, as per the figures in Table 4.7 below (Q.42 on the online questionnaire).

TABLE 4. 7: IMPORTANCE OF PEER SUPPORT IN ASSISTING AND INFORMING CARE DELIVERY

Question	Not at all important		Slightly important		Moderately important		Very important		Extremely important		Total	Mean
Interactions via Discussion Forums	4%	8	10%	19	19%	35	35%	65	31%	58	185	3.79
Interactions via Video Meetings	3%	5	6%	11	12%	22	44%	82	35%	65	185	4.03
Interactions via Message / Private Chat feature	14%	25	14%	25	28%	49	27%	47	17%	30	176	3.18

Comments from HBC-HBE participants support these figures. Participants valued sharing their experiences and stories with each other:

> *the most important thing to me was the interaction with other participants, I found it so helpful hearing their stories and it made you feel that there were others who were facing the same problems as you, which is very supportive. I liked hearing the other people's stories and the problems they were struggling with (OQR: 21).*

Learners felt that their peers 'really understood' their situations (OQR: 59), and it was this diversity of experience that was helpful. Sharing 'with other learners…makes you feel you aren't the only one in your situation' (OQR: 8). Conor expanded on this point during our interview. In answer to my direct question 'was the course a support to you? Conor replied:

> *Hugely yes, am both emotionally, from the point of view of hearing others in solidarity and others who were going through something similar or something very different or they were my age or older than me or at times younger than me. That was a great thing as well that you saw that it wasn't just a, it could affect anyone (Conor, joint primary carer).*

Sharing stories and experiences also made some people realise that their situation could have been worse. Jessica had this answer to the same question 'did you find the course supportive at all for you?':

> *Yeah, definitely I did yeah. I learned a lot on the course Fergus you know and sometimes you know you think you're the only one that's going through this. And you think that this situation that you're in is the worst in the world. And what the course actually made me realise was first of all you're not on your own. And second of all you're actually very lucky because Dad was in a situation at that stage of the game where he was relatively well managed, you know. We had supports coming in (Jessica, primary carer).*

A lot of learners felt an emotional connection to other carers (this will be explored further in theme five below), as evidenced by this comment:

> *I found it most helpful speaking to the other participants. They were experiencing a lot of the same things, but also feelings and emotions as myself. It was nice to speak to someone outside of my immediate family who could relate to my experience (OQR: 91).*

Some also felt that it was positive hearing from other dementia family carers about what lies ahead, and this comment is typical of this sentiment:

> *Alzheimer's was completely new to us. We never had any dealings with dementia in our family. The group session was extremely good as it gave us an idea of what to expect but also how to deal with situations (OQR: 266).*

This is a very important quote as will be revealed in theme five. Knowing what to expect is useful (but for some very scary). Therefore, combining this knowledge with ideas and tips about how to ‘deal with situations’ is vital.

Others commented about strong bonds and friendships that were facilitated by participating on the course. This long quotation from a female secondary carer whose father was a spousal carer (and participated on the same HBC-HBE course cohort as her) sums up a lot of the positive sentiments around peer support:

> *Other participants were a huge support. Many were able to offer their own stories, and suggestions from their own experience. Learning from one another was brilliant. Some Carers had loved ones further along the stages of dementia and were able to give us tips because they had already gone through the stage our mother is in. The tutors facilitated great discussions and offered guidance when we needed clarity on certain topics. Hearing about other Carers experiences was of huge benefit to my dad, the primary carer. It helped him feel less alone and more supported on this journey. He*

> *has formed bonds and friendships with other Carers who took the course. He relies hugely on those other carers, in terms of advice and guidance' (OQR: 195).*

Finally, one participant noted that they 'found myself able to advise others who were in distress and that lifted my morale' (OQR: 109).

The provision of information was important for HBC-HBE participants as outlined in theme one above. There is a link between Course Materials and Informational Support, as the materials are the primary method of putting across a lot of information about dementia and the supports that may be available to course participants. Table 4.5 above showed that seventy percent of respondents found the course materials to be supportive – fifty percent very supportive, and twenty percent extremely supportive.

Respondents were asked how supportive they found individual elements of Course Materials (Q.36 online questionnaire). Their responses are summarised in Table 4.8 below. Factsheets and other documents appear to be the most important, followed by embedded videos within e-books and lastly text in E-books.

TABLE 4. 8: IMPORTANCE OF COURSE MATERIALS IN ASSISTING AND INFORMING CARE DELIVERY

Question	Not at all important		Slightly important		Moderately important		Very important		Extremely important		Total	Mean
Text in e-books	2%	4	8%	15	31%	58	40%	75	20%	37	189	3.67
Embedded videos in e-books	2%	3	6%	12	21%	38	45%	84	26%	48	185	3.88
Factsheets and other documents	0%	0	8%	15	18%	34	46%	86	27%	51	186	3.93

This individual comment shows the importance of course materials to this participant:

> *This was a fantastic course I still refer to the leaflets provided, and it gave me a better understanding of this awful Illness and I in turn could relay the information to my family (OQR: 23).*

Participants valued the information in the factsheets which were described as ‘excellent’ (OQR: 40), and the course materials which some felt were ‘the most significant and important’ part of the course (OQR: 96). The fact that materials were available into the future was also valued by participants one of whom commented ‘I still refer to some of those now as I need them’ (OQR: 38), while another respondent had the opinion that reading material was very useful, and that engagement with the materials ‘was very well rewarded’ (OQR: 285). There were suggestions for improving content and presentation of course materials and these will be outlined in theme three below.

While most learners felt supported by individual elements of the ‘instructional dynamic’ (Ball and Forzani, 2007) – peers, tutors and course materials – to varying degrees, a common theme was that many felt it was not easy to distinguish between the relative importance of each individual element. Indeed, many felt all components of the dynamic supported and reinforced each other, as exemplified by this quote:

> *The interactions with the tutor and participants in the weekly video meeting were equally important, the tips and tricks from these conversations are invaluable. These interactions enhance the information in the course materials (OQR: 271).*

This was explored in a little more depth in the interviews where interviewees were asked directly where they got most support from – peers, tutors or course materials. Conor’s response is particularly noteworthy as it neatly encapsulates this view:

> *Oh, okay well I see them as quite different and equally important, because at times when you need like that factual practical tips, the actual material is excellent. The guidance, if it was just a group of people getting together and chatting, it would be lovely, but it was very much a guided reflection but very natural by the tutors. But then also the peer-to-peer conversations (Conor, joint primary carer).*

4.5.1 Discussion

HBC-HBE participants found the various elements of the ‘instructional dynamic’ (Ball and Forzani, 2007) – peers, tutors and teaching materials – to be supportive to their caring role. Many participants could not separate out the relative importance of each of these elements – to many they were mutually dependent and reinforcing.

The important role of the tutor highlighted by HBC-HBE participants confirms previous research findings where participants on *Mastery over Dementia* said feedback from a personal coach ‘was considered both supportive and critical at times….and allowed them [participants] to feel less alone’ and that working through the intervention together led to ‘an intensified relationship….and deepened their existing bond’ (Boots *et al.*, 2018, p. 7).

Tutors are faced with a difficult challenge between kindness and efficiency. They need to show kindness and empathy towards the participants who join the video meeting late, flustered, stressed and maybe struggling with the technology. At the same time, they need to respect those that have turned up on time to the video meeting, even though they are also busy and have had a difficult day and want to, and need to, get the most out of the hour long session. How do tutors get that balance? Perhaps this would make an ideal subject for new future research. Overall, the data in this research would suggest that tutors on HBC-HBE meet this challenge most (but not all) of the time. Further reflections on the role of the tutor will be presented in theme four and in chapter five.

This theme also supports previous literature which outlined the importance of peer support in various interventions such as *Diapason* (Cristancho-Lacroix et al., 2015) and *UnderstAID* (Núñez-Naveira et al., 2016). But it provides a much deeper understanding as to how and why peer support is important, and how it helped individual carers. It demonstrates that most learners valued hearing from a variety of different care experiences, especially if this is combined with tips on coping with and managing various challenges.

This theme also demonstrates the importance of multi-component interventions for dementia family carers. Multi-component interventions have been described as ‘those that combined psychoeducation, the learning of psychological strategies and skills for coping with caregiving, interaction with a professional and contact with other caregivers (i.e. forums)’ (Etxeberria, Salaberria and Gorostiaga, 2021, p. 1175). According to the same systematic review, these multi-component interventions ‘achieved the best results as regards reducing depression, anxiety, grief and burden and increasing quality of life, empathy and knowledge about dementia (Blom et al., 2015; Cristancho-Lacroix et al., 2015; Hicken et al., 2017; Núňez-Naveira et al., 2016; Torkamani et al., 2014)’ (p. 1175).

While each element of the instructional dynamic is important in itself, evidence from this thesis suggests they reinforce and complement each other, leading to high levels of learner satisfaction (theme three) and emotional well-being (theme four). Materials by themselves are of limited use, but they provide some underpinning knowledge and their availability for a prolonged period is valued by participants. For many learners information comes alive and is authenticated when the experiences of tutors and other course participants are shared and discussed.

4.6 Theme 3: Learners were mostly satisfied with the HBC-HBE course, though there were suggestions on how to improve it

Building on themes one and two above, this theme describes learners’ feelings of satisfaction with the HBC-HBE course. This theme will discuss how most learners expressed satisfaction with their learning experience. Some learners reported that HBC-HBE made a significant difference to their care situation. Given these feelings, many learners expressed gratitude to ASI and could not offer any suggestions on how to improve the course. However, not everyone was totally satisfied with HBC-HBE, and learners offered some very useful and practical suggestions about how to improve the course.

4.6.1 Expressions of satisfaction

A significant number of learners expressed satisfaction about attending the course. Overall, there were eighty-nine positive comments from respondents related to course satisfaction. One respondent to the online questionnaire said that they ‘enjoyed the course’ and ‘attended follow-up / support group meetings online’ (OQR: 9). Others used positive adjectives to describe the course such as ‘brilliant’ (OQR: 38), ‘extremely beneficial’ (OQR: 63), ‘extremely helpful’ (OQR: 235), ‘very helpful’ (OQR: 201), ‘excellent course’ (OQR: 182), ‘perfect’ (OQR: 21) and ‘top class (OQR: 151). The quote below is indicative of learner satisfaction:

> *The HBC-HBE course has enhanced how I manage my father who is living with dementia. This in turn has had a direct positive impact on the quality of his relationship with myself, siblings and extended family. I learned so much and received really great practical advice. It's a great programme and I have recommended it to colleagues (OQR:96).*

Contributing to this feeling of satisfaction, several learners were appreciative that they will be able to access the course page on Moodle Workplace containing the materials for five years, as shown in this quote:

> *In the future, I think the course materials will become more important as dad's needs change and I know I have the course materials and resources to draw on when that time comes (OQR: 122).*

The quotation above links the availability of materials into the future with the fact that dementia is a progressive degenerative condition, and that future care needs change as symptoms progress (Whitlatch and Orsulic-Jeras, 2017). One person described this as being ‘particularly beneficial and very useful’ (OQR: 41). These views were expanded on by Nathan who made the connection between ongoing access to resources regarding information about other services and supports, and future care needs of his father. Nathan said that ‘this was brilliant to have, to know that when the time came, we knew where to go to look for help’.

This is a significant finding because a lot of the interventions described in chapter two were studies of new or pilot initiatives, for example *E-Care* (Finkel *et al.*, 2007), *Videophone Psychosocial Intervention* (Czaja *et al.*, 2013), *Story-Call* (Davis *et al.*, 2014), *Diapason* (Cristancho-Lacroix *et al.*, 2015) and *STAR* (Hattink *et al.*, 2015) – full details in Table 2.4. As such it was not possible or was difficult to determine if access to the intervention was ongoing or had any potential lasting impact. HBC-HBE has the potential to have a sustained positive impact. This is also evident in Figure 4.3 where respondents reported their intention to continue to introduce new ideas into the future.

A substantial number of learners (twenty-four) described how participation on HBC-HBE led to significant change in how they cared for the person living with dementia in their family. This quote is quite typical:

> *I found the course extremely beneficial. The space to voice concerns and speak openly without judgement should not be underestimated. It provided a great source of comfort to me, and I could not speak highly enough of it (OQR: 270).*

One respondent said the standard ‘was by far well above any other course I had partaken in’ and praised ‘the level of professionalism, reliability and empathy’ throughout the course (OQR: 107). One person lamented that they left it so late to decide to take the course, ‘I am only sorry that I didn’t do the course sooner’ (OQR: 20). Another participant who is trying to cope with a mother with dementia and father who is an alcoholic praised the tutors who advised the participant to get support for herself – she described this advice as ‘life-changing’ (OQR: 141).

Jessica provided an insight into how participating on the course changed the way she cared for her father, where she now practices ‘person-centred care’. Person-centred care is linked to notions of acceptance and respecting the personhood of the relative with dementia (Kitwood, 1997; Terkelsen, Petersen and Kristensen, 2020). One aspect of person-centred care means recognising the perspective of the person being cared for, as Jessica describes in this quote:

> *.... what I have learned is that it's not black or white it's actually grey, and blue.... you have to look at the holistic approach, ... you have to.... frame your .... message .... very much around what's going on for him at that time.... my father is very much, he's still a person, you know it's not either right or appropriate for me to, to either speak for him or make decisions for him (Jessica, primary carer).*

Julia described tips around continence care as being ‘invaluable…totally invaluable’. One participant described HBC-HBE as ‘an education, a life education’ (OQR: 59).

Given the level of satisfaction many experienced on HBC-HBE, thirty-one learners expressed gratitude to ASI more widely, as well as the team involved in delivering the course. The comment below is typical of this attitude:

> *I'm glad you're doing this work… it is badly needed and will make big changes to very vulnerable people so fair play to you. I can honestly say these courses should be compulsory if families wish to care for the people in their own homes… education is key to quality care…. Thank you. (OQR: 39).*

Many offered comments like 'thank you' (OQRs: 26, 39, 47, 148, 136,123, 237), some were 'grateful' or 'very grateful' (OQRs: 49, 58), and some said 'huge thanks' (OQR: 151).

Responding to Q.46 of the online questionnaire 'What improvement do you think we could make to how the course is delivered?', a sizable number of learners (thirty-six) felt that they could not offer any suggestions for improving the course. The quote below is a typical response to Q.46:

> *I have nothing to offer to this question.... I think the attitude of the course tutors and ethos in the way the course is delivered is just right! (OQR: 208).*

Many other responses included words such as 'none' (OQRs: 2, 33, 89, 154, 155, 198, 258) in their response to the same question.

4.6.2 Some learners were dissatisfied with the course and had ideas on how to improve it

Feelings of satisfaction were not universal. Some learners were not satisfied with their experience on HBC-HBE. General dissatisfaction about the course was in some cases not particularly well articulated, as in this quote:

> *Perhaps it was my situation, I was the secondary carer. And I suppose you could follow up all the information provided and study and think about the information in your own time to get more out of the course. But there was just something about it that didn't meet my needs, sorry (OQR: 32).*

This respondent's answers to other questions in the online questionnaire were examined further. Additional investigation revealed that this respondent had been caring for less than one year and completed the course in 2020. She was a secondary carer of a parent, and she reported the course had no impact on the way she provided care. She chose mainly answers of 'slightly' or 'moderately' to various questions in the online questionnaire, though she did note that peer support via discussion forums and video meetings was 'very important'. She also noted that ‘hearing concrete examples of caring for a person with dementia by course participants’ as being the most important element in contributing to her learning experience on this course (Q.43 online questionnaire). In response to Q.46 what improvements do you think we could make to how the course is delivered, she suggested that we ‘allow participants to speak more.’ This is likely to be related to her experience at video meetings where tutor facilitation skills are very important as explored in theme two above. It appears that OQR 32 only engaged in video meetings.

Another participant felt ‘that doing the course online to be of little benefit to me. I know with the current COVID restrictions that it wasn’t possible any other way’ (OQR: 140). This view is consistent with the feelings expressed by some learners on HBC-HBE who would have preferred face-to-face training. This will be examined further in theme four.

A different learner was clearer in outlining her dissatisfaction, ‘I did not feel the course was of benefit to me. There were too many others on the course who wanted to discuss their situations and I did not feel I had the same issues’ (OQR: 81, female, sixty-two years of age, primary carer to a parent for less than one year). This was an intriguing viewpoint and runs counter to many of the viewpoints noted in themes three and four. To better understand the reasons behind this viewpoint the rest of OQR: 81’s online questionnaire responses were examined.

She reported no difficulties navigating Moodle Workplace, reported the course as having no impact on her, rated peer and tutor support as ‘not at all important’, did not contribute to discussion forums, attended the first three video meetings, then left as she felt ‘she was getting no benefit from it’. She did engage with the course materials and rated them as ‘slightly supportive’. OQR 81 did suggest ‘smaller group sizes’ on the video meetings to facilitate more interaction, or perhaps interaction with other participants who had ‘the same issues.’

It is possible that OQR 81 who is a new carer could have been exhibiting what Chiu and Eysenbach (2011) called ‘usage behavior’ (sic) which asserts that ‘When the service matched their learning needs, the caregivers would apply what they had learned in real life situation. Usage behavior (sic) means more than reviewing the information; it encompasses the processes of active learning, problem solving, and real-life practice’ (p.757). OQR 81 may not have met many challenges, and therefore had not engaged in problem-solving and real-life practice. Or perhaps OQR 81 was in a group with other participants who were further along in their care journey. This may explain the ‘I didn’t feel I had the same issues’ comment.

Participants had a range of suggestions related to content, format and presentation of the course. The quote below relates to having a review week in the middle of the course:

> *It would be very beneficial to add an extra week mid-course (say after week 3 or 4) for a review as some of the topics have a lot of information and oftentimes it’s not until a week or so after that discussion points/questions come to mind and by the final weeks review they are forgotten about (OQR: 271).*

Currently, HBC-HBE has a review week at the end of the course. This is designed to provide time and space for participants to reflect on what they have learned on the course and to plan ahead. Perhaps ASI should consider an extra week in the middle of the course to provide more space for participants to engage with the materials. One participant felt that the course could be longer ‘than the few weeks it was’ (OQR: 146), another that it should contain less content as, ‘the course is very short for the amount of information being delivered’ (OQR: 84).

Other HBC-HBC participants recommended changes to course content and presentation. As dementia family carers lives can be so busy, one learner suggested ‘maybe a relaxation exercise before each class to bring the carer down to a relaxed state’ (OQR: 72). Another suggestion was to have ‘different professionals like a nutritionist or occupational therapist…give advice on meal plans and activities’ (OQR: 251).

In terms of content, a course participant felt the course did not cover the particular care issues associated with younger onset dementia:

> *The course material seems to cover Dementia in the elderly. The person I care for has early onset and only one other participant was in his age range, 57 at that time. The speed of the decline was very shocking and there was very little information to prepare us for that (OQR:167).*

In terms of course presentation, Julia suggested that collating all the Factsheets (there are eighteen Factsheets located across the course and arranged by topic) into one PDF booklet would be helpful. Emma, another interviewee, said she would like shortened versions of course materials as she is ‘a bullet point kind of person…I want to see it straight away…. I just want the main basic points….and then again, I wouldn’t have the time to be reading too much anyway’ (Emma, secondary carer).

Emma’s view may be related to what Chiu and Eysenbach (2011) call ‘perceived efforts’, ‘Caregivers felt that the perceived efforts to use the technology seemed to be greater when they were under stress, which made them more reluctant to use the support intervention’ (p. 760). In other words, if HBC-HBE participants are stressed (by the technology or by their care situation), they are less likely to use the intervention if the perceived effort is too great. One way around this is to simplify how to use the intervention, and this will be explored in theme four below.

Some learners would have liked some follow-up or ongoing support from ASI:

> *I think it would be great if on the anniversary of the course all the participants were invited to a video meeting to see how we are getting on and to reconnect with each other (OQR: 22).*

Respondents ‘felt isolated after the course was over’ (OQR: 54). One learner wrote that ‘it would be great if there was a monthly / quarterly follow-up meeting to keep us going’ (OQR: 36). Another participant felt that ‘a monthly catch-up would be beneficial’ (OQR: 182).

ASI do run Online Support Groups (OSGs) for dementia family carers. These were introduced in summer 2020 following the reduction in face-to-face services and supports due to COVID-19. Interestingly OQR: 36 completed the course in 2019, while OQR: 182 completed it in 2020. So, at the time they completed HBC-HBE it is possible that OSGs were not available but have since been introduced.

Group dynamics were an issue for some HBC-HBE participants, especially when they were attending the live video meetings.

> *Perhaps smaller breakout groups might be worth considering? Although I understand that you have limits on the staff available to you. Overall, I found the course very helpful (OQR:101).*

Some learners felt that the group size (twenty per cohort) 'was difficult for the tutor to manage and ensure that everyone's voice was heard' (OQR: 96). Others agreed and would have liked a smaller group size (OQR: 81), or 'one-to-one slots with the tutor' (OQR: 85). In agreement with the above, and to counter the challenge of facilitating larger groups, Emma suggested using break out groups more regularly, with this comment:

> *I would prefer people who were in my situation. Like, for example, if you're having the breakout group, you know if you had people who are caring for a parent, because that's obviously different for somebody caring for a spouse (Emma, secondary carer).*

Emma's point was taken up by one respondent who is caring for her husband and noted 'it could be useful to have focussed sub-groups of carer categories or roles….to discuss difficulties that arise with more intimate matters when a partner / spouse has dementia' (OQR: 163).

Finally, whilst probably outside the area of research in this thesis, one learner wanted more specialised courses to help them on their dementia care journey.

> *I would really like to see the Alzheimer's Ass doing courses for rare dementia. I have found wonderful support and learning in the courses and family support groups, but I've had to go UK support groups to get proper information, living with and coping with symptoms as well as progression with Frontotemporal Dementia and that was after 8 years. Thank you [OQR: 75].*

4.6.3 Discussion

What is clear from the above is that many learners on HBC-HBE felt satisfied, sometimes deeply so, and grateful about their education experience. Many could not offer any suggestions to improve the course. Similar sentiments were expressed by one learner, on *Cuidate Cuidador 'Caregiver, take care of yourself'*, who was grateful for the invitation to attend the intervention and reported feeling 'calm, confident and strong in the front of this new challenge….thank you' (Pagán-Ortiz *et al.*, 2014, p. 9).

An interesting finding about satisfaction was that learners noted how the course could be of benefit to them on an ongoing basis, as the dementia progressed into the future. This reported future benefit is linked to future planning and finding out what is ahead, as outlined in theme one above. It is also evident from several of the quotes above that participants have stated they shared information and knowledge gained on HBC-HBE with wider family and colleagues.

However, it is also clear that some learners were not satisfied with their course experience. In some instances, dissatisfaction was sometimes ambiguous and not particularly well articulated. It is difficult to have concrete solutions to some of the ambiguous dissatisfaction reported by participants. Others offered a clear range of views on how HBC-HBE could be improved. Suggestions included increasing the duration of the course, having more follow-up with participants, changes or additions to content and ensuring members of groups have similar backgrounds so that sharing of experiences is more relevant. To aid follow-up, perhaps HBC-HBE could signpost participants to 'dementia café's' which in a recent study (Teahan, Fitzgerald and O'Shea, 2020) have been shown to provide strong personal support to dementia family carers.

The suggestions regarding content, format and presentation are well made and deserve serious consideration. There is also clearly an issue at least for some learners with tutor facilitation skills. Tutor facilitation skills could be related to the size of cohorts. Breakout rooms or smaller group work might allay some of these concerns. These suggestions will form part of recommendations for practice set out in chapter five below.

The duration of the HBC-HBE course is an important consideration. As noted in 2.6.1.2 above the length of the interventions (where stated) varied and ranged from the *RHAPSODY* intervention at six weeks (Metcalfe et al., 2019) to six months for the *Intervention programme for frontal dementia carers* (Gossink et al., 2018). Several interventions lasted between six and eight weeks, for example *iCare* (Kajiyama *et al.*, 2013), *Mastery over Dementia* (Blom *et al.*, 2015), *Tele-Savvy* (Griffiths *et al.*, 2016), *Partner in Balance* (Boots *et al.*, 2018), *Online Cognitive Behavioural Therapy* (Meichsner, Theurer and Wilz, 2019), *RHAPSODY* (Metcalfe *et al.*, 2019) *and the CaFCa app* (Kabir *et al.*, 2020). The HBC-HBE course lasts seven weeks. Perhaps ASI should consider an additional week in the middle of the course to give participants additional time to read and digest materials or to catch up on forum discussions.

The findings in this theme relating to mixed groups are challenging. They are contrary to the views to be reported on earlier that HBC-HBE participants felt they benefitted from the variety and varying views and experiences of members of groups. This helped many learners and contributed to feelings of reassurance (theme five) and impactful peer support (theme two).

Participants self-select which video meeting they can attend from a choice of four different day / time options. The video meeting group they chose then becomes their cohort for the remainder of the course. However, within the video meeting it would be possible to divide the cohort of twenty participants into thematic groups to discuss particular issues from their own perspective, before re-joining the full cohort for other parts of the meeting.

4.7 Theme 4: The online environment mostly facilitated learning

This theme explores learners' views on the online learning environment. For many HBC-HBE participants the learning environment facilitated learner-learner and tutor-learner interaction – see themes one and two above. However, this was not always the case, and some participants suggested ways to make using the online learning environment easier, as will be outlined in 4.7.2.

4.7.1 Moodle Workplace enabled learner engagement

Respondents were asked how easy or difficult they found the Moodle Workplace Learning platform (Q.45 of the online questionnaire). Their answers are summarised in Table 4.9 below. While most respondents found using Moodle Workplace easy or very easy to use, there were significant numbers of people (around twenty percent) who reported problems logging in for the first time and finding their way around the course page as being either 'difficult' or 'very difficult'. The mean scores for logging in for the first time and finding my way around the course page are almost identical 3.58 and 3.59. These issues will be examined in 4.7.2 below.

Participating in video meetings which were held using 'BigBlueButton' via the Moodle

Workplace platform appeared easier with a mean score of 4.14, with only 6 per cent finding this ‘difficult’ or ‘very difficult’. Many learners were positive in their views about Moodle Workplace. They found Moodle ‘quite easy to access as an online platform’ (OQR: 158), ‘fine, no issues’ (Anne, secondary carer), or ‘efficient, no issues, it was all very clear’ (Frances, secondary carer).

TABLE 4. 9: LEARNER VIEWS OF MOODLE WORKPLACE

Question	Very difficult		Difficult		Neither difficult nor easy		Easy		Very easy		Total	Mean
Logging on for the first time	2%	3	18%	35	23%	45	35%	69	22%	44	196	3.59
Finding my way around the course page	1%	2	18%	36	26%	50	32%	63	23%	45	196	3.58
Participating in video meetings	2%	3	4%	7	12%	23	45%	89	38%	74	196	4.14

Some learners valued the convenience of being able ‘to go back over things at my pace’ (OQR: 266), and one learner who thought they would prefer face-to-face meetings ‘was surprised that I enjoyed and settled into the weekly video meetings’ (OQR: 263).

Many learners were positive in their views about Moodle Workplace. This learner found the course structure logical, as shown in this quote:

> *I found the course was well structured with lots of useful information and links… (OQR: 101).*

Participants described how the course was well structured ‘divided into separate and specific modules which provided a natural and logical progression into all aspects of dementia care’ (OQR: 126).

Most respondents to the online questionnaire said they engaged with the online course components as shown in Table 4.10 below.

TABLE 4. 10: LEARNER ENGAGEMENT LEVELS WITH COURSE COMPONENTS

Question Number in the Online Questionnaire	Course Component	Yes	No
Q.34	E-books, Audio Books, Factsheets (n=207)	197 (95%)	10 (5%)
Q.37	Discussion Forums (n=206)	139 (67%)	67 (33%)
Q.40	Video Meetings (n=206)	192 (93%)	14 (7%)

More people engaged with course materials (ninety-five percent) and video meetings (ninety-three percent), with a lower proportion of respondents (sixty-seven percent) engaging regularly in Discussion Forums (regular was defined as posting up five messages during the seven week course).

Many learners praised the video meetings, as in this quote:

> *I found the video meetings great, ideal way to get support (OQR: 157).*

Other learners mentioned the specific benefits of the video meetings which included, ‘asking your own specific question and get different perspectives on care’ (OQR: 276). Participants also valued gaining immediate ‘real-time answers to difficult questions’ (OQR: 158). This is linked to the requirement to customize interventions to the specific needs of each participant. As one systematic review stated, ‘Combining tailored information with the help of a coach and the possibility to interact with other caregivers results in successful outcomes for dementia caregivers’ (Boots *et al.*, 2014, p. 343).

Some learners found the discussion forums ‘useful’ (Violet Interviewee four), and another learner stated that ‘interactions with the tutors and other participants on the forum and weekly chat were the most beneficial for me’ (OQR: 141). However, some learners had issues with participating in discussion forums. One participant found the video meetings ‘were more involved and more friendly’ than discussion forums (OQR: 171). Another commented that their group ‘didn’t interact with the discussion forums [which] was a pity’ (Jessica, primary carer). These difficulties will now be explored further in section 4.7.2 below.

4.7.2 The learner experience could be more user friendly

Table 4.10 above showed the majority of learners engaged with online course components including Course Materials, Discussion Forums and Video Meetings. However, not all did so, and respondents provided explanations about causes of lack of engagement with HBC-HBE. Lack of time was a recurring issue for many learners on HBC-HBE:

> *Too busy. Work 14-hour days at the time. My partner was pregnant, and we also have a five-year-old. I coached his soccer team too for my own little breather from the house (OQR: 59).*

Lack of time was also mentioned by other learners (OQRs: 12, 91, 196, 232 and 246), or put slightly differently one learner felt they 'had other preoccupations' (OQR: 105).

Participants mentioned lack of time *and* finding the software clunky to navigate, as in this quotation:

> *I found I had little time available to give to Discussion Forums. I work full time, have a family and was the full-time carer for my mother every weekend. …. I found the software clunky to navigate. It was my first time using such software. But time restrictions were the main reason (OQR: 285).*

Another learner found 'the online forums a little intimidating. It took some time to get accustomed to using the Moodle system, and this was a bit distracting at the beginning' (OQR:101). Emma explained that she didn't participate in the Discussion Forums because she 'found it a bit time consuming even trying to get in to understand them, so I just stuck with the with the [video] meetings' (Emma, secondary carer).

Perhaps this perceived lack of time outlined above is also related to respondents' views about usability of the platform. Usability 'is defined by the International Standards Organization as "the effectiveness, efficiency, and satisfaction with which specified users can achieve goals in particular environments"' (Hattink et al., 2016, p. 2). Several of the studies in chapter two examined usability of proposed interventions, for example the *Internet Caregiver Support Service (ICSS)* (Chiu *et al.*, 2009) and the *STAR* programme (Boyd *et al.*, 2014).

Several HBC-HBE participants made comments related to the usability of Moodle as a learning platform. Some were quite blunt:

> *Get a different provider, Moodle is fairly poor' (OQR: 59).*

Jessica who had a positive course experience described Moodle as 'clunky'. When asked to clarify what she meant by 'clunky', she said 'okay, not intuitive, and too many clicks.' Others mentioned how a combination of factors impacted their participation. These included issues related to difficulty navigating Moodle 'it took me some time to learn how to navigate the system', together with their own lack of IT skills, or their own equipment, 'having trouble with my laptop' (OQR: 204). Others just mentioned their 'lacking in confidence with navigating around the site' (OQR: 276) as inhibitors to participation. Another learner found they could not attend the video meetings 'due to their own poor internet quality' (OQR: 169).

A couple of learners felt that it was difficult to find information on the Moodle page, as shown in this quote:

> *I found there was an awful lot of information [on Moodle, which was] definitely a good thing, but at times I found it extremely overwhelming….and found it took me some time to come to grips with the system (OQR: 91).*

Another thoughtful insight into Moodle usability came from this learner who commented:

> *I found Moodle hard to navigate, especially having to scroll through the information to see where I had left off in terms of completed coursework. I also was unsure which questions were private and which were for the group in the coursework discussions (OQR: 136).*

The first part of this comment is relatively easy to rectify by using the 'highlight current week' feature in Moodle Workplace. However, the second part of this comment probably relates to some of the 'Choice' activities on the course and who could see individual's responses to questions such as 'how long have you been caring?' While it is obvious that all Discussion Forum posts are viewable to everyone in the cohort of twenty learners plus two tutors, this comment makes it clear that some learners were unsure who could see responses in these 'Choice' activities. This will be addressed in chapter five.

Several people commented that they felt the course might not suit other family members who ‘were not overly familiar with IT’ (OQR 156). Learners related that they felt their parents’ lack of IT skills did or could hinder their participation on HBC-HBE. One learner’s mother tried to join the video meeting ‘but she couldn’t really work the technology out and was also very stressed at the time so didn’t engage as she might have’ (OQR 139). While another learner ‘was encouraging my dad to sign up for a class as well, but in hindsight he would have found it difficult’ (OQR: 205).

An interesting comment was made by one user who said they use Moodle in another job and find it ‘an unintuitive and over-complicated platform’ (OQR: 286). There was a sense from this and some other comments that previous negative experience of using Moodle may (unsurprisingly) have influenced people’s perceptions of Moodle usability on the HBC-HBE course. Mary commented that she had used Moodle for another academic course which contained homework, so her ‘associations with Moodle was I had to do my homework, I had to do my prep…’ (Mary, primary carer).

Some learners, including Jane, would simply have preferred the mode of delivery of the course to be face-to-face rather than online:

> *Didn’t like the online…. especially because of dementia as it’s such a touchy subject, and such an emotional subject…. I feel I would have got a lot more out of it if I was sitting in a group of 10 people in a room (Jane, Interviewee 1).*

However, there was a realisation and acceptance that face-to-face was not possible during the COVID pandemic, summed up by this quote:

> *Would love to have had the course in person…. webcam is just not conducive to participation. I know with Covid this was not possible but such a shame (OQR: 66).*

A small number of learners mentioned the dynamics and relationships within groups:

> *I was very happy with how it was delivered on the whole. Sometimes course attendees may have dominated the session with an issue they were having, I think the tutors need to take charge of these situations (in a sensitive manner*

> *of course) and take the discussion offline so that the course material/schedule for that session can be completed (OQR: 152).*

Others made comments relaying that ‘the group was too large, and some people unwilling to share’ (OQR: 74), or that they ‘lost interest in the course as one or two took over’ (OQR: 265). This feedback needs to be seen in relation to tutor facilitation skills which many respondents were happy with as discussed in theme four above. As outlined earlier, it is difficult for tutors to find the balance between the needs of individual participants and the requirements of the full group, whilst maintaining kindness, empathy, and guidance. It is a very tricky balancing act. Actions relating to improving tutor facilitation skills will be outlined in chapter five.

Some learners had technical issues with the video conferencing software, as shown in this comment by a learner, who showed perseverance and ingenuity to solve the issue:

> *I was able to log on without any issues and use the chat facility but was unable to use the audio on the same device, so I ended up using 2 different devices in order to hear/speak as well as see/read the chats (OQR: 139).*

Some participants conflated the learning platform Moodle Workplace with ‘BigBlueButton’ (the video conferencing software within Moodle which is used for the weekly live video meetings on HBC-HBE) in some of the comments below. Some of these comments related to the visual appeal of the software, ‘I could only see thumbnails of people; Zoom may have been better (OQR: 30). For other participants, it was a technical difficulty that was ‘disappointing’ (OQRs: 141 and 170).

Other learners commented that these technical difficulties actually impacted not just on the individual having the problems, but also the wider group ‘as there was often time spent on getting people logged in and sound working’ (OQR: 170). It was also acknowledged that some of these difficulties could have been caused by learners’ own ‘issues with broadband’ (OQR: 9). While HBC-HBE includes a ‘test video meeting’ during Week 1, not everyone chooses or is able to attend.

A number of respondents had interesting and useful suggestions on how to improve Moodle Workplace usability.

> *Just an idea. The tutor could demonstrate the functions and show how to access material on the ASI website. There is so much information there it can be overwhelming to a less internet savvy person (OQR:126).*

It is interesting that OQR 126 made this suggestion as it is already part of the lesson plan for the first HBC-HBE video meeting. Tutors normally share their screen and navigate through the HBC-HBE course on Moodle. There are also 'support videos' on the main course page which demonstrate how to move around the course. Perhaps more emphasis needs to be given to these support measures, so that all HBC-HBE participants are aware of them. We have seen that some people did not 'participate' in forums or read through course materials for various reasons including lack of time, but also perhaps because they found it difficult to use the site.

There were other practical suggestions to make Moodle more user friendly. These ranged from 'a detailed instruction on how to use the system' (OQR: 115), which the same respondent admits 'maybe I didn't read it enough' (OQR: 115). Another suggestion was to make Moodle more 'visually accessible…some features were in very small text and difficult to navigate…. a more modern look would help' (OQR: 64). A similar sentiment was expressed by a learner on *STAR*, 'Make tools bigger and clearer and include a search bar on website' (Boyd *et al.*, 2014, p. 4141). A couple of learners wanted a simpler, more streamlined look and feel to Moodle – 'making access "one click" easy' (OQR: 135), or just 'to simplify the number of tabs to get through the course materials' (OQR: 191).

Another suggestion was to have 'more emphasis on the time needed to familiarise oneself with it before the course starts could be emphasised' (OQR: 212), though another user countered by saying that investing time getting to know Moodle is well rewarded, 'however, once you keep at it, you get it….absolutely delighted I pushed myself to stay with it, and support was 100 per cent there at the push of a button' (OQR: 263). Some learners wanted easier and earlier access to the following weeks materials (OQR: 223), which 'would have given us more time to read over [them] and prepare our thoughts' (OQR: 118).

4.7.3 Discussion

Most respondents were easily able to log into and find their way around Moodle Workplace (Table 4.9). Engagement with individual course components was very high (Table 4.10) with over ninety percent of respondents accessing course materials and video meetings. Video meetings were especially important for many learners, as facilitators of tutor and peer support, as documented in Tables 4.6 and 4.7 in theme four above. This finding is consistent with the systematic review by Hu et al., (2015) which referred to ‘the novel approach’ of video conferencing and urged that future interventions ‘take advantage of the interactivity possible through internet technologies, such as discussion forums and group videoconferencing, to connect caregivers with the medical team as well as peer support’ (p.206). It seems HBC-HBE has taken advantage of these potentialities.

Discussion Forums were less widely used and some learners on HBC-HBE found them problematic. This is similar to some other studies as revealed by this quote from a dementia family carer who was a participant on the *Diapason* intervention, ‘[Diapason] is too impersonal and “cold,” I tried to use the forum, but I need to look at the person in front of me’ (Cristancho-Lacroix *et al.*, 2015, p. 11). It appears for many that connecting with others is easier via video conferencing than via Discussion Forums. In their review of trends and patterns in distance education Bozkurt and Zawacki-Richter (2021) note ‘learning and teaching in DE [distance education] have been supported by various synchronous and asynchronous media and tools; in particular, video-based formats have gained importance in the years that were analyzed (sic) [2014-2019] (p. 26)’. Perhaps this presents an opportunity for ASI to re-examine the use of Discussion Forums and in particular how they can more readily support a community of inquiry pedagogy where ‘students learn to collaborate and take responsibility for their own learning and for that of their peers’ (Lower, 2022, p. 1).

In their revealing study of dementia family carers’ usage behaviour of the online intervention *Internet Caregiver Support Service (ICSS)* Chiu and Eysenbach (2011) differentiated between reflective and interactive learner types. The former were much less likely to interact with the tutor, ‘but actively used the information’ (p. 760). The findings relayed above imply that most learners on HBC-HBE were active learners, with relatively fewer reflective learners.

While many learners felt that online learning was a positive experience, others felt challenged by it. Some would simply have preferred the programme to be delivered face-to-face. This sentiment has also been noted in other studies where participants were of the view that the *RHAPSODY* resource ‘though useful, should not replace the individualised advice that face-to-face consultations with a professional allow’ (Metcalfe *et al.*, 2019, p. 1461).

The lack of time is consistent with feedback from two earlier studies examined in chapter two. In the *Online Training and Support Programme* based in India, a thirty-five year old family carer commented ‘If using the program needs long hours then people might not have the time for it as most people have multiple responsibilities’ (Baruah et al., 2020, pp. 526–527). While for the *Internet Based Caregiver Support Service* (ICSS), ‘The reasons for dropping out of the program included a lack of time (too busy to complete the questionnaire or use the service)’ (Chiu et al., 2009, p. 329).

Others had problems and didn’t like the technology used to deliver the course (Moodle Workplace and ‘BigBlueButton’). Some of the concerns about Moodle Workplace were related to navigation and information overload, others more about aesthetics – the look and feel of the page. There was considerable frustration that the video conferencing technology (‘BigBlueButton’ which is a Moodle plug-in), did not work for some users, leading to some learners’ feeling frustrated in these meetings. Similar sentiments were presented in a recent study where learners in Croatia expressed ‘a somewhat lower evaluation [of] reliability and performance without difficulties’ of the ‘BigBlueButton’ video conferencing software (Čižmešija and Bubaš, 2020, p. 67).

It is difficult to know how to weigh up views about usability whilst also taking cognisance of the participants’ IT skills. In 4.2 above, participants described their IT skills as mostly advanced, with only three percent describing themselves as ‘slightly confident’, and thirteen percent as ‘somewhat confident’ using computers and IT. Perhaps it is this relatively small number of less confident IT users who made these comments. However, the implication of this feedback relating to usability is that the course page may need to be redesigned with less headings, and more downloadable documents in folders to reduce the number of clicks.

An earlier study by Chiu and Eysenbach (2011) provides a useful insight into the behaviour and usage patterns of dementia family carers accessing the *Internet Based Caregiver Support Service (ICSS),* one of the interventions examined in chapter two. They found that the needs of carers were an important determinant of usage patterns. These needs were different for new carers compared to experienced carers. New carers are initially desperate for information. However, they can then become overwhelmed by the vast amount of information presented to them via the intervention. Simultaneously, they struggled to provide daily care in the early stages of their dementia family caring. Their engagement with the intervention can be meaningless ‘until they encounter the situation in real life’, where they can use their new knowledge to engage in ‘the processes of active learning, problem solving, and real-life practice’ (p. 757).

This may explain some of the low engagement levels on HBC-HBE, especially in relation to the views expressed about information overload. But it is not consistent with the learner view of valuing hearing about the diversity of peers’ experiences. On HBC-HBE many learners enjoyed listening to their peers and finding out what is ahead and storing this information until such a time as they may need to use it.

It is also possible that some HBC-HBE participants did not get the opportunity to put new knowledge into practice. This may have been the case for new family carers in particular. It is also possible that some participants could not empathise with other members of their group or cohort. Empathy might not have been possible as the challenges faced may have appeared to be different, for example, spousal carers who are emotionally very close to the person living with dementia, versus secondary carers who are usually a little removed from the person living with dementia. Evidence from a recent study of dementia family carers in Ireland found that ‘Co-residence was significantly positively associated with carer burden’ (Teahan *et al.*, 2021, p. 353) implying spousal carers could be more stressed and therefore require different supports to new carers. This lack of connection may have contributed to some HBC-HBE participants feeling that the course had no or little positive impact on them.

4.8. Theme 5: The course supported many learners psychologically, though some learners were not emotionally ready to fully participate on HBC-HBE

This theme outlines the importance of psychological and emotional supports to dementia family carers. Theme two above outlined how learners on HBC-HBE gained support through engagement with course materials, tutors and peers. This theme demonstrates that many participants felt that HBC-HBE supported them psychologically. This led to improved emotional wellbeing for many course participants. However, this feeling was not universal, and some learners did not feel emotionally ready to engage fully with HBC-HBE.

4.8.1 HBC-HBE improved emotional wellbeing for many learners

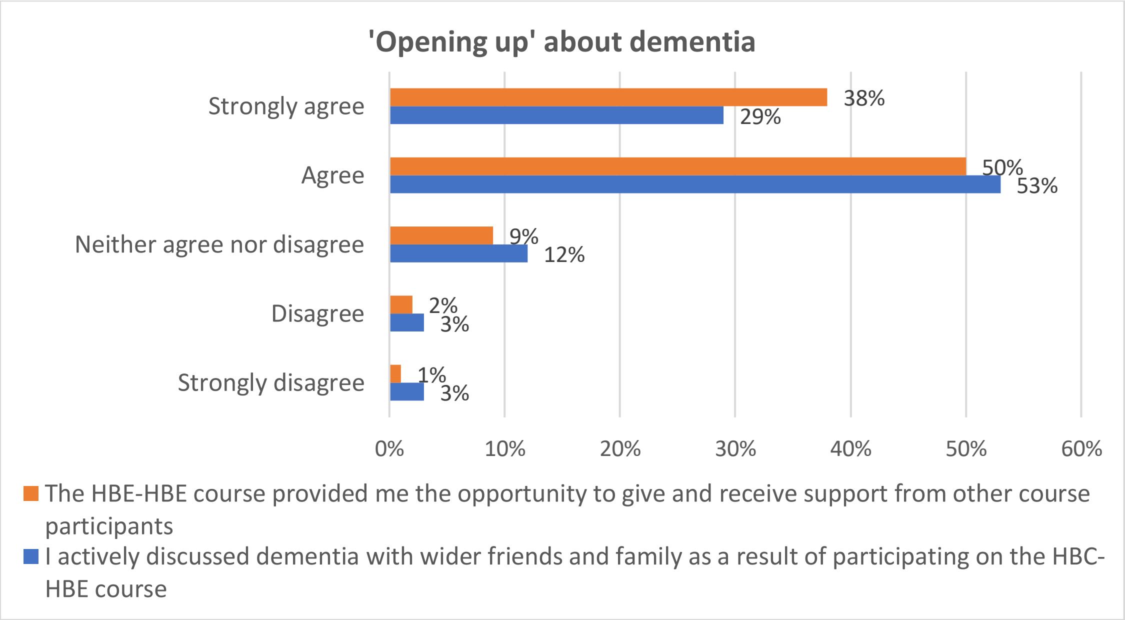
As noted in chapter two, psychological wellbeing (Huis in het Veld *et al.*, 2015) was an important component of self-management techniques for dementia family carers. Learners commented that HBC-HBE was an emotional support, especially during the COVID pandemic, when social contact between individuals was greatly reduced.

> *This course was also a great emotional support to me, especially during COVID, when other supports were not available. I have recommended the course to others in the same situation as myself (OQR: 256).*

Psychological wellbeing is possibly tied into a range of emotions around participants' care experiences. Many respondents made comments about the importance of emotional support for dementia family carers, with Violet describing it as 'key', while Louise commented that 'you can't leave the emotion out of it [the course]'.

Figure 4.3 below shows that eighty-eight percent of respondents agreed that HBC-HBE offered them a chance 'to give and receive support from other course participants', with fifty percent agreeing, and thirty-eight percent strongly agreeing (Q.25 online questionnaire). In a related finding eighty-two percent of respondents felt much more likely to discuss dementia *as a result of participating on the course* (my emphasis), with fifty-three percent agreeing or twenty-nine percent strongly agreeing with the statement 'I actively discussed dementia with wider family and friends as a result of participating on the HBC-HBE course' (Q.25 online questionnaire).

FIGURE 4. 3: ‘OPENING UP’ ABOUT DEMENTIA



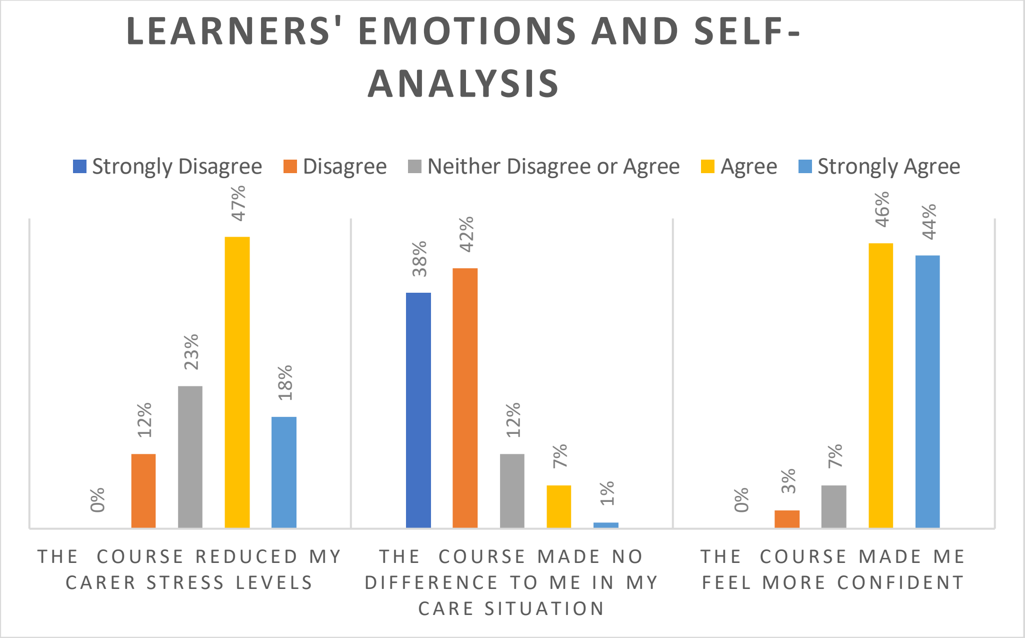
This willingness to talk about dementia within the course, and externally with wider family and friends is a significant positive feature of the course for many participants.

> *Before the course I’d never spoken out about my mother. I’d found the whole being a carer very lonely and frustrating. Having the course let me see I’m not alone. I had the courage to ask for help (OQR: 146).*

One respondent said the course gave them ‘a chance to voice my frustration in my caring role, and to ask others for ideas that work in their caring role’ (OQR: 157), while for another learner the course ‘reduced my anxiety about caring, made me able to tell others about my mother’s dementia’ (OQR: 160).

This ‘opening up’ about dementia is related to the issue of emotional readiness which will be discussed in section 4.8.2 below. Most people, it seems from the findings in Figure 4.3, were able to confront dementia as a topic within their family and outside of it. Many learners said that participating on HBC-HBE had a positive impact on a range of their emotions, and these changes impacted on their care situation. Figure 4.4 below shows responses to Q.30 of the online questionnaire where ninety percent agreed or strongly agreed that the HBC-HBE course made them feel more confident (forty-six percent agreeing and forty-four percent strongly agreeing). A lower, but still significant number of learners – sixty-five percent - agreed or strongly agreed that HBC-HBE reduced their carer stress levels (forty-seven percent agreed and eighteen percent strongly agreed). Eight out of ten learners (eighty percent) *disagreed* with the statement that HBC-HBE made no difference to their care situation (thirty-eight percent strongly disagreed and forty-two percent disagreed).

FIGURE 4. 4: HBC-HBE IMPACT AND LEARNERS' EMOTIONS



Individual comments support the figures in Figure 4.4. One learner said:

> *It [the course] helped me cope during tough times and the skills I learned helped me to enjoy the last few months of my caree life. Instead of being worn out and stressed, I could focus my energy on activities and care that eased the transition. For that I'm truly grateful (OQR: 199).*

This increased tendency to 'open-up' and talk about dementia is important. It may be caused by having more knowledge of dementia or be a result of being more confident and re-assured about the situation. Either way, it is healthier in terms of stress and strain to be able to discuss dementia and makes it more likely that HBC-HBE participants will ask for support either within or outside their family network. This in turn can alleviate some of the negative consequences of dementia care highlighted in chapter two of this thesis – stress, strain, burden, exhaustion (Schoenmakers, Buntinx and Delepeleire, 2010), especially as these have been reported to have been exacerbated during the COVID-19 pandemic (The Alzheimer

Society of Ireland, 2021) .

This tendency to 'open-up' about dementia is related to feeling connected. This is similar to emotional help offered by Dementia Cafés, which were described in a recent study as a 'support network offering[ed] advice, understanding, empathy and reassurance among carers.' (Teahan, Fitzgerald and O'Shea, 2020, p. 6). A big feature related to 'opening up' is feeling less isolated and alone:

> *I think the course made me feel like there was a lot more support out there than I had been aware of. Also, I felt like I wasn't alone. It was really useful chatting and listening to other participants stories. It gave me a sense of belonging and helped me be more patient and understanding (OQR: 136).*

Another online questionnaire respondent commented 'I found being connected with other carers and having the ability to share stories and having some support while learning was invaluable' (OQR: 7). Another said 'it [the course] provided a connection to others in a similar situation' (OQR: 271). A different participant made the point that 'it felt good to interact with other carers and learn new ways of coping with stress in the process' (OQR: 240).

Moreover, other research respondents said that HBC-HBE gave them 'reassurance about the care path I was following, which in turn helped reduce my stress levels' (OQR: 84). One learner commented 'it [HBC-HBE] confirmed my current practice as being appropriate' (OQR: 48). Another learner felt reassured that 'the guilt component is very common and that at the end of the day all we can do is do our best' (OQR: 10).

Feelings of reassurance and increased knowledge of dementia led many to express increased confidence levels, as in this quote:

> *I felt more confident in knowing what to look out for in a person with dementia and trying trial and error with different ways of support, to pick the correct course of action to my father's needs, the course helped me to realize that not everything is perfect, and each person may require a different approach to care (OQR: 171).*

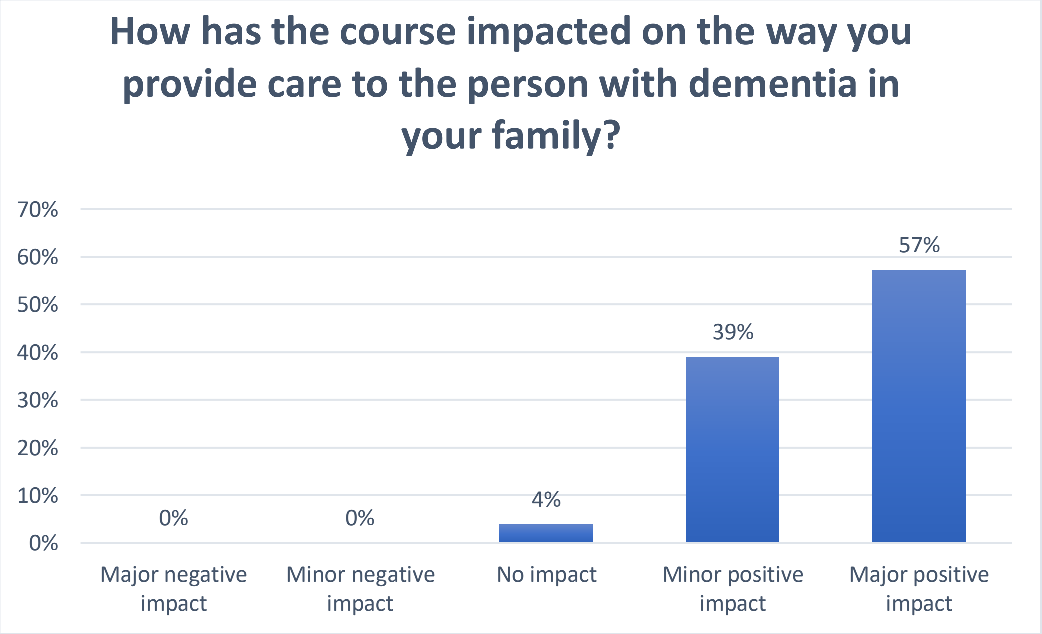
Course participants also commented on feelings of increased confidence and empowerment.

One learner commented that the course ‘gave me more confidence to learn that I was on the right track with how I was looking after my mother and doing a good job’ (OQR: 197). Another learner felt ‘more confident and comfortable caring for my mother’ (OQR: 146).

Participants also mentioned that they ‘found the course very empowering. A MASSIVE thank you to all involved (OQR: 67 – emphasis in original). This confidence and empowerment gave one learner ‘confidence to organise family calls and get other members of the family involved in caring for my father’ (OQR: 273). Louise elaborated on how she felt strong enough to act as family spokesperson to external care authorities and with her own siblings to better organise care for her father.

Overall, ninety-six percent of respondents felt that participating on the course had a positive impact on ‘the way you provide care directly or indirectly to the person with dementia’ – thirty-nine percent reported a minor positive impact, while fifty-seven percent reported a major positive impact. No respondents reported a negative impact, while four percent reported no impact (Q. 28 online questionnaire). The full set of figures are provided in Figure 4.5 below.

FIGURE 4. 5: POSITIVE IMPACT OF HBC-HBE ON DEMENTIA FAMILY CARERS



HBC-HBE participants expressed feelings of reassurance which helped them realise they were doing the right thing, or trying their best:

> *It made me feel that I wasn't alone, it confirmed that a lot of what I was already doing was okay, it put me in touch with other carers and we could ask one another questions, it gave me a new insight into understanding dementia far better, I got information I needed as to who to go to in the community to instigate getting outside care help. I would highly recommend family members who are* carers *to do this course (OQR: 44).*

The course also gave learners an opportunity to benchmark their care practice against their peers, as noted in the observation from the participant above. Other positive emotional changes included feelings of empathy for other dementia family carers. One participant noted that they 'got an insight to what some families have to contend with, and you learn from their resilience' (OQR: 263).

4.8.2 Participation levels were impacted by learners' situation and emotional characteristics

A diagnosis of dementia can have a major impact on families. In chapter two (section 2.5 above) it was noted that caregiver burden has two dimensions – one related to the characteristics of the person with dementia, and the other associated with the attributes of the family carer. The latter includes 'gender, cultural values, the relationship with the person with dementia, the amount of formal and informal care available and the caregivers' physical and mental status, personality and coping strategy' (Chiao, Wu and Hsiao, 2015, p. 341).

What became clear in this thesis is that relations with wider family members such as siblings or other adults within the family, may also contribute to carer burden. In several cases, these complex and sometimes challenging wider family relations impacted on the dementia family carer's ability to participate on HBC-HBE, as evidenced in the following quote:

> *Although I was engaged in everyone else's story, I was going through a difficult situation with my siblings regarding my mother's care. I felt uncomfortable sharing my experiences because of this (OQR: 39).*

Perhaps this is related to comments made by participants in *Mastery over Dementia,* where 'The discussion forum was not used because caregivers struggled with shame in the early stages, and sharing their story felt like a betrayal to the care recipient' (Boots *et al.*, 2018, p. 7). These complexities within family relations included family members' 'reluctance to acknowledge that a family member has dementia' (OQR: 239). One respondent whose family were in 'a very difficult situation' requested 'some discussion on future courses' related to family dynamics (OQR: 239).

Some respondents also related that family dynamics can be a facilitator to taking action or participating on HBC-HBE. Violet, who is a pharmacist, 'and the unofficial family doctor' ended up taking responsibility for her mother – 'I'm the eldest so in my family, the eldest had duties. The others got away with murder, you know.' Being the eldest and living 'nearest' to the person needing care was also a facilitator for Louise becoming the *de facto* 'care coordinator' for her father who had Lewy Body dementia.

Given the array of challenges involved in being a dementia family carer outlined in section 2.5 above, it should be no surprise that many participants on HBC-HBE found it difficult to cope with their caring responsibilities. Mary, who enrolled on the course during the COVID pandemic, and despite having a strong will to participate, succumbed to feeling exhausted:

> *But it was in the midst of COVID when everything was online and work was online and your life was online, and I just thought this was one more thing online and actually… the energy, my energy flagged. Yes, it got a bit overwhelming I suppose…. (Mary, primary spousal carer).*

Perhaps this feeling of being overwhelmed is related to carer burden. As Chiao, Wu and Hsiao (2015) note, 'Spouse caregivers and adult children caregivers experience the greatest burden compared with other informal caregivers of people of dementia' (p. 348).

For one person this experience of being overwhelmed was because they had just 'received the diagnosis' and this led that person to 'engage to some extent, but I will go back to the resources as I need them' (OQR: 85). Other respondents mentioned shyness (OQRs: 11 and 247), or lack of confidence as reasons for not participating in various aspects of the course, which for one participant meant she was 'afraid I would say the wrong thing' (OQR:183).

Others cited fear of upsetting other participants as reasons for low levels of participation on course activities:

> *I did contribute slightly but wasn't in the headspace to be more involved because I knew my sister was more advanced than the others and I didn't*

> *want to distress the others. It's quite difficult to establish when should we disclose the level to the other course members (OQR: 39).*

This is a fascinating viewpoint and one that has not emerged in earlier research. It shows how caring and compassionate learners are for the welfare of their peers. It also demonstrates the very tricky balance between a learner's need for support through sharing, and their need to not feel they are negatively impacting on other learners' feelings and emotions.

Linked to a feeling of being overwhelmed, is this sub-theme of 'emotional readiness'. Psychologists have used the Transtheoretical Model (TTM) to assess the emotional readiness of people to become adoptive parents (Prochaska *et al.*, 2005). Emotional readiness in this thesis refers to learners not being emotionally ready to participate and learn on the HBC-HBE course. In other words, their emotional state acts as a barrier to more meaningful engagement on HBC-HBE. It has featured in previous research on the *Diapason* intervention where one respondent commented that she tried to use the intervention, but she found reading that her mother to whom she was providing care would lose her memory and abilities, was 'painful for me (…) I am anxious….I am not ready for that' (Cristancho-Lacroix et al., 2015, p. 11).

The issue came to prominence during the pilot interview with Jane. Jane expressed her view that she did not find the course to be supportive, and that she did not want any of her emotions addressed or catered for in the HBC-HBE course. She was conflicted because she realised, probably after she started the course, that she was not emotionally ready to take the course (or at least all components of it), while at the same time feeling she had to take the course as her situation was so desperate.

Jane's interesting response warranted further investigation. During the interview Jane said she had enrolled on the course because she was 'very isolated', and 'on my own'. Her father had recently passed away, and her mother's dementia was having a real 'impact on life'.

When she became aware of this course in autumn 2020, she felt it was what she needed, 'somebody to tell me what to do…a magic wand to solve my problem'. At the time of the interview in May 2022, Jane had come to realise that these expectations were 'very naïve' and admits that her emotional state when she did the course was 'so bad, all over the place, I was very angry at the course, very angry at the people on the course…I was very cross because I just wanted answers, and I didn't get the answers I wanted'.

In the interview Jane went on to reveal that while she did not find the course to be supportive, she 'doesn't think this was the courses' fault…I think that was what I was going through at the time'. She felt the course was 'more of a counselling session', where:

> *one or two spoke about their mother. I didn't want to hear about their mother…and I didn't want to hear about the ones who were in 24-hour care, because I knew that was in front of me, and then I was jealous of the ones who were able to shop on their own (Jane, secondary carer).*

Similar sentiments were expressed by some participants in *Mastery over Dementia,* where the authors noted, 'Reading about other people's misery was considered undesirable.' (Boots *et al.*, 2018, p. 7). As reported earlier, reading about other people's challenges and hearing about potential solutions from peers and tutors was seen by HBC-HBE participants to be valuable.

It also emerged during the interview with Jane that her mother got dementia when she was fifty-one years of age (early onset). Following on from this, Jane's father died. Her mother was quite independent when Jane took the course, in that she could dress herself. But Jane now feels her mother had depression at the time she was on HBC-HBE, as she 'was definitely crying a lot'. Jane attended about four of the seven weekly video meetings. She missed the others because of time pressure, she had started a new job and had 'lots going on'.

Jane herself made it clear that she hadn't read the pre-course information sent to all applicants which outlined the course format and content. 'No matter what you said to me, I was going to do that course, because I wanted to fix Mammy'. During the interview she called this an 'arrogance'. This is similar to some findings in the *Mastery over Dementia* intervention where the author's note that 'Some participants, (however), were frustrated that not every situation has a solution, whereas others experienced a more accepting attitude' (Boots *et al.*, 2018, p. 7).

Jane felt that she would be more emotionally ready now, as even during our interview, she could feel herself starting to get a little upset (though this was not visible), whereas on the course she never cried or ‘validated her emotions’ about her mother’s dementia. During the interview we discussed what would have happened had we done a pre-course interview with her before she came onto HBC-HBE and found that she wasn’t emotionally ready for the course – she thought that would have ‘sent me right over the edge!’

It was interesting to note that she saw ‘the course’ as the video meeting only. She missed quite a lot of the materials – she didn’t engage with the books or factsheets. It seems that Jane only engaged with the emotional elements of the course, and not the informational aspects. This shows the importance of multicomponent interventions. Perhaps she hadn’t wanted to admit to the dementia almost to herself – in her words she ‘never validated her emotions’, she didn’t want to, perhaps she was too scared to do so. Then the course offered her a chance to confront those emotions, and she didn’t want to, or was not ready to do so at that time.

It also emerged in the interview that ‘she was outvoted by other members of her family’ on care-related issues regarding her mother – indicating possible conflict within the family, which itself can exacerbate carer burden (Etters, Goodall and Harrison, 2008, p. 425). Jane’s feelings of stress may have led her to not engaging fully as reported earlier, as the ‘perceived effort’ was too great (Chiu and Eysenbach, 2011).

Jane’s self-reported need for immediate solutions has arisen in previous research. Etters, Goodall and Harrison (2008) stated that ‘Coping strategies, such as emotion-focused coping, deal with the feelings associated with major strain, whereas problem focused coping, aims to confront the reality of major strain by dealing with the tangible consequences’ (p.424). It appears that Jane favoured a problem focussed coping strategy.

Indeed, Jane’s course experience was very interesting. It drew attention to the important issue of ‘emotional readiness’ that had been mentioned by some respondents to the online questionnaire. It raised some very important questions: How can ASI know in advance if each dementia family carer is emotionally ready to take the course? How can ASI, as course provider, ensure other learners do not have the same experience as Jane?

Given the importance of these questions, and that Jane was the first interviewee, other interviewees were asked about their own emotional readiness and how they thought ASI could minimise the chances of learners having the same experience as Jane. What follows is a selection of their responses.

Jessica felt that it was interesting that Jane felt she was coming to the course ‘for a solution’. Jessica felt that dementia family caring was ‘not something you can take a tablet to’. It was not like a headache that you could just cure. Jessica saw dementia as ‘a condition that has to be managed’. Jessica felt that if you are lucky, you learn the skills to manage the condition. She was quite reflective and accepting in her attitude and approach, as she said ‘some days you get it right, some days you don't. But you learn from it, and you try again the next day’.

Knowing when someone is emotionally ready to take the course is especially difficult, as we have seen learners not be emotionally ready at the beginning of the course, and yet they go on a journey through the course, so that by the end of the course they are more accepting of their situation. This arose in the conversation with Frances (Interviewee two). Frances is a psychotherapist by profession and feels that ‘readiness is everything’. This is an issue that comes up a lot in her own work. Frances feels that ‘it is okay if someone is not ready to actually engage in a group’. She felt that this should be emphasised by ASI to dementia family carers in our publicity materials.

Frances differentiated between the ‘functional’ element of the course – such as practical tips, communication techniques – and the ‘emotional’ element which would include the psychological support from tutors and peers. This is a similar terminology used in one systematic review which noted that online interventions for dementia family carers could be categorised as ‘informative or interactive’ (Etxeberria, Salaberria and Gorostiaga, 2021, p. 1173). Frances felt ASI should very clearly present both of these elements to potential participants, and then it would be up to participants to ‘find the answers within (themselves) on the journey’.

Nathan had a slightly different view, and a different experience. Unlike Jane, Nathan participated in both HBC-HBE and the follow on course Later Stage Dementia Care – Blended Learning for Families (LSDC) https://dementia-care-downloads.moodlecloud.com/course/view.php?id=6). He did not have any issues emotionally whilst on HBC-HBE. But he did find LSDC ‘very challenging mentally…because it really laid out the progressive nature of things, and what the future held…very sobering'. He puts this shift in his emotional readiness down to the symptoms of his father. These were relatively mild during HBC-HBE, but had become more pronounced during LSDC.

During the interviews several ideas were explored to help identify and determine learners' emotional readiness before they started the course. Among the ideas proposed by other learners were a pre-course interview or questionnaire designed to elicit the emotional state of applicants. Jane herself proposed a pre-course interview, 'I think it's such an important course, I wonder would an interview first with one-to-one might be better. I think I would have; I think, somebody would have spotted it (her emotional state)'. However, as reported earlier, Jane herself would not have been happy if resulting from a pre-course interview or questionnaire she was refused a place on the course.

Jessica wondered if ASI could 'tailor[ed]) the questionnaire that you complete before you join [to]) ask something specific like what do you want to get out of it'. That would allow course applicants to set out their expectations. These could be vetted by ASI staff and those 'looking for a solution' could be spotted, and a follow-up conversation could take place. Another idea was put forward by Mary. She suggested a pre-course (HBC-HBE) intervention, 'an onboarding exercise' to try to ascertain the emotional state of the would-be participants.

Another suggestion from Frances related to how ASI market and publicise the course. She felt that ASI needed to make it very clear to participants that they will have to find their own solutions, with the support of the course. Frances felt that dementia is so varied and 'no two people experience it the same'. However, Frances also felt that there can be commonalities, 'so it's like a framework, some modules might connect more with other people'. The key point for Frances was about being explicit that HBC-HBE is aimed at *'*helping the individual inform themselves, support themselves, enlighten themselves, have a forum…to learn something different*'*.

Most HBC-HBE participants seemed content to 'open up' about dementia (Figure 4.3). However, some learners felt uncomfortable with the idea of 'opening up' emotionally to larger groups that they felt they did not know very well.

> *I didn't feel safe to open up within the group' (OQR: 74).*

The comment above is a little worrying, as it is unclear why the person would not feel safe. Perhaps 'safe' is another way of saying 'comfortable'. Other comments relate to learners' preference to engage passively as 'lurkers', where one person said, 'I would be more comfortable listening than talking' (OQR: 83).

Another response noted feeling intimidated as, 'there were so many people involved, especially outside my own group' (OQR: 101). This comment is puzzling, as nobody outside each group can see interactions on Discussion Forums or are invited to video meetings. Perhaps this learner did not know that Discussion Forums were private, which is potentially an area the course provider could address with more clarity. Overall, these sentiments might imply that having smaller groups, or more breakout sessions could improve levels of comfort for learners.

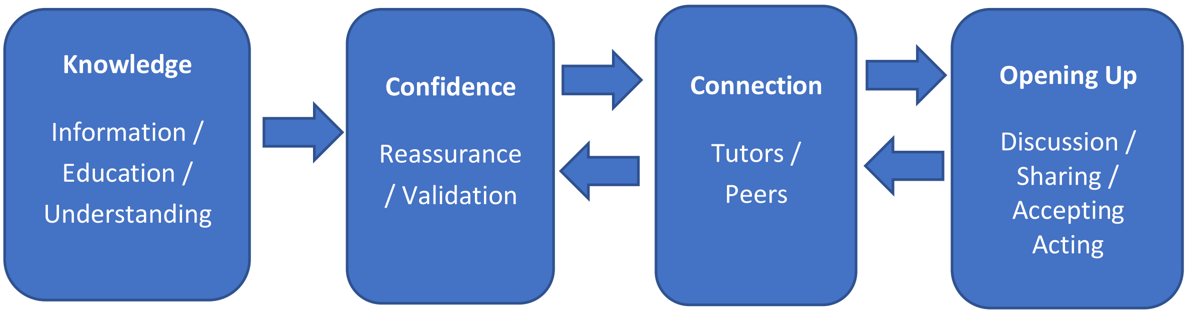
4.8.3 Discussion

What we are seeing in this theme is some course participants making links between how aspects of the course led to emotional changes within themselves. This was one of the gaps identified in previous research, namely that whilst other interventions led to reductions in burden, it was not always clear or possible to determine what led to such changes (McKechnie, Barker and Stott, 2014; Hopwood *et al.*, 2018).

The issue of acceptance seems to be important for dementia family carers and has arisen in previous research. A participant on *Diapason* expressed how he was initially in denial about his situation, but over time has found the programme interesting, 'Mr. L, husband, 80 y/o: "At the beginning I did not feel concerned, I was wrong. Maybe I was in denial. Now I find (in the program) a lot of interesting advice" (Cristancho-Lacroix *et al.*, 2015, p. 11).

Figure 4.6 below is an attempt to diagrammatically represent how some HBC-HBE participants move from initial position of having little or no knowledge and feeling ill-prepared for their dementia care tasks, to a position where they feel ready to take action. It is offered as a potential outline of the dementia family carer 'journey of acceptance' (Frances, secondary carer).

FIGURE 4. 6: DEMENTIA FAMILY CARER 'JOURNEY OF ACCEPTANCE'



It starts with gaining more knowledge and information about the disease during HBC-HBE, which leads to a better understanding of the symptoms, and behaviours of the person living with dementia. This leads to feelings of confidence, with dementia family carers feeling reassured that what they are doing is okay. Their experience is validated. This is linked to, feeds and is fed by feelings of connection to peers initially, and also with the tutors and possibly to a lesser extent to the materials (Tables 4.6, 4.7 and 4.8) as described in Theme two above. These connections and sense of belonging led to participants 'opening up' about dementia (Figure 4.3). Discussing and sharing experiences reiterated the underpinning knowledge gleaned through information, education and understanding (Theme one). This all contributed towards feelings of acceptance and allowed many to take action to improve their care situation.

Many of these themes have emerged in previous research. For example, the *Internet Based Caregiver Support Service (ICSS)*, allowed participants to discuss the situation with the therapist, who provided suggestions and guidance around implementing these suggestions. Though some of the suggestions were not new to the carer, they nevertheless validated her own approach and 'this gave her confidence to manage the situation' (Chiu et al., 2009, p. 332).

However, not everyone experienced positive emotional changes. We have seen that participation levels were influenced by a range of issues including emotional readiness, family dynamics, and other issues, which for some acted as inhibitors against course participation. These emotional issues included feeling overwhelmed by the dementia care situation, not feeling emotionally ready for the course, and not feeling the need for emotional support from others. Issues around privacy and feeling uncomfortable about contributing were also important factors for some HBC-HBE participants.

4.9 Chapter Summary

This chapter has presented findings from the case study used in this thesis. The final codebook template has been presented for the reader in the form of five themes. These themes have been used to address the two research questions. Evidence to support each theme has been provided in the form of descriptive statistics together with a range of direct quotations from learners on HBC-HBE.

HBC-HBE has supported the vast majority of learners. This is clearly evident from statistics related to reductions in stress and increases in confidence (Figure 4.4). These statistics are supported by an array of individual learner comments from the two research instruments.

This chapter has also provided an insight into how HBC-HBE supports learners. It crystallised the importance of interactions with peers (Table 4.7) and the course tutors (Table 4.6). It documented the importance of information and course materials (Table 4.8). Learner support is also apparent from the large number of participants who felt that HBC-HBE had a positive impact on their care delivery as outlined in Figure 4.5. These positive impacts were outlined too in the range of practical supports and care skills participants reported learning on the course.

However, while most people were satisfied with their learning experience on the course, this feeling was not universal. Many learners provided useful suggestions as to how HBC-HBE could provide better support to dementia family carers. Some of these related to usability issues with the virtual learning environment, while others involved ensuring learners are emotionally ready for the course. Linked to the issue of emotional readiness, the chapter finished by offering a model of how learners might progress along the journey of acceptance. This chapter has presented and discussed the findings of this case study. In the chapter that follows, final conclusions and recommendations will be outlined to the reader.

Chapter 5: Conclusions and Recommendations

5.1 Introduction

This chapter will present final conclusions and recommendations gathered from and based on the evidence collected through this case study's qualitative and quantitative data. Recommendations will be presented at policy level, and in relation to practice on how ASI could make improvements to HBC-HBE for future participants. Limitations of the thesis will be offered to the reader, before areas for potential future research in this area will be outlined. Thereafter I will offer a final reflection to close the thesis.

This thesis has presented a case study of the HBC-HBE online education course for dementia family carers. In chapter one the context and the aims of the research were established. It included a rationale for the research, a description of the HBC-HBE course, an outline of the research questions to be studied and the overall structure of the thesis. Chapter two provided a detailed overview and analysis of relevant literature related to this topic. The chapter concluded with the important supportive elements in online dementia family carer training. These included the learning environment, peer contact, information, education, professional / tutor / expert advice and psychological support. These elements were the foundations on which the rest of the thesis was built as they informed the construction of the online questionnaire, the first step in the iterative process of data gathering and analysis.

In chapter three the case study research methodology used in this thesis was outlined in detail. The abductive approach to theory development was described and the researcher demonstrated how this aligned to the iterative approach used in template analysis. The chapter also described and justified the research and data analysis methods used in this thesis. Findings and discussion relating to the two research questions were presented in chapter four. These were presented in five themes, as follows: (1) Many learners gained a range of skills and practical tips from participating on HBC-HBE, (2) Learners gained support through engagement with tutors, peers and course materials, (3) Learners were mostly satisfied with the HBC-HBE course, though there were suggestions on how to improve it, (4) The online environment mostly facilitated learning, and (5) The course supported many learners psychologically, though some learners were not emotionally ready to participate on HBC-HBE. This final chapter presents overall conclusions and recommendations resulting from this study. These conclusions will be of benefit to ASI as it seeks to improve HBC-HBE for future course participants. Other NGOs especially those working with different carer groups may be interested in this research particularly in relation to how HBC-HBE supported participants and how they felt it can better support them. For example, this thesis has shown the importance of the use of video conferencing to help foster a sense of connection between learners and this may be particularly instructive to other organisations. It will also be of wider interest to the academic community, especially those involved in developing and / or delivering online learning. Policy makers in the fields of health and dementia care may also be interested in the study.

5.2 Answering the research questions

This thesis set out to explore how HBC-HBE, an online education course provided by an Irish NGO, supported dementia family carers. The thesis addressed two specific and closely related research questions:

How does HBC-HBE support dementia family carers?

How can HBC-HBE better support dementia family carers?

Conclusions related to these two research questions are set out below.

5.2.1 Research Question 1

How does HBC-HBE support dementia family carers? Most research participants thought HBC-HBE supported them as they gained practical skills in communication and care delivery and that these helped them manage responsive behaviours. They also benefitted from getting new and key information about dementia and support services available to them. This finding confirms conclusions from earlier research about the importance of topics including communication (Finkel *et al.*, 2007; Kajiyama *et al.*, 2013; Blom *et al.*, 2015), information about dementia (Chiu *et al.*, 2009; Chiu and Eysenbach, 2011; Pagán-Ortiz *et al.*, 2014) and dementia support services (Cristancho-Lacroix *et al.*, 2015; Metcalfe *et al.*, 2019), and that these need to be included in 'multi-component interventions' (Etxeberria, Salaberria and Gorostiaga, 2021) for dementia family carers, as reported in chapter two.

Many learners on HBC-HBE derived support from tutors, fellow course participants and from the course materials. The role of the tutor was particularly important for most learners. Their knowledge, advice, empathy and guidance were greatly appreciated by course participants. This finding adds to the existing literature from earlier studies of various interventions such as *WeCareAdvisor* (Kales *et al.*, 2017) and *Cuidate Cuidador 'Caregiver, take care of yourself'* (Pagán-Ortiz *et al.*, 2014) by providing detail on *how* support was derived by HBC-HBE course participants.

The role of peer support was also very important. Many learners enjoyed and gained strength from listening to other course participants. This was seen to be useful to many carers as they saw direct evidence of carer resilience. They could also compare their own troubles and anxieties to those of their peers and this produced for many feelings of reassurance. This finding is also consistent with some earlier studies of online interventions aimed at supporting dementia family carers including *Virtual Healthcare Neighbourhood* (Fowler, Haney and Rutledge, 2014) and *UnderstAID* (Núñez-Naveira *et al.*, 2016). The course materials in HBC-HBE provided a foundation in terms of knowledge and understanding dementia, and this was strongly linked to the provision of information.

Given that most respondents reported gaining support from HBC-HBE, many learners expressed how satisfied they were with the course. Many were deeply satisfied and provided clear evidence that the course had a profound impact on their care situation. This suggests some participants may have experienced 'transformative learning [which] transforms problematic frames of reference - sets of fixed assumptions and expectations (habits of mind, meaning perspectives, mindsets) – to make them more inclusive, discriminating, open, reflective, and emotionally able to change' (Mezirow, 2003, p. 58). Many learners expressed feelings of gratitude to ASI, and to tutors and support staff for delivering the course to them. Many could not offer any suggestions about how ASI could improve the course.

For most respondents the online learning environment mostly facilitated their learning and participation on the course. Possibly coinciding with the COVID pandemic and the move 'to multiple different communication channels' (Ion *et al.*, 2021), most learners found using various elements of Moodle Workplace easy or very easy, especially the video meetings which were accessed by ninety-three percent of respondents. Course participants felt that video meetings were especially important for providing a platform to learn from the tutor and their peers. Many found the course structure logical and easy to follow.

A recent Irish study has shown that carer burden among family carers of people with dementia is greater than for other types of family carers (Teahan *et al.*, 2021). Participating on HBC-HBE, and 'opening-up' about dementia, led to sizable increases in confidence and reductions in stress for the majority of learners. Connecting with tutors and peers on the course had a strong impact on HBC-HBE participants. Firstly, it made learners feel less alone and isolated. Secondly, it brought the course materials to life by providing authentic, real-life evidence of what it was like to be a dementia family carer. Thirdly, it personalised learners' care practice, in that many received answers to their own queries, or stored up information and advice received from others to use at a later point in their care journey. These factors led to many learners expressing feelings of empowerment whereby they could and did take action to improve their situation. Almost 60 per cent of learners reported the course as having a major positive impact on the way they provide care. Nobody articulated that the course had a negative impact on the way they provide care.

5.2.2 Research Question 2

How can HBC-HBE better support dementia family carers? There were a number of learners who felt that the course could have been more supportive, thus addressing the second research question. Some HBC-HBE participants felt tutors could have better facilitation skills. This provides a challenge for tutors who also need to show kindness and empathy for learners, especially those older learners who might be out of their comfort zone using technology (Li *et al.*, 2021).

Others did not connect with the course for a range of reasons. Time was the enemy of many learners, which is not a surprise given the demands of dementia care (Chiao, Wu and Hsiao, 2015). Some learners chose, or only had time, to attend video meetings. They did not fully engage with course materials. This may have impacted negatively on how the course supported them. ASI, as the course provider, therefore needs to consider how it could make the HBC-HBE course materials more attractive and engaging to ensure that as many learners as possible access them. This issue will be explored further in section 5.5.2.

Though many learners were satisfied with the course, this was not a universal feeling. There were a number of suggestions made in relation to format, content and presentation, as well as the size and characteristics of groups of learners. Many learners also requested follow-up support. Some learners on HBC-HBE provided suggestions about how to improve the learner experience on Moodle Workplace. These related to usability more generally, and the 'BigBlueButton' video conferencing software more specifically. These will be presented in section 5.5.3 below.

Finally, while the majority of learners gained in confidence from participating on HBC-HBE, the emotional nature of dementia family caring proved a barrier for other learners. Many respondents felt overwhelmed by their care situation. Participation on HBC-HBE was difficult for these learners. Some persevered by attending video meetings early in the course, but they ran out of energy and disengaged later in the course. This gave rise to the issue of 'emotional readiness' as an important factor that led to some learners having a diminished course experience, and consequently to feeling that HBC-HBE was not supportive to their situation. Research participants offered suggestions on how to address 'emotional readiness' and these will be outlined in section 5.5.4 below.

5.3 Contribution to knowledge

To the best of my knowledge, this is the first study to examine the experiences of mostly Irish dementia family carers who were participating on an online training course designed to support their care practice. It therefore contributes to the canon of existing international research in this field. This thesis suggests that HBC-HBE as one such 'multi-component' intervention (Etxeberria, Salaberria and Gorostiaga, 2021) utilising information, tutor and peer support and delivered via the Moodle Workplace online learning platform, has provided most participants with practical and emotional support. This is further evidence of the potential for online learning to support dementia family carers already established in various systematic reviews (Boots *et al.*, 2014; Christie *et al.*, 2018; Klimova *et al.*, 2019).

By using a case study methodology with multiple methods this thesis has provided a detailed analysis of how online learning can support dementia family carers. Many earlier studies such as *E-Care* (Finkel *et al.*, 2007) and *Tele-Savvy* (Griffiths *et al.*, 2016) showed that participating in online interventions reduced a range of psychological symptoms (stress, strain and burden). However, it was not always clear how these reductions had been achieved. By using a case study methodology (Yin, 2014) with multiple methods, this study has provided a detailed narrative account of the feelings and experiences of course participants. Quantitative data on emotions such as stress, confidence and attitudes towards tutors, peers and course materials have added to our understanding of the depth of feelings across our research respondents.

This thesis has contributed to knowledge by addressing research gaps identified by earlier systematic review studies and outlined in chapter two. It has provided an opportunity to hear from dementia family carers as 'the end-user' of the intervention (Christie *et al.*, 2018). It has analysed which aspects of the intervention are most useful to course participants (Hopwood *et al.*, 2018). An interesting finding is that the individual components (tutor, peer, and course materials) are useful in themselves, but for many learners the three components were equally important and mutually reinforcing. This contributes to and extends our understanding of how learners actually learn in an informal online learning course.

There are some other notable contributions to knowledge. For example, the study included primary *and* secondary carers. According to one systematic review, earlier studies had focussed on interventions that targeted primary carers only (Etxeberria, Salaberria and Gorostiaga, 2021). It was also evident in the study that many HBC-HBE participants shared resources, information and knowledge with wider family and colleagues. This suggests that HBC-HBE may positively impact more people than the number of participants shown in Table 1.1. Further research may be required to fully understand the extent of this potentially welcome finding.

This research also had a temporal aspect in two ways. Firstly, this case study has examined an *established* intervention. Many of the studies reported earlier were of proposed interventions such as *CaFCa - Care of family carers of persons with dementia* (Kabir *et al.*, 2020), or pilot courses like *Care to Plan* (CtP) (Gaugler, Reese and Tanler, 2016). HBC-HBE has been delivered since 2016 and is an established course. Secondly, this thesis is based on the findings from research respondents who participated in the course over a three-year period. Chapter two highlighted the number of studies of pilot or exploratory studies (section 2.6.1.4), and the fact that scholars had called for future studies to carry out research on interventions beyond the initial or trial period (Christie *et al.*, 2018). As such this thesis is perhaps unique in that it has investigated an intervention beyond the initial, pilot or development phase, with a range of respondents across a prolonged period. This adds a distinctive angle to knowledge in this area.

This research has also provided interesting insights into the issue of ‘carer burden’ (Chiao, Wu and Hsiao, 2015). It suggests that intra-family tensions – or ‘family functioning’ which includes ‘the differentiation of roles and functions for each family member’ (Heru and Ryan, 2006, p. 223) may sometimes contribute to dementia family carer stress levels (though it can also alleviate stress).

5.4 Recommendations for future policy

The National Dementia Strategy was published in 2014 (Department of Health, 2014). The important role of dementia family carers was acknowledged in the strategy. A follow-up review report on the implementation of the National Dementia Strategy was published in 2018 (National Dementia Office and Department of Health, 2018). This follow-up report records progress made against various targets set out in the initial strategy. It reports that education and training for dementia family carers is a ‘non-funded action’ (as opposed to various funded actions such as a public awareness campaign). The report recommends ‘Rolling out education programmes for health and social care staff, family carers, customer facing staff and the general public, and developing new programmes’ (p.9). However, disappointingly, no further details about the rolling out of education and training specifically for family carers are provided in the report.

This thesis has highlighted the importance and positive impact of online dementia family carer training. HBE-HBE supports dementia family carers in a multitude of ways. Future policy in this domain needs to set out a framework and funding stream for dedicated quality assured online dementia family carer training. Evidence from this thesis demonstrates that HBC-HBE supports a large number of dementia family carers. The course needs to be resourced properly by the government.

In Ireland the government's digital literacy policy is set out in the Adult Literacy for Life document (Government of Ireland, 2021). This strategy document also addresses the related issues of adult literacy and numeracy. The strategy calls for expanded 'investment in digital skills provision across formal and non-formal routes' (p. 64), with an overall target to 'decrease the share of adults in Ireland without basic digital skills from 47 per cent to 20 per cent' (p.66). Disappointingly, this strategy does not contain specific quantifiable actions to achieve this goal.

In section 4.7.2 above, research respondents reported that they felt their elderly parents, who were often primary carers, might struggle with participating on HBC-HBE due to their lack of IT skills. The Digital Inclusion in Ireland Report (National Economic and Social Development Office, 2021) is a welcome attempt to invigorate an active citizenry so that everyone can benefit from online learning. Particularly welcome are the aspects of the report that address 'gaps in relation to older people' (p. 46). The actions in this report including helping older people access digital technology should constitute government policy and action in this area.

Future policy in the field of digital skills, especially for the elderly, should be much more specific, targeted, adequately resourced, transparent, and quantifiable. It should include the 'roll-out [od] an ongoing national digital skills learning programme, integrating new digital hubs in towns with existing community infrastructure' (Age Action, 2020, p. 12). This would upskill potential new learners who would benefit from HBC-HBE in the future.

It is hoped that the positive findings in this thesis will lead to some policy changes within ASI. The new ASI strategy which is currently under construction should clearly state the effectiveness of HBC-HBE in supporting dementia family carers. The strategy should set out ambitious targets to reach larger numbers of dementia family carers and should commit to seeking funding resources from the National Dementia Office or central government.

5.5 Recommendations for future practice

Many research participants reported positive feelings toward HBC-HBE. They gained support through participation on the course. ASI needs to be mindful of this finding, as it suggests HBC-HBE is working well for a lot of participants. Research question two asked how HBC-HBE could better support dementia family carers. There were several very useful suggestions made by learners and these are set out below.

5.5.1 Tutor skills

HBC-HBE tutors have to perform a difficult balancing act between ‘a pedagogy of care’ (Noddings, 2003, 2010), that is kindness, empathy and support on the one hand, and efficiency in facilitating video meetings on the other. Most tutors seem to get this right most of the time. Nevertheless, more training in facilitation skills may be required for tutors to give them more confidence and guidance in this area. Furthermore, tutors should be encouraged to avail of training and development opportunities to increase their knowledge of related areas such as nutrition. A mentoring scheme could also be put in place in which tutors could be paired together to share best practice. Similar schemes have been used in nursing practice as preceptorships, ‘which include some traditional elements of mentoring such as modelling the “roles, skills and virtues” of the profession’ (Mott 2002 quoted in Miller, Vivona and Roth, 2016, p. 2015). Finally, weekly tutor meetings will be held at which all tutors will be invited to share their experiences and support each other with ideas about best practice.

5.5.2 Course format and content

ASI needs to give serious consideration to a ‘reflective week’ in the middle of the HBC-HBE course. This would allow participants to catch up with earlier material. There is also a number of areas where course content can be improved. The introduction of a relaxation activity should be considered at the start of each video meeting to help alleviate carer stress (Etters, Goodall and Harrison, 2008). More information is required about younger onset dementia as in the *RHAPSODY* programme (Metcalfe *et al.*, 2019). There needs to be more targeted information and advice specifically for spousal carers (Brennan *et al.*, 2017).

The challenge will be how to include these niche elements within a course that aims to support all kinds of dementia family carers – primary, secondary, spousal – as well as those at various stages in the care trajectory. In addition, changes to how the course is marketed and publicised will be made. It will be clear to potential participants that both ‘emotion and problem focussed coping strategies’ (Etters, Goodall and Harrison, 2008) will be addressed, and that participants will be encouraged and supported to find their own solutions along the journey of acceptance.

5.5.3 Moodle usability

While the majority of respondents to this study felt able to use Moodle Workplace, about 20 per cent did report difficulties in this regard. This is interesting given that most respondents to the online questionnaire reported feeling confident using IT and computers. Participants made a range of constructive suggestions (some of which have already been implemented, such as tutors sharing their screen to give learners a tour of the course page). However, to further understand the learner experience, a review of the support measures such as videos and ‘how to’ guides already in place will be carried out so that they can be improved. In addition, ASI will continue to seek ongoing feedback from HBC-HBE participants about how difficult or easy they find using the online learning platform.

One systematic review of factors affecting e-learning in health sciences identified ‘lack of user-friendly IT’ as one of the key challenges of making e-learning successful’ (Regmi and Jones, 2020, p. 8). Learners on HBC-HBE reported the need to reduce the ‘number of clicks’ on the course and this should be a priority for ASI. External Moodle experts should be consulted to recommend changes to the course structure to reduce scrolling and clicking. Participants’ recommendations regarding presentation of materials could be improved in two ways: Firstly, by having a bullet pointed concise version of course books and secondly, through the collation of all Factsheets into one downloadable folder. The current week of the programme will be highlighted for all to see, and there will be clearer information on privacy and confidentiality settings.

5.5.4 Emotional readiness

ASI needs to address the issue of emotional readiness that impacted Jane and others’ learning experience on HBC-HBE. There are a number of possible courses of action open to ASI. A pre-course interview with at least 100 applicants every quarter might be beyond the reach given our current resources. However, a mandatory pre-course questionnaire such as the ‘Trait Emotional Intelligence questionnaire’ (Petrides, 2009) could be introduced to gain an insight into learners’ emotional state. This could form part of an onboarding exercise in which ASI engages with learners prior to the start of the course to make sure they understand the emotional nature of the content and the constructivist pedagogical approach.

Additionally, ASI could consider ‘exit points’ whereby learners who are not satisfied mid-way through the course (during the proposed reflective week) could leave HBC-HBE and be signposted to various other more appropriate information resources. Exit interviews could be introduced to offer HBC-HBE participants the opportunity to explain why they want to leave the course, and to outline their immediate needs regarding information, services or other supports and how these could be met.

Relatedly, group dynamics should be re-examined in order to get the maximum possible impact from video meetings. The use of breakout rooms to facilitate active learning engagement has been highly rated by students (Ahshan, 2021). Using breakout rooms to divide cohorts of twenty HBC-HBE participants into groups that share common experiences should be considered in some video meetings. This should foster greater ‘connection’ between peers. This is vital to increasing the propensity of course participants to ‘open-up’ about dementia, which in turn can lead to beneficial effects of increases in confidence, acceptance and empowerment.

5.6 Limitations of the thesis

Participants in this research project described themselves mainly as being comfortable using IT and computers (see chapter four). However, it would have been very interesting to hear the views of those who were more challenged by IT. Nevertheless, feedback received from research respondents has provided many useful and authentic suggestions on how HBC-HBE can better support dementia family carers.

The voices of some cohorts of dementia family carers were not heard in this research. It would be interesting to get an insight into the particular challenges faced by younger carers (Elf *et al.*, 2012), carers of people in later stage dementia (Ashton *et al.*, 2016) or those caring for people with younger onset dementia (Millenaar *et al.*, 2018). It should be noted that most of the participants on the online questionnaire were relatively new to caring and had been doing so for less than three years. In addition, and as mentioned previously, the voice of the tutors is not present in this thesis. Their views on how they felt HBC-HBE supported learners, and how it could better support them, would be useful. Nevertheless, tutors will be consulted during the implementation of the findings contained in this thesis.

5.7 Recommendations for future research

This research has highlighted the views of dementia family carers participating in an online training course. It would be interesting to investigate the views and experiences of related stakeholders. For example, the views and experiences of HBC-HBE tutors especially in relation to how they might find the balance between kindness, empathy and efficiency would be useful.

Delivering this course to as many as dementia family carers as possible must be a central priority for ASI. Investigating and quantifying the ‘knock on’ potential beneficial impact of HBC-HBE participation on wider family and friends would also be interesting. This might demonstrate how HBC-HBE is value for money to ASI, which in turn may convince funders about the worthiness of investing in this kind of course. In addition, given the importance of tutor and peer support, it would be useful to examine in future research how future HBC-HBE courses with potentially larger numbers of participants could maintain and protect these connections and the sense of support evident in this thesis.

It would be interesting also to investigate the dementia family carer ‘journey of acceptance’ which was graphically represented in Figure 4.6 above. This would build on the ‘adaptation – coping model’ (Brooker, Dröes and Evans, 2017) which has examined how people with dementia and their family carers adapt to receiving a dementia diagnosis. Specifically, further research could explore how learners themselves visualise this journey, and how they feel that online education may facilitate a more comfortable adjustment to the ongoing changes and complex challenges presented by dementia family caring.

Possible areas for future research could include an overall evaluation of the programme. This could feature the tutors’ reflections and experiences. It could look at the teaching and learning processes involved in the course from tutor and learner perspectives, it could examine the pre-service training engaged in by the tutors and the qualifications and relevant experience they brought to the course; it could also explore avenues for CPD and in service training for tutors. The role of tutor as facilitator was mentioned on a number of occasions and tutor experience, training and qualifications in this aspect of the course delivery could also form part of the evaluation. Other areas that might be focussed on include how the programme and its management operates and is regarded within the organisation itself, what future is envisaged for the programme including the development of appropriate strategies regarding how it might be developed and grown.

5.8 Final Reflection

This research project has provided the author with a much deeper understanding of how HBC-HBE supports dementia family carers, and how it could be improved to better support them. It has been heartening to hear the positive stories and feelings of course participants. The deep satisfaction and levels of gratitude expressed by many learners has at times been very moving. As a reflexive researcher I had to ask myself if I was reporting these positive comments fairly and accurately.

It has been tremendously important to drill down and examine the less positive feedback and experiences of learners. The fact that learners were balanced in reporting their views contributes to the validity and worthiness of this research. Additionally, it provides a range of suggestions for ASI to improve HBC-HBE for future participants. And that is exactly what was hoped for when I began this research. Dementia family carers need and deserve the best possible education and training to support them to deliver the best possible care for their family members.

References

Adams, C. and Rose, E. (2014) ‘Will I ever connect with the students?” Online Teaching and the Pedagogy of Care’, *Phenomenology & Practice,* 8(1), pp. 5–16. Available at: https://doi.org/10.29173/pandpr20637.

Age Action (2020) *Supporting Digital Literacy Among Older People*. Briefing Paper 6, p. 13. Available at: https://www.ageaction.ie/sites/default/files/supporting_older_peoples_digital_literacy_briefing_paper_6_january_2020_update_of_paper_5_first_published_march_2018.pdf (Accessed: 27 November 2022).

Ahshan, R. (2021) ‘A Framework of Implementing Strategies for Active Student Engagement in Remote/Online Teaching and Learning during the COVID-19 Pandemic’, *Education Sciences,* 11(9), p. 483. Available at: https://doi.org/10.3390/educsci11090483.

Alley, S., Jackson, S.F. and Shakya, Y.B. (2015) ‘Reflexivity: A Methodological Tool in the Knowledge Translation Process?’, *Health Promotion Practice,* 16(3), pp. 426–431. Available at: https://doi.org/10.1177/1524839914568344.

Alzheimer Europe (2020) *Dementia in Europe Yearbook 2019 - estimating the prevalence of dementia in Europe*. Luxembourg. Available at: https://www.alzheimer-europe.org/sites/default/files/alzheimer_europe_dementia_in_europe_yearbook_2019.pdf (Accessed: 13 January 2021).

Alzheimer’s Disease International (2015) ‘The global impact of dementia’. Available at: https://www.alz.co.uk/sites/default/files/pdfs/global-impact-dementia-infographic.pdf (Accessed: 4 November 2020).

Alzheimer’s Disease International (No date) *About Alzheimer’s & Dementia*. Available at: https://www.alzint.org/about/ (Accessed: 11 August 2022).

Archibald, M.M. *et al.* (2019) ‘Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants’, *International Journal of Qualitative Methods,* 18, p. 1609406919874596. Available at: https://doi.org/10.1177/1609406919874596.

Ashton, S.E. *et al.* (2016) ‘End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia – A qualitative study’, *Dementia,* 15(5), pp. 958–975. Available at: https://doi.org/10.1177/1471301214548521.

Atalaia, A. *et al.* (2020) ‘A guide to writing systematic reviews of rare disease treatments to generate FAIR-compliant datasets: building a Treatabolome’, *Orphanet Journal of Rare Diseases,* 15(1), p. 206. Available at: https://doi.org/10.1186/s13023-020-01493-7.

Ball, D.L. and Forzani, F.M. (2007) ‘What Makes Education Research “Educational”?’, *Educational Researcher,* 36(9), pp. 529–540.

Baruah, U. *et al.* (2020) ‘Perspectives on Components of an Online Training and Support Program for Dementia Family Caregivers in India: A Focus Group Study’, *Clinical*

Gerontologist, 43(5), pp. 518–532. Available at: https://doi.org/10.1080/07317115.2020.1725703.

Bellefeuille, G., Martin, R.R. and Buck, M.P. (2005) ‘From Pedagogy to Technagogy in Social Work Education: A Constructivist Approach to Instructional Design in an Online, Competency-Based Child Welfare Practice Course’, *Child and Youth Care Forum*, 34(5), pp. 371–389. Available at: https://doi.org/10.1007/s10566-005-5909-2.

Bergström, A.L. and Hanson, E. (2018) ‘An integrative review of information and communication technology based support interventions for carers of home dwelling older people’, *Technology and Disability*, 29(1–2), pp. 1–14. Available at: https://doi.org/10.3233/TAD-160158.

Blom, M.M. *et al.* (2015) ‘Effectiveness of an Internet Intervention for Family Caregivers of People with Dementia: Results of a Randomized Controlled Trial’, *PLOS ONE*. Edited by N. Walker, 10(2), p. e0116622. Available at: https://doi.org/10.1371/journal.pone.0116622.

Boots, L.M. *et al.* (2014) ‘A systematic review of Internet-based supportive interventions for caregivers of patients with dementia’, *International Journal of Geriatric Psychiatry*, 29(4), pp. 331–344. Available at: https://doi.org/10.1002/gps.4016.

Boots, L.M. *et al.* (2016) ‘Effectiveness of the blended care self-management program “Partner in Balance” for early-stage dementia caregivers: study protocol for a randomized controlled trial’, *Trials*, 17, pp. 1–9. Available at: https://doi.org/10.1186/s13063-016-1351-z.

Boots, L.M. *et al.* (2017) ‘Implementation of the Blended Care Self-Management Program for Caregivers of People With Early-Stage Dementia (Partner in Balance): Process Evaluation of a Randomized Controlled Trial’, *Journal of Medical Internet Research*, 19(12), p. e423. Available at: https://doi.org/10.2196/jmir.7666.

Boots, L.M. *et al.* (2018) ‘Effectiveness of a Blended Care Self-Management Program for Caregivers of People With Early-Stage Dementia (Partner in Balance): Randomized Controlled Trial’, *Journal of Medical Internet Research*, 20(7), p. e10017. Available at: https://doi.org/10.2196/10017.

Boyd, K. *et al.* (2014) ‘An investigation into the usability of the STAR training and re-skilling website for carers of persons with dementia’, in *2014 36th Annual International Conference of the IEEE Engineering in Medicine and Biology Society*. *2014 36th Annual International Conference of the IEEE Engineering in Medicine and Biology Society*, pp. 4139–4142. Available at: https://doi.org/10.1109/EMBC.2014.6944535.

Bozkurt, A. and Zawacki-Richter, O. (2021) ‘Trends and Patterns in Distance Education (2014–2019): A Synthesis of Scholarly Publications and a Visualization of the Intellectual Landscape’, *The International Review of Research in Open and Distributed Learning*, 22(2), pp. 19–45. Available at: https://doi.org/10.19173/irrodl.v22i2.5381.

Braun, V. and Clarke, V. (2006) ‘Using thematic analysis in psychology’, *Qualitative Research in Psychology*, 3(2), pp. 77–101. Available at: https://doi.org/10.1191/1478088706qp063oa.

Braun, V. and Clarke, V. (2014) ‘What can “thematic analysis” offer health and wellbeing researchers?’, *International Journal of Qualitative Studies on Health and Well-being*, 9(1), p. 26152. Available at: https://doi.org/10.3402/qhw.v9.26152.

Braun, V. and Clarke, V. (2019) ‘Reflecting on reflexive thematic analysis’, *Qualitative Research in Sport, Exercise and Health*, 11(4), pp. 589–597. Available at: https://doi.org/10.1080/2159676X.2019.1628806.

Braun, V. and Clarke, V. (2021) ‘One size fits all? What counts as quality practice in (reflexive) thematic analysis?’, *Qualitative Research in Psychology*, 18(3), pp. 328–352. Available at: https://doi.org/10.1080/14780887.2020.1769238.

Brennan, S. *et al.* (2017) *De-Stress: a study to assess the health and wellbeing of spousal carers of people with dementia in Ireland*. The Alzheimer Society of Ireland. Available at: http://www.dementia-neurodegeneration.ie/sites/default/files/publications/de-stress-report-2017.pdf (Accessed: 25 October 2019).

Brooker, D. (2006) *Person-Centred Dementia Care: Making Services Better*. London, UNITED KINGDOM: Jessica Kingsley Publishers. Available at: http://ebookcentral.proquest.com/lib/dcu/detail.action?docID=334135 (Accessed: 12 November 2022).

Brooker, D., Dröes, R.-M. and Evans, S. (2017) ‘Framing outcomes of post-diagnostic psychosocial interventions in dementia: the Adaptation-Coping Model and adjusting to change’, *Working With Older People*, 21(1), pp. 13–21. Available at: http://dx.doi.org.dcu.idm.oclc.org/10.1108/WWOP-12-2016-0039.

Brooks, J. *et al.* (2015) ‘The Utility of Template Analysis in Qualitative Psychology Research’, *Qualitative Research in Psychology*, 12(2), pp. 202–222. Available at: https://doi.org/10.1080/14780887.2014.955224.

Cahill, S., O’Shea, E. and Pierce, M. (2012) ‘Future Dementia Care in Ireland, Sharing the Evidence to Mobilise Action’. Available at: https://health.gov.ie/wp-content/uploads/2014/03/future_dementia_care.pdf (Accessed: 31 March 2019).

Care Alliance Ireland (2015) ‘Family Caring In Ireland’. Available at: https://www.carealliance.ie/userfiles/files/Family_Caring_In_Ireland_March2015.pdf (Accessed: 5 January 2021).

Carter, L. *et al.* (2021) ‘Intensive home care supports, informal care and private provision for people with dementia in Ireland’, *Dementia*, 20(1), pp. 47–65. Available at: https://doi.org/10.1177/1471301219863580.

Casey, D. *et al.* (2020) ‘The feasibility of a Comprehensive Resilience-building psychosocial Intervention (CREST) for people with dementia in the community: protocol for a non-randomised feasibility study', *Pilot and Feasibility Studies*, 6(1), p. 177. Available at: https://doi.org/10.1186/s40814-020-00701-2.

Chalmers, I., Hedges, L.V. and Cooper, H. (2002) 'A Brief History of Research Synthesis', *Evaluation & the Health Professions*, 25(1), pp. 12–37. Available at: https://doi.org/10.1177/0163278702025001003.

Chan, W.C. *et al.* (2010) 'Lived Experience of Caregivers of Persons with Dementia in Hong Kong: a Qualitative Study', *East Asian Archives of Psychiatry*, 20(4), pp. 163–8.

Cheng, M. and Yuen, A.H.K. (2018) 'Student continuance of learning management system use: A longitudinal exploration', *Computers & Education*, 120, pp. 241–253. Available at: https://doi.org/10.1016/j.compedu.2018.02.004.

Cheng, S.-T. and Zhang, F. (2020) 'A comprehensive meta-review of systematic reviews and meta-analyses on nonpharmacological interventions for informal dementia caregivers', *BMC Geriatrics*, 20(1), p. 137. Available at: https://doi.org/10.1186/s12877-020-01547-2.

Chiao, C.-Y., Wu, H.-S. and Hsiao, C.-Y. (2015) 'Caregiver burden for informal caregivers of patients with dementia: A systematic review', *International Nursing Review*, 62(3), pp. 340–350. Available at: https://doi.org/10.1111/inr.12194.

Chickering, A.W. and Gamson, Z.F. (1999) 'Development and Adaptations of the Seven Principles for Good Practice in Undergraduate Education', *New Directions for Teaching & Learning*, 1999(80), p. 75. Available at: https://doi.org/10.1002/tl.8006.

Chiu, T. *et al.* (2009) 'Internet-Based Caregiver Support for Chinese Canadians Taking Care of a Family Member with Alzheimer Disease and Related Dementia*', *Canadian Journal on Aging / La Revue canadienne du vieillissement*, 28(4), pp. 323–336. Available at: https://doi.org/10.1017/S0714980809990158.

Chiu, T.M.L. and Eysenbach, G. (2011) 'Theorizing the health service usage behavior of family caregivers: A qualitative study of an internet-based intervention', *International Journal of Medical Informatics*, 80(11), pp. 754–764. Available at: https://doi.org/10.1016/j.ijmedinf.2011.08.010.

Christie, H.L. *et al.* (2018) 'A systematic review on the implementation of eHealth interventions for informal caregivers of people with dementia', *Internet Interventions*, 13, pp. 51–59. Available at: https://doi.org/10.1016/j.invent.2018.07.002.

Čižmešija, A. and Bubaš, G. (2020) 'An Instrument for Evaluation of the Use of the Web Conferencing System BigBlueButton in e-Learning', in *Central European Conference on Information and Intelligent Systems*. Varazdin, Croatia: Faculty of Organization and Informatics Varazdin, pp. 63–71. Available at: https://www.proquest.com/docview/2531368788/abstract/B0E18D56F594DCDPQ/1 (Accessed: 30 November 2022).

Clouston, T.J. (2018) 'Transforming learning: teaching compassion and caring values in higher education', *Journal of Further and Higher Education*, 42(7), pp. 1015–1024. Available at: https://doi.org/10.1080/0309877X.2017.1332359.

Coe, R. *et al.* (2017) *Research Methods and Methodologies in Education*. 2nd Edition. London: SAGE.

Cohen, L., Manion, L. and Morrison, K. (2011) *Research Methods in Education*. 7th Edition. Routledge.

Cramp, A. (2015) 'Meaningful dialogue in digitally mediated learning for in-service teacher development', *Technology, Pedagogy and Education*, 24(1), pp. 1–16. Available at: https://doi.org/10.1080/1475939X.2013.822417.

Cranton, P. and Hoggan, C. (2012) 'Chapter 32 Evaluating Transformative Learning', in Taylor, E. W. and Cranton, P., *The Handbook of Transformative Learning: Theory, Research and Practice*. Hoboken, UNITED KINGDOM: John Wiley & Sons Limited. Available at: https://ebookcentral-proquest-com.dcu.idm.oclc.org/lib/dcu/reader.action?docID=821727.

Creswell, J.W. (2014) *Research design: qualitative, quantitative, and mixed methods approaches*. 4th ed. Thousand Oaks: SAGE Publications.

Cristancho-Lacroix, V. *et al.* (2015) 'A Web-Based Psychoeducational Program for Informal Caregivers of Patients With Alzheimer's Disease: A Pilot Randomized Controlled Trial', *Journal of Medical Internet Research*, 17(5), p. e3717. Available at: https://doi.org/10.2196/jmir.3717.

Czaja, S. *et al.* (2013) 'A Videophone Psychosocial Intervention for Dementia Caregivers', *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry*, 21. Available at: https://doi.org/10.1016/j.jagp.2013.02.019.

Daly, M. (2003) 'Methodology', in Brewer, J., *The A-Z of Social Research*. 1 Oliver's Yard, 55 City Road, London England EC1Y 1SP United Kingdom: SAGE Publications, Ltd. Available at: https://doi.org/10.4135/9780857020024.

Datta, S.S. and Agrawal, S. (2017) 'Can e-learning help you to connect compassionately? Commentary on a palliative care e-learning resource for India', *Ecancermedicalscience*, 11(770–791), pp. 1–5. Available at: https://doi.org/10.3332/ecancer.2017.ed72.

Davis, B. *et al.* (2014) 'Developing a pilot e-mobile app for dementia caregiver support: Lessons learned | OJNI', *Online Journal of Nursing Informatics*, 18.

Day Ashley, L. (2017) 'Case study research', in Coe, R. et al., *Research Methods and Methodologies in Education*. 2nd Edition. SAGE Publications.

D'Cruz, H., Gillingham, P. and Melendez, S. (2007) 'Reflexivity: A Concept and its Meanings for Practitioners Working with Children and Families', *Critical Social Work*, 8(1). Available at: https://doi.org/10.22329/csw.v8i1.5744.

Dementia Understand Together (2022) *Dementia training and education*, *Dementia*. Available at: https://www.understandtogether.ie/training-resources/dementia-training-and-education/https:/www.understandtogether.ie/Training-resources/Dementia-training-and-education/ (Accessed: 12 November 2022).

Dempster, M. (2003) ‘Systematic review’, in R. Miller and J. Brewer (eds) *The A-Z of Social Research*. 1 Oliver’s Yard, 55 City Road, London England EC1Y 1SP United Kingdom: SAGE Publications, Ltd, pp. 312–316. Available at: https://doi.org/10.4135/9780857020024.n110.

Department of Health (2012) *The National Carers’ Strategy - Recognised, Supported, Empowered*. Available at: https://health.gov.ie/wp-content/uploads/2016/02/National-Carers-Strategy.pdf (Accessed: 11 April 2019).

Department of Health (2014) *The Irish National Dementia Strategy*. Available at: https://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf (Accessed: 28 February 2019).

Dziuban, C.D. *et al.* (2016) *Conducting Research in Online and Blended Learning Environments, New Pedagogical Frontiers*. New York and London: Routledge Taylor and Francis Group.

Elf, M. *et al.* (2012) ‘Young carers as co-designers of a web-based support system - the views of two publics’, *Informatics for Health & Social Care*, 37(4), pp. 203–216. Available at: https://doi.org/10.3109/17538157.2012.678450.

Etters, L., Goodall, D. and Harrison, B.E. (2008) ‘Caregiver burden among dementia patient caregivers: A review of the literature’, *Journal of the American Academy of Nurse Practitioners*, 20(8), pp. 423–428. Available at: https://doi.org/10.1111/j.1745-7599.2008.00342.x.

Etxeberria, I., Salaberria, K. and Gorostiaga, A. (2021) ‘Online support for family caregivers of people with dementia: a systematic review and meta-analysis of RCTs and quasi-experimental studies’, *Aging & Mental Health*, 25(7), pp. 1165–1180. Available at: https://doi.org/10.1080/13607863.2020.1758900.

European Commission (No date) *Erasmus+ EU programme for education, training, youth and sport*. Available at: https://erasmus-plus.ec.europa.eu/about-erasmus/what-is-erasmus (Accessed: 22 August 2022).

Farrington, C.J. (2014) ‘Blended e-learning and end of life care in nursing homes: a small-scale mixed-methods case study’, *BMC Palliative Care*, 13(1), p. 31. Available at: https://doi.org/10.1186/1472-684X-13-31.

Finkel, S. *et al.* (2007) ‘E-Care: A Telecommunications Technology Intervention for Family Caregivers of Dementia Patients’, *The American Journal of Geriatric Psychiatry*, 15(5), pp. 443–448. Available at: https://doi.org/10.1097/JGP.0b013e3180437d87.

Flick, U. (2018) ‘Using CAQDAS for Advancing the Quality of Qualitative Research’, in *Managing Quality in Qualitative Research*. 55 City Road, London: SAGE Publications Ltd, pp. 41–52.

Floyd, A. and Arthur, L. (2012) ‘Researching from within: external and internal ethical engagement’, *International Journal of Research & Method in Education*, 35(2), pp. 171–180. Available at: https://doi.org/10.1080/1743727X.2012.670481.

Fowler, C., Haney, T. and Rutledge, C.M. (2014) ‘An Interprofessional Virtual Healthcare Neighborhood for Caregivers of Elderly With Dementia’, *The Journal for Nurse Practitioners*, 10(10), pp. 829–834. Available at: https://doi.org/10.1016/j.nurpra.2014.08.012.

Fowler, C.N., Haney, T. and Lemaster, M. (2016) ‘Helping Dementia Caregivers Through Technology’, *Home Healthcare Now*, 34(4), pp. 203–209. Available at: https://doi.org/10.1097/NHH.0000000000000372.

Frias, C.E. *et al.* (2020) ‘Effectiveness of a psychoeducational intervention for caregivers of People With Dementia with regard to burden, anxiety and depression: A systematic review’, *Journal of Advanced Nursing*, 76(3), pp. 787–802. Available at: https://doi.org/10.1111/jan.14286.

Gagné, R., Mills (2005) *Principles of Instructional Design*. 5th edn. Belmont, CA: Thomson / Wadsworth.

Gaugler, J.E., Reese, M. and Tanler, R. (2016) ‘Care to Plan: An Online Tool That Offers Tailored Support to Dementia Caregivers’, *The Gerontologist*, 56(6), pp. 1161–1174. Available at: https://doi.org/10.1093/geront/gnv150.

Gauthier, S. *et al.* (2021) *World Alzheimer Report 2021: Journey through the diagnosis of dementia*. London, England: Alzheimer’s Disease International, p. 314. Available at: https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf.

Gillespie, P. *et al.* (2015) ‘Longitudinal costs of caring for people with Alzheimer’s disease’, *International Psychogeriatrics*, 27(5), pp. 847–856. Available at: https://doi.org/10.1017/S1041610214002063.

Gillham, B. (2000) *Case Study Research Methods*. London, UNITED KINGDOM: Bloomsbury Publishing Plc. Available at: http://ebookcentral.proquest.com/lib/dcu/detail.action?docID=564247 (Accessed: 25 January 2020).

Given, L. (2008) *The SAGE Encyclopedia of Qualitative Research Methods*. 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc. Available at: https://doi.org/10.4135/9781412963909.

Godwin, K.M. *et al.* (2013) ‘Technology-Driven Interventions for Caregivers of Persons With Dementia: A Systematic Review’, *American Journal of Alzheimer’s Disease & Other Dementias®*, 28(3), pp. 216–222. Available at: https://doi.org/10.1177/1533317513481091.

Gossink, F. *et al.* (2018) ‘An intervention programme for caregivers of dementia patients with frontal behavioural changes: an explorative study with controlled effect on sense of competence’, *Psychogeriatrics*, 18(6), pp. 451–459. Available at: https://doi.org/10.1111/psyg.12351.

Gough, D., Oliver, S. and Thomas, J. (2017) *An Introduction to Systematic Reviews*. 2nd edn. Los Angeles: SAGE.

Government of Ireland (2021) *Adult Literacy For Life: A 10–Year Adult Literacy, Numeracy And Digital Literacy Strategy*. Available at: https://www.solas.ie/f/70398/x/b78324692b/15607_all_strategy_web.pdf (Accessed: 2 December 2022).

Grant, M.J. and Booth, A. (2009) 'A typology of reviews: an analysis of 14 review types and associated methodologies: A typology of reviews', *Health Information & Libraries Journal*, 26(2), pp. 91–108. Available at: https://doi.org/10.1111/j.1471-1842.2009.00848.x.

Greenwood, N. *et al.* (2009) 'Informal primary carers of stroke survivors living at home–challenges, satisfactions and coping: A systematic review of qualitative studies', *Disability and Rehabilitation*, 31(5), pp. 337–351. Available at: https://doi.org/10.1080/09638280802051721.

Griffiths, P.C. *et al.* (2016) 'Development and Implementation of Tele-Savvy for Dementia Caregivers: A Department of Veterans Affairs Clinical Demonstration Project', *The Gerontologist*, 56(1), pp. 145–154. Available at: https://doi.org/10.1093/geront/gnv123.

Guba, E.G. and Lincoln, Y.S. (1994) 'Competing paradigms in qualitative research', in N.K. Denzin and Y.S. Lincoln (eds) *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage, pp. 105–117.

Guba, E.G. and Lincoln, Y.S. (2005) 'Paradigmatic controversies, contradictions, and emerging confluences.', in N.K. Denzin and Y.S. Lincoln (eds) *The SAGE handbook of qualitative research*. 3rd edn. Thousand Oaks, CA: SAGE, p. 99 191-215.

Hanson, E. *et al.* (2019) 'The extended palliative phase of dementia – An integrative literature review', *Dementia*, 18(1), pp. 108–134. Available at: https://doi.org/10.1177/1471301216659797.

Harrop, E. *et al.* (2018) 'The challenge pathway: A mixed methods evaluation of an innovative care model for the palliative and end-of-life care of people with dementia (Innovative practice)', *Dementia*, 17(2), pp. 252–257. Available at: https://doi.org/10.1177/1471301217729532.

Hattink, B. *et al.* (2015) 'Web-Based STAR E-Learning Course Increases Empathy and Understanding in Dementia Caregivers: Results from a Randomized Controlled Trial in the Netherlands and the United Kingdom', *Journal of Medical Internet Research*, 17(10), p. e241. Available at: https://doi.org/10.2196/jmir.4025.

Hattink, B. *et al.* (2016) 'Evaluation of the Digital Alzheimer Center: Testing Usability and Usefulness of an Online Portal for Patients with Dementia and Their Carers', *JMIR Research Protocols*, 5(3), p. e144. Available at: https://doi.org/10.2196/resprot.5040.

Heru, A.M. and Ryan, C.E. (2006) 'Family Functioning in the Caregivers of Patients with Dementia: One-Year Follow-up', *Bulletin of the Menninger Clinic*, 70(3), pp. 222–31.

Ho, D.W.H. *et al.* (2015) ‘Development of a Web-Based Training Program for Dementia Caregivers in Hong Kong’, *Clinical Gerontologist*, 38(3), pp. 211–223. Available at: https://doi.org/10.1080/07317115.2015.1008115.

Hopwood, J. *et al.* (2018) ‘Internet-Based Interventions Aimed at Supporting Family Caregivers of People With Dementia: Systematic Review’, *Journal of Medical Internet Research*, 20(6), p. e9548. Available at: http://dx.doi.org.dcu.idm.oclc.org/10.2196/jmir.9548.

Hu, C. *et al.* (2015) ‘Reducing caregiver stress with internet-based interventions: a systematic review of open-label and randomized controlled trials’, *Journal of the American Medical Informatics Association*, 22(e1), pp. e194–e209. Available at: https://doi.org/10.1136/amiajnl-2014-002817.

Hudson, P. and Aranda, S. (2014) ‘The Melbourne Family Support Program: evidence-based strategies that prepare family caregivers for supporting palliative care patients: Table 1’, *BMJ Supportive & Palliative Care*, 4(3), pp. 231–237. Available at: https://doi.org/10.1136/bmjspcare-2013-000500.

Huis in het Veld, J.G. *et al.* (2015) ‘The effectiveness of interventions in supporting self-management of informal caregivers of people with dementia; a systematic meta review’, *BMC Geriatrics*, 15(1), pp. 1–10. Available at: https://doi.org/10.1186/s12877-015-0145-6.

Ion, R. *et al.* (2021) ‘International nurse education leaders’ experiences of responding to the COVID-19 pandemic: A qualitative study’, *Journal of Advanced Nursing*, 77(9), pp. 3797–3805. Available at: https://doi.org/10.1111/jan.14892.

Jackson, D. *et al.* (2016) ‘A systematic review of the effect of telephone, internet or combined support for carers of people living with Alzheimer’s, vascular or mixed dementia in the community’, *Archives of Gerontology and Geriatrics*, 66, pp. 218–236. Available at: https://doi.org/10.1016/j.archger.2016.06.013.

Jones, B. *et al.* (2018) ‘Availability of information on young onset dementia for patients and carers in six European countries’, *Patient Education and Counseling*, 101(1), pp. 159–165. Available at: https://doi.org/10.1016/j.pec.2017.07.013.

Jütten, L.H., Mark, R.E. and Sitskoorn, M.M. (2019) ‘Empathy in informal dementia caregivers and its relationship with depression, anxiety, and burden’, *International Journal of Clinical and Health Psychology*, 19(1), pp. 12–21. Available at: https://doi.org/10.1016/j.ijchp.2018.07.004.

Kabir, Z.N. *et al.* (2020) ‘Care of family caregivers of persons with dementia (CaFCa) through a tailor-made mobile app: study protocol of a complex intervention study’, *BMC Geriatrics*, 20(1), p. 305. Available at: https://doi.org/10.1186/s12877-020-01712-7.

Kajiyama, B. *et al.* (2013) ‘Exploring the effectiveness of an Internet-based program for reducing caregiver distress using the iCare Stress Management e-Training Program’, *Aging & Mental Health*, 17(5), pp. 544–554. Available at: https://doi.org/10.1080/13607863.2013.775641.

Kales, H.C. *et al.* (2017) ‘WeCareAdvisor^{TM}: The development of a caregiver-focused, web-based program to assess and manage behavioral and psychological symptoms of dementia’, *Alzheimer disease and associated disorders*, 31(3), pp. 263–270. Available at: https://doi.org/10.1097/WAD.0000000000000177.

King, N. (2012) ‘Doing Template Analysis’, in G. Symon and C. Cassell (eds) *Qualitative Organizational Research: Core Methods and Current Challenges*. Los Angeles: SAGE.

King, N. and Brooks, J. (2018) ‘Thematic Analysis in Organisational Research’, in C. Cassell, A. Cunliffe, and G. Grandy (eds) *The SAGE Handbook of Qualitative Business and Management Research Methods: Methods and Challenges*. 1 Oliver’s Yard, 55 City Road London EC1Y 1SP: SAGE Publications Ltd, pp. 219–236. Available at: https://doi.org/10.4135/9781526430236.n14.

Kitwood, T. (1997) ‘The experience of dementia’, *Aging & Mental Health*, 1(1), p. 11.

Klimova, B. *et al.* (2019a) ‘E-learning as valuable caregivers’ support for people with dementia – A systematic review’, *BMC Health Services Research*, 19(1), p. 781. Available at: https://doi.org/10.1186/s12913-019-4641-9.

Klimova, B. *et al.* (2019b) ‘E-learning as valuable caregivers’ support for people with dementia – A systematic review’, *BMC Health Services Research*, 19(781). Available at: https://doi.org/10.1186/s12913-019-4641-9.

Knapp, M. *et al.* (1997) ‘The cost consequences of changing the hospital–community balance: the mental health residential care study’, *Psychological Medicine*, 27(3), pp. 681–692. Available at: https://doi.org/10.1017/S0033291796004667.

Lafferty, D.A. *et al.* (2014) *Research Findings Family Carers of Older People: Results of a National Survey of Stress, Conflict and Coping*. National Centre for the Protection of Older People. University College Dublin and the Health Service Executive, p. 2.

Lee, E. (2015) ‘Do Technology-Based Support Groups Reduce Care Burden Among Dementia Caregivers? A Review’, *Journal of Evidence-Informed Social Work*, 12(5), pp. 474–487. Available at: https://doi.org/10.1080/15433714.2014.930362.

Leng, M. *et al.* (2020) ‘Internet-Based Supportive Interventions for Family Caregivers of People With Dementia: Systematic Review and Meta-Analysis’, *Journal of Medical Internet Research*, 22(9), p. e19468. Available at: https://doi.org/10.2196/19468.

Lewis, M.L., Hobday, J.V. and Hepburn, K.W. (2010) ‘Internet-Based Program for Dementia Caregivers’, *American Journal of Alzheimer’s Disease & Other Dementias*, 25(8), pp. 674–679. Available at: https://doi.org/10.1177/1533317510385812.

Lewis-Beck, M., Bryman, A. and Futing Liao, T. (2004) ‘Systematic Review’, in *The SAGE Encyclopedia of Social Science Research Methods*. 2455 Teller Road, Thousand Oaks California 91320 United States of America: Sage Publications, Inc. Available at: https://doi.org/10.4135/9781412950589.n998.

Li, W. *et al.* (2021) ‘Barriers to learning a new technology to go online among older adults during the COVID-19 pandemic’, *Journal of the American Geriatrics Society*, 69(11), pp. 3051–3057. Available at: https://doi.org/10.1111/jgs.17433.

Lloyd, J., Patterson, T. and Muers, J. (2016) ‘The positive aspects of caregiving in dementia: A critical review of the qualitative literature’, *Dementia,* 15(6), pp. 1534–1561. Available at: https://doi.org/10.1177/1471301214564792.

Lower, M.L.P. (2022) ‘Communities of inquiry pedagogy in undergraduate courses’, *The Law Teacher,* 0(0), pp. 1–15. Available at: https://doi.org/10.1080/03069400.2022.2075109.

Ma, M. *et al.* (2018) ‘Alzheimers’ disease and caregiving: a meta-analytic review comparing the mental health of primary carers to controls’, *Aging & Mental Health,* 22(11), pp. 1395–1405. Available at: https://doi.org/10.1080/13607863.2017.1370689.

Magnusson, L., Hanson, E. and Borg, M. (2004) ‘A literature review study of Information and Communication Technology as a support for frail older people living at home and their family carers’, *Technology and Disability,* 16(4), pp. 223–235. Available at: https://doi.org/10.3233/TAD-2004-16404.

Mahoney, R. *et al.* (2005) ‘Anxiety and Depression in Family Caregivers of People With Alzheimer Disease: The LASER-AD Study’, *The American Journal of Geriatric Psychiatry,* 13(9), pp. 795–801.

McGowan, B. *et al.* (2019) *Non Cognitive Symptoms of Dementia (NCSD) - Guidance on Non-pharmacological Interventions for Healthcare and Social Care Practitioners*. Tullamore: National Dementia Office. Available at: https://healthservice.hse.ie/filelibrary/non-cognitive-symptoms-of-dementia-guidance-document.pdf (Accessed: 16 January 2021).

McHale, C. *et al.* (2019) ‘Insights into Dementia- an Integrated Care Approach to Family Support’, *Age and Ageing,* 48. Available at: https://doi.org/10.1093/ageing/afz103.213.

McKechnie, V., Barker, C. and Stott, J. (2014) ‘Effectiveness of computer-mediated interventions for informal carers of people with dementia—a systematic review’, *International Psychogeriatrics,* 26(10), pp. 1619–1637. Available at: https://doi.org/10.1017/S1041610214001045.

Mears, C.L. (2017) ‘In-depth interviews’, in R. Coe et al. (eds) *Research Methods and Methodologies in Education*. 2nd Edition. London: SAGE Publications Ltd.

Mehta, K.M. *et al.* (2018) ‘iSupport, an online training and support program for caregivers of people with dementia: study protocol for a randomized controlled trial in India’, *Trials,* 19(1), p. 271. Available at: https://doi.org/10.1186/s13063-018-2604-9.

Meichsner, F., Theurer, C. and Wilz, G. (2019) ‘Acceptance and treatment effects of an internet-delivered cognitive-behavioral intervention for family caregivers of people with dementia: A randomized-controlled trial’, *Journal of Clinical Psychology*, 75(4), pp. 594–613. Available at: https://doi.org/10.1002/jclp.22739.

Mercer, J. (2007) ‘The Challenges of Insider Research in Educational Institutions: Wielding a Double-Edged Sword and Resolving Delicate Dilemmas’, *Oxford Review of Education*, 33(1), pp. 1–17.

Merriam, S. (1988) *Case Study Research in Education*. San Francisco: Jossey-Bass.

Metcalfe, A. *et al.* (2019) ‘Online information and support for carers of people with young-onset dementia: A multi-site randomised controlled pilot study’, *International Journal of Geriatric Psychiatry*, 34(10), pp. 1455–1464. Available at: https://doi.org/10.1002/gps.5154.

Mezirow, J. (2003) ‘Transformative Learning as Discourse’, *Journal of Transformative Education*, 1(1), pp. 58–63.

Mierlo, L.D.V. *et al.* (2015) ‘Evaluation of DEM-DISC, customized e-advice on health and social support services for informal carers and case managers of people with dementia; a cluster randomized trial’, *International Psychogeriatrics*, 27(8), pp. 1365–1378. Available at: https://doi.org/10.1017/S1041610215000423.

Millenaar, J.K. *et al.* (2018) ‘Exploring perspectives of young onset dementia caregivers with high versus low unmet needs’, *International Journal of Geriatric Psychiatry*, 33(2), pp. 340–347. Available at: https://doi.org/10.1002/gps.4749.

Miller, J., Vivona, B. and Roth, G. (2016) ‘Nursing Preceptors and Meaning Making’, *The Qualitative Report*, 21(11), pp. 2014–2032. Available at: https://doi.org/10.46743/2160-3715/2016.2539.

Muijs, D. (2004) *Doing quantitative research in education with SPSS*. London ; Thousand Oaks: Sage Publications. Available at: http://modares.ac.ir/uploads/Agr.Oth.Lib.23.pdf.

National Dementia Office and Department of Health (2018) ‘Mid-Term Review of the Implementation of the National Dementia Strategy’. Government of Ireland. Available at: https://www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/National-Dementia-Strategy-Mid-Term-Review.pdf (Accessed: 9 April 2019).

National Economic and Social Development Office (2021) *Digital Inclusion in Ireland: Connectivity, Devices and Skills*. Council Report No. 154, p. 77. Available at: http://files.nesc.ie/nesc_reports/en/154_Digital.pdf (Accessed: 19 November 2022).

Noddings, N. (2003) *Caring: a feminine approach to ethics and moral education*. 2nd ed. Berkeley, California: University of California Press.

Noddings, N. (2010) ‘Moral education and caring’, *Theory and Research in Education*, 8(2), pp. 145–151. Available at: https://doi.org/10.1177/1477878510368617.

Núñez-Naveira, L. *et al.* (2016) ‘UnderstAID, an ICT Platform to Help Informal Caregivers of People with Dementia: A Pilot Randomized Controlled Study’, *BioMed Research International*, 2016. Available at: https://doi.org/10.1155/2016/5726465.

Osaki, T. *et al.* (2016) ‘Caregiver burden and fatigue in caregivers of people with dementia: Measuring human herpesvirus (HHV)-6 and -7 DNA levels in saliva’, *Archives of Gerontology and Geriatrics*, 66, pp. 42–48. Available at: https://doi.org/10.1016/j.archger.2016.04.015.

Pagán-Ortiz, M.E. *et al.* (2014) ‘Use of an online community to provide support to caregivers of people with dementia’, *Journal of gerontological social work*, 57(6–7), pp. 694–709. Available at: https://doi.org/10.1080/01634372.2014.901998.

Paul, L., Johnson, A.O. and Cranston, G.M. (2000) ‘A Successful Videoconference Satellite Program: Providing Nutritional Information on Dementia to Rural Caregivers’, *Educational Gerontology*, 26(5), pp. 415–425. Available at: https://doi.org/10.1080/03601270050111841.

Pekrun, R. *et al.* (2011) ‘Measuring emotions in students’ learning and performance: The Achievement Emotions Questionnaire (AEQ)’, *Contemporary Educational Psychology*, 36(1), pp. 36–48. Available at: https://doi.org/10.1016/j.cedpsych.2010.10.002.

Petrides, K.V. (2009) ‘Psychometric Properties of the Trait Emotional Intelligence Questionnaire (TEIQue)’, in J.D.A. Parker, D.H. Saklofske, and C. Stough (eds) *Assessing Emotional Intelligence*. Boston, MA: Springer US (The Springer Series on Human Exceptionality), pp. 85–101. Available at: https://doi.org/10.1007/978-0-387-88370-0_5.

Picciano, A.G. (2016) ‘Paradigms, Methodologies, Methods, and the Role of Theory in Online and Blended Learning Environments’, in Dziuban, C. D. et al., *Conducting Research in Online and Blended Learning Environments New Pedagogical Frontiers*. Routledge Taylor & Francis.

Pierce, M., Cahill, S. and O’Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland, 2011-2046*. Available at: https://www.genio.ie/system/files/publications/Dementia_Prevalence_2011_2046.pdf (Accessed: 1 March 2019).

Prochaska, J.M. *et al.* (2005) ‘Assessing emotional readiness for adoption using the transtheoretical model’, *Children and Youth Services Review*, 27(2), pp. 135–152. Available at: https://doi.org/10.1016/j.childyouth.2004.07.001.

Qualitative analysis using Template Analysis: What it is and how it may be used (2015). Available at: https://www.youtube.com/watch?v=jH_CjbXHCSw (Accessed: 24 March 2022).

Regmi, K. and Jones, L. (2020) ‘A systematic review of the factors – enablers and barriers – affecting e-learning in health sciences education’, *BMC Medical Education*, 20(1), p. 91. Available at: https://doi.org/10.1186/s12909-020-02007-6.

Robson, C. and McCartan, K. (2016) *Real world research: a resource for users of social research methods in applied settings*. Fourth Edition. Hoboken, NJ: Wiley, p. Available at: http://capitadiscovery.co.uk/dcu/items/786410 (Accessed: 18 August 2021).

Saldaña, J. (2021) *The Coding Manual for Qualitative Researchers*. 4th edn. 55 City Road, London: SAGE Publications Ltd.

Salmon, G. (2013) *E-Tivities: The Key to Active Online Learning*. London, UNITED KINGDOM: Taylor & Francis Group. Available at: http://ebookcentral.proquest.com/lib/dcu/detail.action?docID=1221514 (Accessed: 21 March 2023).

Salvador, R.O. (2019) ‘The trolley problem: A social constructivist pedagogy approach’, *Journal of Education for Business*, 94(5), pp. 333–341. Available at: https://doi.org/10.1080/08832323.2018.1527749.

Saunders, M., Lewis, P. and Thornhill, A. (2019) *Research Methods for Business Students Ebook*. Harlow, UNITED KINGDOM: Pearson Education, Limited. Available at: http://ebookcentral.proquest.com/lib/dcu/detail.action?docID=5774742 (Accessed: 9 March 2022).

Schoenmakers, B., Buntinx, F. and Delepeleire, J. (2010) ‘Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review’, *Maturitas*, 66(2), pp. 191–200. Available at: https://doi.org/10.1016/j.maturitas.2010.02.009.

Sefotho, M.M. (2015) ‘A Researcher’s Dilemma: Philosophy in Crafting Dissertations and Theses’, *Journal of Social Sciences*, 42(1–2), pp. 23–36. Available at: https://doi.org/10.1080/09718923.2015.11893390.

Sherifali, D. *et al.* (2018) ‘Impact of Internet-Based Interventions on Caregiver Mental Health: Systematic Review and Meta-Analysis’, *Journal of Medical Internet Research*, 20(7). Available at: http://dx.doi.org/10.2196/10668.

Stake, R.E. (1995) *The Art of Case Study Research*. SAGE.

Stewart, A. (2014) ‘Chapter 9 Case Study’, in Mills, J., *Qualitative Methodology: A Practical Guide*. 1 Oliver’s Yard, 55 City Road London EC1Y 1SP: SAGE Publications, Inc. Available at: https://doi.org/10.4135/9781473920163.

Svendsboe, E. *et al.* (2016) ‘Caregiver burden in family carers of people with dementia with Lewy bodies and Alzheimer’s disease’, *International Journal of Geriatric Psychiatry*, 31(9), pp. 1075–1083. Available at: https://doi.org/10.1002/gps.4433.

Teahan, Á. *et al.* (2021) ‘An analysis of carer burden among family carers of people with and without dementia in Ireland’, *International Psychogeriatrics*, 33(4), pp. 347–358. Available at: https://doi.org/10.1017/S1041610220000769.

Teahan, Á., Fitzgerald, C. and O’Shea, E. (2020) ‘Family carers’ perspectives of the Alzheimer Café in Ireland’, *HRB Open Research*, 3, p. 18. Available at: https://doi.org/10.12688/hrbopenres.13040.2.

Terkelsen, A.S., Petersen, J.V. and Kristensen, H.K. (2020) ‘Mapping empirical experiences of Tom Kitwood’s framework of person-centred care for persons with dementia in institutional settings. A scoping review', *Scandinavian Journal of Caring Sciences*, 34(1), pp. 6–22. Available at: https://doi.org/10.1111/scs.12709.

The Alzheimer Society of Ireland (2017) 'A Brief Overview of the Founding and 35-Year History of The Alzheimer Society of Ireland (ASI)'. Available at: https://alzheimer.ie/wp-content/uploads/2019/02/History-Doc-ASI.pdf.

The Alzheimer Society of Ireland (2018) 'The Alzheimer Society of Ireland: Strategy 2018-2020'. Available at: http://www.alzheimer.ie/getattachment/About-Us/Openness-and-transparency/Strategy-2018-2010/ASI-Strategy_web.pdf.aspx (Accessed: 27 October 2018).

The Alzheimer Society of Ireland (2019) *Family Carer Training*, *Alzheimer*. Available at: https://alzheimer.ie/about-dementia/family-carer-training/ (Accessed: 25 April 2019).

The Alzheimer Society of Ireland (2021) *Caring and coping with dementia during COVID-19: Expereiences of people living with dementia and family carers*, p. 54. Available at: https://alzheimer.ie/wp-content/uploads/2021/06/ASI_Covid_Report.pdf (Accessed: 24 September 2022).

The Alzheimer Society of Ireland (2022) *About our Services and Support*. Available at: https://alzheimer.ie/get-support/our-services-and-support/.

Timmons, F. (2018) 'Reimagining and Transferring a Conventional Face-to-Face Course to a Purely Online Format - Reflections of Online Course Design and the Importance of an Iterative Approach', in L.G. Chova, A.L. Martinez, and I.C. Torres (eds) *12th International Technology, Education and Development Conference (inted)*. Valenica: Iated-Int Assoc Technology Education & Development, pp. 5186–5194. Available at: https://library.iated.org/view/TIMMONS2018REI.

Timmons, F., Olstad, K. and Vansteenkiste, E. (2016) 'Developing Online Training for Family Carers of People with Dementia - the Challenges and Experiences of Developing and Implementing a Pan-European Project', in L.G. Chova, A.L. Martinez, and I.C. Torres (eds) *Inted2016: 10th International Technology, Education and Development Conference*. Valenica: Iated-Int Assoc Technology Education a& Development, pp. 7132–7141. Available at: https://library.iated.org/view/TIMMONS2016DEV.

Torgerson, C., Hall, J. and Lewis-Light, K. (2017) 'Systematic Reviews', in R. Coe et al. (eds) *Research Methods and Methodologies in Education*. 2nd Edition. London: SAGE Publications.

Torp, S., Bing-Jonsson, P.C. and Hanson, E. (2013) 'Experiences with using information and communication technology to build a multi-municipal support network for informal carers', *Informatics for Health and Social Care*, 38(3), pp. 265–279. Available at: https://doi.org/10.3109/17538157.2012.735733.

Tracy, S., J. (2010) 'Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research', *Qualitative Inquiry*, 16(10), pp. 837–851. Available at: https://doi.org/10.1177/1077800410383121.

Vygotsky, L.S. (1978) *Mind in Society: Development of Higher Psychological Processes*. Harvard University Press. Available at: https://doi.org/10.2307/j.ctvjf9vz4.

Wallace, S.J. *et al.* (2021) 'Do caregivers who connect online have better outcomes? A systematic review of online peer-support interventions for caregivers of people with stroke, dementia, traumatic brain injury, Parkinson's disease and multiple sclerosis', *Brain Impairment*, pp. 1–27. Available at: https://doi.org/10.1017/BrImp.2021.5.

Waller, A. *et al.* (2017) 'Computer and telephone delivered interventions to support caregivers of people with dementia: a systematic review of research output and quality', *BMC Geriatrics*, 17(1), p. 265. Available at: https://doi.org/10.1186/s12877-017-0654-6.

Waring, M. (2017) 'Chapter 3 Finding your theoretical position', in R. Coe et al. (eds) *Research Methods and Methodologies in Education*. 2nd Edition. London, UK: SAGE Publications.

Wee, B.V. and Banister, D. (2016) 'How to Write a Literature Review Paper?', *Transport Reviews*, 36(2), pp. 278–288. Available at: https://doi.org/10.1080/01441647.2015.1065456.

Whitlatch, C.J. and Orsulic-Jeras, S. (2017) 'Meeting the informational, educational and psychosocial support needs of persons living with dementia and their family caregivers', *The Gerontologist*, 58(S1), pp. 58–73. Available at: https://doi.org/10.1093/geront/gnx162.

Wimo, A. (2018) *Global estimates of informal care*. London: Alzheimer's Disease International and Karolinska Institutet, p. 24. Available at: https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf (Accessed: 3 November 2020).

World Health Organisation (2017) *Dementia: Key Facts, Fact Sheets / Detail / Dementia*. Available at: https://www.who.int/news-room/fact-sheets/detail/dementia (Accessed: 31 March 2019).

World Health Organisation (2021) *Dementia*. Available at: https://www.who.int/news-room/fact-sheets/detail/dementia (Accessed: 11 March 2022).

Yin, R.K. (2014) *Case Study Research: Design and Methods*. 5th edn. Thousand Oaks, CA: SAGE.

Appendix A: The HBC-HBE Tutor Team 2019-2021: Background and Experience

	Qualified Nurse	Current of Ex Family Carer	Postgraduate Gerontology / Dementia Qualification	10+ years dementia care experience
Tutor 1	Yes	Yes	Yes	Yes
Tutor 2	Yes	Yes	No	Yes
Tutor 3	Yes	No	Yes	No
Tutor 4	Yes	No	Yes	No
Tutor 5	No	No	Yes	Yes
Tutor 6	No	No	Yes	Yes

Appendix B: Individual Interventions – Name, Type and Description

Author / Year / Country	**Name**	**Type**	**Description**
Paul, Johnson and Cranston, (2000) USA	Alphabet Soup: The Power of Nutrition in Caregiving	Distance Education Teleconference programme	Format: Videoconferencing with taped video segments of mealtimes at long-term care facilities. Participants viewed the videos and could call experts on a phone line with questions or queries. Length: not stated
Finkel *et al.*, (2007) USA	E-Care Telecommunications Technology Psychosocial intervention	Online course	*Information* about dementia, Content: safety, communication, self-care, social support, management of behavioural problems. Format: 12 sessions using Computer-Telephone Integrated System Length: 6 months
Chiu *et al.*, (2009) Canada	Internet-based Caregiver Support Service ICSS	Information website	Website with 400-page *information* booklet; personalized therapeutic email service password protected. Format: No peer support element Length: Not stated
Chiu and Eysenbach, (2011) Canada	Internet-based Caregiver Support Service ICSS	Information website	Website with 400-page *information* booklet; personalized therapeutic email service password protected. Format**:** No peer support element Length: Not stated
Czaja *et al.*, (2013) USA	Videophone Psychosocial intervention	Blended Delivery	Format: Technology based multi component psychosocial intervention In house sessions and videophone support Length: 5 months
Kajiyama *et al.*, (2013) USA	iCare Stress Management E-Training Programme	Online course	Content: 8 modules: about dementia, dealing with stress, learning how to relax, activities, communication skills, managing difficult behaviours, healthy habits, *information* for planning the future Flexible: 7 to 10 days per module
Boyd *et al.*, (2014) Europe	STAR	Web portal	Web portal to provide online training - this paper investigated web usability issues and proposed solutions
Davis *et al.*, (2014) USA	Story-Call Mobile App for Dementia Caregivers	App	Mobile App designed to provide *information* and services, support, reassurance to carers Format: Personalized story-telling support, dementia care information, and community resources. Length: Not stated
Pagán-Ortiz *et al.*, (2014) USA	Cuidate Cuidador 'Caregiver, take care of yourself'	Information Website	Format: Website in Spanish with *information* about dementia, manage dementia related behaviours and symptoms, real stories from caregivers, plus audio component, comment section for interaction between caregivers and an Ask the Expert section Length: About 15-17 weeks
Cristancho-Lacroix *et al.*, (2015) France	Diapason Psychoeducation programme	Online Course	Content: Caregiver stress; Understanding dementia; Maintaining autonomy; Coping with behaviours, Communications; Improving daily lives; Avoiding falls; *Information* on supports; planning the future Format: Mixture of text, video from professionals and a practice guide for applying the session's content in real life. Private anonymous forum Length: 12 weekly sessions each lasting 15-30 minutes
Hattink *et al.*, (2015) Netherlands / UK	STAR (European Skills training and Reskilling) for informal carers *plus* formal carers	Online Course	Aim: Focus on understanding and dealing with dementia Content: 8 modules, plus a Learning Path Adviser, plus access to a community of carers via Facebook & LinkedIn Content: what is dementia; living with dementia; practical difficulties in daily life; emotional impact of dementia; support strategies to help cope with dementia; positive communication; looking after yourself. Format: E-Multi-lingual learning tool Length: 2 to 4 months

Author / Year / Country	Name	Type	Description
Ho *et al.*, (2015) Hong Kong	Dementia E-Learning Programme	Online course	Dementia education, psychological & emotional support Length: Not stated
Mierlo *et al.*, (2015) Netherlands	DEM-DISC (Dementia Digital Interactive Social Chart)	Internet based interactive tool	Format: A customized e-advice tool with *information* on health and social support services for case managers and informal carers Length: Not stated
Blom *et al.*, (2015) Netherlands	Mastery over Dementia	Online course	Content: behavioural problems; relaxation; arranging help from others; changing non-helping thoughts into helping thoughts; and communication. Format: Guidance of a coach monitoring student progress. *Information* exercises, and homework, regular evaluations**.** No social interaction between participants Length: Not stated - 8 lessons
Hattink *et al.*, (2016) Netherlands	Digital Alzheimer Centre (DAC)	Digital hub	*Information* on diseases, community sections, and information on events/news. Practical tips on living with changes, financial and legal matters, stress management. Format: Forum for exchange of ideas and practice moderated by professional. Length: not stated
Fowler, Haney and Lemaster, (2016) USA	Virtual Healthcare Neighbourhood	Information website	Content: (1) sleep issues; (2) online social support; (3) strategies for empowerment; (4) caregiver issues related to "worry". Format: Discrete website to connect dementia caregivers with a range of professionals. Weekly *information* on relevant topics, Q&A, and peer blogging.
Gaugler, Reese and Tanler, (2016) USA	Care to Plan (CtP)	Online resource / tool	Format: Online resource that generates tailored support recommendations plus offers guidance to facilitate the caregiver's selection of a recommended support option
Griffiths *et al.*, (2016) USA	Tele-Savvy	Online course	Internet version of evidence-based psychoeducation 'Savvy Caregiver Programme' (see https://savvycaregiver.com/) Format: using synchronous and asynchronous elements to engage dementia caregivers in their homes Length: 7 weeks
Núñez-Naveira *et al.*, (2016) Den/Pol/Sw	UnderstAID ICT Platform	Online course	Content: Cognitive Decline; Daily Tasks; Behavioural Changes; Social Activities; You as a Caregiver. Format: Daily task section and social networking where participants can interact with other participants Length: not stated
Kales *et al.*, (2017) USA	WeCareAdvisor	Online course	Web based programme to help family caregivers of people with dementia to assess and manage behavioural and psychological symptoms Length: not stated https://wecareadvisorstudy.com/about-wecareadvisor/
Boots *et al.*, (2016), (2018) Netherlands	Partner in Balance	Blended course, but content delivered online	Face-to-face induction, online thematic modules, face-to-face evaluation Content: Acceptance, Activities, Communication, Stress, Positivity, Self-understanding, Change, Social relations, and support (Boots 2016) Length: 8 weeks
Gossink *et al.*, (2018) Netherlands	Intervention programme for frontal dementia carers	Not stated	Format: Multicomponent intervention consisting of psychoeducation, social support & behavioural cognitive stimulation therapy Length: 6 months
Mehta *et al.*, (2018) India	iSupport	Online course	Format: Personalized online education tool with a maximum of 23 lessons Content: Introduction to dementia, being a carer, caring for me, providing everyday care, dealing with behaviour changes. Format: online course with no peer support**.** Length: not stated

Author / Year / Country	**Name**	**Type**	**Description**
Meichsner, Theurer and Wilz, (2019) Germany	Online Cognitive Behavioural Therapy (CBT)	Online course	Content: 10 therapy modules on CBT including strengthening problem-solving abilities, self-care, coping with grief, stress management and emotional regulation. Format: Participants exchanged 8 weekly messages with a therapist Length: 8 weeks
Metcalfe *et al.*, (2019) England /France/ Germany	RHAPSODY Online Information and Support	Online course	Based on REACH II programme. Content: nature of Younger Onset Dementia, medical explanations, common problems, symptoms management, adapting to relationship changes, care and support *information*, self-care suggestions. Format: Multimedia format text and video, case-studies, presentations from professionals, and downloadable materials Length: 6 weeks
Baruah *et al.*, (2020) India	Online Training and Support Programme	Online course	Online Training and Support Programme This paper investigated what carers would like to see in the format and content of a proposed course. Format: Suggested an interactive element so participants could speak to each other and expert Length: N/A
Kabir *et al.*, (2020) Sweden	CaFCa - Care of family carers of persons with dementia	App	Format: App will be used to provide 'professional support' from healthcare professionals in 5 districts in Sweden to family carers of PWLD. 8-10 family cares to obtain peer & expert support on dealing with cognitive / behavioural issues. Expert and peer support. Mindfulness events Length: 8 weeks

Appendix C: Individual Interventions - Study Aims, Methodology and Findings

Author / Year / Country	**Intervention name**	**Study Aims & Methodology**	**Findings**
Paul, Johnson and Cranston, (2000) USA	Alphabet Soup: The Power of Nutrition in Caregiving	To outline the programme and to assess the general acceptance of videoconferencing as an educational medium in rural Montana M: n=not stated	QN data: intervention very acceptable to users, 97% rated it as 'good or better', 100% would attend another videoconference. QL: participants valued immediate responses, convenience, interactions with others & information provided. Suggested addressing technical difficulties, different time, more expertise (social worker).
Finkel *et al.*, (2007) USA	E-Care Telecommunications Technology Psychosocial intervention	Evaluate effectiveness of intervention **P** **QN n**=46	Improvements in depression for experiment group; same for social support; though some results not statistically significant. Evaluation results more positive, e.g., experiment group increased confidence levels
Chiu *et al.*, (2009) Canada	Internet-based Caregiver Support Service ICSS	Assess usability and evaluate effects on health outcomes **M**: **QN n**=28 **QL n**=10	This study indicates that caregivers can benefit from receiving professional support via asynchronous e-mails and a dedicated information web site
Chiu and Eysenbach, (2011) Canada	Internet-based Caregiver Support Service ICSS	Improve understanding of family carers use of web-based intervention **QL n**=14	Usability 3 factors influenced the use of the intervention: caregiver needs; ICT factors including accessibility barriers, and perceived efforts to use the tech; individual preferences for using technology
Czaja *et al.*, (2013) USA	Videophone Psychosocial intervention	Evaluate feasibility and efficacy of tech-based psychosocial intervention **P** **QN n**=110	Those who received intervention reported decrease in burden, increase in perceived social support, and positive perceptions of caregiving experience. No differences in depression
Kajiyama *et al.*, (2013)USA	iCare Stress Management E-Training Programme	Explore effectiveness of iCare for reducing carer distress **E** **QN n**=57	Change in stress significant for experiment group. Changes in other measures not significant. High dropout rate 33%
Boyd *et al.*, (2014) Europe	STAR (European Skills training and Reskilling) E-Multi-lingual learning tool for informal carers *plus* formal carers	Investigate usability of STAR training and reskilling website	Identified 21 usability issues, and offered solutions
Davis *et al.*, (2014) USA	Story-Call Mobile App for Dementia Caregivers	Discusses development of the App **P** **QN n**=4	High positive responses to Kaye scale. Engagement with the app
Pagán-Ortiz *et al.*, (2014) USA	Cuidate Cuidador 'Caregiver, take care of yourself'	Development and evaluation of Website content **M: QN n**=72 **QL n**=23	Quant positive findings not statistically significant possibly due to small sample size Qualitative data from focus groups showed favourable views on caregivers' experiences of using the website.

Author / Year / Country	**Intervention name**	**Study Aims & Methodology**	**Findings**
Cristancho-Lacroix *et al.*, (2015) France	Diapason Psychoeducation programme	Evaluate efficacy and acceptability of web-based psycho educational programme **P** **RCT** **M QN n**=25, control **n**=24 **QL n**=49	**QN**: No sig diffs in self-perceived stress; experimental group improved dementia knowledge; users did not use the website after course finished. **QL**: male caregivers most disposed toward the programme (caregivers without a clear opinion toward the program (5/25, 20%) and those with a clearly positive (3/25, 12%), qualified (11/25, 44%) or negative (6/25, 24%) opinion). Participants wanted personalised support, extensive information, specific assistance, and more communication with professionals and peers.
Hattink *et al.*, (2015) Netherlands / UK	STAR (European Skills training and Reskilling) E-Multi-lingual learning tool for informal carers *plus* formal carers	Evaluate user-friendliness, usefulness, and impact of STAR **P** **RCT** **QN** **n**=142 of which Informal caregivers **n**=72	Usefulness / user friendliness: Usefulness, Satisfaction Ease of use Questionnaire, Knowledge of dementia, Approaches to dementia. Secondary outcome measures were empathy, quality of life, burden, and sense of competence. Statistically significant differences between experiment and control groups. 8 modules were positively valued by caregivers in terms of usability and user friendliness. Participants indicated that the course made them feel more secure about their quality as a caregiver.
Ho *et al.*, (2015) Hong Kong	Dementia E-Learning Programme	Explored family carers opinions of an online dementia training programme **QN n**=279	Handling behavioural and psychological symptoms were the most expected learning goal of the programme. Other expected learning goals – improved communication and understanding of care recipients; delaying dementia progression; planning for the future; alleviating carer stress & identifying community resources (information).
Mierlo *et al.*, (2015) Netherlands	DEM-DISC (Dementia Digital Interactive Social Chart)	Evaluate user friendliness and usefulness of DEM-DISC **RCT** Experimental n=41, control **n**=32	Mixed results. Informal carers felt more competent, but reported more needs and more unmet needs
Blom *et al.*, (2015) Netherlands	Mastery over Dementia	Assessed the effectiveness of Mastery over Dementia **RCT** **QN** **n**=175	Caregivers in experimental group showed significantly lower levels of depression and anxiety post intervention. Effect sizes were moderate for anxiety and small for depression? Sizable drop out in experimental group (59)
Boots *et al.*, (2016, 2018) Netherlands	Partner in Balance	Effectiveness of Partner in Balance **RCT** **QN n**=81	Significant increase in favour of the intervention group for self-efficacy, mastery and quality of life. No significant differences for depressive symptoms, anxiety, or stress.

Author / Year / Country	**Intervention name**	**Study Aims & Methodology**	**Findings**
Hattink *et al.*, (2016) Netherlands	Digital Alzheimer Centre (DAC)	Investigate usability and usefulness of DAC. **M** – observations, online survey, interviews. Dementia patients n=88, carers **n**=199	Usability: 8 categories of errors, 3 of which were critical; only about half respondents used the hub. Usefulness: hub seen to be especially useful for understanding dementia 64% patients and 62% of carers
Fowler, Haney and Lemaster, (2016) USA	Virtual Healthcare Neighbourhood	Description of project **QL**: observation / interview, but not clearly stated n=?	Programme viewed as positive
Gaugler, Reese and Tanler, (2016) USA	Care to Plan (CtP)	Utility and feasibility of CtP **P** **M n**=21	Participants found the intervention easy to understand, especially in terms of the layout. They also found that the individualized recommendations could meet the needs of users.
Griffiths *et al.*, (2016) USA	Tele-Savvy	To test fidelity and initial efficacy of Tele-Savvy **P** **QN**: Scales Plus evaluation questionnaires **n**=30	Significant decreases in burden, anxiety, and depressive symptoms. Participants agreed or strongly agreed with positive aspects of the programme
Núñez-Naveira *et al.*, (2016) Denmark/Poland/Sweden	UnderstAID ICT Platform	Testing exploring technical & pedagogical specifications and evaluating impact on psychological status of participants **P, RCT, QN n**=61	Poor results. 33% caregivers satisfied with the platform, and only 50% said it was technically and pedagogically acceptable. But decrease in depressive scale on experimental group
Kales *et al.*, (2017) USA	WeCareAdvisor	Investigated style and approach 'look and feel' of online course, and types of psychoeducation most needed by carers **E, QL n**=26	Participants expressed need for advice – speak with someone, contact through daily email with words of encouragement and tailored support to meet individual needs
Gossink *et al.*, (2018) Netherlands	Intervention programme for carers of dementia patients with frontal behaviour changes	Measure changes in sense of competence **P, RCT** **M**: **QN** scales plus **QL** evaluations, emails **n**=30	Increase sense of competence. Burden, stress, and depression decreased but not significantly
Mehta *et al.*, (2018) India	iSupport	Study protocol **QN n**=208	No findings as this paper just describes how they will carry out the RCT
Meichsner, Theurer and Wilz, (2019) Germany	Online Cognitive Behavioural Therapy	Evaluate the efficacy of intervention **RCT** **QN n**=39	Significant treatment effects of medium size found for coping with grief. No significant treatment effects for burden or depression. Emotional wellbeing improved as the intervention progressed. Overall satisfaction with treatment was excellent.

Author / Year / Country	**Intervention name**	**Study Aims & Methodology**	**Findings**
Metcalfe *et al.*, (2019) Eng/France/Germany	RHAPSODY Online Information and Support	Assess user acceptability and satisfaction with the programme **P, RCT** **M**: **QL**: interviews with thematic analysis **QN**: scales **n**=61	76% described RHAPSODY as useful and easy to use; 85% intend to use it in future; Reductions in stress levels following completion of programme; reductions in carers negative reaction to memory symptoms
Baruah *et al.*, (2020) India	Online Training and Support Programme	Identify the components of and understand the acceptability a proposed online course **QL** – interviews **n**=100 professionals **n**=13 carers	Detailed outline of components including symptom management, dementia stages, food to be given, provision of information on care services, caring for the carer, family dynamics, connecting with other caregivers, addressing stress and burden
Kabir *et al.*, (2020) Sweden	CaFCa - Care of family carers of persons with dementia	Study protocol **M**: **QN** at 3 points of intervention. **QL** interviews **n**=78	No findings, this paper describes the process of setting up the intervention and how it will be assessed

Key: **P** = Pilot study**; R** = RCT**; E** = Exploratory study**; M** = Mixed Methods**; QN** = Quantitative**; QL** = Qualitative **n**= number of research participants

Appendix D: Systematic Review / Meta Analyses of Individual Interventions

Authors	**Years Covered**	**Research Focus**	**Findings**
Godwin *et al.*, (2013) USA	1990-2012	"psychosocial effects (i.e. depression, burden, stress and strain) of technology-driven interventions targeted toward informal caregivers of people with dementia" (Godwin *et al.*, 2013, p. 217)	8 interventions: content and methods varied considerably. 6/8 studies reported decreases in anxiety or depression. However, insufficient evidence to support or refute technology driven interventions (p.221)
Boots *et al.*, (2014) Netherlands	1998-2013	"(i) to present an overview of the evidence of the effectiveness and quality of Internet interventions for the informal caregivers of patients with dementia; (ii) to assess which types of interventions are most effective (i.e., provide the best outcome for the participants); and (iii) to indicate the feasibility of such interventions." (Boots *et al.*, 2014, p. 332)	12 interventions: "The outcomes demonstrate that Internet interventions can result in positive effects on the wellbeing of informal dementia caregivers…especially multicomponent programmes that include guidance by a coach and online interaction between caregivers" (Boots *et al.*, 2014, pp. 340–342).
McKechnie, Barker and Stott, (2014) United Kingdom	2000-2012	"How effective are computer mediated psychosocial interventions for informal carers of people with dementia?" (McKechnie, Barker and Stott, 2014, p. 1620)	14 interventions: complicated, "but programme impact measures indicate general acceptability of these interventions…. higher quality studies found that interventions did have an effect on these variables (carer burden/stress, anxiety and depression. Due to interventions being multicomponent and complex, it is difficult to disentangle the efficacy of individual intervention components, with a large range of factors having potential effects (McKechnie, Barker and Stott, 2014, p. 1634)
Hu *et al.*, (2015) USA	Up to 2013	This systematic review assesses the effectiveness of internet-based interventions to decrease caregiver stress	24 studies – Random Controlled Trials and Open Label Trials – not all dementia specific
Huis in het Veld *et al.*, (2015) Netherlands	2003-2013	*Systematic meta review:* "What scientific evidence exists for the effectiveness of various types of professional self-management support interventions for informal caregivers of persons with dementia? Which participant and intervention characteristics of self-management support interventions for informal caregivers of people with dementia are associated with larger effects?" (Huis in het Veld *et al.*, 2015, p. 2)	10 interventions (half of which were focussed on online interventions): "Effective interventions within this target were caregiver support group interventions… Evidence was also found for the effectiveness of professional self-management support interventions targeting information on increasing caregivers' knowledge… it is noteworthy that psycho-education was integrated in most self-management support interventions that were found to be effective" (Huis in het Veld *et al.*, 2015, p. 8)

Lee, (2015) USA	? - 2013	Do technology-based support groups reduce care burden among dementia caregivers? *Not a systematic review, but a review.*	5 studies: Quantitative analysis only "The outcomes of all five studies demonstrated that technology-based social support groups reduced care burden among dementia caregivers." Importance of video conferencing
Jackson *et al.*, (2016) Australia	? - 2015	A systematic review of the effect of telephone, internet or combined support for carers of people with Alzheimer's, vascular or mixed dementia in the community	22 studies: of which 5 were internet only, 4 combination internet/phone "Overall studies have shown that information and support services have positive benefits for family carers. However there are still some gaps in the evidence base, particularly in the area of newer technology-driven interventions and in supporting specific types of dementia."(Jackson *et al.*, 2016, p. 225)
Waller *et al.*, (2017) Australia	1990-2016	"The aims of this review were to examine the extent to which computer and telephone delivered interventions for caregivers of people with dementia have been examined in the literature, including the: 1) volume and type of data-based publications; 2) methodological quality of intervention studies according to Effective Practice and Organisation of Care (EPOC) criteria; and 3) the effectiveness, acceptability and utilisation of interventions in studies that met minimum criteria for quality." (Waller *et al.*, 2017, p. 2)	34 interventions of which 10 delivered by computer only "In the only study of computer-based interventions to meet all EPOC criteria, psychoeducation with strategic access to clinicians via coaching support improved depression and anxiety…Interventions that include psychoeducation via multiple formats, practical strategies and skills training to manage care, and peer and/or clinician contact hold promise."(Waller *et al.*, 2017, p. 17)
Christie *et al.*, (2018) Netherlands	2007-2017	"The objectives of this review are (1) to explore the evidence on the topic of implementing eHealth interventions for informal caregivers of people with dementia, and (2) to identify determinants that influenced whether the intervention was successfully implemented."	"Recent reviews have shown that eHealth interventions for informal caregivers of people with dementia are effective in improving a range of psychological outcomes in caregivers, such as the reduction of caregiver depression, anxiety, stress and burden, as well as increasing positive aspects of caregiving, caregiver self-efficacy, and confidence (Boots et al., 2014; Jackson et al., 2016; Lee, 2015; Parra-Vidales et al., 2017; Scott et al., 2016; Tyack and Camic, 2017)." (Christie *et al.*, 2018, p. 52)
Hopwood *et al.*, (2018) United Kingdom	1990-2018	"This review aimed to (1) identify the key components of existing internet-based interventions designed to support family caregivers of people with dementia, (2) develop an understanding of which components are most valued by caregivers, and (3) consider the evidence of effectiveness of internet-based interventions designed to support family caregivers of people with dementia."	31 interventions (40 papers): Themes: 1. Peer Support: "Qualitative data suggested that participants found many benefits from peer interaction…" 2.Contact with professionals: "On the whole, evaluation data from the studies showed that interaction with professionals was a positive experience for caregivers." P.5 3.Provision of information: "Use of the information provision parts of the intervention was associated with reduced strain…However…other

			components such as interaction with professionals (were) more beneficial" p.5 4.Decision making support: most studies didn't explain this part of intervention; "decision-making tools were poorly used… participants gained decision support from other components of the interventions, such as discussion with peers or professionals" p.6 5.Psychological Support: "self-guided or professionally guided. Few used standardized forms of psychological interventions or therapy, but therapeutic relaxation techniques were commonly used. Overall, studies assessing psychological support suggested a positive effect on a variety of factors, including improving caregiver distress, depression, anxiety, and strain." p.6
Sherifali *et al.*, (2018) Canada	1995-2017	"The primary outcome of interest for this systematic review was mental health, specifically including depressive symptoms, stress/distress, anxiety, coping, overall mental health, quality of life, and overall health." (Sherifali *et al.*, 2018, p. 3). Note: not dementia specific	13 studies: "Our systematic review and meta-analysis showed small to moderate beneficial effects of internet-based interventions on caregiver mental health including a reduction in symptoms of depression, stress or distress, and anxiety."(Sherifali *et al.*, 2018, p. 7)
Klimova *et al.*, (2019) Czech Republic	2010-2018	"The present article focused on the exploitation of elearning as a support for informal caregivers of people with dementia and considered its benefits and limitations to provide proper and relevant care for this target group of people and maintain the quality of life of their caregivers."(Klimova *et al.*, 2019, p. 2)	6 studies: "The findings of this study show that e-learning educational programs/courses help caregivers feel more confident about dementia care, reduce their stress and enhance their feelings of empathy, understanding and concern [53]. The results of this systematic review also show that the exploitation of e-learning as a support tool, especially for informal caregivers, in the management of dementia may be a promising method, but its implementation requires professional training of informal caregivers in the use of this technology." (Klimova *et al.*, 2019, p. 6)
Cheng and Zhang, (2020) Hong Kong	2006-2018	Meta review to synthesize findings from systematic reviews on non-pharmacological interventions for informal caregivers of people with dementia.	60 articles: "We found consistent support across reviews for various types of nonpharmacological interventions to reduce caregiver depression, and emerging evidence for enhancing mastery and QoL (Quality of Life)". P.19 "In terms of intervention types, we found evidence for psychoeducation (reducing depression and enhancing mastery and

			QoL), counseling/psychotherapy (reducing depression), mindfulness-based interventions (reducing depression), OT interventions (enhancing mastery), and multicomponent interventions (reducing depression and possibly enhancing mastery).” P. 19 “it is important to note that multicomponent interventions are a heterogeneous set of programs, and their effectiveness depends on the exact components included and whether the components match the needs of the caregivers.” P.20
Frias *et al.*, (2020) Spain	2005-2018	The aim of this systematic review was to assess the effectiveness of psychoeducational interventions with respect to burden, anxiety and depression in family caregivers of People With Dementia living at home.	20 studies: Technology based interventions & group-based interventions Both have advantages: “Technology-based Interventions significantly affect burden while Group-based Interventions affect anxiety, depression, insomnia and burden and quality of life and self-efficacy. 787 “psychoeducational interventions are practical interventions that can have protective effects on the caregiver through provision of information on the illness and advice on how to respond to certain situations, which can improve self-efficacy, reduce anxiety and have an impact on level of depression. They are also cost-effective if technological methods are used for the follow-up of caregivers, so that travel can be avoided” p. 799
Leng *et al.*, (2020) China	? - 2020	Systematic review and meta-analysis “The primary objectives of this study were to assess the efficacy of internet-based supportive interventions in ameliorating health outcomes for family caregivers of people with dementia and examine whether specific types of internet-based supportive interventions had a beneficial impact on family caregivers’ health outcomes” P. 2 Looked at impact on caregivers + people with dementia	14 studies: “The meta-analysis showed that internet-based supportive interventions significantly ameliorated depressive symptoms, perceived stress, anxiety, and self-efficacy in dementia caregivers.” P. 9 “However, current evidence failed to support the efficacy of internet-based supportive interventions on caregiver burden, coping competence, caregiver reactions to behavioral symptoms, or quality of life. The results based on 6 studies showed that internet-based supportive interventions had potential benefits on the quality of life and neuropsychiatric symptoms in care recipients.”
Etxeberria, Salaberria and Gorostiaga, (2021)	2014-2018	“The specific aims are therefore: (a) to analyze the characteristics of the online interventions identified; and (b) to present an overview of the level of evidence, effectiveness	10 studies (RCTs and quasi-experimental studies): “The results revealed that online interventions may have positive effects on caregivers’ psychological wellbeing…. multicomponent, i.e., those that combined psychoeducation, the learning of psychological

Spain		and methodological quality of studies assessing online interventions aimed at this target population.” P. 1166	strategies and skills for coping with caregiving, interaction with a professional and contact with other caregivers (i.e., forums), achieved the best results as regards reducing depression, anxiety, grief and burden and increasing quality of life, empathy and knowledge about dementia (Blom et al., 2015; Cristancho-Lacroix et al., 2015; Hicken et al., 2017; Núňez-Naveira et al., 2016; Torkamani et al., 2014).” P. 1175 “Online interventions focusing on more specific aspects, such as teaching caregivers to cope with problem behaviors and to manage specific health needs and formal resources, obtained more modest results. However, positive results were found in relation to reducing stress and increasing caregiver confidence for coping with problem behavior (Kales et al., 2018), increasing confidence and reducing burden (Zimmerman et al., 2018) and, finally, increasing caregivers’ sense of competence (Van Mierlo et al., 2015). Nevertheless, the results presented should be interpreted cautiously…p. 1176
Wallace *et al.*, (2021) Australia	? – September 2020	1. What evidence is available for online interventions that provide peer support to caregivers of people with stroke, dementia, TBI, Parkinson’s disease or multiple sclerosis? 2. Are online peer-support interventions effective in improving outcomes for caregivers? 3. Are caregivers of stroke survivors with aphasia included in online peer-support intervention studies?	18 studies, 17 interventions – not all dementia specific Nevertheless: “11 studies reported statistically significant changes in one or more of the following domains: caregiver knowledge (Cristancho-Lacroix et al., 2015), mental health (Marziali & Garcia, 2011), stress (Han et al., 2020; Marziali & Donahue, 2006; O’Connor et al., 2014), depression (Griffiths et al., 2018; Han et al., 2020; Lorig et al., 2012; Núňez-Naveira et al., 2016; Smith et al., 2012), distress (Marziali & Garcia, 2011), burden (Griffiths et al., 2018; Lorig et al., 2012), self-efficacy (Boots et al., 2018; Han et al., 2020; Marziali & Garcia, 2011), mastery (Boots et al., 2018), helplessness (Han et al., 2020) and perceived support (Dam et al., 2017) …. Two studies (Bateman et al., 2017; McKechnie et al., 2014) that provided peer support only (with no educational component to the intervention) did not show any significant changes in their outcome measures of caregiver burden, stress, self-efficacy, anxiety or depression following the intervention.” P. 20

Appendix E: ASI Letter of permission for conducting research

THE ALZHEIMER
SOCIETY of IRELAND

Pat McLoughlin
Chief Executive Officer
The Alzheimer Society of Ireland
Blackrock
Co. Dublin

29th April 2021

RE: Fergus Timmons EdD Research Project

To Whom It May Concern

The above-named Fergus Timmons is an employee of The Alzheimer Society of Ireland. He is undertaking a Doctor of Education (EdD) programme at Dublin City University, and his student number is 18213561.

Fergus has briefed myself and my colleagues as to the nature of his research project. It aims to investigate through a consultation process with our learners how The Alzheimer Society of Ireland can make improvements to its online learning course for family carers of people with dementia. The online learning course is an important service and support for family carers. So, it is vital that we provide the best possible education and training course for this target group. This research project is therefore timely and highly relevant to the development of our services. Fergus has our full permission to carry out this research project.

I understand that during the process of conducting his research Fergus will need to access personal details of previous course participants. ASI has gathered this personal data in full compliance with GDPR regulations. In compliance with GDPR best practice, I further understand that Fergus will only contact those previous course participants who have given their consent to be contacted for events of interest. Individuals will then decide if they wish to take part in the study.

I hope this letter contains all the information you require, but please do not hesitate to contact me should you require any further details.

Yours sincerely,

Pat McLoughlin

Pat McLoughlin
CEO, The Alzheimer Society of Ireland

The Alzheimer Society of Ireland
National Office
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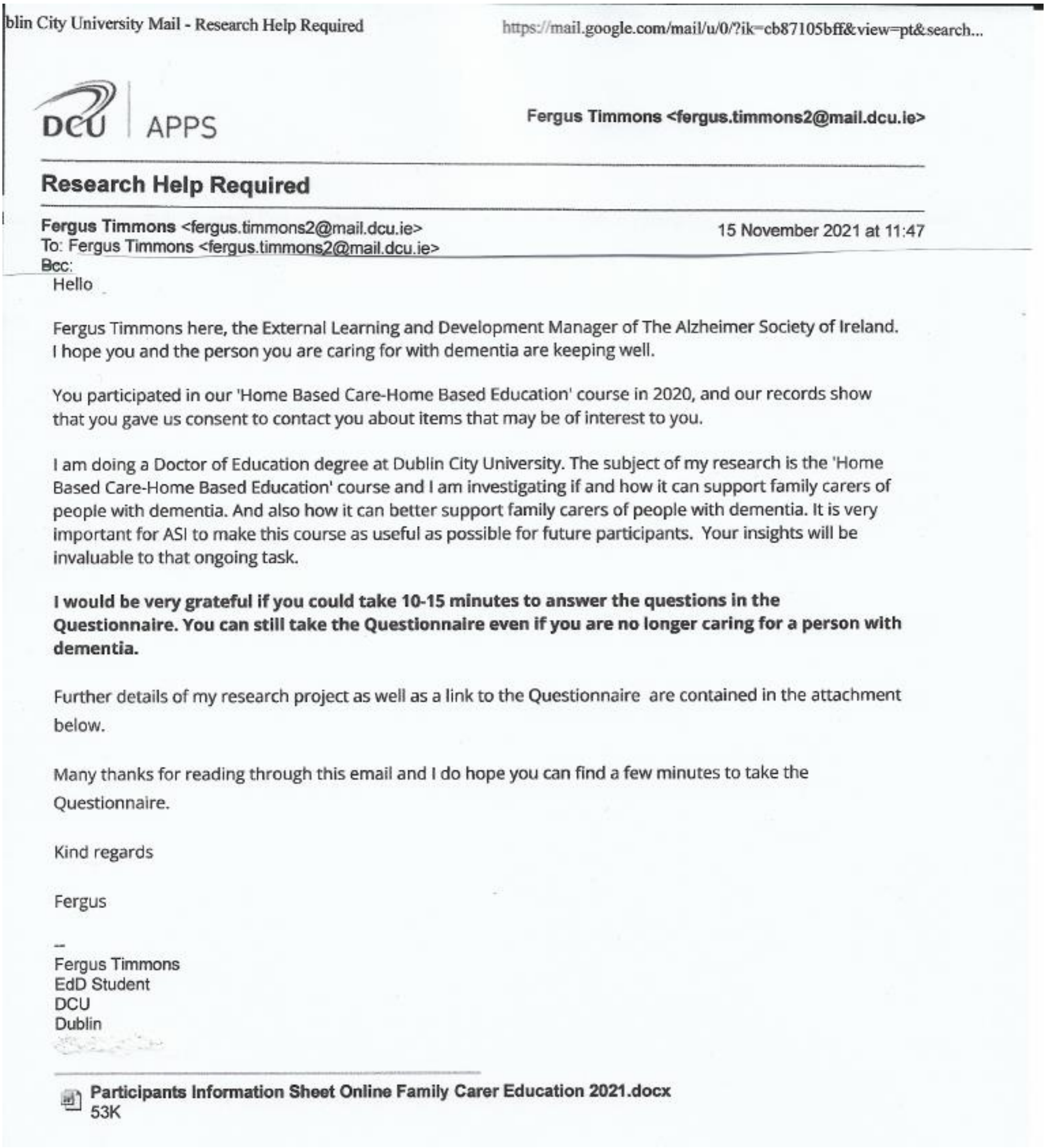
Appendix F: Invitation Emails for Online Questionnaire (Part A)



blin City University Mail - Research Help Required https://mail.google.com/mail/u/0/?ik=cb87105bff&view=pt&search...

DCU APPS

Fergus Timmons <fergus.timmons2@mail.dcu.ie>

Research Help Required

Fergus Timmons <fergus.timmons2@mail.dcu.ie> 15 November 2021 at 11:47
To: Fergus Timmons <fergus.timmons2@mail.dcu.ie>
Bcc:

Hello

Fergus Timmons here, the External Learning and Development Manager of The Alzheimer Society of Ireland. I hope you and the person you are caring for with dementia are keeping well.

You participated in our 'Home Based Care-Home Based Education' course in 2020, and our records show that you gave us consent to contact you about items that may be of interest to you.

I am doing a Doctor of Education degree at Dublin City University. The subject of my research is the 'Home Based Care-Home Based Education' course and I am investigating if and how it can support family carers of people with dementia. And also how it can better support family carers of people with dementia. It is very important for ASI to make this course as useful as possible for future participants. Your insights will be invaluable to that ongoing task.

I would be very grateful if you could take 10-15 minutes to answer the questions in the Questionnaire. You can still take the Questionnaire even if you are no longer caring for a person with dementia.

Further details of my research project as well as a link to the Questionnaire are contained in the attachment below.

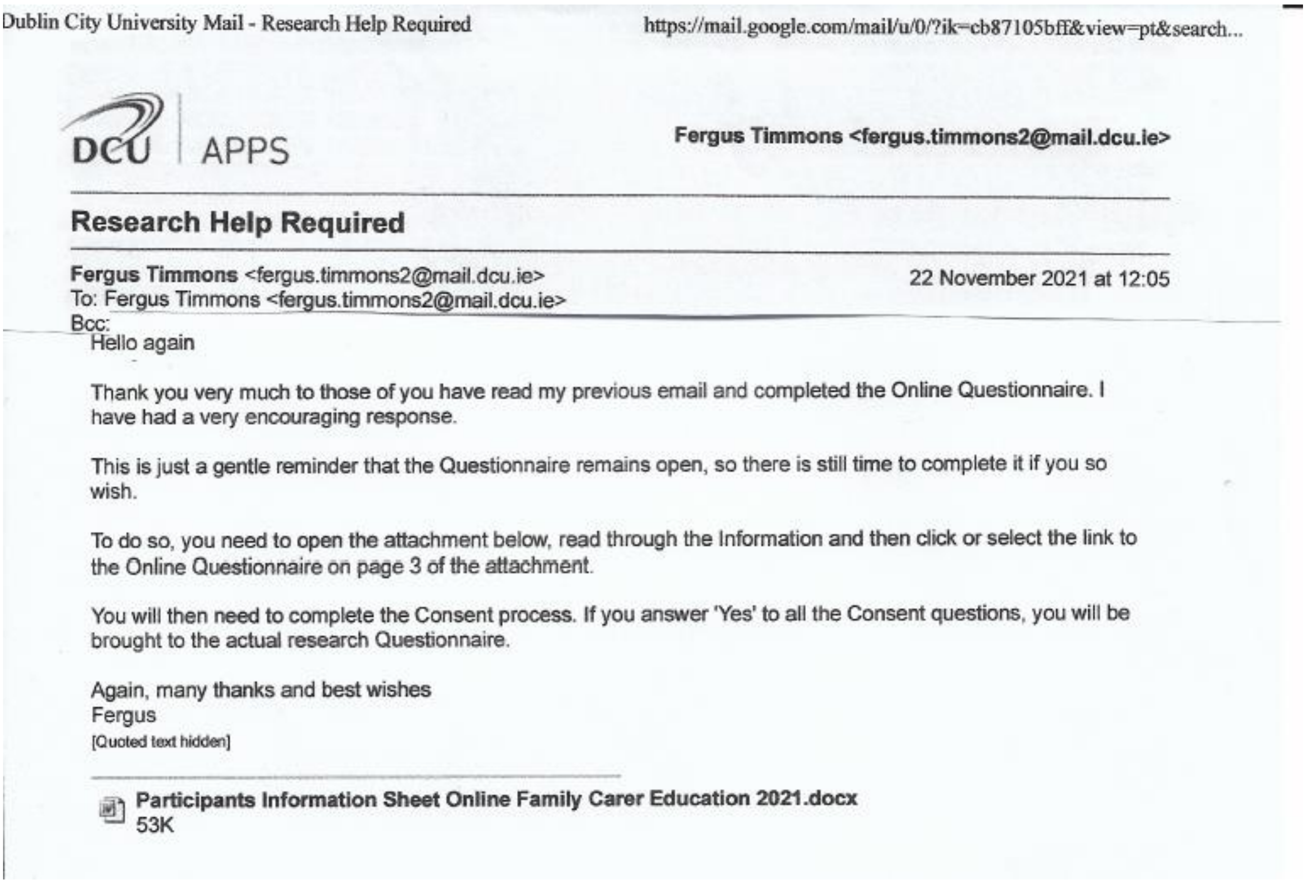
Many thanks for reading through this email and I do hope you can find a few minutes to take the Questionnaire.

Kind regards

Fergus

--
Fergus Timmons
EdD Student
DCU
Dublin

Participants Information Sheet Online Family Carer Education 2021.docx
53K



Dublin City University Mail - Research Help Required https://mail.google.com/mail/u/0/?ik=cb87105bff&view=pt&search...

DCU | APPS

Fergus Timmons <fergus.timmons2@mail.dcu.ie>

Research Help Required

Fergus Timmons <fergus.timmons2@mail.dcu.ie> 22 November 2021 at 12:05
To: Fergus Timmons <fergus.timmons2@mail.dcu.ie>
Bcc:

Hello again

Thank you very much to those of you have read my previous email and completed the Online Questionnaire. I have had a very encouraging response.

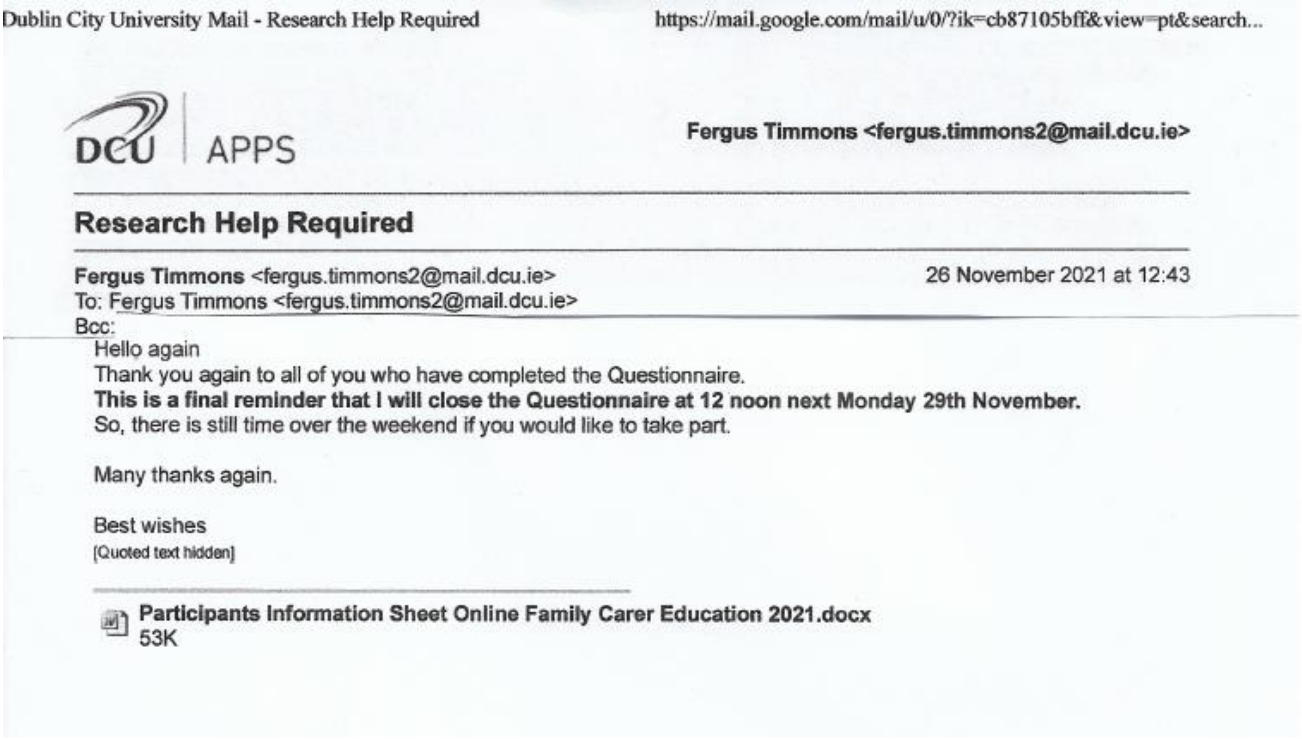
This is just a gentle reminder that the Questionnaire remains open, so there is still time to complete it if you so wish.

To do so, you need to open the attachment below, read through the Information and then click or select the link to the Online Questionnaire on page 3 of the attachment.

You will then need to complete the Consent process. If you answer 'Yes' to all the Consent questions, you will be brought to the actual research Questionnaire.

Again, many thanks and best wishes
Fergus
[Quoted text hidden]

Participants Information Sheet Online Family Carer Education 2021.docx
53K



Dublin City University Mail - Research Help Required https://mail.google.com/mail/u/0/?ik=cb87105bff&view=pt&search...

DCU | APPS

Fergus Timmons <fergus.timmons2@mail.dcu.ie>

Research Help Required

Fergus Timmons <fergus.timmons2@mail.dcu.ie> 26 November 2021 at 12:43
To: Fergus Timmons <fergus.timmons2@mail.dcu.ie>
Bcc:

Hello again
Thank you again to all of you who have completed the Questionnaire.
This is a final reminder that I will close the Questionnaire at 12 noon next Monday 29th November.
So, there is still time over the weekend if you would like to take part.

Many thanks again.

Best wishes
[Quoted text hidden]

Participants Information Sheet Online Family Carer Education 2021.docx
53K

Appendix G: Information Sheet for Online Questionnaire (Part A)

Information Sheet

PART A: Anonymous Online Questionnaire

Introduction to the Research Study

My name is Fergus Timmons and I work for The Alzheimer Society of Ireland (ASI). As part of my Doctor of Education (EdD) degree I am carrying out research into if and how our online education and training course Home Based Care-Home Based Education (HBC-HBE) can better support family carers of people with dementia.

This information sheet will provide you with more details about the research. The research is being carried out by Fergus Timmons, External Learning and Development Manager at The Alzheimer Society of Ireland under the supervision of Dr. Enda Donlon (enda.donlon@dcu.ie), 01 7009120, and Dr. Peter Tiernan (peter.d.tiernan@dcu.ie), 01 700 9159, Dublin City University, Institute of Education.

Privacy Notice

This research study will collect personal data about you. Personal data is defined as any information relating to an identified or identifiable person. Therefore, under the terms of GDPR legislation, and to follow best practice at DCU, I need to make you aware of the following:

- This research study is titled: '**How can online education better support family carers of people with dementia? a case study from an Irish NGO.** ' The Data Controllers are Dublin City University (DCU).
- The Data Protection Office at DCU is Mr. Martin Ward (data.protection@dcu.ie Ph.: 7005118 / 7008257).
- The personal data is being collected about you to assist the research project. The overall aim of the research is to improve understanding of how learners participate in online learning with a view to improving the course for future participants.
- The data will be held to assist the researcher gain a better understanding of how to improve the online learning experience of family carers of people with dementia. In addition, the research findings will be used in my EdD thesis and as the basis for producing academic outputs such as conference papers, book chapters or journal articles.

- The research data will be held for a period of two years after which time it will be destroyed.
- If you have any concerns about the data, you can contact the *Irish Data Protection Commission.*
- You have the right to access the personal data we hold on you. To do so, please contact either of the Data Protection Officers listed above Mr. Martin Ward
- You can withdraw your consent to participate in this research study without any penalty at any time by contacting the researcher Fergus Timmons (fergus.timmons2@mail.dcu.ie) in writing.
- Please note that personal information will be anonymized in the research publications for the purposes of confidentiality. For survey data, your IP address will remain on the Qualtrics platform until the research is complete. Overall trends will be analysed in the survey responses and pseudonyms will be used for individual quotations for any qualitative data.

Statement as to whether the research data is to be destroyed after a minimum period

The research data will be destroyed two years after submission of his thesis.

Details of what being involved in the Research Study will require

There are two parts to the research study.

Part A: Anonymous Online Questionnaire and

Part B: Individual Interview.

If you agree to participate in Part A you will be asked to give your consent indicating that you understand that you are being asked to participate in a research study, and that you can refuse to continue to be part of this research study at any time without any penalty, and the information you provide will be held in the strictest confidence. Once you consent to take part in the study, you will then proceed to an anonymous online questionnaire. Any personal information you provide in the online questionnaire will be fully anonymised. The online questionnaire should take approximately 15 minutes to complete. The results of the questionnaire will be held on the researcher's laptop, which is password encrypted and password protected.

Potential risks to participants from involvement in the Research Study (if greater than that involved in everyday life)

There is little possibility of potential physical risks in taking part in this Research Study. If you become upset by any of the questions or the answers provided by you when completing the anonymous online questionnaire, then support will be available to you through my colleagues at The Alzheimer Society of Ireland or external agencies as appropriate. A list of support options will be provided at the end of the anonymous online questionnaire.

Benefits (direct or indirect) in taking part in the Research Study

The findings of the Research Study will be used to help ASI make improvements to their online learning HBC-HBE programme, so that it becomes a more impactful and effective course for family carers. Please be open and honest in your responses to the research questions. ASI is keen to offer this course to as many people as possible so that the levels of care and support offered to people with dementia is effective, appropriate and of the highest possible quality. The research will also contribute to the wider field of dementia education in Ireland and beyond, especially in relation to online learning.

Advice as to arrangements to be made to protect confidentiality of data

The responses to the online questionnaire will be anonymous. Confidentiality of information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law. For example, it is possible for data to be subject to subpoena, freedom of information claim, or mandated reporting for some professions. For example, in accordance with the National Safeguarding Act and as an employee of ASI the researcher has a legal obligation to disclose information to the national safeguarding office if I feel adults are vulnerable to or being abused.

Only the researcher and his supervisors will have any access to the data.

Advice as to whether data will be destroyed after a minimum period

The online questionnaire returns will be destroyed after a period of 2 years.

Statement that involvement in the Research Study is voluntary

Your participation in this Research Study is voluntary and you may withdraw at any time without any penalty.

Any other relevant information

The researcher is the manager of External Learning and Development at The Alzheimer Society of Ireland. He is responsible for the development and delivery of all education and training programmes for family carers and other stakeholders. He would like to make it clear that your decision to participate, or not to participate in this Research Study will have no implications for your participation on the Home Based Care-Home Based Education course, or any other courses or interventions offered by The Alzheimer Society of Ireland. In addition, he is aware of the potential ethical challenges of researching his own work-practice and has discussed the challenge of power relationships as an insider researcher with his research supervisors.

How do I take part?

To commence participation please click on the following link and complete the survey. Thank you.

Click **here** to start the consent process for the online questionnaire.

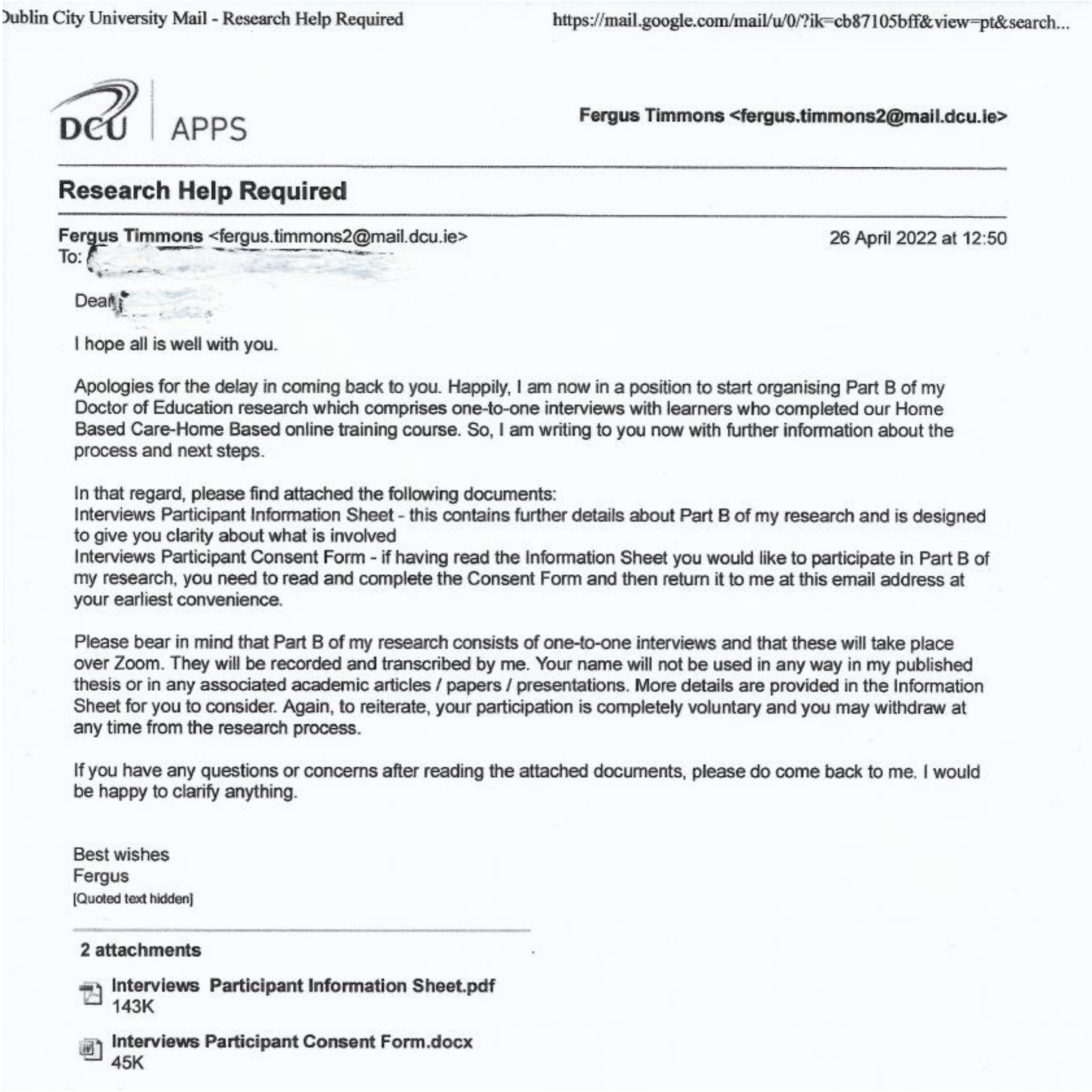
The direct link is:
https://dcueducation.fra1.qualtrics.com/jfe/form/SV_00Q6eBJOfqJqwl0

Once you complete the consent process, you will be able to access the questionnaire directly.

If you have any have concerns about this study and wish to contact an independent person, please contact:

The Secretary, Dublin City University Research Ethics Committee, c/o Research and Innovation Support, Dublin City University, Dublin 9. Tel 01-7008000, e-mail rec@dcu.ie

Appendix H: Invitation Email for Interview (Part B)



Dublin City University Mail - Research Help Required https://mail.google.com/mail/u/0/?ik=cb87105bff&view=pt&search...

DCU | APPS

Fergus Timmons <fergus.timmons2@mail.dcu.ie>

Research Help Required

Fergus Timmons <fergus.timmons2@mail.dcu.ie> 26 April 2022 at 12:50
To: [redacted]

Dear [redacted]

I hope all is well with you.

Apologies for the delay in coming back to you. Happily, I am now in a position to start organising Part B of my Doctor of Education research which comprises one-to-one interviews with learners who completed our Home Based Care-Home Based online training course. So, I am writing to you now with further information about the process and next steps.

In that regard, please find attached the following documents:
Interviews Participant Information Sheet - this contains further details about Part B of my research and is designed to give you clarity about what is involved
Interviews Participant Consent Form - if having read the Information Sheet you would like to participate in Part B of my research, you need to read and complete the Consent Form and then return it to me at this email address at your earliest convenience.

Please bear in mind that Part B of my research consists of one-to-one interviews and that these will take place over Zoom. They will be recorded and transcribed by me. Your name will not be used in any way in my published thesis or in any associated academic articles / papers / presentations. More details are provided in the Information Sheet for you to consider. Again, to reiterate, your participation is completely voluntary and you may withdraw at any time from the research process.

If you have any questions or concerns after reading the attached documents, please do come back to me. I would be happy to clarify anything.

Best wishes
Fergus
[Quoted text hidden]

2 attachments

Interviews Participant Information Sheet.pdf
143K

Interviews Participant Consent Form.docx
45K

Appendix I: Information Sheet for Interviews (Part B)

Research Study:

How can online learning better support family carers of people with dementia? A case study from an Irish NGO.

Information Sheet

PART B: Individual One to One Interviews

I. Introduction to the Research Study

As part of my Doctor of Education (Ed. D) course I am carrying out research into if and how The Alzheimer Society of Ireland (ASI) online education and training course Home Based Care-Home Based Education (HBC-HBE) can better support family carers of people with dementia. The findings of the research will be used to improve the course for future participants. Your involvement in the research study is voluntary, and you may withdraw at any time without penalty.

The Research is being conducted by Fergus Timmons External Learning and Development Manager, The Alzheimer Society of Ireland under the supervision of Dr Enda Donlon and Dr Peter Tiernan, Institute of Education, Dublin City University.

II. Privacy Notice

This research study will collect personal data about you. Personal data is defined as any information relating to an identified or identifiable person. Therefore, under the terms of GDPR legislation, and to follow best practice at DCU, I need to make you aware of the following:

This research study is titled: How can online learning better support family carers of people with dementia? A case study from an Irish NGO.

- The Data Controllers are Dublin City University.

- The Data Protection Office at DCU is Mr. Martin Ward (data.protection@dcu.ie Ph.: 7005118 / 7008257).
- The personal data is being collected about you to assist the research project. The overall aim of the research is to improve understanding of how learners participate in online learning with a view to improving the course for future participants.
- The data will be held to assist the researcher gain a better understanding of how to improve the online learning experience of family carers of people with dementia. The data will also be used to make improvements to the online course. In addition, the research findings will be used in my Doctor of Education thesis and as the basis for articles to be published in academic journals.
- The types of personal data that will be collected during the research project will include your name, age and gender and also information regarding your care duties.
- The research data will be held for a period of two years after which time it will be destroyed.
- If you have any concerns about the data, you can contact the *Irish Data Protection Commission.*
- You have the right to access the personal data we hold on you. To do so, please contact either of the Data Protection Officers listed above Mr. Martin Ward
- You can withdraw your consent to participate in this research study without any penalty by contacting the researcher Fergus Timmons (fergus.timmons2@mail.dcu.ie) in writing.
- Please note that personal information will be anonymized in the research publications for the purposes of confidentiality. Individual quotations for any qualitative data.

III. Statement as to whether the research data is to be destroyed after a minimum period

The research data will be destroyed two years after submission of this thesis.

IV. Details of what being involved in the Research Study will require

If you agree to participate in Part B of this research you will be asked to sign a Consent Form again indicating that you understand that you are being asked to participate in a research study, and that you can refuse to continue to be part of this research study at any time without any penalty, and that the information you provide will be held in the strictest confidence. If you consent to being involved in Part B, you will then be invited to an interview. Interviews will be held online using the Zoom platform. Individual interviews will last approximately 1 hour. They will be recorded and transcribed. Once the researcher is finished transcribing the interviews, each interviewee will be sent a copy to check it for accuracy. The interview data will be kept for 2 years after which time the transcripts will be deleted and the video files also deleted.

V. Potential risks to participants from involvement in the Research Study (if greater than that involved in everyday life)

There is little possibility of potential physical risks in taking part in this Research Study. If you become upset by any of the questions or the answers provided by you during Part B, then the interviewer will outline a range of support measures that will be available to you either through colleagues at The Alzheimer Society of Ireland or external agencies as appropriate. Confidentiality will be ensured when presenting the findings of this Research Project and pseudonyms will be used as necessary.

VI. Benefits (direct or indirect) in taking part in the Research Study

The findings of the Research Study will be used to help ASI make improvements to their online learning HBC-HBE programme, so that it a more impactful and effective course for family carers. Please be open and honest in your responses to the research questions. ASI is keen to offer this course to as many people as possible so that the levels of care and support offered to people with dementia is effective, appropriate and of the highest possible quality. The research will also contribute to the wider field of dementia education in Ireland and beyond.

VII. Advice as to arrangements to be made to protect confidentiality of data

Confidentiality of information provided cannot always be guaranteed by researchers and can only be protected within the limitations of the law – i.e., it is possible for data to be subject to subpoena, freedom of information claim, or mandated reporting for some professions. For example, the national safeguarding act*. Interview data will be held on an encrypted and password protected laptop computer located in the home of the researcher. Only the researcher and the principal investigators will have any access to the data.

*As an employee of ASI I have a legal obligation to disclose information to the national safeguarding office if I feel adults are vulnerable to or are being abused.

VIII. Advice as to whether or not data will be destroyed after a minimum period

All results will remain confidential, and every effort will be made to protect the anonymity of the participants involved (except for the safeguarding issue mentioned above). No data that could identify participants will be included in the findings. The participants who participate in Part B will be offered the opportunity to review interview transcripts for accuracy before they are analysed by the researcher. Once the researcher is finished with the transcripts, they will be stored securely for two years, and after the two years they will be destroyed as will the online questionnaire responses (Part A of this Research Project).

IX. Statement that involvement in the Research Study is voluntary

Your participation in this Research Study is voluntary and you may withdraw at any time without any penalty.

X. Any other relevant information

The researcher is the manager of External Learning and Development at The Alzheimer Society of Ireland. He is responsible for the development and delivery of all education and training programmes for family carers and other stakeholders. He would like to make it clear that your decision to participate, or not to participate in this Research Study will have no implications for your participation on the Home Based Care-Home Based Education course, or any other courses or interventions offered by The Alzheimer Society of Ireland. In addition, he is aware of the potential ethical challenges of researching his own work-practice and has discussed the challenge of power relationships as an insider researcher with his research supervisors.

XI. How do I take part?

The researcher Fergus Timmons will email you the Part B Consent Form. You need to provide full consent to participate in Part B. Full consent means:

- agreeing (answering ‘Yes’ to all questions in the Consent Form)
- signing and dating the Consent Form

Once you have provided full consent, please return the completed and signed Part B Consent Form to Fergus Timmons at fergus.timmons2@mail.dcu.ie. If you don’t have access to email, please contact Fergus on his mobile 0868106466 to make alternative arrangements.

Once Fergus receives the signed Consent Form, he will contact you to arrange a date for the interview.

Thank you.

Appendix J: Consent Form For Interviews (Part B)

Research Study:

How can online learning better support family carers of people with dementia? A case study from an Irish NGO.

Consent Form

PART B: Individual One to One Interviews

As part of my Doctor of Education (Ed. D) course I am carrying out research into if and how The Alzheimer Society of Ireland (ASI) online education and training course Home Based Care-Home Based Education (HBC-HBE) can better support family carers of people with dementia. The Research is being conducted by Fergus Timmons External Learning and Development Manager, The Alzheimer Society of Ireland under the supervision of Dr Enda Donlon and Dr Peter Tiernan, Institute of Education, Dublin City University, as part of his Doctor of Education course requirements.

E: fergus.timmons2@mail.dcu.ie or M: 0868106466

The aim of the research is to investigate if and how the 'Home Based Care-Home Based Education' online training programme for family carers of people with dementia supports and can better support course participants. The findings of the research will be used to improve the course for future participants. Your involvement in the research study is voluntary, and you may withdraw at any time without penalty.

Participant – please complete the following (by deleting Yes/No for each question)

I have read the Information Sheet (already circulated) Yes / No

I understand that the interview will take approximately 60 minutes to complete

Yes / No

I understand that I will not benefit directly for participating in the study Yes / No

I understand the information provided in relation to data protection Yes / No

I understand that my identity and all the information I provide will remain anonymous within the legal limitations of the law Yes / No

I understand that the survey results will be retained in a password protected computer Yes / No

I understand that under freedom of information legislation I am entitled to access the information I have provided during the two years after publication Yes / No

I understand that my data will only be used for analysis in this study and associated papers in academic journals Yes / No

I understand that I am free to contact any of the people in the research to seek further information or clarification on any aspect of the research Yes / No

I consent to the publication of this research study including my anonymized data Yes / No

Signed: ____

Date: __________________________

Please return the completed Consent Form to fergus.timmons2@mail.dcu.ie

Appendix K: The Online Questionnaire (Part B)

How can online learning support family carers of people with dementia?

Start of Block: Informed Consent Block

Q1 **How can online education better support family carers of people with dementia? a case study from an Irish NGO.** *Institute of Education, Dublin City University.*

The Research is being conducted by Fergus Timmons External Learning and Development Manager, The Alzheimer Society of Ireland under the supervision of Dr Enda Donlon and Dr Peter Tiernan, Institute of Education, Dublin City University.

E: fergus.timmons2@mail.dcu.ie or M: 0868106466

The aim of the research is to investigate if and how the Home Based Care-Home Based Education online training programme for family carers of people with dementia supports and can better support course participants. The findings of the research will be used to improve the course for future participants. Your involvement in the research study is voluntary, and you may withdraw at any time without penalty.

Participant – please complete the following (by clicking Yes/No for each question)

Q2, I have read the Plain Language Statement

○ Yes (1)

○ No (2)

Skip To: Q3 If I have read the Plain Language Statement = Yes

Skip To: End of Survey If I have read the Plain Language Statement = No

Q3, I understand that the Questionnaire will take 10-15 minutes to complete

○ No (1)

○ Yes (2)

Skip To: Q4 If I understand that the Questionnaire will take 10-15 minutes to complete = Yes

Skip To: End of Survey If I understand that the Questionnaire will take 10-15 minutes to complete = No

Q4, I understand that I will not benefit directly from participating in the study

○ No (1)

○ Yes (2)

Skip To: Q5 If I understand that I will not benefit directly from participating in the study = Yes

Skip To: End of Survey If I understand that I will not benefit directly from participating in the study = No

Q5, I understand the information provided to me in relation to data protection

○ No (1)

○ Yes (2)

Skip To: End of Survey If I understand the information provided to me in relation to data protection = No

Skip To: Q6 If I understand the information provided to me in relation to data protection = Yes

Q6, I understand that my identity and all the information that I provide will remain anonymous within the legal limitations of the law

○ No (1)

○ Yes (2)

Skip To: Q7 If I understand that my identity and all the information that I provide will remain anonymous within... = Yes

Skip To: End of Survey If I understand that my identity and all the information that I provide will remain anonymous within... = No

Q7, I understand that the Questionnaire results will remain in a password protected computer

○ No (1)

○ Yes (2)

Skip To: Q8 If I understand that the Questionnaire results will remain in a password protected computer = Yes

Skip To: End of Survey If I understand that the Questionnaire results will remain in a password protected computer = No

Q8
I understand that my data will only be used for analysis in this study and the production of academic outputs such as conference presentations, book chapters and academic articles.

○ Yes (1)

○ No (2)

Skip To: Q9 If I understand that my data will only be used for analysis in this study and the production of acad... = Yes

Skip To: End of Survey If I understand that my data will only be used for analysis in this study and the production of acad... = No

Q9, I understand that I am free to contact the researcher Fergus Timmons to seek further information or clarification on any aspect of the research

○ No (1)

○ Yes (2)

Skip To: Q10 If I understand that I am free to contact the researcher Fergus Timmons to seek further information... = Yes

Skip To: End of Survey If I understand that I am free to contact the researcher Fergus Timmons to seek further information... = No

Q10, I consent to the publication of this research study including my anonymized data

○ No (1)

○ Yes (2)

Skip To: Q11 If I consent to the publication of this research study including my anonymized data = Yes

Skip To: End of Survey If I consent to the publication of this research study including my anonymized data = No

Q11
Please note that as soon as you click 'Continue to Questionnaire' and then 'Next' to start the process of completing the online questionnaire, your data will be fully anonymized in compliance with Data Protection law.

○ Continue to Questionnaire (1)

Page Break

End of Block: Informed Consent Block

Start of Block: Demographics and other information

Q12 **Section 1**: A little about you. In this section I will ask about you and your background. I will analyse the data in terms of overall results and also according to some of the categories in this section, for example to see if there are any differences between the overall responses of primary versus secondary carers.

Q13 What is your gender?

○ Male (1)

○ Female (2)

○ Non-binary / third gender (3)

○ Prefer not to say (4)

Q14 What age are you?

____

Q15 What is your ethnic or cultural background? (categories taken from 2006 Census of Ireland and 2017 Revisions)

○ White Irish (1)

○ White Irish Traveller (2)

○ Any other white background (3)

○ Black or Black Irish (African) (4)

○ Black or Black Irish (Any other Black background) (5)

○ Asian or Asian Irish (Chinese) (6)

○ Asian or Asian Irish (Any other Asian background) (7)

○ Other, including mixed background (8)

○ Roma (9)

○ Indian / Pakistani / Bangladeshi (10)

○ Arabic (11)

○ Mixed (12)

Q16 How confident are you with using computer / IT equipment?

- ○ Not at all confident (1)
- ○ Slightly confident (2)
- ○ Somewhat confident (3)
- ○ Moderately confident (4)
- ○ Extremely confident (5)

Q17 In what year did you complete the course?

- ○ 2019 (1)
- ○ 2020 (2)
- ○ 2021 (3)

Q18 Was this the first online course you had participated in?

- ○ No (1)
- ○ Yes (2)

Q19 What was the main device you used to access the course?

- ○ Laptop computer (1)
- ○ Desktop computer PC (2)
- ○ Android Smart Phone (3)
- ○ Tablet (4)
- ○ iPhone (5)
- ○ iPad (6)
- ○ Other device (7)

Q20 How long had you been a family carer when you took this course?

- ○ 0-1 years (1)
- ○ 1-2 years (2)
- ○ 2-3 years (3)
- ○ 3-4 years (4)
- ○ 4-5 years (5)
- ○ Over 5 years (6)

Q21 When you were taking this course, which of the following best describes your caring role?

○ I was the primary or main carer of the person with dementia in my family (1)

○ I was a secondary carer which means I try to support the primary carer and also the person with dementia when possible (2)

Skip To: Q22 If When you were taking this course, which of the following best describes your caring role? = I was the primary or main carer of the person with dementia in my family

Skip To: Q23 If When you were taking this course, which of the following best describes your caring role? = I was a secondary carer which means I try to support the primary carer and also the person with dementia when possible

Q22 If you were a primary carer, to whom were you providing support?

○ Spouse (1)

○ Sibling (2)

○ Parent (3)

○ Mother or Father-in-law (4)

○ Other relative (5)

○ I am not the primary carer (6)

Q23 If you were a secondary carer, to whom were you providing support?

○ Spouse (5)

○ Sibling (1)

○ Parent (2)

○ Mother or Father-in-law (3)

○ Other relative (4)

○ I am not the secondary carer (6)

End of Block: Demographics and other information

Start of Block: Supporting Family Carers of People with Dementia

Q24 **Section 2**: In this block of questions, I would like to investigate the overall impact that participating on the ‘Home Based Care - Home Based Education’ (HBC-HBE) course had on you in your dementia care situation. In your dementia care situation, you may have been the primary carer, providing direct care to your family member with dementia, or you may have been a secondary carer, providing support to the primary carer and / or the person with dementia.

Q25 **Emotional Support**
Please indicate to what extent you agree with the following statement. Thank you.

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
I actively discussed dementia with wider friends and family as a result of participating on the HBC-HBE course (4)	○	○	○	○	○
The HBE-HBE course provided me the opportunity to give and receive support from other course participants (2)	○	○	○	○	○

Q26 **Informational Support**

Please indicate to what extent you agree with the following statements. Thank you.

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
The HBC-HBE course provided me with important information about dementia (7)	○	○	○	○	○
The HBE-HBE course provided me with relevant information about other support services (6)	○	○	○	○	○
The HBC-HBE course provided me with new information about dementia (8)	○	○	○	○	○

Q27 **Practical Support**

Please indicate to what extent you agree with the following statements. Thank you.

	Strongly disagree (1)	Disagree (2)	Neither agree nor disagree (3)	Agree (4)	Strongly agree (5)
The HBC-HBE course gave me helpful ideas about how to maintain a safe care environment (1)	○	○	○	○	○
The HBC-HBE course provided new ideas about how to maintain an active lifestyle for myself (3)	○	○	○	○	○
The HBC-HBE course provided useful ideas about how to maintain an active lifestyle for the person with dementia (4)	○	○	○	○	○
The HBC-HBE course provided me with beneficial ideas about how to provide personal care (5)	○	○	○	○	○

Q28 How has the course impacted on the way you provide care directly or indirectly to the person with dementia in your family?

○ Major negative impact (1)

○ Minor negative impact (3)

○ No impact (7)

○ Minor positive impact (4)

○ Major positive impact (6)

Q29 How likely is it that you will continue to introduce new ideas to the care you provide to your family member because of doing this course?

○ Extremely unlikely (1)

○ Unlikely (2)

○ Neither likely nor unlikely (3)

○ Likely (4)

○ Extremely likely (5)

Q30 **Overall impact of the HBC-HBE course**

In terms of your role as either a primary or secondary carer, to what extent do you agree with the following statements?

	Strongly Disagree (1)	Disagree (2)	Neither Disagree nor Agree (3)	Agree (4)	Strongly Agree (5)
I feel the HBC-HBE course improved the care I provided (1)	○	○	○	○	○
The HBC-HBE course made me feel more confident (2)	○	○	○	○	○
The HBC-HBE course reduced my carer stress levels (5)	○	○	○	○	○
The HBC-HBE course made no difference to me in my care situation (6)	○	○	○	○	○
The HBC-HBE course improved my care skills (4)	○	○	○	○	○

Q31 Use the space below to elaborate or explain in your own words how participating on this course may have supported you in your care situation? Thank you.

____

Page Break

End of Block: Supporting Family Carers of People with Dementia

Start of Block: Course Components

Q32 **Section 3**: This part of the Questionnaire aims to examine if and how the various course delivery mechanisms may have been of some support to you in your role as a family carer.

Q33
How supportive did you find the following learning activities of the course?

To what extent did they help you provide care in your dementia situation.

	Not at all supportive (1)	Slightly supportive (2)	Moderately supportive (3)	Very supportive (4)	Extremely supportive (5)
Reading course materials: e-books, factsheets (1)	○	○	○	○	○
Interactions with your Tutor (2)	○	○	○	○	○
Interactions with your fellow course participants (3)	○	○	○	○	○
Completing the Weekly Reflective Assignment (4)	○	○	○	○	○

Q34 Did you engage with the course materials, that is the books, factsheets, audiobooks?

○ Yes (1)

○ No (2)

Skip To: Q36 If Did you engage with the course materials, that is the books, factsheets, audiobooks? = Yes

Skip To: Q35 If Did you engage with the course materials, that is the books, factsheets, audiobooks? = No

Q35 If you did not access the course materials can you explain why you did not read them please

____

Q36 How important were the various **Course Materials** listed below in assisting or informing the care you deliver?

	Not at all important (1)	Slightly important (2)	Moderately important (3)	Very important (4)	Extremely important (5)
Text in e-books (1)	○	○	○	○	○
Embedded videos in e-books (2)	○	○	○	○	○
Factsheets and other documents (3)	○	○	○	○	○

Q37 Did you make regular contributions to the Discussion Forums (regular means posting up more than 5 forum messages during the course)?

○ No (1)

○ Yes (2)

Skip To: Q38 If Did you make regular contributions to the Discussion Forums (regular means posting up more than 5... = No

Skip To: Q39 If Did you make regular contributions to the Discussion Forums (regular means posting up more than 5... = Yes

Q38 If you answered no to the previous question, can you tell us why you chose not to contribute to the Discussion Forums.

____

Q39 How important were the following **Tutor Support** elements in assisting or informing the care you deliver?

	Not at all important (1)	Slightly important (2)	Moderately important (3)	Very important (4)	Extremely important (5)
Interactions with Tutors on Discussion Forums (1)	○	○	○	○	○
Interactions with Tutors at Video Meetings (2)	○	○	○	○	○
Feedback from tutors on Weekly Reflective Assignments (3)	○	○	○	○	○

Q40 Did you regularly attend the weekly video meetings?

○ No (1)

○ Yes (2)

Skip To: Q41 If Did you regularly attend the weekly video meetings? = No

Skip To: Q42 If Did you regularly attend the weekly video meetings? = Yes

Q41 If you answered no to the previous question, can you tell us why you did not regularly attend the video meetings?

____

Q42 How important was **Peer Support** (support / advice from other learners on the course) in assisting or informing the care you deliver?

	Not at all important (1)	Slightly important (2)	Moderately important (3)	Very important (4)	Extremely important (5)
Interactions via Discussion Forums (1)	○	○	○	○	○
Interactions via Video Meetings (2)	○	○	○	○	○
Interactions via Message / Private Chat feature (3)	○	○	○	○	○

Q43, Can you explain which of the elements above (Information in the Course Materials, Interactions with Tutors, or Interactions with other course participants) were most important in contributing to your learning experience on this course. Thank you.

____

Page Break

End of Block: Course Components

Start of Block: Learning Platform

Q44 **Section 4**: This section of the questionnaire investigates your views about the Moodle Workplace learning platform

Q45 How did you find using various aspects / components of Moodle Workplace?

	Very difficult (1)	Difficult (2)	Neither difficult nor easy (3)	Easy (4)	Very easy (5)
Logging on for the first time (1)	○	○	○	○	○
Finding my way around the course page (2)	○	○	○	○	○
Participating in video meetings (4)	○	○	○	○	○

Q46 What improvements do you think we could make to how the course is delivered?

____

Q47 Finally, is there anything else you would like to add that may not have been covered in any of the questions above, but you feel are important for this research project? Thank you.

____

Q48
That is the end of the survey. Thank you very much for your time and effort in completing it.
If you require any information or support in relation to dementia, please call The Alzheimer Society of Ireland Helpline on 1800 341 341 or visit www.alzheimer.ie.

You also should still have access to the Moodle site where your course is located. Please contact familycarertrainnig@alzheimer.ie if you have any other queries.

Part B of this research project consists of individual interviews with family carers to explore some of the themes emerging from this Questionnaire. If you would like to be considered for Part B of this research, please email fergus.timmons2@mail.dcu.ie at your earliest convenience. Interviews are likely to take place early in 2022. Thank you.

Please click 'Next' to submit your answers.

End of Block: Learning Platform

Appendix L: The Interview Guide

Part B: Interview Guide

Question guide to follow 8 themes identified in my Codebook 25/4/2022, *but also aligned to the RQ, which is: How can online learning better support family carers of people with dementia? and related sub-questions:*

Theme 1	Learners were mainly satisfied with the course and could articulate how it would continue to benefit them in the future **[how did the course support you?]**
Theme 2	Many learners gained a range of skills and practical tips from participating on the course **[to what extent did you find the practical tips supported you in your care role?]**
Theme 3	The course helped to support learners psychologically in terms of meaningful connections with tutors and other carers which caused increased levels of confidence and feelings of reassurance **[can you describe what being supported felt like?]**
Theme 4	Learners valued each component of the instructional dynamic, though some found it difficult to distinguish between their individual contribution to their learning experience **[can you describe how contact with the course materials and/or tutors and/or fellow learners may have supported you in your care role?]**
Theme 5	Most learners agreed that the online learning environment allowed them to interact meaningfully, but some felt challenged by it **[can you describe your experience of using our online learning platform? what were the advantages and disadvantages of it?]**
Theme 6	Participation and engagement with course activities and materials was impacted by Moodle usability issues and also by characteristics of learners **[was there anything else that impacted on how you participated on the course?]**
Theme 7	More needs to be done to support this cohort of learners in terms of wider supports and more education and training
Theme 8	We need to make Moodle more user-friendly and easier to use **[how could the course organisers make the course more engaging and/or user friendly?]**

Before interview

Demographics: Age, Gender, Primary / Secondary Carer, Year took the course – I may know this in advance of the interview but will confirm with each interviewee. Could be useful to have profile of each interviewee.

Introductory Questions:

At the time you participated on the course, can you tell me a little about your care situation please – who are you caring for, how long had you been caring, where are you caring?

Can you tell me why you decided to take the course?

Block 1: Support – How might the online course have supported learners

Did you feel that participating on the course supported you in your role as a family carer of a person living with dementia? Please explain your answer.

Follow-up / supplementary questions:

How did the course support you in your care role?

For example, to what extent did you find the practical tips supported you in your care role?

Can you describe what being supported felt like?

Block 2: Did any elements of the 'instructional dynamic' contribute to learners feeling supported

Can you describe how contact with the course materials and/or tutors and/or fellow learners may have supported you in your care role? [Might ask each element separately]

Follow-up / supplementary questions

Were any of these more important than others? If so, please explain why.

Block 3: The online learning platform

Can you describe your experience of using our online learning platform?

Follow-up / supplementary question:

What were the advantages of using it?

What were the disadvantages of using it?

How could we improve the learning environment?

Block 4: Learner Engagement and Participation

Were there any other obstacles to your participation?

Were there any enablers to your participation?

Block 5: Any other issues

Have you anything else you would like to add that we haven't already discussed earlier in the interview?

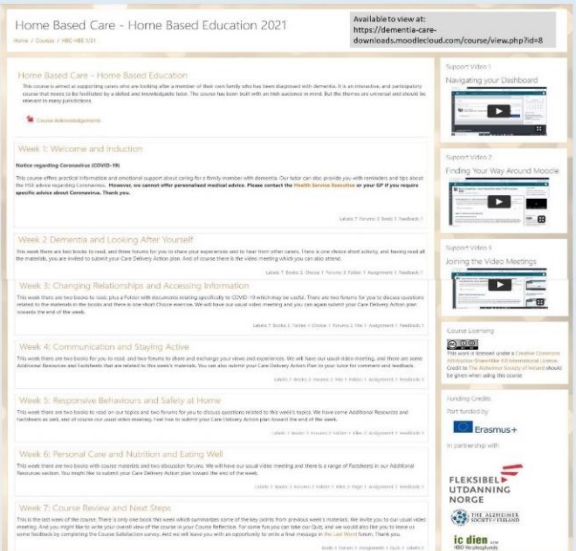
Appendix M: Reliability of Online Questionnaire (Cronbach Alpha Scores)

Question(s)	**Topic**	**No. of items**	**Cronbach's alpha**	**Comments**
Q.25	Psychological Support	2	0.598	Probably low due to small number of items
Q.26	Informational Support	3	0.892	
Q.27	Practical Support	4	0.867	
Q.30	Overall Impact	5	0.397	Too wide a concept to measure
Q.33	Learning Activities	4	0.757	
Q.36	Course Materials	3	0.810	
Q.39	Tutor Support	3	0.828	
Q.42	Peer Support	3	0.783	
Q.45	Using Moodle	3	0.821	
Q.25, Q.26, Q.27, Q.30 together	Block 2 of Questionnaire: Supporting Family Carers of People with Dementia	14	0.896	
Q33, Q36, Q39 and Q42 together	Block 3 Course Components	13	0.904	
Q.45 Using Moodle Workplace	Block 4 Using Moodle Workplace	3	0.821	

Appendix N: Poster for Alzheimer Disease International Conference, June 2022

How can online learning better support family carers of people living with dementia? A case study from an Irish NGO.

The Online Learning Course



Home Based Care - Home Based Education 2021

Home / Courses / HBC HBE 1/21

Available to view at: https://dementia-care-downloads.moodlecloud.com/course/view.php?id=8

Home Based Care - Home Based Education

This course is aimed at supporting carers who are looking after a member of their own family who has been diagnosed with dementia. It is an interactive and participatory course that needs to be facilitated by a skilled and knowledgeable tutor. The course has been built with an Irish audience in mind. But the themes are universal and should be relevant to many jurisdictions.

Course Acknowledgements

Week 1: Welcome and Induction

Notice regarding Coronavirus (COVID-19)

This course offers practical information and emotional support about caring for a family member with dementia. Our tutor can also provide you with reminders and tips about the HSE advice regarding Coronavirus. **However, we cannot offer personalised medical advice. Please contact the Health Service Executive or your GP if you require specific advice about Coronavirus. Thank you.**

Week 2 Dementia and Looking After Yourself

This week there are two books to read, and three forums for you to share your experiences and to hear from other carers. There is one choice short activity, and having read all the materials, you are invited to submit your Care Delivery Action plan. And of course there is the video meeting which you can also attend.

Week 3: Changing Relationships and Accessing Information

This week there are two books to read, plus a Folder with documents relating specifically to COVID-19 which may be useful. There are two forums for you to discuss questions related to the materials in the books and there is one short Choice exercise. We will have our usual video meeting and you can again submit your Care Delivery Action plan towards the end of the week.

Week 4: Communication and Staying Active

This week there are two books for you to read, and two forums to share and exchange your views and experiences. We will have our usual video meeting, and there are some Additional Resources and Factsheets that are related to this week's materials. You can also submit your Care Delivery Action Plan to your tutor for comment and feedback.

Week 5: Responsive Behaviours and Safety at Home

This week there are two books to read on our topics and two forums for you to discuss questions related to this week's topics. We have some Additional Resources and Factsheets as well, and of course our usual video meeting. Feel free to submit your Care Delivery Action plan toward the end of the week.

Week 6: Personal Care and Nutrition and Eating Well

This week there are two books with course materials and two discussion forums. We will have our usual video meeting and there is a range of Factsheets in our Additional Resources section. You might like to submit your Care Delivery Action plan toward the end of the week.

Week 7: Course Review and Next Steps

This is the last week of the course. There is only one book this week which summarizes some of the key points from previous week's materials. We invite you to our usual video meeting. And you might like to write your overall view of the course in your Course Reflection. For some fun you can take our Quiz, and we would also like you to leave us some feedback by completing the Course Satisfaction survey. And we will leave you with an opportunity to write a final message in the Last Word forum. Thank you.

Support Video 1
Navigating your Dashboard

Support Video 2
Finding Your Way Around Moodle

Support Video 3
Joining the Video Meetings

Course Licensing

This work is licensed under a Creative Commons Attribution-ShareAlike 4.0 International License. Credit to The Alzheimer Society of Ireland should be given when using this course.

Funding Credits

Part funded by

Erasmus+

In partnership with

FLEKSIBEL UTDANNING NORGE

THE ALZHEIMER SOCIETY of IRELAND

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Course Duration: 7 Weeks
Group Size: Maximum of 20 participants with one tutor
Teaching Materials – E-books, Audiobooks / Podcasts; Factsheets (PDFs); Videos
Synchronous 'live' activities: Online Video Meeting Zoom / BigBlueButton
Asynchronous activities: Discussion Forums; Questionnaires; Weekly Reflective Exercise; Course Quiz; Final Reflection
Participation, social learning and peer support all encouraged, but not forced

Family Carer Support Framework

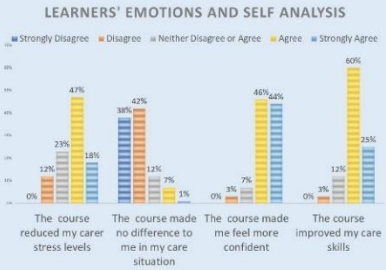
Information
- Dementia & Services
- Signs & Symptoms
- Progression
- Legal and Financial planning

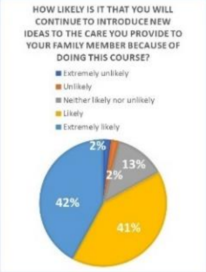
Education
- Communication
- Family relations
- Managing Behaviours
- Stress & Risks
- Activities & Lifestyle
- Decision making
- Care Skills

Support Through
- Course Materials
- Peers
- Professioinals
- Learning Environment = Learning Management System + Care Situation

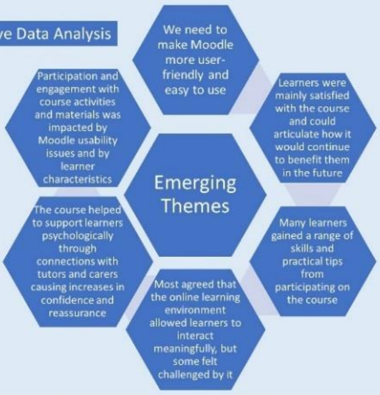
My research project: Doctor of Education 2018 to 2022
Case Study Methodology with multiple methods
Part A: Online Questionnaire (November 2021) open & closed questions
Distributed to course participants 2019, 2020 and 2021
n = 208; approximately 30% return rate
Survey instrument: Qualtrics; Analysis: Qualtrics and SPSS for Quantitative Data; NVivo for Qualitative Data using Template Analysis form of Thematic Analysis
Part B: One to one Interviews (May 2022) n=12
Analysis: Template Analysis form of Thematic Analysis
Sampling Strategy: Convenience Random Sampling

Preliminary Findings





Qualitative Data Analysis



Emerging Themes

We need to make Moodle more user-friendly and easy to use

Learners were mainly satisfied with the course and could articulate how it would continue to benefit them in the future

Many learners gained a range of skills and practical tips from participating on the course

Most agreed that the online learning environment allowed learners to interact meaningfully, but some felt challenged by it

The course helped to support learners psychologically through connections with tutors and carers causing increases in confidence and reassurance

Participation and engagement with course activities and materials was impacted by Moodle usability issues and by learner characteristics

Better Support – Learner Suggestions

Emotional Readiness
- Pre-course audit
- Exit points
- Non-social courses
- Breakout Rooms

Improving Moodle usability
- Less clicking!
- Support videos for different devices
- Video Conferencing Support
- Summary Learning Materials
- Balance Information Overload
- Pre-course Moodle course

Bright Ideas
- Follow-up events
- More courses for more people
- 'The Carer Journey'
- Educate other stakeholders

Fergus Timmons, External Learning and Development Manager, The Alzheimer Society of Ireland and Doctor of Education Student at Dublin City University Contact: fergus.timmons@alzheimer.ie; M: + 353 867831237; T: @FergusEDITS

THE Alzheimer SOCIETY OF IRELAND

from 1982 - 2022 40 Years of Caring

Appendix O: Author's Case Study Protocol

1. Overview of the Case Study

Mission:

To get a better understanding of how family carers get support from an online learning programme, with a view to using this feedback to improve how the online learning course supports and assists learners.

The 'unit of analysis' is an online learning course called Home Based Care-Home Based Education offered to family carers of people living with dementia.

The researcher is the manager of this online course. Findings from the Case Study will inform the researcher's future work practices.

Case Study Questions:

How does an online learning course called Home Based Care-Home Based Education (HBC-HBE) support family carers of people looking after a person living with dementia?

How can an online learning course called HBC-HBE better support family carers of people looking after a person living with dementia?

Theoretical Model:

From the academic literature 'support' for family carers looking after a person living with dementia consists of Educational Support, Informational Support and Emotional Support. See key readings by Huis in het Veld *et al.*, (2015); Whitlatch and Orsulic-Jeras, (2017); Hopwood *et al.*, (2018).

In the context of this study, this 'support' is delivered through the 'Instructional Dynamic' (Ball and Forzani, 2007); that is through learner interaction with course materials, tutor expertise & support, peer support and the learning environment.

I want to find out if and how the course supported learners in the care they provide for their family member living with dementia.

I also want to find out how important were the various elements of the instructional dynamic because if we are to scale up our online learning opportunities, we need to know how to design these courses so that they meaningfully support learners.

2. Data Collection Procedures

The research subjects are a subset of learners who have completed HBC-HBE in the years 2019, 2020 and 2021.

Part A – Online Questionnaire (Distributed November 2021) – pilot tested with 17 learners and refined using feedback from 5 learner interviews, plus interview with Head of Research at ASI.

Questionnaire developed and administered using Qualtrics. Link to the Online Survey sent to learners who had consented to be contacted by email. First part of the Online Questionnaire contained Consent Questions. Survey Instrument could not be accessed unless full consent provided by learners.

Part B – One to one semi- structured interviews (May 2022)

Cohorts of learners emailed and asked to respond if they were interested in being interviewed. Interested learners sent Information Sheet and Consent Form. Those learners who returned signed and dated Consent Forms were contacted and a mutually convenient interview date arranged.

Interviews carried out over Zoom. Interviews recorded and transcribed fully by the researcher.

Transcripts returned to interviewee for checking.

Sampling Strategy: Random convenience sampling strategy for Part A and Part B of the research project.

Ethics:

Researcher completed Research Integrity online course 17th April 2021

Dublin City University Research Ethics Committee Approval on 15th June 2021: Ref. DCUREC/2021/139

3. Data Collection Questions

Questions *for the researcher* to keep me on track (Level 2 Questions [Yin 2014: 90-91]):

Did learners find the course was a support to them?

How did it support them – emotionally, practically, informationally, educationally?

What is educational support? Can they describe how the course educated them in a way that supported their role as family carers?

What is informational support? Can they describe how the course provided them with useful information that supported their role as family carers?

What is emotional support? Can they describe their emotions and if or how participating on the course changed their emotional outlook, in such a way that it supported their role as family carers?

What does support feel like?

How should we organise future courses for a potentially larger audience?

Which elements of the instructional dynamic did they find supportive?

How important were the various elements of the instructional dynamic – materials, tutors, peers, environment? Is it possible to distinguish between the importance of various elements in the instructional dynamic?

How do the various elements in the instructional dynamic impact on or potentially support each other in terms of the learner experience?

How could the course be more supportive to them?

Why do some people engage with the course more than others?

What influences levels of engagement and therefore, possibly how supported learners feel?

How did they find the Moodle Workplace LMS? Was it difficult or easy to use?

Would they recommend any changes to how the course is delivered?

4. Guide for the Case Study Report

Audience**:**

Primary: EdD supervisors and examiners

Secondary: My employer, myself as a guide to future action to make the HBC-HBE course more supportive.

Tertiary: Wider educational community who may be interested in how online learning can support a vulnerable cohort of usually well-motivated learners.

Format:

EdD Thesis with following chapters: Introduction to the study; Literature Review; Methodology; Findings and Discussion; Conclusions and Implications for Future Courses.

Appendix P: Dublin City University REC Approval Letter

Ollscoil Chathair Bhaile Átha Cliath
Dublin City University

DCU

Fergus Timmons
DCU Institute of Education

Dr. Enda Donlon
School of STEM Education, Innovation & Global Studies

Dr. Peter Tiernan
School of STEM Education, Innovation & Global Studies

15th June 2021

REC Reference:	**DCUREC/2021/139**
Proposal Title:	A case study of family carers of people with dementia participating in online learning.
Applicant(s):	Fergus Timmons, Dr. Enda Donlon, Dr. Peter Tiernan

Dear Colleagues,

Thank you for your application to DCU Research Ethics Committee (REC). Further to expedited review, DCU REC are pleased to issue approval for this research proposal.

DCU REC's consideration of all ethics applications are dependent upon the information supplied by the researcher. This information is expected to be truthful and accurate. Researchers are responsible for ensuring that their research is carried out in accordance with the information provided in their ethics application.

Materials used to recruit participants should note that ethical approval for this project has been obtained from the Dublin City University Research Ethics Committee. Should substantial modifications to the research protocol be required at a later stage, a further amendment submission should be made to the REC.

Yours sincerely,

DCU
Research & Innovation

Geraldine Scanlon

Dr. Geraldine Scanlon
Chairperson
DCU Research Ethics Committee

Taighde & Nuálaíocht Tacaíocht
Ollscoil Chathair Bhaile Átha Cliath,
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Appendix Q: Part B Interviews: Research Participants Support Plan

Part B: One-to-one Interviews

If a research participant becomes upset during the interview, the researcher will take the following steps:

1. Invite the interviewee to take a moment to compose themselves.

2. Ask the interviewee if they would:

I I. like to continue with the interview, or

I II. like to reconvene at a later date, or

I III. like to withdraw from interview / research process

3. In all cases, the researcher will ask the interviewee would they like interviewer to recommend some support resources, as set out below:

Advice and support about dementia or behavioural issues involving person with dementia:
One-to-one support session with an Alzheimer Society of Ireland Dementia Adviser – Dementia Advisers work with people with dementia their families and carers to provide a highly responsive and individualized information and signposting service (more details available here)
Access to a range of Information Leaflets on particular subjects raised in the interview, or that caused distress e.g. hallucinations, wandering, behavioural issues
Offer of an appointment with The Alzheimer Society of Ireland Information and Helpline on 1800 341 341.
Support around bereavement of a family member with dementia
Offer one to one support from one of our tutors who deliver Later Stage Dementia Care-Blended Learning for Families course
Provide contact details for organisations who could offer specialist support, e.g.
Irish Hospice Foundation

ALONE

Family Carers Ireland

Support around Mental Ill health / Depression

Offer one-to-one support from one of ASI's Mental Health First Aid responders. From July 2021 ASI will have 15 Mental Health First Aiders (see here for course information).

Provide contact details of organisations who provide support around mental health:

Mental Health Ireland

Pieta House

Samaritans

4. In all cases before the end of the researcher will check again how the interviewee is feeling, and if they would like any further information / sources of support.