

# Caring at home for a spouse/relative with Dementia: Male caregivers’ experiences

## Introduction

As persons become older the possibility of developing dementia increases. There are 35 million people worldwide living with Alzheimer’s disease and other dementias and this figure is expected to double by 2030 and more than triple by 2050 to 115 million (Alzheimer’s disease International, 2013). There are 41,740 people with dementia in Ireland, of whom 26,000 live at home (Cahill et al. 2012). There are 50,000 carers in Ireland (O’Shea, 2007). Men constitute 40% of these carers (McCarron et al. 2011).



## Rationale

A review of the studies on caregivers’ experiences of caring for persons with dementia illustrates that a limited number of male caregivers participated. The studies were predominantly quantitative. Therefore, it was timely that a study using a qualitative method elicited the views of male caregivers. No such a study had been undertaken in the North West region of Ireland.

## Study Overview

### Study Aim

To explore the caring trajectory as experienced by male informal caregivers residing in the North West of Ireland caring for a spouse/relative with dementia.

### Study Objectives

1. To explore the process of becoming, and of being a caregiver, from the perspective of a man caring for a spouse/relative with dementia.
2. To explore the sources and perceived effectiveness of the supports utilised by male caregivers.

*For the purpose of this poster objective one will be addressed only.*

## Methodology

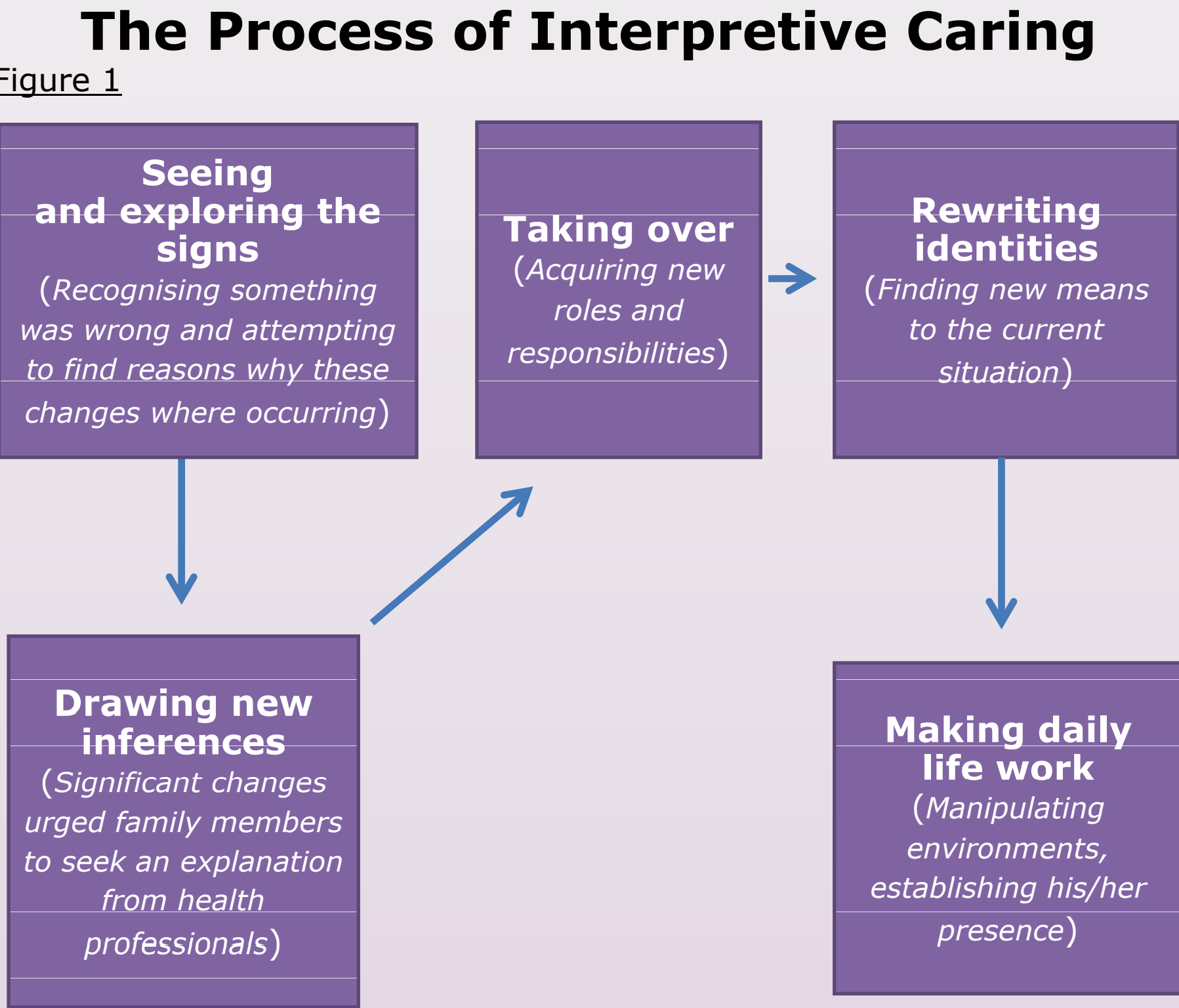
- A descriptive exploratory research design was used.
- A purposeful sample of 13 male caregivers participated.
- Data was collected from male caregivers via in-depth interviews.
- Data was analysed thematically.
- Ethical approval was received from the local Research Ethics Committee. Ethical principles were adhered to.



## Presentation of Findings

The findings will be presented utilising a theoretical framework which was generated by Perry (2002) as a process of ‘interpretive caring’.

This ‘interpretive caring’ process will be presented as it evolved under five concepts in Figure 1.



Perry, J.A. (2002) Wives giving care to husbands with Alzheimer’s disease: a process of interpretive caring. *Research in Nursing and Health*. 25, pp. 307- 316.

**Seeing and Exploring The Signs**

**Subtle changes**

Initially, signs were subtle but as time progressed these changes became more prevalent implying something more sinister was occurring.

*"... questions started cropping up on a repetitive basis"*

**Drawing New Inferences**

**Realisation of the need for a diagnosis**

Marker events encouraged caregivers to seek explanation for the changes.

*"I brought her in to a GP on a Monday. She was in a psychiatric hospital on Wednesday. She had been treated for depression. We were getting no where with the cocktail of tablets, at one stage they thought it might be a tumour. I was hoping it might be a tumour, so they could remove it, that would solve it. She had a number of brain scans it was there (hospital) she was diagnosed with pre-senile dementia"*

**Communication of the diagnosis**

*"The GP never told me it was Alzheimer’s even though she was on Aricept. I suppose they diagnosed it in their own minds, but didn’t think to tell the carer ... They didn’t communicate ... they never mentioned the term"*

**Taking Over**

**Transition to the role**

For some taking over the role was relatively easy however, caring presented challenges if the added responsibilities restricted their own normal routine.

*"... I had to do it, the whole lot. She used to run the house and all I had to do was get the money in. It’s very hard, you just sort of had to adjust to it as it went along the line"*

**Rewriting Identities**

**Maintaining the presence of the person**

Caregivers reflected on their loved ones prior life achievements.

*"She ran our newsagent shop, she was very busy running the house and minding the children, she was smart and brainy"*

**Changing relationships**

For caregivers missing that person that they would have previously confided in was disheartening.

*"... it’s a second childhood no responsibility for anything, I mean she was the most responsible person in terms of management and decision making, I would have referred to her and I can’t refer to her now"*

**Making Daily Life Work**

**Coping strategies**

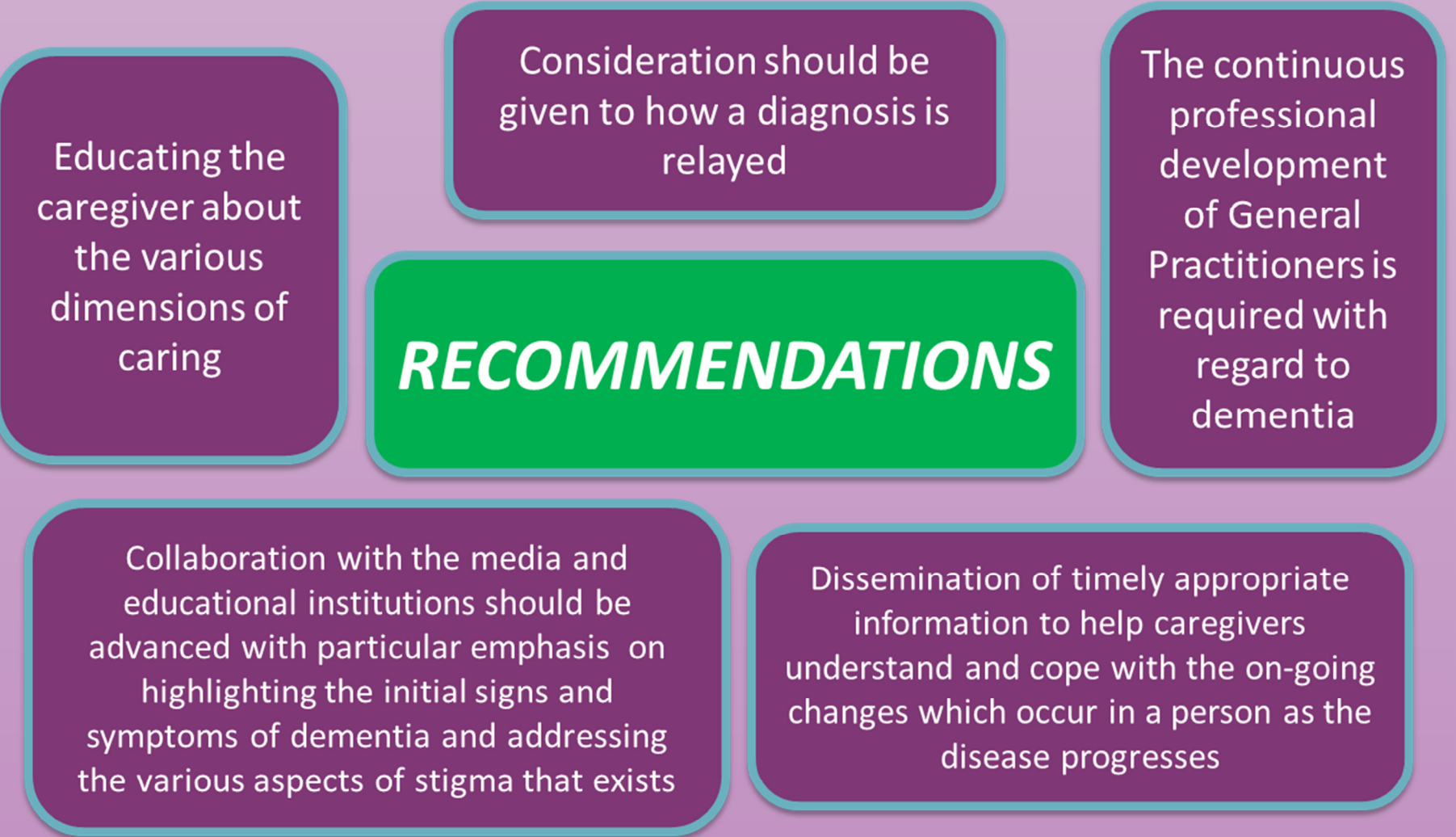
Caregivers utilised strategies to support them in their caring role.

*"if you’re tired and the fuse gets a bit shorter, you have to realise that she can’t help it and make allowances and say a few prayers"*

**Stigma**

Society’s attitudes to or its lack of appreciation about the manifestations of dementia impacted on the ability of caregivers and their relatives to engage in normal social activity.

*"... and she’ll go into a pub and have one drink, but the trouble is that she’ll meet all the people and my problem is when the conversation moves up I can’t say well my wife has Alzheimer’s, because they’ll shrink away from her or they’ll come up talking to her about it, which causes problems ... they’ll say she is drunk. So the social outlet is gone as well ... "*



**Conclusion**

The data revealed that male caregivers care in an insightful manner, striving at all times to maintain their spouses/relatives personhood. Obtaining an early diagnosis for a spouse/relative was essential in addition to obtaining timely appropriate information. There is a crucial need to raise awareness of the presenting features of dementia in the general public both to aid early warning signs being acted on promptly and ensuring that members of the public respond appropriately to persons with dementia and their caregivers.

