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Research Article

A Qualitative Study of a Family Carer Training Programme for Carers of People Living with Advanced Dementia

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Abstract

Background & Purpose: There is a limited amount of research on training programmes for family carers of people with advanced dementia. A blended learning Family Carer Training Program (FCTP) was developed in response to the self-identified needs of family carers of people in later stage dementia. Blended Learning combines online education with face-to-face learning. This research explored family carers' experiences of participating in such a programme that focused on caring for people with advanced dementia.

Methods: A qualitative design was used. Data were gathered using telephone semi-structured interviews with eight family carers and two facilitators who delivered the training.

Conclusion: Overall, both carers and facilitators had a positive view of the blended approach to the programme. The ability to access online materials and engage with others was helpful. However, carers need to have adequate computer skills to do so. In addition to an online component, carers value face-to-face contact with other carers and the facilitators.

Implications: Organisers need to be aware of the time commitment and potential burden of travelling to and from meetings. A blended care training programme for dementia caregivers in the advanced stages is effective in increasing caregiver knowledge and skills.

Keywords: Advanced dementia; Blended learning; Carers; Face-to-face; Facilitators; Family carer program; Online learning; Qualitative research

Introduction and Background

In 2017, the World Health Organisation (WHO) [1] estimated that 47 million people currently live with dementia around the world and that this number will triple by the year 2050. Currently, most individuals living with dementia are cared for by families and friends, who are essential to the care recipient's quality of life [2]. Approximately 64,000 people are living with dementia in Ireland. That number is expected increase to approximately 150,000, by 2045. The health and social care system will need to respond with more flexible and person-centred services and supports that address the needs of the growing number of people with dementia [3]. The Alzheimer Society of Ireland (ASI) has been providing educational support for family carers for over 11 years.

The ASI has been delivering face-to-face training to family carers since 2009. In 2015, following a successful funding bid to Erasmus+, The ASI started to develop an online version of the flagship course Insights into Dementia - Informing and Empowering Family Carers. The online version of the course was called Home Based Care-Home Based Education (HBC-HBE). In 2018, ASI carried out research to investigate the experiences of family carers who had completed HBC-HBE. One of the research recommendations was to develop a follow-on course that would focus on the needs of family carers who were preparing for or delivering care to family members with later stage dementia. The ASI submitted another successful funding application to Erasmus+ in 2018 for what has now become the Later Stage Dementia Care-Blended Learning for Families (LSDC) course. The course is blended in that it contains a mixture of face-to-face and online components. In the autumn of 2019 two pilot courses for LSDC were delivered in two counties in Ireland.

There is a limited amount of academic research on training programmes for family carers of people with dementia. Sousa, et al. [4] provide an integrative review outlining features of such programmes in Europe. This review found that the programmes assist nurses by increasing their awareness of the basic assumptions supporting training programmes for family members responsible for individuals with dementia living at home. Whitlatch and Orsulic-Jeras [5] suggest that effective programs help families manage the challenges they will face of persons living with dementia and their family caregivers.

In the Netherlands between 2014 and 2016, Boots et al. [6] evaluated the first blended care intervention programme for caregivers of people with early-stage dementia. This research was a single-blind randomized trial that evaluated the effectiveness of the blended care self-management program, Partner in Balance, compared to a control group. Eighty-one family caregivers of community-dwelling people with mild dementia were included. Participants were randomly assigned to either the 8-week, blended care self-management Partner in Balance programme (N=41) or a waiting-list control group (N=40) receiving usual care (low-frequent counselling). The programme was a combination of face-to-face facilitation with tailored web-based modules. The findings indicated a significant improvement in self-efficacy, mastery, and quality of life after receiving the Partner in Balance intervention, compared to a waiting-list control group receiving care as usual. According to Boots et al. [6], the Partner in Balance program can provide accessible preventative care to future generations of caregivers of people with early-stage dementia.

However, these publications do not address the unique issues involved in caring for a person with dementia in the later stages of the condition. And there is no research that addresses these topics in Ireland. Thus, an evaluation of a blended learning Family Carer Training Program (FCTP) was developed in response to the self-identified needs of family carers of people in later stage dementia. This research is unique in that it fills a significant gap in knowledge related to family carers' experiences of participating on such a programme that focused on caring for people with advanced dementia. It will be of interest to social care policy makers, dementia educators and researchers in higher and community education, those interested in blended learning models of educational provision, and family carers of people with dementia [7,8].

Aim and Objectives

The aim was to evaluate a blended learning Family Carer Training Program (FCTP) focused on carers for people living with advanced dementia.

Objectives: To

Explore carers' perceptions and experiences of participating on the FCTP;

Explore the perceptions and experiences of facilitators who delivered the FCTP;

Capture carers and facilitators, perspectives and experiences of content and the blended learning delivery method (i.e. the blend between online and face-to-face learning);

Identify barriers and facilitators to engaging with and completing the blended learning FCTP.

Research Design

A qualitative descriptive design based on the work of Sandelowski [9] was used to meet the aim and objectives. Qualitative research is focused at providing an in-depth and interpreted understanding of the social world of research participants by exploring their experiences and perspectives [10], and is particularly useful to explore areas about which there is little known [11].

Sample

A total 24 carers of people with advanced dementia completed the programme across two different sites. All carers that completed the FCTP from each site were invited to participate in telephone interviews (interview questions - Appendix 1) to capture detailed accounts of carers' experiences. Thus, purposive sampling was used to ensure that the participants had experience of the phenomenon being studied [12]. FCTP facilitators responsible for delivering the programme were interviewed by telephone (n=2) to capture their experience of delivering the programme content and identify any factors that hindered or facilitated delivery (interview questions - Appendix 2). Also, two people living with advanced dementia, whose family carers took part in the FCTP, were invited to attend a one-to-one interview. In total, eight carers and two facilitators participated. No person with advanced dementia agreed to participate in the study.

Recruitment Process

Recruitment Process of Carers and Facilitators

The FCTP ASI co-ordinator was the gatekeeper and was not a member of the research team. The co-ordinator agreed to contact carer participants and facilitators to share information about the study. A participant covering letter and participant information leaflets and consent forms were emailed to the participants by the ASI programme co-ordinator. They were asked to contact the study lead (SS) directly if they are interested in participating in the study. The ASI co-ordinator sent three email reminders to participants.

Recruitment Process of Persons Living with Advanced Dementia

The recruitment process for the two persons with advanced dementia was directly consulted and given an opportunity to voice their views. Only participants living with advanced dementia that had the capacity to consent either independently or via the legally appointed assisted decision makers were included. If an assisted decision maker had not been appointed, SS who is also a registered mental health nurse would have contacted the person with advanced dementia and talked with them face-to-face, utilising the steps outlined by the Alzheimer Society of Ireland in their position paper on Assisted Decision Making (Capacity) Act 2015 [13]. If this assessment indicated that capacity of the person to give consent was in doubt, and an assisted decision maker had not been appointed, they were not to be included in the study.

Data Collection

Data were collected by telephone semi-structured interviews, which were considered an acceptable data collection method, as the interviews were short, specific and were not too personal [14]. Also, half of the FCTP was delivered using videoconferencing meaning that participants were comfortable with remote methods such as telephone interviews. Furthermore, the anonymity associated with telephone contact helped participants to be more forthcoming with their responses [15]. The researchers also were able to slowly and coherently repeat interview questions if necessary. This strategy provided adequate time for participants to consider questions and respond [16]. Moreover, it was important for the participants to have a good research experience as they may be more open to participating in future research [16].

The interview questions (Appendix 1 and 2) were developed by the authors, who were experienced researchers/academics with interviewing expertise in the field of dementia with input from the Patient-Public Involvement (PPI) contributors. Each interview was conducted once only with carer and facilitator, and lasted approximately 35 minutes. All ten interviews were audio recorded by the researchers and transcribed verbatim by a transcriber.

Ethical Approval and Considerations

A University Research Ethics Committee granted ethical approval for this research. The participant information leaflet identified that participation was voluntary with emphasis on the right to withdraw from the study, at any stage, without providing a reason. In addition, the lead researcher (SS) included contact details on the information leaflets. A distress protocol for the person with advanced dementia was developed to ensure that their well-being and rights were protected.

The researchers adhered to the guiding principles that addressed issues such as confidentiality, privacy, equity, integrity, respect for people's rights, dignity, beneficence and non-maleficence [17]. The ethical principles of the Helsinki Declaration [18] governing research with human subjects and the Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives [19] were the ethical frameworks that guided the research.

Data Analysis

The data were analysed using 'Thematic Analysis' (TA) based on the work of Braun & Clarke [20] (Appendix 3). It is an approach for identifying, analysing, and interpreting patterns of meaning ('themes') within qualitative data, and is a step-by-step process that offers a pragmatic and detailed approach in conducting TA.

The computer software package NVivo 12 [21]. QSR International was used to assist the storage and management of the qualitative data. Two researchers (CH & SS) were involved in the initial data analysis and development of the coding framework. These researchers selected one carer interview transcript, and independently analysed and coded the transcripts within NVivo. The two researchers compared the developing themes and agreed the coding. A coding framework was then developed. Each researcher then independently coded one (the same) transcript using the adapted framework. As recommended by McHugh [22] both percentages and Cohen's 'Kappa' score, which scientifically measures the degree of agreement between coders were then used to determine the level of inter-rater reliability. The percentage of agreement was moderate (0.61-0.80) [22]. All interview data were then analysed using the coding framework. Throughout the analysis process ongoing peer debriefing and discussions took place among the data analysis team (CH & SS) to clarify any coding queries or concerns. Data saturation was reached in the research process when no new information was appearing in the data analysis [14].

Rigour

Four criteria: credibility, dependability, confirmability and transferability were used to ensure rigour for the research [23]. Credibility was sought when the participants confirmed accuracy of the interviews content directly after the interviews were finished with the researcher. Dependability and confirmability were achieved by ongoing engagement in reflectivity of the research process, which enabled a safeguarding of the participant voices. Furthermore, an evidence based analysis framework was used, so that participant experiences were represented in a transparent way. Also, SS worked with two carers who were the PPI contributors from the onset of the research. They both have experience of being a family carer for a person living with later-stage dementia.

Demographic data were collected from both cares and facilitators participants (Tables 1, 2).

Characteristics	n (%)
Gender: n (%)	
Male	
Female	8 (100)
Location of Programme: n (%)	
Cork	2 (25)
Galway	6 (75)
Age Range: n (%)	
40-49	1 (12.5)
50-59	1 (12.5)
60-69	6 (75)
Current Employment Status: n (%)	
Employed	5 (62.5)
Self-employed	1 (12.5)
Home-maker	2 (25)
Highest Level of Education Attended: n (%)	
Secondary education / post-leaving cert certification	3 (37.5)
Technical / vocational education / third level non-degree	2 (25)
Third level degree or above / professional qualification	3 (37.5)
Duration Caring for a Person with Dementia: n (%)	
2 - 4 years	1 (12.5)
5 - 7 years	6 (75)
8 - 10 years	1 (12.5)
Relationship to Person with Dementia: n (%)	
Mother	7 (87.5)
Father	1 (12.5)
Dementia Education/Training: n (%)	
Previous dementia educational course attended	8 (100)
Type of previous course attended:	
Online only	2 (25)
Face-to-face	4 (50)
Both - online / face-to-face	2 (25)

Table 1: Demographics for Participating Carers.

Characteristics	n (%)
Gender: n (%)	
Female	2 (100)
Location of Programme: n (%)	
Site 1	1 (50)
Site 2	1 (50)
Age Range: n (%)	
50-59	2 (100)
Highest Level of Education Attended: n (%)	
Third level degree or above / professional qualification	2 (100)
Duration Facilitating a Course with Carers: n (%)	
12 - 24 months	2 (100)

Table 2: Demographics for Participating Facilitators.

Three main themes were developed from the analysis. Each theme had a number of sub-themes identified to further examine the experiences and perceptions of the FCTP. (Table 3) outlines the main themes and sub-themes. Quotations are provided from participants (CA), carers and (FAC) facilitators, to illustrate some of the salient issues.

Themes	Sub-themes
Engaging Online	Computer Savvy Skills
	Benefits of Engaging Online
	Challenges to Engaging Online
Making Connections	Face-to-Face Meetings
	Finding Support
Shared Learning Experience	Sharing Experiences
	Programme Resources

Table 3: Themes and Sub-themes.

Engaging Online

The theme 'engaging online' focuses on both carers' and facilitators' perceptions of engaging with the online material, and the technical skills required to complete the programme.

Computer Savvy Skills

This sub-theme describes the perceptions of the online component of the programme. There were mixed views as some carers found the online components of the programme accessible and manageable, as they had already acquired good computer skills before embarking on the programme. Others had little experience of using computers, which was a barrier to engaging with the online elements.

For carers with experience of working online, the online component of the programme was unproblematic:

'I work from home as well … no problem with the connection … I found it [learning material] very easy to access, easy to understand as well. I suppose it doesn't require a huge amount of skill, I mean you get a user name and password most people use email nowadays anyway. There wasn't much technical about it, I mean it's just clicking on links and clicking on videos and reading through material …' CA03.

Similarly, other carer participants reported that using a laptop regularly at work, and being comfortable with technology, made it easier to engage with the material online.

'But my profession is in accountancy so I always have a tablet or a laptop going anyway' CA05.

'… I didn't find anything unsatisfying because I found I suppose I was okay using laptops or devices … I have been using technology in work as well' CA07.

Also, facilitator participants were satisfied with their input regarding the technology components. They felt they were supported, which in turn helped in supporting carers:

'I had no concerns about the technology because I knew that the support was there' FAC2.

'No, we had a few problems with people, I think one person was operating from a mobile phone … so I actually discovered at one of the face-to-face meetings that they were missing part of the screen. But I did discover … they realised I was talking about something they weren't aware of and they said it to me … I went through the screen with them …' FAC1.

Other carers had little knowledge of how computers function, including sound and camera, which posed problems with the online component of the programme:

'… I mean I didn't know how to turn on the sound. I didn't know what the package they were talking about and it happened to be on my computer … I'd never done anything like that so that was completely new to me and I reckon if I could figure it out and get through it anybody could' CA06.

'I suppose for me it wasn't clear that you had to go and get a camera for your computer, so I had to go and buy because I'm not, I hadn't done skype thing before that. So I had to go and get a camera but once we had that on maybe it's a bit weird … I wouldn't have done that kind of thing looking at other people ...' CA08**.**

Another carer described not having the technical skills to use a computer, but the excellent support received from the facilitators made it possible to manage the programme:

"… I'm not on the computer much and I suppose not computer savvy' … I mean they [facilitators] were very helpful because I had a few glitches in the beginning getting on the face-to-face and that so I mean you could just email them … they were always there for back-up … I really felt great support … doing the course… they'd get in touch with you during the week so you felt you had support. Which I thought was brilliant' CA02.

One carer also had a learning difficulty and commented that the face-to-face was the preferred option:

'… so I did put that down that it would have been nicer if we had the face-to-face first … I have dyslexia and I find it difficult to say listen I'm sorry I don't know how to do that … I think if we had done a face-to-face and because of the age group of the people, it wasn't just me that experienced the difficulties … I know it's cheaper…' CA04.

Nevertheless, for some carers, overcoming the challenges of using computers gave them a sense of accomplishment:

'… I'm not great with computers and I thought that I would get a little bit of a clue beforehand and I went to another lady that is in my support group who is very au fait with computers and she couldn't get it either. So it was only a matter of trial and error and hoping I could get it … I got there … was proud of getting that …' CA04.

'I was able to manage it and, … obviously the first session … I had to be told how to turn the voice thing on, where to find it, what the icon looked like … it was step by step. I wasn't the only one because somebody else said to me they were the same so when I was asking the questions they were listening to the answer … it was nice then for someone to say to me, yeah I'm the same' CA06.

From a facilitator's perspective, there were also some anxieties starting out delivering the programme so to prevent any technology glitches:

'I was a little apprehensive … I suppose I have a little bit of experience in that in the online stuff … I suppose for me the challenge at a personal level is just the technology of that. And there's a video support once a week and just making sure the camera is working and the Wi-Fi is working and nobody has turned it off...' FAC2.

Another facilitator commented that it is important to focus on the level of the carer when using technology, and that support is necessary in facilitating accessibility:

'I think they all [technologies] have to be available for people to avail of; some people wouldn't have any skills you know with regards to technology. Like when you are not doing it all the time you know sometimes we assume that everybody is using technology all the time like basic technology but they are not. And I know from my own experience that I loose skills, I only a few years did my masters … I would have lost technology skills that I would have had then' FAC1.

Benefits of Engaging Online

This sub-theme 'benefits of engaging online' reflected participants' positive experiences with the online component of programme such as its flexibility and reduced need for travel.

Some carers highlighted that the flexibility of the online components was a facilitator as it made it possible to continue working and still engage with the learning material.

'No, I think the nature of it being online … that you could log on and go through the theory at any time that suited you was very good. And particularly suited someone like me who is working … it did make it for someone like me yeah it was, the fact it was online made it easier for me to engage. Because I am a bit strapped for time' CA03.

'… we had to do our own kind of read-up on parts of it … give your own opinion. So you could do that any time you wanted to' CA07.

In particular, the online component made it possible for carers to work anywhere in the world and still complete the programme:

'… the reason I went for the online side of things was because I do be over in Spain some of the time' CA05.

A facilitator suggested that the online meant that travel could be reduced:

'I think like going ahead could be … getting groups like from a demographical point of view … have the face-to-face meetings so that there isn't … a lot of travel on people' FAC1.

Another facilitator reported that the online meant that carers could complete the programme due to the flexibility in delivering the content:

'… there are people especially the younger people so we had one lady like who had kids you know under five and I think she engaged very heavily online and stuff … she's well used to the online and perhaps less on the face-to-face stuff …' FAC2.

Challenges to Engaging Online

In this sub-theme 'challenges to engaging online', participants highlighted some of the barriers associated with work commitments and homework tasks during the delivery of the content.

Some carer participants expressed views about the pressure of having to get course work completed:

'I found sometimes trying to do the homework. They had these kind of questions and answers and I know it was week to week but you'd be under a bit of pressure sometimes to get them done. I found sometimes depending on what would happen one week you mightn't get to do it … you'd have a stressful week or something would go wrong or a hospital appointment with them … I found like homework questions kind of a little bit compulsory … and then you'd say oh God I haven't got that finished, I have to have that done before next week' CA01.

Similarly, another carer participant indicated that the online component was stressful and was considered a barrier to engaging with the other carers:

'… I was very nervous and when you try to say something you're cutting across other people ... it was breaking down … So I found that a bit unnerving ... kind of this is anxious talking. Like I'm not used to doing that facetime, that was my first time … by the third meeting I just kind of sat there and said nothing. Like there's always some people in a group that are more outgoing than others' CA02.

A facilitator also acknowledged that the online elements could take up a lot of time; it requires daily ongoing monitoring of comments and responding to participants:

'… I found that there was you know I put a lot of time into it. Probably more time into it than would have been like... I think it takes more time, the fact that it's online and you are responding, reading comments you know on a daily basis. And then responding to them' FACI.

Making Connections

This second main theme examines both carers and facilitators' experiences of the importance of connecting with each other whilst doing the programme.

Face-to-Face Meetings

This sub-theme describes the carer views of the face-to-face components of programme delivery. Overall, the programme facilitated opportunities to meet and to get to know carers in person and as a group in a relaxed way:

'Well when I signed up for it I was a bit apprehensive about going to the face-to-face meetings, so I actually enjoyed going to the face-to-face much more … if you asked me before the course I was thinking oh God there's three workshops, I don't know will I go to them … I actually found them [workshops] very beneficial … like we were all very kind of shy coming forward but when we're in the group it's easier to communicate ...' CA02.

'… I much prefer the face-to-face one to be honest with you … If we'd had the face-to-face first we could have met the other participants … got to know them a little bit first … sometimes you can feel on your own if you isolate yourself and that makes your mental health, everything is affected but when you've other people and socializing and engaging with other people does make a difference …' CA04.

'There's something real about the whole thing [Face-to-face] … for those that can do the face-to-face I think it's great but for those who is just not possible … the online is obviously the way to go but … I would have preferred … face-to-face ... where you can relax afterwards and get to know people' CA06.

The views described above is representative of many of the carers and these views are further reinforced below, as it was evident that the face-to-face elements added to the programme and complemented the online component by being able to discuss their "Homework":

'… you did a bit of homework on online … you could read everybody else's … having a face-to-face and then when you meet up … when you met face-to-face they would show some captions on video and we'd all discuss it' CA01.

'it's good to meet up with people … I think it was a good aspect to it rather than being completely online. It's still nice to meet up with people and it was a nice environment and there was a break and everyone had a cup of tea and biscuit and you know it makes you a lot more familiar with the people I suppose and it probably made it easier to communicate with them on the forum then because you had met them as well …' CA03.

A carer acknowledged feeling less isolated due to the face-to-face connections:

'… you could feel isolated if you don't have that ... so you see the people online beforehand and then you get to meet them face-to-face, so that was good' CA01.

Also, facilitators shared similar experiences about the face-to-face programme component:

'The most satisfying aspect was really having the time to interact and to reply to people. I also found that I got to know people better ... face-to-face kind of helps when you can talk to people on a one-to-one or you will know by their body language how comfortable they are or how comfortable they are not … you can't get that … well I can't get that sense on a video call' FAC1.

'I suppose it [face-to-face] was an opportunity to allow people to explore that and to develop an understanding of that and dementia care within end of life care and palliative care and where that journey is going nowadays. So it was bringing awareness really is what I enjoyed personally about it…' FAC2.

The same facilitators describe how the online delivery was beneficial in that the carers got to know each other better:

'Well overall I would prefer as a facilitator I really liked the blended learning because you had that mix of you know meeting people face-to-face … then there was also the mix of the online. I really felt I got to know everybody much better than if it was face-to-face only … there was one participant who said to me at a face-to-face that she had previously done an online course and loved it because it gave her the opportunity to interact' FAC1.

'People got to know each other absolutely' FAC2.

Finding Support

This sub-theme 'finding support' revealed that there were many supports found and offered which were very beneficial during the running of the programme:

'… a not to be hard on yourself. It's more like a course where you're getting a bit of counselling …, it definitely helps the carer and then because they have that support I think they can manage better with their loved one … 'And then also it's very good for people who are kind of isolated, they think they're on their own. It's very good, like that man, I think it was a life support for him, I really do … we'd have a cup of tea and all afterwards and it was great' CA01.

The same carer also reproted the satisfaction felt while attending the face-to-face meetings, and described how the overall programme was such a beneficial thing to do for self:

'But that was okay because it was kind of like a break for me, I got a break away for a night, it was like a little bit of a treat. I would definitely recommend it because I was at a stage a few years ago I got the shingles from the stress of it, right, and I was giving, I was giving up caring for her, I was saying I'm not doing this anymore and then someone said to me you really should do a course in that because if you learn more about it you'll understand it' CA01.

Carers appreciated the social aspect of participating on the training programme:

'… we organized to have a cup of tea halfway through and that was really important because I'll tell you, and my life is so busy, I go to my parents and then I come home every evening and bringing somebody to football training, I don't have time for a cup of tea sometimes and it's so lovely to have a cup of tea and somebody else to give it to you …It's such a small little thing because of your busy schedule and everything … I'm only talking about people's experiences, it's absolutely fantastic' CA04.

'… just more or less reaffirming … it kind of gave me a bit of confidence that … what I was doing was right. And that's my biggest mistake because I need to do that, I need to keep in touch with people' CA02.

'I made a special effort to go to the face-to-face one because I like to attend those … it was good to meet up with people face-to-face …'I think it was a good aspect to it rather than being completely online. It's still nice to meet up with people and it was a nice environment and there was a break and everyone had a cup of tea and biscuit … it makes you a lot more familiar with the people I suppose and it probably made it easier to communicate with them on the forum then because you had met them as well' CA03.

Also, carers felt supported by engaging with the group chats online:

'we also set up a WhatsApp group and we're in contact on a regular basis and support each other. But I do really think … it's important … sometimes you can feel on your own if you isolate yourself and that makes your mental health, everything is affected but when you've with other people and socializing and engaging with other people does make a difference …' CA04.

While, a facilitator shared similar comments about the supportive nature of the programme:

'…they [carers] seemed to engage, certainly the online stuff was quite actionable and people were very supportive on that … and then on the face-to-face people helped each other, people support … it's very warm and lots of tea and coffee … I actually thought it worked very well' FAC2.

The same facilitator indicated that the online and face-to-face blend worked really well in terms of supporting the carer participants:

'I mean I would think its complementary [online and face-to-face] of each other … actually there's a supportive video one hour a week but that's actually optional … and people were not just invited to come but suggested that they would come and of course then part of it if they could … it was the way to go to be honest, I think sometimes the online can be, you can miss people you know people don't engage whereas the other one [face-to-face] was actually more supportive and in dementia care that's important … I would advocate that it [online and face-to-face] is a better way in my limited experience' FAC2.

Also, the same facilitator advocates that organisations need to support families with information and knowledge when their loved ones have to move into long term care:

'But for people at the end of their lives … the real situation or the reality for them is that they have to make the decision to actually perhaps push for the want of a better word their transition into long term care for people … that's the journey for most people with dementia and people find that hard to do and for us to include in ethical shared decision framework within the course was really significant for me personally and to support people along that journey. So yes … there's loads there and there's loads of information and knowledge that needs to be given out there and ASI [Alzheimer Society of Ireland] need to embrace that as a role' FAC2.

A carer conveyed the grim reality that family members face when they are unable to care for the person with dementia living at home:

'… it just got to the stage where she went downhill very fast all of a sudden … so sad wasn't able to manage things at home and we weren't there fulltime, none of us could be there fulltime with work and kids and whatever …' CA05.

Another carer describes that support from others is valued: 'You do need help from people' CA08.

Furthermore, a carer participant really benefitted from the support by the facilitators delivering the content:

'… they did more beyond they needed to do. I thought they were very good, I felt that you get enough from the course, and they're always there, there's always a phone number there if you want to ring back on anything" CA01.

Sharing Learning Experiences

This third main theme 'sharing learning experiences' focuses on the perceived carers' experiences of the value and benefit of sharing knowledge and ideas during the programme.

Sharing Experiences

This sub-theme 'sharing experiences' explores how the programme facilitated sharing personal experiences such as exchanging tips for caregiving and knowledge development. This is demonstrated in the following viewpoints:

'… we got more tips from other people about there was some occupational therapists and we watched some videos and we went through some videos … I put that into practice with my mum now, I find she's in a much better humour with music … it was because I wouldn't have known about that otherwise' CA03.

'It was very good … well you got to meet other people, talk to them and their experiences … of dementia … it was good to be able to meet up with people' CA07.

This carer expressed a similar view:

'We spoke about the knowledge, the background in dementia and how it progresses. And just the tips around I suppose communicating with someone who has dementia and you know things that are helpful for them especially towards the later stages that they can still listen to music … they are the main learnings from it' CA05.

Carers also commented on the value of talking to people with similar experiences and describes how the programme facilitated gaining and sharing information about many topics such as practical tips:

'… it [programme] make you feel maybe you weren't in the only boat … it was a great course to have and you know have people to talk to. I think that's half the battle with carers that they do not have someone to talk to … there's other people … so everyone kind of helped each other that way … get some insights from them because everyone has different experiences and different ways of coping mechanism and things that work … it was a great course to have and … have people to talk too' CA05.

'It's both sharing experiences because I got the tips online where we all meet up and talk … having a little chat and then if someone had a problem the following week they might ask us, they'd say how did you get on with that, did you try this, did you try that …' CA01.

'I made a special effort to go to the face-to-face one because I like to attend those … it was good to meet up with people face-to-face I suppose that's even more engagement and tips … I got some information on the fair deal form and you know if I needed to fill that out at any stage as well it was helpful to hear from someone who had gone through that process as well' CA03.

Another carer's view, however, was how the programme benefitted them in gaining psychological support and the importance of learning to be more empathic towards their loved one:

'Well it's not so much IT skills, stuff like that, I think you learn more emotional, emotional skills. Like I now would be … a bit more empathic, which in the past I didn't even know what empathy was, now that's the truth' CA01.

A carer also stated that they benefited from knowing more about dementia, however, was more aware of the true reality of caring for someone with the disease, and is aware that there is no way back:

'I suppose sometimes you don't realise with someone that has Alzheimer's that it is, it is a palliative care situation that you are doing all the time. Someone isn't going to get any better … its worse they are going to get. It is the reality and I think that's what people need to hear sometimes. That that's what we are dealing with … all in all now it was I suppose I'm delighted that I done it, because it does prepare you for, for the palliative care part of it … because we are all frightened when we hear that word … it's very frightening for the family' CA08.

Similarly, a carer established that the programme helped to reconnect with the person with dementia, and thus got to know the person much better. This carer, therefore, welcomed this component of the programme.

'… what I found about the course is I was so wrapped up in minding my mother-in-law and … has she enough to eat and what's in the fridge and what did she eat and did she eat that and all of a sudden … it kind of came back to me well you're minding the person but what about the person … herself, interact with her more, talk to her kind of thing. Whereas I'd just go down and I'd check the fridge and I'd do the shopping and I'd change the sheets and I wasn't spending time, because I'd lost my best friend … I was kind of looking at her more as a patient rather than a person. So that really hit … reconnect with her… I kind of realized … I'm getting so wrapped up in the minding … I'm losing touch with her. So I have to kind of get to know the person she is now' CA02.

Throughout the interviews carers valued information in relation to the necessity of carers having a voice. Some expressed concern about inadequate financial and emotional support received from the state:

'I think the main thing that I learned from it is there has to be a change and there has to be a voice from the carers and the government has to listen to the people on the ground who are involved in the care of people that have dementia. If they don't, if things are going to be the same then there's an awful lot of carers out there who aren't receiving any state help at all, … financially I mean … if you haven't been working prior to taking care of somebody you're means tested to see if you get an allowance. Now my sister doesn't get a penny … she wasn't even eligible because she had savings and she had worked hard to save up all the years. It's the emotional support as well I think' CA04.

Programme Resources

This sub-theme 'programme resources' refer to many positive comments of the materials and resources given over the course of the programme. Participants voiced the need for the useful resources and commented on the variety of material delivered:

'… I found it good. It gave you options to read up items and links to other sites that you could look up. And it gave me a different look at things … to kind of step back a little bit from it and be, just not to get stressed out with it … it definitely helps the course…' CA01.

'And gave you the opportunity to be able to share information ... definitely … 100% because I have all that back-up now and I have it, … printed out so I can go back and refer to things … every time I go back I think oh gosh I'd forgotten that … just more or less reaffirming … it kind of gave me a bit of confidence … what I was doing was right' CA02.

Two carers established that they found the video delivery methods beneficial because…:

'They used to show sometimes video captions of different scenarios … when you met face-to-face they would show some captions on video and we'd all discuss it … I think more visual, more visual than reading … reading with questions and answers' CA01.

'… there was two or three workshops but we did kind of video links every week. No, it was very interesting now I have to say. And as I said all the online stuff, or all the video links were helpful …' CA05.

Some cares also identified that they received useful information to help cope better with family situations:

'it [the programme] has allowed me now to be able to say to the rest of the family, I've a brother now and he would have been her male carer you know it's okay not to come in, he doesn't want to come in to see his mammy like that. And you know that's okay … I give him the report every day and you know she's not eating and you know that this[death] is going to happen … it will be just a couple of days now. And not to be denying the fact … that you have to be straight with people now and that it's not going to be six months or whatever its only going to be a matter of days …' CA08.

'The main thing that I learned is, a new thing that I hadn't realized is the carer support and the situation … if they've early onset dementia, that you don't get the support but you do if they have the medical card. And I think that needs to be changed. Because for people who are looking after a loved one their income gets cut so … It's terrible that if you've to quit work to look after them and they're not earning either then how are you supposed to survive like if you've to go to the doctor or anything and like it's fifty or sixty quid [euro]. So for me that was a really big learning curve because I hadn't realised that' CA04.

Furthermore, some carers spoke about the usefulness of having access to the learning material after completion of the programme:

'I have all that back-up now and I have it, … printed out so I can go back and refer to things and … every time I go back I think oh gosh I'd forgotten that… you can read over it again and again just if you forget it' CA02.

Some carers also described that the programme was just right in terms of its length, and identified that it was possible to complete the programme within the identified time frame:

'… I think the length of the course is perfect. I don't think you need any longer … you can do with the time they give you' CA01.

'… was manageable enough in terms of time' CA03.

Carers offered other comments that the online resources were useful and accessible and that they were valuable support from the facilitators delivering the content:

'I found the tutors very good in their, that they were always listening and even if all the information wasn't given out straightaway there was a link to it and if it wasn't, if the link wasn't there it was put up during the week in the column. So that's where I felt they were very good at listening to everybody in the group so that if there was additional information that somebody was looking for it was put up at the side or a link sent to us or whatever. So I felt that was very good, that I got the information I was looking for …' CA06.

'… all the video links were helpful … he [facilitator] was always there and [facilitator] was there if anything needed to get more information on the Alzheimer's if you weren't getting all the information you wanted and you didn't want to bring it up at a video conference you could, she was there to contact privately as well by email' CA05.

Similarly, a facilitator reported that the programme ran smoothly and that the carers engaged well:

'My input was less in relation to the technicalities and the running of it … but no it worked very well. I wouldn't have any difficulty at all with that, it worked fine' FAC2.

Discussion

This qualitative study reports on the first Irish study evaluating a blended learning Family Carer Training Program (FCTP) that focused on carers for people living with advanced dementia. Our findings propose that the willingness and ability of the carers partaking in the programme meant that they found enjoyment and that learning was beneficial.

In this study, most of the carer participants were satisfied engaging with the on-line elements and partaking in the discussions. However, a few participants found the on-line components stressful, as they had not used a computer prior to commencing the programme. Many carers enjoyed the face-to-face components, as this helped with connectively and sharing of experiences. Particularly, carers reported that they got support from each other, especially from the facilitators who freely offered guidance and assistance when necessary. This is similar to findings by Boots et al. [6] who identified that carers developed a good relationship with their coaches. Also, an earlier qualitative study exploring the needs of informal caregivers of people in the early stages of dementia found that the facilitators helped with increasing caregiver confidence by being positive with their encounters [24]. This underlines the importance of approachable facilitators to ease caregivers concerns when partaking on a blended learning programme.

The current study also revealed that many participants made valuable connections, especially during the coming together of the face-to-face elements of the programme. They found opportunities to talk and get to know each other, and valued each other's company while learning. Thus, the social aspect of the programme was important for the carers. In addition, the 'WhatsApp' group that was set up by the carers was useful in that they could connect with each other on a regular basis about issues relating to the programme.

The facilitators had positive views on how the group engaged with the programme overall, and reported that both modes of delivery were achievable for the carers as they were supported well. Carers also reported great benefit from sharing personal experiences and exchanging knowledge and carers gained dementia-specific knowledge and skills and learnt how to be more empathic with the person with dementia. In addition, participants highlighted that the online resources were useful and accessible and that they received great support from the facilitators delivering the content. Carers offered other comments that they were able to share and exchange information about the dementia disease, and got practical tips from each other to care for their loved one. These findings reflect what has been found elsewhere; studies have indicated that disease-specific knowledge and relationship changes can improve caregiver confidence [25,26].

Conclusion

Overall, both carers and facilitators positively evaluated the blended approach to programme delivery. The ability to access online materials and engage with others was helpful but carers need to have adequate computer skills to do so. In addition to an online component, carers valued the face-to-face contact with other carers and the facilitators. However, the organisers of such programmes need to be cognisant of time commitment and potential burden of travelling to and from meetings. Overall, this study indicates that a blended care training programme for dementia caregivers in the advanced stages is effective in increasing caregiver knowledge and skills.

Strengths and Limitations

To our knowledge, this is the first type of study to be carried out to evaluate a blended learning family carer training program (FCTP) focused on carers for people living with advanced dementia. The findings from this study can inform future programme development.

This research is limited by a small sample size. However, through rigorous analysis it represents the views of participants in a transparent way. Although approached, no person living with advanced dementia participated in the study.

Recommendations

For future blended learning programme development, organisers/stakeholders need to consider the barriers and facilitators identified in the delivery of such programme, for example, a practice session or specific guidance for facilitators prior to commencing programmes. There also needs to be larger, multi-centre evaluations of such programmes to confirm these initial findings. Longitudinal research is needed to learn more about the impact of such programmes over time and how they influence the experience of caring for a person living with advanced dementia. Furthermore, to understand more fully how this type of programme, the perspectives and experiences of those living with advanced dementia needs to be captured in a meaningful way.

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Conflict of Interest

The authors declare that there is no conflict of interest.

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