

The expectations and experiences of Dementia Caregivers engaged with Empowered Carers in Bolton

2022

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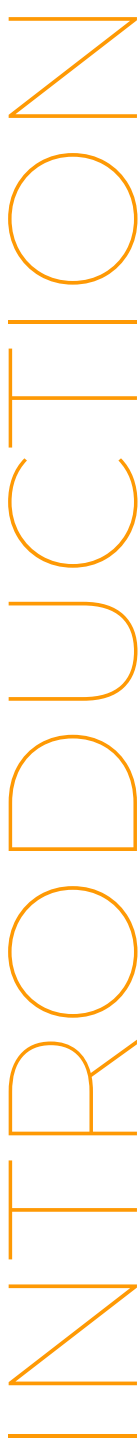
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Summary

What are the expectations and experiences of Dementia carers who have engaged with Empowered Carers in Bolton?



The National Dementia Strategy for England identifies family carers as, “the most valuable resource for people with dementia,” with 600,000 family carers providing an estimated £8 billion per year of unpaid dementia care in the United Kingdom alone. Carers are a vital determinant of positive outcomes for people living with dementia (Housing, L. I. N. 2009)

Carers or supporters of people living with dementia have increased stress, anxiety and depression than noncarers. Depression occurs in one in three of caregivers, it occurs more frequently in those who care for people living with dementia than in caregivers of people with other chronic illnesses. Changing of roles within the relationship, a continuous mourning process and the uncontrollable nature of the illness can render caring for a person with dementia to be a unique experience (Schoenmakers, Buntinx & Delepeleire, 2010).

Given that family carers of people living with dementia are such an important resource, it is important to ensure that their own quality of life (QOL) is satisfactory. The term, Quality of life is defined by the World Health Organization as the evaluation by an individual of their position in life, assessed in the context of one's culture, values, goals, expectations, standards, and concerns (World Health Organization, 2023). Factors influencing QOL include the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and environmental support. (Farina et al., 2017).

The present study aimed to gain insight into the expectations and experiences of Empowered Carers from the perspective of Dementia caregivers living in Bolton. Three participants took part in individual interviews that were conducted online using zoom software. Each participant was asked the same four questions as illustrated below.

Question 1: What were your hopes and expectations of working with Empowered Carers in one to one session's?

Question 2: Can you tell me about any changes for you from having Empowered Carers one to one sessions. Have things changed in anyway in the approach to the way you care? Or any changes in the way you communicate with the person you care for?

Question 3: Have you noticed any changes in your relationship between you and the person you care for since working with Empowered Carers?

Question 4: What has been your experience of using technology such as zoom for your one to ones?

The interviewer asked the four questions only and did not respond in any other way to ensure no bias was given in the answers from participants. The interviews duration ranged between 7 and 14 minutes.

Participants

All the following participants have been given alternative names in order to protect their personal identity.

Participant 1: Lisa

Lisa supports her dad who has Alzheimer's (A-typical variant) and also her mum who has been diagnosed with Mild Cognitive Impairment (MCI). Lisa has been a carer for both parents now for over eighteen months. Lisa is married with young children and works full time. Lisa lives nearby to her parents and has been working with Empowered since March 2022. Lisa came to Empowered as she initially struggled to process the diagnosis of her father's Dementia and found herself stranded looking for support.

Participant 2: Eesha

Eesha is supporting her mum who lives with her at their family home. Eesha has been supporting her mum now for over 6 years. Eesha's mum has mixed Vascular Dementia. Eesha has a large family unit however finds herself to be the main carer for mum as most of her family live at a distance. Eesha has worked with Empowered from April 2022. Eesha came to Empowered as she found herself close to crisis point, unable to cope with her caring role and being diagnosed with major depressive disorder.

Participant 3: Rita

Rita has been supporting her mum for over four years at their family home. Rita's mum lives with Lewy-Body Dementia. Rita works part time as well as being her mum's primary carer. Rita has worked with Empowered since July 2022. Rita came to Empowered wanting to gain further insight and knowledge around her mums' Dementia. Rita also felt that she was struggling to know what is best for her own wellbeing as well as her mum's emotional needs.

A Thematic Analysis was conducted, and transcriptions taken from the video interviews. From the analysis three main themes were developed and three sub-themes were also recognised. These themes may give further depth to what Dementia carers in Bolton are saying about their personal experiences engaging with Empowered Carers.

Sub Theme 1: Expectations from a carer of what they initially desire from external support.

This sub theme identifies the individual carers initial hopes and expectations before starting to work with Empowered Carers. The extracts below are from each participant and highlight what at the time they felt they wanted from Empowered Carers. The participants talk about the importance of somebody to voice their thoughts to. Having a safe, non-judgemental environment to do this in is also important. Gaining useful information and deeper understanding of Dementia is also discussed.

Lisa:

“more understanding, to make sure that I’ve done all the things that I can do to support my parents.

Because obviously since both my parents have been diagnosed with memory problems, there’s so much information to take in, all the things you need to do. But because obviously you’re taking in so much yourself, there’s the shock of the diagnosis and you know it’s all very overwhelming.”

Eesha:

"I think being able to talk to somebody would be a hope. Because you can talk to family and friends but it's not the same, sometimes you feel there's things that you can't tell family and friends. You feel like they would be offended or not understand the way you're saying it. So having somebody else ... not knowing anything about your family, would make a big difference.

I think sometimes you just need someone to listen to you and just to...you know get advice from them. I think more than anything just having someone else to listen.

sometimes when you just talk about it, I think that helps in yourself, that takes away a bit of the stress."

RITA:

"I THINK WHAT I WAS HOPING FOR WAS TO BE ABLE TO HAVE A CONVERSATION AND GET SOME SUPPORT WITHOUT BEING JUDGED.

IT'S VERY DIFFICULT BEING A CARER, BECAUSE YOU DON'T REALLY KNOW WHAT YOU'RE DOING, YOU DON'T REALLY KNOW WHETHER YOU'RE DOING THE RIGHT THING. IT CAN BE QUITE TERRIFYING IN SOME RESPECTS BECAUSE YOU JUST HAVEN'T GOT A CLUE."

Sub Theme 2: Challenging experiences and emotions that may lead to Dementia carers in Bolton seeking external support with Empowered Carers.

This sub theme highlights some of the factors that may have contributed to the participants seeking external support with Empowered Carers. Within the extracts below the participants talk about their daily stresses and emotional turmoil that develops whilst supporting a loved one with Dementia. Changes within family roles, not being able to cope, depression and loss of independence are also discussed.

Lisa:

“So obviously I’ve lost the people I confide in, and I’ve lost the security blanket that I had growing up and now I’ve become their security. So that’s quite an unnerving feeling because your parents have always usually been there for you.

I’m angry you know because they’ve got this disease. I’m angry because of the change in them, I’m angry because my life is changing.

There is so many emotions going on and the last thing you want to do is take those emotions out on the people that you love.”

Eesha:

“Being there for mum 24/7 day in, day out. Night and day as well because mum does wake up in the middle of the night. Having to deal with that every day and the dementia is getting worse. It was just too much for me I couldn’t cope. I was getting really stressed out, I was getting angry.

I was getting worked up in myself as well, so much to the point that I told the doctor and they actually suggested that I started taking depression tablets.”

Rita:

“prior to becoming a carer for my mum. I was very independent very self ...what’s the word self-sufficient. I was always one of those people who is like I can do it myself.

What I found in the past, is that if I ask for help and somebody turned me down I’d take it quite personally because it’s a big thing for me to ask for help and it takes a lot of courage in some respects.”

Sub theme 3: Positive response to online support for a carer supporting a person living with Dementia

This sub theme demonstrates a majority positive response to Empowered Carers one to one support being available online. In the extracts below the participants discuss traveling, getting support to look after their loved one with Dementia, childcare and working as barriers that have been removed by having online support. This theme may suggest that online support may give a Dementia carer access to valuable support that they may have not been able to engage with pre online availability.

Lisa:

“I love it because I’ve been able to join the evening sessions after my daughter had gone to bed. It would have been a nightmare trying to get somewhere. So obviously that’s been really convenient the fact that you can be in your own home.”

“So, It’s been really easier and much more beneficial. It’s just the easiness I suppose, it’s nice to be at home and have a break and get a brew and stuff.

Today I’m at work and again it’s easier to do in between work, so yes, it’s more convenient definitely.”

Eesha:

“It's been really convenient for me; it's been really good because I have a study room upstairs.

I'm away from my mum, I'm away from the noise, I've got a carer who's with my mum whilst I'm here.

So doing it online is very convenient for me because I know that for that hour I can literally be here for the hour.

If my mum does need me, I'm there straight away I don't have to go anywhere as such.

So yeah, I definitely find it convenient, a lot easier and I find it comfortable like this as well, yeah so I prefer zoom.”

Rita:

“Well, it's not been a major hurdle for me. It's actually more convenient because it means I don't have 20 minutes in the car trying to get to somewhere, then having a session and then 20 minutes home.

Having to put some form of care in place for mum while I'm not in the house would be difficult,

So yeah, it's just kind of the norm it's not been anything that I've found challenging, it's just the way things are cos I would use it in my day to day work life anyway so yeah, it's convenient.”

Main Themes

The sub themes indicated the general feelings that came from participants around expectations from receiving support. The sub themes also shed light on what other factors may have also motivated the participants to seek support with Empowered Carers. The participants experience of receiving support online is also presented within the sub themes.

There are three main themes that have been established within the present Thematic Analysis. These themes may reveal the actual experiences and outcomes for Lisa, Eesha and Rita that may have occurred through engaging with Empowered Carers

Theme 1: A development of Mentalization skills enabling improved approaches to difficult circumstances/An awareness of the impact of carer behaviour on the person living with Dementia.

This theme relates to changes in the way the participants now process their actions in difficult circumstances. The theme also highlights changes in how the carers think about the impact of their own behaviour on the person they support. These changes may have occurred due to the participants development of Mentalization skills over the duration of Empowered Carers sessions.

The concept of Mentalization can be defined as, 'the imaginative mental activity that enables us to perceive and interpret human behaviour in terms of intentional mental states.' (Fonagy & Luyten, 2009, p. 1357). In other words, to be able to Mentalize is having the ability to genuinely empathise and be fully engaged with an individual's emotional state. A state of Mentalization may also provide a launch pad for an individual to process their own thoughts and anxieties more effectively, encouraging an emotional growth mindset.

In the extracts below Lisa, Eesha and Rita discuss how they now think about the person they care for and how they now view their situations differently after working with Empowered Carers.

Lisa:

“It’s the understanding of why they might do certain things and sometimes there totally out of character, there really bizarre.

Before I was probably confused and my dad’s reacting to my facial expressions. Now it doesn’t matter if he shouts, if he raises his arms or if he stamps his feet like my 4 year old.

My dad’s also a lot more verbal and louder than he was eighteen months ago. I don’t react to those as much.

I understand that people may be watching me, and some people understand, and some others may judge. But that doesn’t matter what’s most important is that my dad is made to feel comfortable, and it doesn’t matter how he reacts and how he shouts, because he is only trying his best to communicate his feelings

So that’s sort of made me understand, actually he’s not doing this on purpose he’s not behaving like this to get his own way. He’s doing this because he’s trying to express himself and it’s just coming out in this way.”

Eesha:

“I definitely think that it’s been helping me to have a better understanding of how I can help me as well as me mum.

if I do get stressed out, if I get upset, my mum does know.

I've definitely seen a change, before I started, I was stressing myself out. I could feel myself getting angry easily and losing my temper quite quickly.

I know that this did affect my mum, she would feel like, "oh I don't want to say to Eesha that I need the loo, or I want to eat". She felt more anxious maybe to tell me that she wanted to do something.

Now she can see that I'm not as stressed out as I was at the beginning. I know that if I feel good and if I'm happy, if I'm dealing with things in a more calmer way, then I can literally pass that on to my mum as well. So yeah, I can definitely see a difference there."

Rita:

"I think acknowledging that sometimes I need to back away from a situation has come about partly from the conversations we've had. So yeah I suppose in that sense that there have been some subtle shifts in the way I do things.

I do feel like I get the support that's valued and valid and not judgmental.

I feel like I'm in a safe space, I feel that you know when we talk about stuff, like the conversations we've been having this morning, I can be honest.

I can say actually I wasn't my best self in that situation, I was difficult, and I made the situation worse. How can I do things different.

You listening, not judging and then sometimes offering an alternative way of doing something is really quite helpful."

Theme 2: Individual changes occurring for the carer/Changes in the perception of their caring role and increased attention to self-reflection.

This theme demonstrates that the participants have been engaging in self-reflection. The apparent increase in self-reflection appears to have given the participants some positive shifts in perception around their caring role. Within the extracts below Lisa, Eesha and Rita discuss personal changes they feel have occurred for them from working with Empowered Carers.

Lisa:

“All those and tips, Ideas and support, it’s just been phenomenal. the support that’s there for you has helped me make changes.

I’ve really benefited from that, I’ve been able to reflect on it and share that with my family and friends and also with other people that I know that have family members diagnosed.

So, I feel erm really you know, in a lot better place than I was eighteen months, two years ago”

I always felt really angry when they first got diagnosed. I think that's me struggling with my feelings.

Sometimes if things got hard, I'd get a bit shouty. I wouldn't mean to shout but it's just the stress and the anger, all the hurt and the upset that comes out. I feel like that's more or less gone now.”

Eesha:

"So, I thought yeah, it's something I need to do to help me out as well. Because as people always say to me, If your well in every way then you can look after the person you're looking after.

So I need to be well, not just physically in health but mentally in my own health as well In order to be there for my mum.

So that in itself I think has been really good for me. Because I've been a lot calmer, I'm having a better understanding of how to deal with my mums need as well.

So in that respect I think that's changed I'm a lot calmer, It's made me understand a lot more and I able to put that forward with when I'm dealing with my mum now"

Rita:

I think acknowledging the fact that I actually needed support was a big one.so that's a big change.

So that was a thing and now I am not embarrassed by the fact that I have these conversations or I'm getting some additional external support.

I don't feel embarrassed by it at all, I don't feel ashamed for want of a better word because I'm not as self-sufficient and as independent as I previously thought I was in the past.

So I think from a personal standpoint just that admission that I do need help and also the fact that I will now ask for it and not feel that I'm going be let down or feel upset now it doesn't feel like that anymore. In terms of my own personal behaviour that's a big shift."

Theme 3: Development and adaptation of communication skills/An acceptance of changes within the relationship related to Dementia.

This theme connects with how the participants have experienced new ways of adapting the way they communicate. There is also an element of further acceptance of their present circumstances. Within the extracts below Lisa, Eesha and Rita talk about some of the subtle, yet powerful, differences they have integrated into communication with the people they support.

Lisa:

“Things are different now, I tend to touch his arm for reassurance. We use some nonverbal now, he’ll give me the wink which you know that wink has meant so much in so many different situations. It might be, getting in the car, we’ve just done the shopping, everybody’s in the car everybody’s buckled up and my dad gives me the wink as if to say we’ve got it, we’ve done it we’re on our way home now. Erm and it’s just those little signs.”

It’s hard for him to speak but it doesn’t stop me from finding other ways to communicate and it doesn’t stop me staying over and having that quality of time.”

Eesha:

“I know things have changed now and that’s fine, we just do things differently.

She’s definitely a lot chirpier as well and if she gets upset now, I’ll just give her a hug and she’ll be fine.

I do feel that, you know she’s having a lot more of a laugh with me now as well, so I do feel that it’s definitely given us a bit more of a stronger bond.”

Rita:

“I think in terms of the communication, just getting different perspectives and insight really.

Because as I said a minute ago you don't really know what you're doing, your just winging it from day to day

so just having that reassurance that actually it's ok to try things differently and that you're not always going to get it right.

So don't kind of overthink it, don't stress yourself out you're doing the best that you can, just keep trying different ways to communicate that's, really helpful.”

Summary

In Summary, there are numerous reasons why a Carer who supports a person living with Dementia may seek support from Empowered Carers. The main driving forces for the three participants who engaged in this research can be seen in **Sub Theme 2**; feeling isolated or abandoned, losing the ability to cope, not knowing what to do best for the person they care for, reaching a crisis point and the onset of potential mental health conditions such as anxiety and depression. Reaching out for external support may not be an easy task for some carers and can cause emotional and moral turmoil for the individual as highlighted in **Sub Theme 2**. It appears that initial engagement with Empowered Carers should be a positive one to support future therapeutic trust. In this scenario therapeutic trust appears to have occurred between the three participants and Empowered Carers facilitators over the duration of their support.

When committing to support with Empowered Carers, the three participants had expectations of what they might be looking to gain from the sessions which is evidenced in **Sub Theme 1**; a therapeutic safe space, non-judgemental environment, to gain knowledge and further understanding of Dementia, someone impartial, not family or friends, to listen to them and give general support with their overall wellbeing.

The participants also found online support invaluable as illustrated in **Sub Theme 3**. Convenience and simplicity were some of the main factors enabling a positive experience for the three carers. Due to the nature of Dementia, in order for a carer to leave the house many contingencies have to be considered. There is a strong possibility that if Empowered Carers support did not have an online option, many Dementia carers would go unnoticed and become isolated, unable to participate with external support.

Whilst working with Empowered Carers, the three people within this study appear to have evoked changes within themselves and also in the way they approach their caring role. As evidenced in **Main Theme 1 and 2**, the participants appear to be able to mentalize further in regard to their lived experience and the lived experience of the person they care for. They appear to be looking at their situation in a different more constructive way. Increased response based empathy and a better understanding of how they may feel and how the person they support may feel. This openness to a deeper thought processes appears to enable the participants to be more creative, thoughtful and understanding when it comes to behavioural challenges and overall problem solving. The increased mentalization may also allow the carers to look more introspectively at their own emotional needs and what may be causing them difficulties. All three of the participants have come to conclusions regarding previous challenging issues. They appear to have come to a realisation regarding their own previous behaviours and may have gained further increases within emotional intelligence from confronting these past dogma's.

The way the three participants previously viewed and applied communication with the person they support appears to have changed as evidenced in **Theme 3**. The carers appear to be in a mindset now where they are curious regarding day to day challenges opposed to being overwhelmed or distressed. There is a definitive acknowledgement that communication can be done differently and creatively with a strong sense that things are different now then they used to be. There is a sense of acceptance of these changes and a willingness to apply alternative ways to communicate from the carers.

Overall, this study gives insight into how Empowered Carers can provide an individual with a fighting chance to support the person they care for at home for as long as possible. Not only this but to also enable the person to gain confidence in what they do, avoid mental health crisis and encourage a more fulfilled and connected relationship between carer and the person they love.

Next Steps:

Further Qualitative Study to be conducted with spousal and other caring dynamics.

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CONTACT

Rachel Yates Hoyles - Empowered Carers
Project Manager

rachelyateshoyles@ageuksalford.org.uk

www.empowered-conversations.co.uk