THE ORCHARD PROJECT

“Till death do us part”

an investigation into the lived experience of the transition to becoming an unpaid carer when a partner is diagnosed with dementia

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1. Introduction

This PhD studentship is part of a wider project developing best practice within a day centre providing dementia care.

The aim of this PhD studentship is to focus upon carer support by understanding the lived experiences of individuals who transition into a care role for their partner.

Every three minutes, someone in the UK develops dementia - it's one of the biggest health challenges of our time. Families affected are often left feeling exhausted and overwhelmed and don’t know where to turn. Frequently the greatest burden falls to a spouse or partner who may also be dealing with their own health concerns.

71% Of carers do not receive appropriate support

52% carers receive no help at all

76% carers have no plan in place if they were unable to care

Dementia carers Count (2024)

Whilst studies have explored the broader impact of dementia upon carers, this study seeks to understand the experience of transitioning into a caring role when a partner is diagnosed with dementia .

2. Purpose

This work links into Integrated Care Northamptonshire’s Dementia Strategy’s ambition to raise awareness and reduce stigma in relation to mild cognitive impairment and dementia.

3. Aim and objectives

This PhD project aims to examine the impact of a dementia diagnosis upon couples by examining the experience of people who transition into an unpaid carer role for their partner.

Research Objectives

1. Explore the existing evidence base of support and resources available when someone transitions into the role of an unpaid carer for a person diagnosed with dementia.
2. Explore the lived experience of unpaid carers when supporting a partner in the early stages of dementia.
3. Identify the aspects of interest and concern for unpaid dementia caregivers.

8. Acknowledgements

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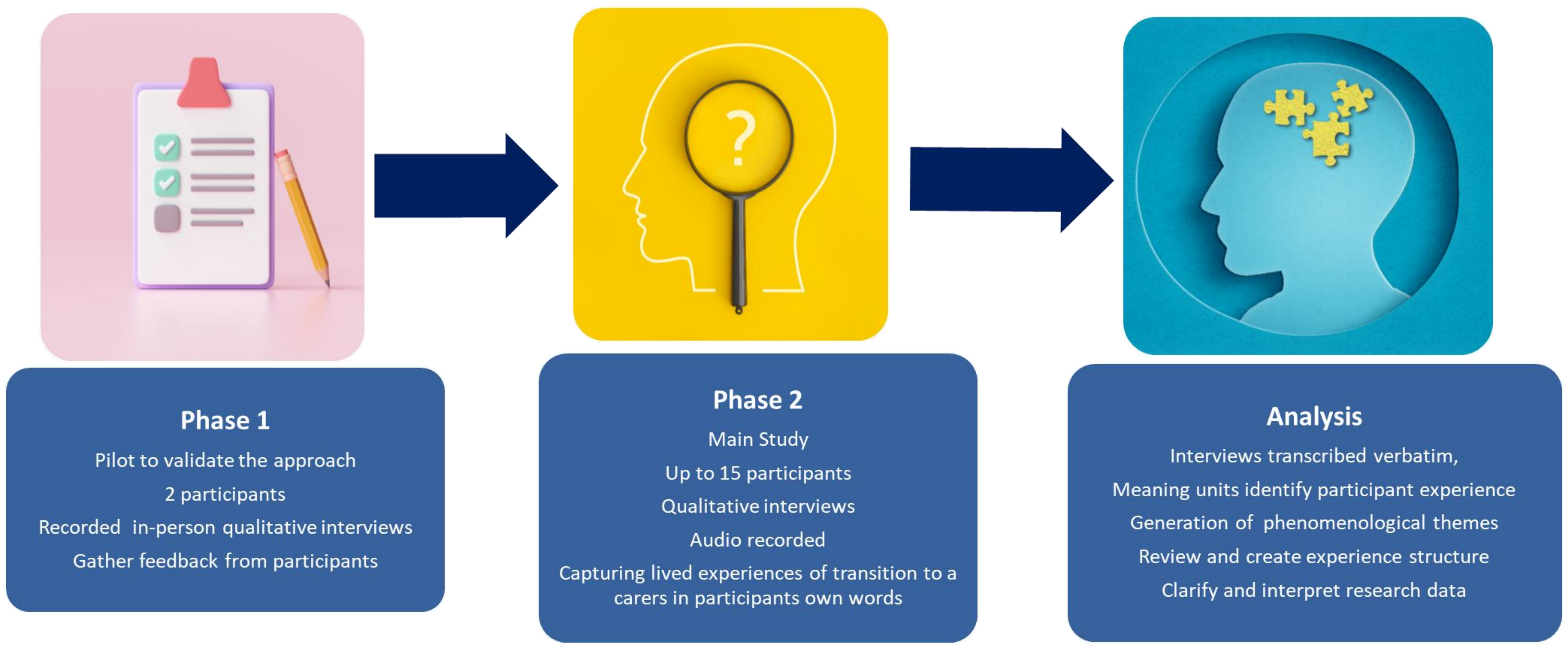
4.Methodology

A descriptive phenomenological approach (Giorgi,2012) will capture the lived experiences of carers in their own words. Qualitative research will engage with participants by immersing into their lifeworld to capture the experiences and perspectives of carers towards understanding the structure of support, resources, information and education needed to maintain good health and wellbeing to care for their loved one at home.



Phase 1
Pilot to validate the approach
2 participants
Recorded in-person qualitative interviews
Gather feedback from participants

Phase 2
Main Study
Up to 15 participants
Qualitative interviews
Audio recorded
Capturing lived experiences of transition to a carers in participants own words

Analysis
Interviews transcribed verbatim,
Meaning units identify participant experience
Generation of phenomenological themes
Review and create experience structure
Clarify and interpret research data

6. Anticipated Outcome

It is anticipated that this project will discover a wide perspective of experiences of becoming a carer. Whilst cautious not to predict the outcome, it is expected that carer experiences will vary across a broad spectrum of burden to positivity. Whilst carer experience has been explored more widely (Hammar et al., 2021; Shim et al., 2012; Tatangelo et al., 2018; Youell et al., 2016), this research seeks to identify the specific experiences of a group of people transitioning into a carer role for a partner with dementia.

There is currently a lack of evidence towards understanding the needs of unpaid carers during this critical life event.

The findings of this study will feed into the overall Orchard Project to inform future services, support and education for unpaid dementia carers.

7. References

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