



empowered
carers

Empowered Carers in Bolton

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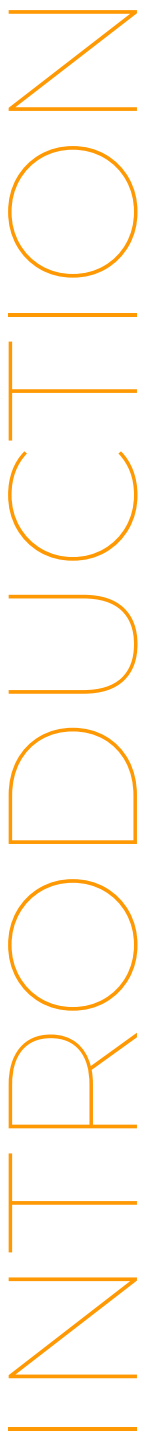
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An interim report on the impact of the ‘Empowered Carers’ intervention for carergivers of people living with Dementia in Bolton.



- On a global scale, there are currently around 50 million people living with dementia and almost close to 10 million new cases every year (World Health Organization, 2020). Dementia is the umbrella term for many forms of the disease, there are over 100 types of Dementia. Alzheimer’s, Vascular, frontotemporal and Lewy bodies are some of the most well-known types of Dementia.
- Dementia can be viewed as a communication disease (Wray, A, 2021) with a collection of symptoms that include memory loss, mood changes and difficulties with communication, personality and reasoning.
- Past research has shown that family members are generally the initial care givers and can continue to do so for the life of the person living with dementia or until sufficient care at home cannot be provided. Becoming a caregiver to a person that is living with dementia can be physically and psychologically demanding (Mahoney, Regan, Katona & Livingston, 2005).
- Carers in comparison to non-carers also tend to suffer from poorer physical health, higher levels of rumination and perceived lower satisfaction with life in self reports (Goren et al., 2016).
- With an increasing aging population, developing care strategies for people living with dementia and their carers will be important. Interventions developed that increase awareness and knowledge of dementia, may help reduce barriers and stigmatization within diagnosis and care (World Health Organization, 2020).

KEY D U S E I F

This report presents interim findings from a service analysis study of the Empowered Carers intervention in Bolton. Empowered Carers is a project of Age UK Salford, the Empowered team specialise in support for caregivers of people living with Dementia through The Empowered Conversations Approach. The Approach includes specialised Dementia communication courses, a monthly bereavement group, a Carers voice group and regular webinars. Empowered services are facilitated online or via telephone.

The study was conducted with 10 participants currently receiving one-one support from Empowered Carers in Bolton. The delivery of this one-one support has been developed from the evidence based research of the New York University Caregiver Intervention (NYUCI) (Gaugler et al. 2004).

The NYUCI has a strong evidence base and consists of six sessions of individual and family counselling within 4 months of enrolment, it is tailored to meet the needs of both the primary caregiver and family. The NYUCI intervention benefits the caregiver's mental and physical health and has been found to delay transitions into external care facilities by up to 557 days. Caregivers have reported increased support from members of their networks and increased satisfaction with that support.

"there's the shock of the diagnosis and you know it its very overwhelming so with the support from Empowered, I've been able to learn and understand more about Dementia."

Empowered Carers provides a safe space to pause and reflect, offering Caregivers emotional and practical support throughout the many different stages of uncertainty within their caring role. The Empowered team encourages curiosity for Caregivers to understand themselves and others, which can enable people to improve connections, relationships and self-care.

The Measures

This study aims to compare the subjective burden and self-perceived wellbeing of carers, before and after receiving six sessions from Empowered Carers. The participants consisted of ten carers who are supporting people living with Dementia at home in Bolton. Each participant completed two valid clinical measures, the Zarit Burden scale (ZBI-12 - as used in the NYUCI) and the Short Warwick Edinburgh Mental Well-Being Scale (SWEMWBS). The Zarit Burden scale measures a person's subjective sense of burden. The SWEMWBS gives an indication of a person's sense of overall wellbeing, level of positive mental health and resilience.

Both measures were taken at the first session and again on the sixth session. Results for the ten participants were analysed using SPSS (Statistical Package for Social Sciences), this is a statistical analysis tool used to process psychological and mathematical raw data.

"I've had one to one's support, sort of therapy support which has been very beneficial, your taking information from all those and tips and Ideas and its just been phenomenal the support group that's there for you."

Results

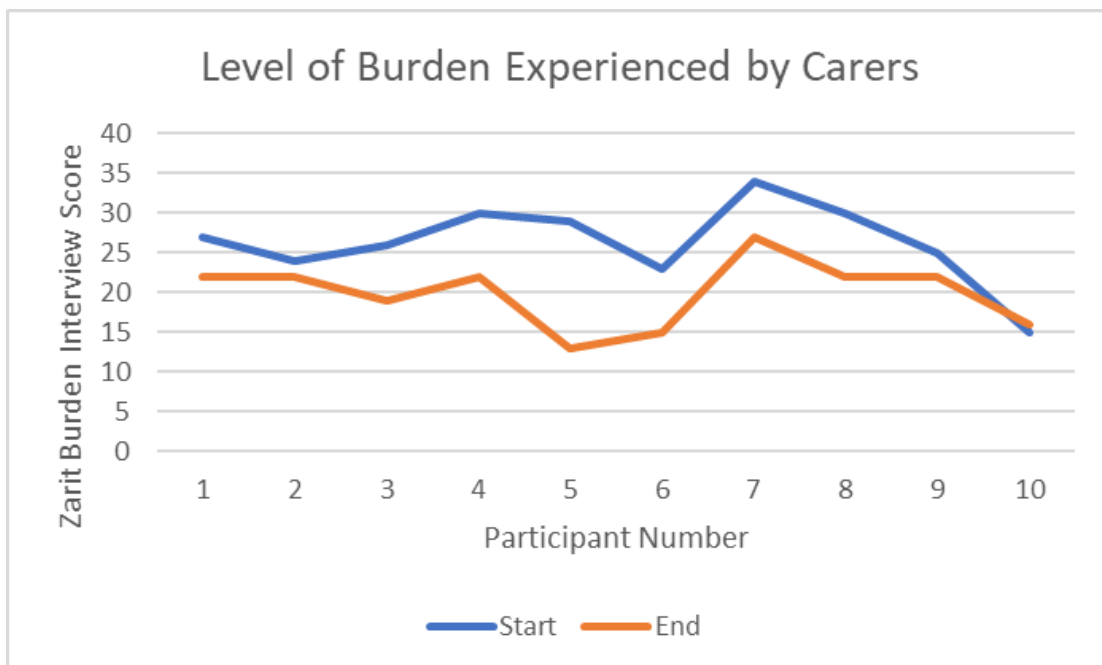
Carer Burden

The short Zarit Burden Interview asks carers to answer twelve questions about the level of burden they feel in their role as caregiver. For example, “Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?”.

Each question has a choice of answers, Never (score=0), Rarely (score=1), Sometimes (score=2), Quite Frequently (score=3), Nearly Always (score=4). This gives a total score ranging from 0 to 48.

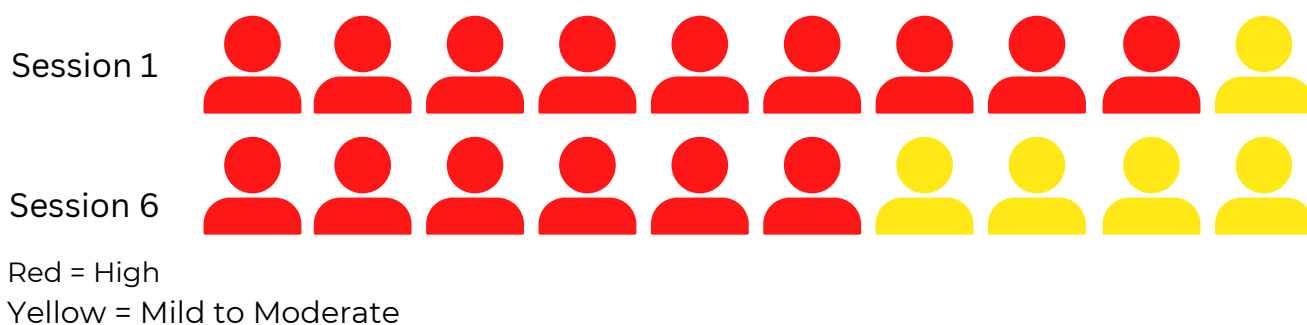
- 0-10: no to mild burden
- 10-20: mild to moderate burden
- >20: high burden

At the start of the sessions, nine people were experiencing a high burden and one person was experiencing mild-moderate burden. The lowest score recorded at the start was 15, the highest was 34 and the average score was 26.3.



At the end of 6 sessions, nine people had experienced a reduction in their level of burden.

The range of this change was between 2 and 16 points. The average change was 6.3 points. The lowest score recorded at the end was 13, the highest was 27 and the average score was 20.



The level of burden had reduced from “High” to “Mild to Moderate” for three caregivers.

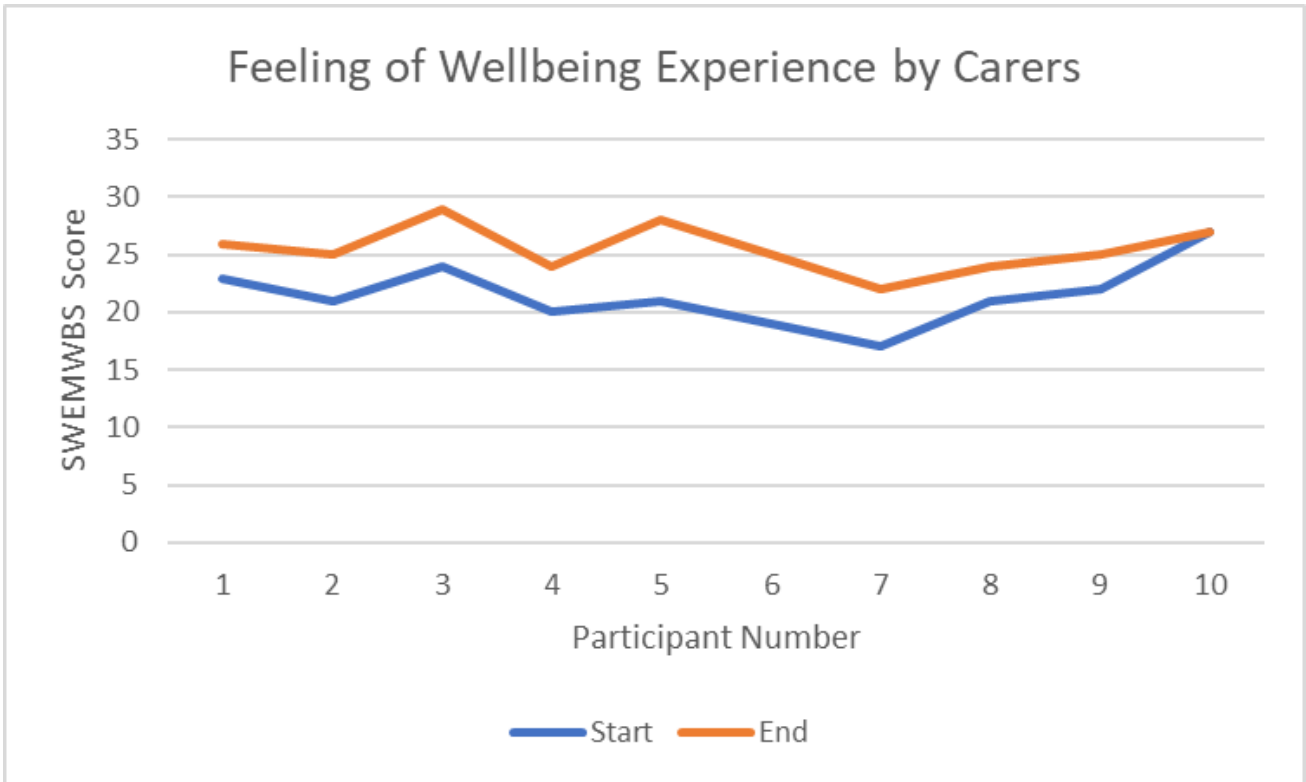
One person’s score increased by 1 point. This person started and remained in the mild-moderate category; they had also experienced the lowest level of burden at the start.

Carer Wellbeing

Participants completed the SWEMWBS which measures a person’s feeling of mental wellbeing. The SWEMWBS asks participants how often they have experienced different feelings, for example, I’ve been feeling optimistic about the future.

Available answers are None of the time (score=1), Rarely (score=2), Some of the time (score=3), Often (score=4), All of the time (score=5). This gives a total score ranging from 7 to 35 (where 35 is the highest feeling of wellbeing).

“so I’ve really benefited from that, and the I’ve been able to share that with my family and friends. and also with other people that I know have had family members diagnosed. so I feel really you know, in a lot better place than I was 18 months 2 years ago”.



At the start of the sessions, the lowest score was 17, the highest score was 27 and the average score was 21.5.

At the end of the sessions, nine of the participants experienced increased feelings of wellbeing.

One person's score remained the same, however this person reported the highest feeling of wellbeing at the start of the course.

The range of this change was between 3 and 7 points. The average change was 4 points. At the end of the sessions, the lowest score was 22, the highest score was 29 and the average score was 25.5.

Evidence suggests family carers have increased vulnerability to stress and depression. "Family carers can develop a sense of loss. They may struggle with the emotional adjustment involved in relationship changes that can occur with the person they now care for" (McEvoy et al., 2019).

Prevention in early admission to external care facilities was highlighted as important to these caregivers who want to care for their family member within their home environment. "People living with dementia demonstrate a better quality of life when they do so" (Hoe et al., 2007). Dementia results in a fivefold increase risk of premature nursing home placement for older people. "Family caregivers help people living with dementia to remain at home, although they vary considerably in their ability to do so" (Gaugler et al., 2000).

The aim of this study was to determine whether participants enrolled in the 'Empowered Carers' intervention in Bolton would undergo any changes within self-perceived carer burden and wellbeing after receiving six sessions of one-one support.

Overall, nine out of the ten participants had a reduced sense of Burden and an increased indicator of overall wellbeing.

The tenth participant stayed relatively in the same position. However, participant 10 had begun with a base line of a "Moderate to Mild" sense of burden and a relatively high wellbeing score of 27.

The NYUCI longitudinal study demonstrated that a reduction in carer burden and improvement in wellbeing delayed the entrance into full time care by 557 days, Mittleman et. al (2004).

NON-SUBTLE CONCERN

An improvement in wellbeing and reduction in burden could reduce the risk of future psychological crisis, such as anxiety and major depressive disorders. This may be due to the carer now being better physically and mentally prepared to deal with potential present and future barriers (Whitlatch & Orsulic-Jeras, 2018).

With an increasing aging population, developing strategies for people living with dementia and their carers is essential. Specialist dementia interventions, such as The Empowered Conversations Approach, increase dementia awareness, improve communication, connections, relationships, quality of life and improve the mental health of caregivers.

"Interventions that help reduce nursing home utilization without overburdening family members will be essential for our society". (Mittelman et al., 2004).

The digital element of The Empowered Conversations Approach intervention has not been discussed in detail here, but can be an effective lifeline for caregivers. This type of digital ability may also provide inclusion for individuals who are generally unable to leave their home environment.

"I've been in touch with other people in the same place as me. So it's not just been a list of things to do or letters through the post, It's also been face to face contact online, that was all really beneficial."

The global population is aging, with an estimated 152 million people affected with dementia by 2050 (World Health Organization, 2020). Empowered Carers offers a means of reducing future financial strains of external dementia care, whilst improving the quality of life for Dementia caregivers and those they support living with dementia.

Next Steps:

Empowered Carers will continue to gather Session 1 and Session 6 measures for Bolton Caregivers over the next few months.

A qualitative study is underway, three in-depth interviews have been completed. Once transcribed, a thematic analysis will be undertaken. The results of this will be combined with these quantitative findings.

These studies are being undertaken by Mike Yates, Empowered team member and internal researcher.

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