Staff perceptions of awareness in people with moderate to late stage dementia

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ABSTRACT

Dementia is a terminal brain disease which can be thought of as progressing through three stages: early, middle and late. Past research asserted that as dementia progressed, people lost the capacity for awareness of themselves, others and their situation. However, emerging research has suggested that individuals can retain some capacity for awareness until the end of the disease process (Clare, 2010). Clare (2010) postulated that awareness operates hierarchically at increasing levels of complexity. She proposed a framework from which awareness can be understood and researched and identifies the biopsychosocial factors that influence its expression (Clare, 2004).

There is a lack of research investigating awareness as perceived by staff carers in specialist Elderly Mentally Infirm settings. Therefore, this current study utilises Clare's (2010) framework to investigate staff perceptions of awareness in the moderate to late stages of dementia, using a Grounded Theory methodology. Understanding staff perspectives is important as responding appropriately to the needs of individuals with dementia is central to promoting quality care.

This study found that some staff members in specialist EMI settings, who provide direct care for people in the moderate to late stages of dementia, perceive residents to be unaware of themselves, others or their context. These findings are discussed in relation to current literature and the implications for clinical practice and staff training are outlined. A methodological critique acknowledges limitations of awareness research and of the current study and it is concluded that further research on awareness is vital for improving person-centred care in dementia.

"Someday those who care for a person with Alzheimer's may be faced with what appears to be an insoluble problem. Caregivers may try anything they have been taught but nothing works. So, they touch the arm of the person with Alzheimer's and speak softly and gently. Because of the patient's apparent distress, the caregiver may hug the person with Alzheimer's or give a kiss and tell the person that he or she is loved. One day, if the caregiver is lucky, a revelation occurs. That person learns that the last thing we ever lose is love. Our memories may be gone. Intellect and logic may have diminished. We may have forgotten your name and where we are, or what we are doing. But we remember love".

Tim Brennan (1999)
From Perspectives: A Newsletter for Individuals with Alzheimer's
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CHAPTER ONE: INTRODUCTION

1.1 OVERVIEW OF THE CURRENT RESEARCH

This introductory chapter aims to provide a context to the current research and guide the reader through to the aims of the present study. The chapter consists of six sections. It begins by defining the scope of the literature review and goes on to provide a brief overview of the key elements of the research in dementia, awareness and care staff perceptions of the cognitive functioning and personhood of their clients. The researcher will critically evaluate the literature on awareness in the moderate to late stages of dementia, on staff perceptions and on the factors which enhance and inhibit awareness. The implications for the current study will be summarised. Finally the rationale and aims of the current study will be outlined.

1.2 THE PROCESS OF THE LITERATURE REVIEW

In the preparation of this chapter, a comprehensive literature review was performed on key data bases and search engines to explore the existing research evidence in this area. It is noteworthy to mention that the literature review carried out was in contrast to a full systematic review, which is beyond the scope of the thesis. Instead, generic themes pertinent to the research were identified and focused upon in this review. The databases, key terms and dates that were used, and process are outlined below.

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1.2.1 Databases and search engines - These included Psychinfo, EMBASE, SCOPUS, Medline, British Nursing Index and Google Scholar, between the dates of 1994 – 2011.

1.2.2 Key terms - The key search terms that were used were "awareness", "insight", "lucidity", "anosognosia", "personhood", "dementia", "Alzheimer's disease", "moderate stage", "middle stage", "end stage", "severe stage", "late stage", "advanced stage", "elderly mental infirm", "residential setting", "residential home", "nursing setting", "nursing home", "staff perception", "staff attitude", staff opinion" and "staff beliefs".

1.2.3 The Process – Boolean operators were used with the key works to maximise the possibilities of search hits and where possible the terms were searched in combination with other related terms from the list above. When options were available to search 'related articles' on the search engines the researcher selected this option. Key references that were cited in relevant articles were chosen by the researcher if they appeared pertinent to the current research. The researcher also reviewed service and policy documents which were accessed via relevant websites (e.g. The Department of Health, Welsh Assembly Government websites).

The literature search showed that over the past 15 years awareness has been studied from both clinical and research perspectives. It has been most closely examined in three different clinical populations, mental illness (Amador & David, 2004), brain injury (Prigatano, Matthes & Hill, 2010), and dementia (Markova & Berrios, 2000). Three distinct and broad frameworks have been used to conceptualise awareness, neurological and/or neuropsychological, general psychiatry, and psychoanalytic perspectives. The review also

highlighted that there is a growing body of information relevant to awareness in early to moderate stages of dementia (Clare, 2002b, 2003a, 2004; Phinney, 2002; Giovannetti, Libon & Hart, 2002). While there was a comparative lack of research investigating awareness in the moderate to late stages of dementia.

1.3 OVERVIEW OF DEMENTIA

1.3.1 Aetiology of dementia

Dementia is an umbrella term used to describe a range of diseases and disorders of the brain (Kerr, 2007). The most common types of dementia are Alzheimer's disease, vascular dementia and dementia with Lewy bodies (Alzheimer's Society, 2011). Dementia results in a progressive decline in multiple areas of cognitive function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. Alongside this, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care and can occur at any stage of the illness (Alzheimer's Society, 2011).

1.3.2 Prevalence and life expectancy

There are estimated to be over 750, 000 people in the UK with dementia and numbers are expected to double within the next thirty years. Age is the biggest risk factor for dementia, affecting 5% of people over 65 years, 20% of people 80 years and over, and 33% of people over 95 years (Dementia UK, 2007). Two thirds of people with dementia are women. Although dementia is primarily a condition associated with older people, there are also a

significant number of people (currently around 15,000) who develop dementia under 65 years of age. Dementia is a terminal condition but generally people live with it for 7–12 years after diagnosis (DOH, 2009). Sixty-thousand deaths per year are directly attributable to dementia (Alzheimer's Society, 2011).

1.3.3 The course of dementia

The World Health Organisation (WHO, 2006) state that dementia can be considered to progress through three stages: early stage, middle stage and late stage. They present a profile of features (see Figure 1 below) that are thought to characterise dementia at different stages and outline some of the risks or challenges that an individual may encounter during the disease. Dementia is unique to every individual and the time course and pattern of the disease will depend on the individual's pre-morbid presentation: their personality, lifestyle, significant relationships, physical health and their cognitive functioning. They acknowledge that not everyone will experience all of the symptoms outlined at each stage and that some individuals may deteriorate more quickly than others. They assert that advances in dementia drug treatment can slow the progression of the disease for some individuals.

Figure 1 Stages and symptoms of dementia (WHO, 2006)

Early stage (1-2 years)
The early stage of dementia is often overlooked. Relatives and friends (and sometimes professionals) see it as 'old age' or just a normal part of the ageing process. The onset of dementia is gradual, so it is often difficult to be sure exactly when it begins. The person may:
- Have language problems (e.g. word finding difficulties)
- Have significant memory loss – particularly for things that have just happened
- Not know the time of day or the day of the week
- Become lost in familiar places
- Have difficulty making decisions
- Become inactive and unmotivated
- Show mood changes (e.g. depression or anxiety)
- React unusually angrily or aggressively on occasion
- Show a loss of interest in hobbies and activities

Middle stage (2-5 years)
As the disease progresses, limitations become clearer and more restricting. The person with dementia has difficulty with day-to-day living and:
- May become very forgetful – especially of recent events and people's names
- Can no longer manage to live alone without problems
- Is unable to cook, clean or shop
- May become extremely dependent on their family and caregivers
- Needs help with personal hygiene, i.e. toilet, washing and dressing
- Has increased difficulty with speech
- Shows problems with wandering and other behaviour problems such as repeated questioning and calling out, clinging and disturbed sleeping
- Becomes lost at home as well as outside
- May have hallucinations (seeing or hearing things which are not there)

Late stage (5 years +)
This stage is one of near total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious. The person may:
- Have difficulty eating
- Be incapable of communicating
- Not recognise relatives, friends and familiar objects
- Have difficulty understanding what is going on around them
- Be unable to find their way around in the home
- Have difficulty walking
- Have bladder and bowel incontinence
- Display inappropriate behaviour in public
- Be confined to a wheel chair or bed

It is noteworthy that Figure 1 is predominantly a model of pathology, impairment and disability, which emphasises the features of dementia that increase care requirements. Given that the WHO (2006) definitions are commonly cited by other organisations when developing policy, standards and training materials (e.g. National Health Service, NICE Guidelines, and Alzheimer's Society), such depictions of the stages of dementia will be likely to shape health professionals' and carers' perceptions. However, the WHO (2006) framework is neither comprehensive nor systematic in its description of the neuropsychological or cognitive underpinnings of this process. Nor does it state whether the features presented are cumulative (e.g. sleep disturbance is only mentioned in the middle stage). Moreover, it is unclear if the process described is conceptualised as a series of self-contained stages or as a progressive decline across which the impairments and disabling features of dementia increase in number and severity.

Although the potential of pharmacological interventions are acknowledged in the WHO framework (2006), there is little consideration of psychosocial interventions which may ameliorate or exacerbate deterioration trajectories through the provision or absence of appropriate support. No reference is made to how a person's awareness may be impacted across the course of dementia. Without a doubt, there is a need for more systematic exploration from a psychological perspective about changes in less well understood areas (e.g. awareness).

More recently a review of the studies concerning the relationship between awareness and dementia across time (Mograbi, Brown & Morris, 2009) showed that only 10/66 studies in this area showed an association between increased awareness deficit and the severity of

dementia. More consistent links are evident between loss of awareness and the duration of the illness (Migliorelli, Teson & Sabe, 1995; Starkstein, Sabe & Chemerinski, 1996) and longitudinal studies show, for instance, that awareness is lost across time (Derouesne, Thibault & Lagha-Pierucci, 1999; Migliorelli et al., 1995). However, awareness is not a unitary construct (Martyr, Clare & Nelis 2011; Gilleen, Greenwood & David, 2011) and there is little known about it in the moderate to late stages of dementia. This is because standard tools for investigating cognitive functioning or awareness through self-report becomes difficult to apply and unreliable, psychometrically and ecologically.

1.3.4 Caring for an individual with dementia

People diagnosed with dementia are often cared for at home by their own families in the earlier stages of the disease. Two thirds of people with dementia live in the community; while one third live in a care home (Alzheimer's Society, 2011). However, as the disease progresses, behavioural patterns such as forgetfulness, changes in behaviour and possible aggressiveness can become more difficult to cope with. When there are discrepancies in perceptions between the person with dementia and their carer regarding aspects of dementia (including awareness), high levels of stress can be experienced by the care giver (De Bettignies, Mahurin & Pirozzolo, 1990).

For those who are not cared for at home or for those whose needs can no longer be met at home, an Elderly Mentally Infirm (EMI) residential or nursing home is generally where the individual with dementia is cared for. The Alzheimer's Society (2011) reported that 64% of those living in care homes have a form of dementia. Residential homes provide

accommodation, meals and personal care to residents and have access to community nursing services that attend the home when required to conduct nursing tasks. A nursing home has the same provisions but differs in that a registered nurse is on duty at all times and is specially trained to care for residents with this kind of illness. Despite the staff in dementia settings having specialist training, the quality of residential care for people with severe dementia has been argued to be in need of improvement (Ballard, Fossey & Chithramohan, 2001). The urgent need to improve the quality of care for this population has also been highlighted by the Department of Health's 'Dignity in Care' campaign (SCIE, 2007) and Joint Committee on Human Rights (Anderson, 2007). One of the reasons for needing such campaigns may be due to the assumption that people in the later stages of dementia lack self-awareness or awareness of their situation (SCIE, 2007).

1.4 OVERVIEW OF AWARENESS

Sections below will outline various perspectives and conceptualisations of awareness that will be discarded for the purpose of this study due to them being too narrow or unsuitable for the area of investigation at hand. It is important to acknowledge that by choosing a particular definition of awareness and omitting other potential definitions, this will have implications for the interpretation of the outcomes of this study. Therefore, the definition chosen for this study will be examined closely before moving on.

1.4.1 What is awareness?

Awareness is a basic aspect of human subjective experience, which has been described by Tulving, (1993) as a general capacity for particular kinds of inner experience and has been viewed as being equivalent to consciousness itself (Zeman, 2001).

Clare (2010) defines awareness as:

> "The ability to hold a reasonable or realistic perception or appraisal of, and or respond to one's environment, situation, functioning or performance. This can be expressed explicitly, through direct self-report, or implicitly, through behaviour" (Clare, 2010, p20).

In this definition, awareness involves being aware of 'something', and being expressed in relation to something specific. This has been termed the 'object' of awareness (Markova, Clare, and Wang, 2005). There are many possible objects of awareness, ranging from internal states, elements of one's own functioning or situation, mental representations and aspects of the self, external stimuli, symptoms, or external events.

It could be argued that Clare's (2010) definition is extremely broad, covering vast areas including perception, environment, situation, functioning, performance, and implicit and explicit behaviour. Many aspects of Clare's definition could potentially result in numerous interpretations from participants, which heavily rely on their subjective judgement (e.g. who

determines what accounts for a 'reasonable' or 'realistic' appraisal?). Furthermore, it could be argued that the breadth of the definition could be interpreted in such a broad manner that is it difficult to pinpoint specific and generalisable conclusions about awareness. Indeed, it could be said that choosing this definition may open up as many questions as it answers about the nature of awareness. However, this is specifically why Clare's (2010) definition was chosen (and other definitions from neuropsychology and general psychiatry, which will be outlined later) were omitted.

On the whole, this research was based on Clare's (2010) framework, as it foundation is build from on comprehensive reviews of the literature on awareness across different stages and perspectives on awareness, and uses the advantage of her expertise in this field.

It is felt that the definition chosen is appropriate for the topic being studies. Its broad parameters being an advantage in that it will allow the researcher to explore perceptions of different levels of awareness, which relatively little is known about. Developing a broad theory in an area that little is known about will give a platform from which more focused and specific research can go from, as opposed to having an in-depth and narrow understanding of a single aspect of awareness.

Clare (2010) also states that is important to distinguish between the concept of awareness and the phenomenon of awareness. The concept of awareness refers to the broad frameworks within which awareness is defined and conceived, while the phenomenon of

awareness refers to the relational aspect of awareness in clinical practice. Distinguishing between the concept and phenomenon of awareness is important as it has implications for the way awareness is researched and the type of phenomenon that is elicited and observed in clinical practice. The conceptualisations of awareness will be examined below.

1.4.2 Conceptualisations of awareness

Awareness has been conceptualised in the literature from three broad perspectives; neurological or neuropsychological, general psychiatry, and psychoanalytic. These perspectives will be briefly considered in turn below.

1.4.2.1 Neurological and neuropsychological conceptualisation of awareness

The concept of awareness from a neurological and neuropsychological perspective predominantly focuses on *loss* of awareness observed in patients who have experienced brain damage (traumatic or non-traumatic) (Prigatano, Matthes & Hill, 2010). From this perspective awareness is conceived of in modular terms, that is, different degrees of awareness are equated with impairment in specific neuro-anatomical systems (e.g. memory, speech and perception) (Hannesdottir & Morris, 2007; Martyr et al., 2011).

1.4.2.2 General psychiatric conceptualisation of awareness

The general psychiatry conceptualisation of awareness is predominantly used in the realm of psychiatric disorders (e.g. psychosis) (Amador & David, 2004) and focuses on whether patients show awareness or insight into their illness. Indeed, unawareness of "madness" was intrinsic to the conceptualisation of madness until the early nineteenth century when it

became evident that patients had a degree of insight into their psychiatric illness (Markova, et al., 2005). Since then the concept of awareness has been considered more generally to include awareness of changes in abnormal thinking and behaviour, judgements about such changes, awareness of the consequences of illness on the self (Jaspers, 1948) and whether patients recognise that they require treatment (McEvoy, Apperson & Appelbaum, 1989). More recently Gilleen et al. (2011) have researched people with schizophrenia's insight into symptoms and cognitive deficits.

1.4.2.3 Psychoanalytic conceptualisation of awareness

The conceptualisation of awareness from a psychoanalytical perspective is conceived as a "deeper" knowledge of changes in the self. Firstly, the knowledge is viewed as encompassing an understanding an individual has of themselves in the context of life experiences and relationships. Also, with the understanding the individual has regarding his or her motivations or unconscious mental processes. Secondly, awareness is viewed as occurring at different levels of understanding (e.g. cognitive, intellectual or emotional levels (Kris, 1975; Morin, 2006). Thirdly, inherent to the psychodynamic concept, motivation for changes in awareness is considered. In this context, denial might be regarded as a psychological coping response designed to protect an individual from the consequences of having awareness or knowledge of their disabilities (Weinstein, Friedland & Wagner, 1994).

1.4.3   Critique of conceptualisations of awareness

The theoretical frameworks outlined above differ greatly in content, breadth, and specificity. The empirical studies that have attempted to explore aspects of awareness in dementia and other conditions are marked by inconsistent findings. This could be explained

to some degree by the varied ways in which awareness has been conceptualised, including the different terminologies used to refer to awareness, the different populations being studied (e.g. brain injury, mental health and dementia), different objects of awareness being selected for investigation and the different empirical measures used to assess awareness.

In order to demonstrate these points the differing terminologies and range of methods for assessing awareness will be considered next, along with discussion regarding the challenges this presents in being able to develop a clear understanding of awareness in dementia. This is not a comprehensive review but a brief overview of some of the challenges presented in studying awareness.

1.4.3.1 Terminology

Within the conceptualisations of awareness outlined above different terminologies are used to refer to awareness. Such terms include "loss/lack of insight" (De Bettignies et al., 1990), "lucidity" (Normann, Asplund & Karlsson, 1998), "lack/impairment of awareness" (Auchus, Goldstein & Green, 1994; Clare, Wilson & Carter, 2002; Green, Goldstein & Sirockman, 1993), "unawareness" (Lamar, Lasarev & Libon, 2002; Vasterling, Seltzer & Foss, 1995; Wagner, Spangenberg & Bachman, 1997), "anosognosia" (Feher, Mahurin & Inbody, 1991; Smith, Henderson & Murdock, 2000), "denial" (Sevush, 1999; Weinstein et al., 1994), "impaired self-awareness" (Kaszniak & Christenson, 1996) and "self-consciousness" (Gil, Arroyo-Anllo & Ingrand, 2001).

While, particular terms often appear to reflect the framework in which awareness is being considered, there can be much variability between the studies and many of the terms are used interchangeably (McGlynn & Schacter, 1989). For example, the term "anosognosia" is commonly used within a neurological and neuropsychological perspective, the terms "insight" and "self-awareness" are commonly used with a general psychiatric framework, and terms such as "denial" and "self-consciousness" are commonly used within a psychodynamic conceptualisation of awareness.

These diverse terms make it difficult to determine whether a universal underlying concept of awareness is being referred to. Further issues arise in the different methods and measured used to research awareness, as outlined below.

1.4.3.2 Methodological issues

A review of the literature highlights that there are many different approaches to assessing awareness. Clare et al. (2005) conducted an in-depth review and critique of the measures. In brief, a wide variety of scales, measures and interviews, are used to assess awareness. These include: clinical rating methods, questionnaire-based methods, performance based methods, phenomenological methods, and multi-dimensional methods. Predominantly, awareness is assessed through calculations of discrepancies between a person with dementia and informant ratings (e.g. family member, carer, or professional) on parallel scales. This generally involves measuring awareness of functioning or performance, on objects of awareness such as memory and activities of daily living. Typically, the persons' awareness of their condition is generally assessed through clinical interview.

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1.4.3.2.1 Clinical rating methods

Clinical rating methods involve rating performance on scales on specific domains of functioning, then making distinctions between the different domains that have been rated. The ratings are made during interviews either of the person with dementia and /or of an informant (e.g. carer, family, staff). For instance, Ott and Fogel (1992) compared participant and clinician ratings of depression, relating this to insight level based on interviews with patients and carers covering awareness in four areas: reasons for visiting doctor, memory problems, impairments in activities of daily living, and progression of deficit. Each item was scored on a 0 to 2 scale, and scores were summed, providing results on a 9-point scale from 0 (insight fully preserved) to 8 (insight totally absent). Loebel, Dager and Berg (1990) explored the relationship between awareness and fluency of speech by a clinician rating of response to questions such as "Do you think that you have memory problems?". An advantage of clinical rating scales is that they are quick to administer and can give a reliable picture of functioning in the domain under investigation. Despite this clinical rating scales are heavily reliant on accurate self-report by the person with dementia or assume that the informant's judgements are an accurate representation of the patient's performance. The phenomenon of awareness elicited through the ratings approach is open to interpretation by the clinician and will be influenced by what is relevant to the clinician (e.g. own assumptions about awareness, societal and cultural expectations about awareness (Clare, Markova & Verney, 2005).

1.4.3.2.2 Questionnaire-based methods

Questionnaire-based methods are diverse but often involve comparisons being made between the person with dementia's self rating on a particular object of awareness, with comparisons of an informant rating (e.g. carer, family, staff). Questionnaire based methods such as the Everyday Memory Questionnaire (Sunderland, Harris & Baddeley, 1983), Memory Observation Questionnaire (McGlone et al., 1990), Activities of Daily Living Scale and Instrumental Activities of Daily Living Scale (Lawton and Brody, 1969) and Clinical Insight Rating Scale (Ott & Fogel, 1992), predominantly rely on the calculations between the discrepancy scores on parallel scales. The objects of awareness being measured can vary and include a single domain (e.g. memory) but the aim is to assess awareness across a range of functions (e.g. memory, language functioning, executive functioning, ADLs, health status, mood, apathy, social interaction, motor functioning, self identity). Often when rating domains, people are asked to evaluate how well someone is currently functioning in relation to previous functioning (e.g. 5-10 years previous).

There are particular methodological difficulties surrounding the discrepancy score methods in that they rest on the assumption that informants are able to give an accurate, valid and objective rating, and make the assumption that the informant ratings are a reliable standard. Any deviation on the part of the person with dementia is taken as a loss of their awareness. Some studies use pre-existing standardized measures, e.g. Everyday Memory Questionnaire (Sunderland et al., 1983), while other investigators have began to develop new measures (Smyth, Neundorfer & Koss, 2002). Questionnaire-based studies have advantages in that they offer standardized methods of collecting information and produce

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uniform data sets across participants, facilitating for example analyses of the impact of unawareness on carers (Rymer, Salloway & Norton, 2002). However, a number of studies fail to offer any psychometric data on the measures used and few investigators directly acknowledge the lack of any validation (Vasterling et al., 1995).

1.4.3.2.3 Performance based methods

Performance-based methods such as the CAMDEX (Roth, Tym & Mountjoy, 1988), seek evidence of the person's deficits in cognitive functioning. These methods involve comparisons of self-report with objective test performance and comparisons of informant ratings with objective test performance in order to identify discrepancies. Limitations of self ratings can include them having low ecological validity, in that it can be difficult for people with dementia to rate their performance on artificial laboratory tasks that are often far removed from everyday experiences (e.g. learning a list of words). Difficulties can arise when comparing subjective self-ratings with objective measures, in that the self-rating and objective measure may not be closely related and result in significant discrepancies between the two. This may lead to inaccurate scores about the person with dementia's actual abilities. More recently studies have begun to develop measures that have more criteria based on familiarity for the person with dementia such as The Memory Awareness Rating Scale (MARS) (Clare et al., 2002a). Some of the challenges of these methods are considered next before reviewing how phenomenological based methods and multi-dimensional methods can offer a different understanding of awareness in dementia, particularly in the later stages.

Challenges to studying awareness in dementia using the above measures

The methods outlined above generally seek to identify correlates and predictors of impaired awareness. They are heavily focused on a medical model, which seek to understand the disease process, and its impact on specific domains of cognitive functioning. In addition to examining the impact of dementia (e.g. increased dependence) on those who care for people with dementia, what is often presented from these studies is a picture of extensive deficits as a result of the dementia.

The methods outlined make it particularly difficult to study awareness in the later stages of dementia, as the vulnerability of the population puts them outside the reach of many commonly applied research methods. The measures above are predominantly relevant for people in the earlier stages of dementia, in that they heavily rely on verbal accounts on the part of the person with dementia. Given that one of the early symptoms of dementia can be a loss of language function and reduced ability to express oneself verbally, these measures are disadvantageous for an individual with progressing dementia. Methods that are language based increase the possibility for incorrect evaluations of awareness in people in the later stages of dementia and consequently of wrongly classifying people as unaware (Clare et al., 2005).

People with moderate to late stages of dementia are commonly unable to demonstrate capacity and therefore to provide informed consent. Thus, involving them in research demanding their active collaboration in sharing information in a specific topic area is

challenging and ethically complicated. Moreover, multiple factors can impact on the person with dementia's performance on neuropsychological assessments, such as depression and anxiety (Grut, Jorm & Fratiglioni, 1993).

Observations of the reactions of people with severe dementia seeing their own reflection in the mirror is one of the few methods that focuses on people with more advanced dementia (see section 1.5.3.1). It is also one of the few measures that offer a non-verbal method of evaluating awareness. Methods that are more sensitive to assessing awareness in the moderate to late stages of dementia have begun to be developed. These measures take into account the biopsychosocial factors that influence the expression of awareness (Clare, 2004), and argue that awareness should not be considered as a symptom of dementia that is directly related to brain pathology (Clare, 2010b).

Methods that attempt to capture the phenomenon of awareness and are considered more suitable for studying awareness at the moderate to late stages of dementia are phenomenological and multi-dimensional methods. These will be considered next.

1.4.3.2.4 Phenomenological methods

Phenomenological approaches have been used to gain a deeper understanding of subjective experiences of awareness, which allow a different perspective to be gained about a person with dementia's experiences. Phenomenological approaches usually involve detailed data

analysis of interview transcripts of participants' and informants' accounts. Using methods such as interpretative phenomenological analysis (Smith, Larkin & Flowers, 2009), grounded theory (Glaser & Strauss, 1967) and content analysis (Mayhew, Acton & Yau, 2001), researchers have attempted to enter into the experiential world of the person with dementia and understand their subjective experiences. Researchers using phenomenological methods tend to view awareness as fluctuating and dynamic rather than a fixed attribute and have attempted to explore and understand expressed awareness in its social and psychological context. From this perspective there is often a theoretical assumption that awareness is related to the experience of the self and identity (Clare, 2010).

A particular strength of phenomenological methods is that they allow the observation of retained awareness instead of a focus on deficits and impairment. These methods also allow the person with dementia to be a collaborator in the research instead of the subject of it. Limitations of these methods are that they are predominantly interpretative and can be influenced by the subjectivity of the researcher and interview situation. However, quality control methods have been established to improve the robustness of phenomenological methodologies (Elliott, Fischer & Rennie, 1999).

1.4.3.2.5 Multi-dimensional methods

Multi-dimensional methods may incorporate assessment of a number of different objects of awareness (see Clare et al., 2005 for review of multi-dimensional methods). Using a variety of the methods that have been outlined throughout this section may increase the possibility

of capturing the complexity of awareness by focusing on specific objects of awareness. However, it still cannot be assumed that these different aspects of awareness will represent an individual's awareness in its entirety, and a fundamental question of validity remains since there is no gold standard against which to evaluate any one measure (Clare et al., 2005).

In summary, it has been highlighted above that there are a number of different approaches to the assessment and measurement of awareness. The measures used to assess awareness empirically vary from study to study and limitations include differing operational definitions, differing terminology, differing criteria, differing objects of awareness, etc. Therefore, it is not clear to what extent they capture similar aspects of awareness and it cannot be assumed they are measuring the same construct (Markova & Berrios, 2000).

Attention will now be directed to studies that have explored awareness in the moderate to later stages of dementia. Prior to this, brief consideration will be given to 'unawareness'.

1.4.4 A word about 'unawareness'

Individuals experience different states of awareness (e.g. during the sleep to wakefulness cycle). However, just as awareness is a basic aspect of human experience (Zeman, 2001) a degree of unawareness is normal too. For instance, an individual faced with the news of serious illness may attempts to defend themselves from this painful or difficult information via the process of denial or avoidance (Weinstein et al., 1994; Charmaz, 1983). Indeed,

minimising the degree of illness severity can be an adaptive way of coping with a challenging situation (Taylor & Brown, 1988).

1.5 AWARENESS IN THE MODERATE TO LATE STAGES OF DEMENTIA

1.5.1 Overview

Awareness has been widely researched in people with early to moderate dementia (Clare, 2002b, 2003, 2004a; Phinney, 2002; Giovannetti, Libon & Hart 2002) and it will not be considered here. Instead this section will focus on what is currently understood about awareness in people with moderate to severe dementia. The research in this area is sparse and emergent. Previously it had been asserted that awareness declined as the disease progressed; thus, at some point there was no awareness retained at all (Verhey, Rozendaal & Ponds 1993; McDaniel, Edland & Heyman, 1995). However, Stuss, Picton and Alexander (2001) argue that awareness is not a unitary concept or an 'all or nothing' phenomenon and there is not a straightforward correlation between the severity of dementia and expression of awareness. They suggested that awareness can be viewed as operating hierarchically and be expressed at several levels of increasing complexity, which should take into consideration the process of the disease, environmental, social and psychological context (Clare, 2004a).

1.5.2 Evidence for awareness in the moderate-late stages of dementia

A comprehensive review of the available evidence regarding awareness in dementia suggests that, while some aspects of awareness are impaired in the moderate to severe

stages of dementia, there is also emergent evidence for the retention of the capacity for awareness and for its expression (Clare, 2010).

Clare (2010) proposed a conceptual framework in which awareness can be understood and researched. Clare's framework suggests that awareness operates hierarchically, at different levels of complexity. It distinguishes fundamental awareness of sensory and perceptual stimuli from complex awareness, which includes three cognitive operations termed; 'on-line monitoring', 'evaluative judgement' and 'meta-representation' (see Figure 2). Each of these levels will be described in more detail below, along with consideration of the evidence for awareness at each level. Clare (2010) asserts that it can be assumed that a fundamental level of awareness is present if an individual is expressing a more complex level of awareness.

Figure 2 Levels of awareness framework (based on Clare, 2010)

Increasing complexity ▲	Complex awareness	Meta-representation. The ability to engage in self-reflection at a meta-cognitive level when reporting on aspects of their situation and its implications.
		Evaluative judgement. The ability to make realistic evaluative judgements about one's functioning and situation (e.g. comparing past performance to current performance, or current performance to expected standard or future state).
		On-line monitoring. The ability to monitor ongoing performance or events accurately (e.g. commenting on own memory or own word finding difficulties, or the ability to recognise oneself in mirror).
	Fundamental awareness	Perceptual and sensory. The ability to register and respond to the immediate situation, stimulus or experiences (e.g. music or touch).

1.5.2.1 Perceptual and sensory awareness

Perceptual and sensory awareness refers to a fundamental level of awareness in which an individual simply registers and responds to their immediate situation, stimulus or experience (e.g. responding to touch or music). Recognising responses to perceptual and sensory stimuli is particularly important in people who can no longer express themselves verbally. Clare, Rowlands and Bruce (2008a) noted that people with severe dementia who can still communicate verbally have indicated awareness of, and sensitivity to, internal stimuli and environmental conditions. A number of studies have reported on observational evidence that people with severe dementia, who no longer communicate verbally, can show a range of behavioural and physiological reactions to various stimuli. Norberg, Melin and Asplund (1986) reported on observations of eye-opening, mouth movements and verbalisation in response to music, touch and to the presentation of objects. Similarly, Asplund, Norberg and Adolfsson (1991) reported on movements of the lips, eyelids, head and jaw in response to different stimuli in individuals with severe dementia who were mute and bedridden.

Clare et al. (2008a) carried out a comprehensive exploration of emotional expression in 82 nursing home residents with severe Alzheimer's disease. The study used codes of facial expressions, supported by reports from family members and nursing staff as to their individual meaning. The findings showed that signs of emotional expression were observed even in individuals at the very late stage of the disease. The expression of emotions (e.g. anger, fear) were present up to the final stage, while expression of some emotions (e.g. interest, sadness, joy) appeared to decline towards the end stages. The expression of

emotion was reported to be aligned to the context. For instance, anger was mostly observed during personal care routines, whereas sadness was expressed at the time when visiting relatives were preparing to leave.

1.5.2.2 On-line monitoring

On-line monitoring refers to the ability to monitor ongoing performance or events accurately (Morris & Hannesdottir, 2004) (e.g. commenting on own memory or own word finding difficulties, or the ability to recognise oneself in mirror). This is usually researched in terms of awareness of current memory or cognitive functioning in people with early stages of dementia by seeking immediate judgements of performance on specific tasks (Anderson & Tranel, 1998). As aforementioned, this approach is not appropriate for people with more moderate to late stage dementia; therefore evidence for awareness at this level comes from qualitative, phenomenological studies. Clare (2008a, 2008b) found that during 304 conversations with 80 residents with the moderate to late stages of dementia, they made comments about their memory or had difficulties trying to find the words they wanted to express at that moment. This was taken as evidence that some people in these stages of dementia show a capacity for monitoring their own performance in some situations.

The mirror-and-mark test is a method that is considered to involve awareness at the on-line monitoring level (Biringer & Anderson, 1992). This test involves evaluating an individual's ability to recognise their own reflection in the mirror, as opposed to responding to the reflection as if it was someone else (e.g. their mother). Biringer and Anderson (1992) found

that 25 out of 29 participants with moderate to severe dementia showed evidence of self-recognition. The most frequent indicator of self-recognition was verbal response. Grewal (1994) found that participants with moderate dementia were able to point to two body parts and identify their image when requested to, while participants with severe dementia were able to point to their body parts 25% of the time and were able to identify their image on 20% of occasions.

Further tests include placing an unfamiliar mark on an individual's forehead and observing their reaction to it (e.g. recognising it, attempting to remove it, touching it). According to Bard, Todd and Bernie (2006), touching the mark would indicate some level of self awareness as an individual agent. Biringer et al. (1988) found that all participants with moderate dementia reacted to an unfamiliar mark on their forehead, but only 50% of those with moderately severe and none of those with severe dementia did so.

1.5.2.3 Evaluative judgments

Evaluative judgements refer to an individual's ability to make realistic evaluative judgements about their functioning and situation (e.g. comparing past performance to current performance, or current performance to expected standard or future state). Awareness at this level is most often measured by comparisons of a participant's and informant's ratings of various aspects of functioning (e.g. memory, activities of daily living) on parallel scales of the same measures. As discussed in the section 1.4.3.2.2, a discrepancy

between the two ratings is most often interpreted as a loss of awareness on the part of the person with dementia. Again, this is not a suitable method for assessing awareness in people with moderate to late stage dementia (Clare, 2010); therefore evidence at this level is limited. Many of the studies that have attempted to use such methods with the moderate to late population are subject to the methodological limitations previously discussed (Vasterling et al., 1995; Kotler-Cope & Camp, 1995; Verhey et al., 1993); therefore it will not be repeated here again.

Clare (2010) suggests that an appropriate approach to gaining evidence of awareness at this level, with people who can still communicate verbally is to hear what individuals say in response to open-ended questions; ideally when they are in their own familiar settings. In Clare et al's. (2008a,b) study of 304 conversations with 80 residents with moderate to late stage dementia, she reported that all participants showed evidence of awareness at the level of evaluative judgement in relation to objects such as aspects of self, relationships with others and the environment. Many individuals expressed awareness that their capabilities had lessened in comparison to before and that they were more dependent on others. They were also able to describe the impact of living in residential care. Thus, even some severely impaired participants were able to demonstrate some degree of awareness in the sense of making evaluative judgements. This typically involved either an inaccurate appraisal of current functioning or a difficulty in making sense of the current situation, leading to attempts to find an explanation based on past experience.

1.5.2.4 Meta representation

Meta-representation refers to the ability to engage in self-reflection at a meta-cognitive level when reporting on aspects of one's situation and its implications. There is little research directly exploring this level of awareness in dementia. However, evidence is provided by Clare et al. (2008a,b) who found that in conversations with 304 individuals with moderate to severe dementia, 64% of participants were able to express thoughtful considerations about aspects of their situations (e.g. living in residential home, loss, dying). Sixty-five percent showed an ability to take on another's perspective and recognise it as different from their own.

In summary, the evidence reviewed here suggests that while some aspects of complex awareness are impaired in moderate to severe stages of dementia, there is mounting evidence for the retention of a substantial capacity for awareness, even in the severe stages of dementia, at each of these different levels (Clare, 2010). The complexity of awareness means that its expression may be different across individuals and that a person with dementia may demonstrate retained and impaired awareness within the same level. Awareness may also fluctuate at any given time dependent on a number of biopsychosocial factors (Normann, Asplund & Karlsson, 2005; Clare, 2010) such as language ability, ill health, affective state, surrounding context, interpersonal dynamics, and may be modulated by psychological processes such as avoidance or denial (Weinstein et al., 1994).

1.5.3 Influencing the expression of awareness

A number of studies have attempted to investigate the extent to which it is possible to influence the expression of awareness. The literature cites evidence that expression of awareness may be promoted and hindered in people with moderate to severe dementia by a range of factors such as the environmental context and the nature of care-giving (Clare, 2010). These findings will be considered below.

1.5.3.1 Promoting the expression of awareness

It was thought that increasing underlying arousal at the sensory and perceptual level could aid a more extensive expression of awareness. Gotell, Brown and Ekman (2003) investigated the influence of different morning care routines on the responses of nine care home residents with severe dementia. Care routines were either carried out as normal by familiar nurses, or accompanied by the caregiver singing or with preferred background music. Participants were more responsive to the caregivers and to the environment in the music conditions, as well as to the process of care by reacting when clothes were put on by adjusting or straightening them. Participants also showed more recognition of objects and their orientation in the environment, used the mirror and appeared to recognise themselves, and used or manipulated items by themselves. These findings were interpreted as that music may have increased underlying levels of arousal in the participants which may have supported a more extensive expression of awareness. Similarly, a number of studies have found support from interventions aimed at increasing underlying levels of arousal, in that people with severe dementia show increased responsiveness or engagement as a

consequence of various kinds of environmental stimulation (e.g. Baker, Bell & Baker, 2001; Holmes, Knights & Dean, 2006; Tribet, Boucharlat & Mylinski, 2008; van Weert, van Dulmen & Spreeuwenberg, 2005).

Bologna and Camp (1997) provided support for increased awareness at an online monitoring level. They carried out an intervention with three individuals with severe dementia who did not recognise their own mirror reflection, either spontaneously or when asked 'Who's that?', and did not respond to the mark-and-mirror test (as outlined in section 1.5.2.2). Four different interventions were attempted with each participant. These involved providing a name badge, giving the person a hat or scarf to hold, giving the person a comb followed by instructions to comb their own hair, or placing a sign on the mirror reading 'Mirror'. All participants engaged in rearranging their clothes or hair in both baseline and intervention sessions, which the authors interpreted as a demonstration of implicit, or covert, self-recognition. During intervention, each participant recognised themselves explicitly following a verbal probe in one of the four conditions (a different condition for each individual). These findings suggested that implicit self-recognition continues to operate in the absence of explicit self-recognition, and that explicit self-recognition can be reinstated temporarily within the immediate context by providing an appropriate cue.

At an evaluative and meta-representative level there were few appropriate methods to assess awareness in the moderate to later stages of dementia; therefore, more studies using phenomenological methods were recommended (Clare, 2010). It was noted that few opportunities were provided for expression of awareness at these levels, particularly at the most complex level. Normann, Norberg and Asplund (2002) found that supporting people in

various ways during conversation could promote awareness. That is, by sharing the person's views, repeating, reformulating and reinforcing the person's positive utterances, episodes of lucidity were more likely to be elicited. They also, reported that awareness was more likely to be demonstrated when carers interacted closely with the person with dementia, did not make demands on them and valued them as people whose experiences were meaningful. These findings were reported across three different nursing homes (Normann et al., 1998).

1.5.3.1 Inhibiting the expression of awareness

Just as a number of studies have reported on the way in which environmental and care-giving factors can promote the expression of awareness at different levels, there is literature to suggest ways in which these same factors may hinder the expression of awareness in people with dementia.

A number of authors reported on how assumptions of unawareness from caregivers could affect the way they interacted with the people with dementia. Magai et al. (1996) reported that nursing staff sometimes made distinctions between residents who were responsive to interactions and those who were not. Norberg et al. (1986) proposed that a lack of contact and stimulation, or sensory overload (e.g. noisy environments) could result in an individual withdrawing, which could potentially lead to a further lack of communication and stimulation (Magai, Cohen & Gomberg, 1996; Norberg et al., 1986). Thus, assumptions of unawareness could create a cycle in which the care-givers' motivation to interact with the individual who has dementia decreases, leading to the individual being less likely to show

signs of awareness, resulting in further reduced interactions by caregivers (Magai et al., 1996; Norberg et al., 1986).

Further to this Ballard et al. (2001) reported how deprived care settings, with non-stimulating environments and a lack of occupation are likely to hinder the expression of awareness. While, Normann et al. (2002) reported that awareness can be impeded by emphasising an individual's errors and making demands upon their attempted speech.

In summary, the findings outlined above have emphasised that the expression of awareness involves an interaction between the individual with dementia and the environmental context. In this interactional framework, the expression of awareness is facilitated by a supportive context and by appropriately sensitive interactions, and when these elements are lacking, the expression of awareness can be inhibited.

But, what do care staff understand about awareness in the moderate to later stages of dementia and their potential to observe, promote or hinder its expression? This is considered next.

1.5.4 Staff perceptions of awareness in the moderate to late stages of dementia
There are suggestions in the literature that carers in residential settings may develop assumptions about the level of awareness their clients with dementia retain (Clare, 2010),

and that nursing aides distinguished between residents they considered to be responsive and unresponsive to interpersonal interactions (Magai et al., 1996). Also, it is noted that even people with dementia who no longer communicate verbally (Laureys, Owen & Schiff, 2004) may demonstrate considerably more awareness than is assumed on the basis of the severity of their illness (Clare et al., 2008a). Yet, there is no research to date that directly explores staff perceptions of awareness or unawareness in clients in the moderate to late stages of dementia.

It is important to acknowledge that the researcher anticipates that 'unawareness' is likely to be the predominant experience that carers will have of working with people in the moderate to late stages of dementia. Clare et al. (2008a) reported that instances of unawareness were more commonly encountered by researchers than instances of awareness, and that staff perceptions may be dominated by biological constructs (e.g. symptomology, deterioration, behavioural difficulties, and increased dependence as a consequence of dementia). However, this research aims to look beyond the impact of the biological aspect of the disease and explore the psychosocial aspect of the staffs' experiences. It is anticipated that staffs' perceptions will be filtered through a range of psychosocial factors such as training, mood, the quality of relationship with the resident, personal experiences of dementia, distress of working with people at the end of their lives, personal coping strategies, and stress factors (Zimmerman, Williams & Reed, 2005; Edvardsson, Sandman & Nay, 2009).

1.6 RATIONALE AND AIMS FOR THE CURRENT STUDY

1.6.1 Background

1.6.1.1 Population changes

Due to successes in combating preventable deaths and improvements in Public Health and Welfare provisions, the demographic tide of society is being reshaped. Life expectancy is increasing, 16% of the UK population are over 65 years (Office for National Statistics, 2009) and the fastest growing age group in the population are those aged 80 years and over (currently constitute 4.5 per cent of the total population). The number of older adults in the UK is forecast to continue growing in the next 10 years, with the population of over 65s increasing by 15% and the population of those over 85 increasing by 27%. It is estimated that in the next 30 years, the number of people with dementia in the UK will double to 1.4 million (Office for National Statistics, 2009). A population that lives longer ultimately means that more individuals will experience dementia (unless advances in dementia medication prevent this). Therefore, it is important to understand more about the capacity for retained awareness throughout the course of the disease in order to be able to respond appropriately to individuals' needs and to promote quality care for people with moderate to severe dementia.

1.6.1.2 Services provisions and policies

Dementia presents a huge challenge to society, both now and increasingly in the future. Recent reports and research have highlighted the shortcomings in the current provision of dementia services in the UK. Dementia currently costs the UK economy £17 billion a year

and, with the costs estimated to treble in the next 30 years to over £50 billion a year. Direct costs of dementia to the NHS and Social Care are in the region of £8.2bn annually (Alzheimer's Society, 2007).

The Government has identified dementia as a national priority and launched The National Dementia Strategy (2009). Two of the strategy's main aims were: to improve understanding of dementia, both among the general public and among health and social care professionals, to and to deliver a high quality of care and support for both those with dementia and their carers. A number of policies have emerged which also have a heavy emphasis on enhancing the quality of life of people with dementia at all stages of the illness through the provision of good-quality care. These include, Alzheimer's Society's Dementia UK report (2007); National Dementia Strategy (DoH, 2009); National Audit Office's Improving services and support for people with dementia; the 'Home from Home' report (Alzheimer's Society, 2008); and 'See me, not just the dementia' (CSCI, 2008).

A key tenet to many of the policies relating to caring for people with dementia is person-centred care, an approach that emphasises the need to enter into and understand the experiential world of the individual with dementia, attempting to see things from their perspective, with the aim of being able to respond more helpfully and offer better support to the individual with dementia (Kitwood, 1997). Yet, despite some policies highlighting the need to implement person-centred care and improving the quality of care for people with dementia, many care homes are still not providing the level of care which is essential,

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('Improving services and support for people with dementia' (National Audit Office, 2007) and 'Home from Home' (Alzheimer's Society, 2008). More recently the Ombudsman report (Care and Compassion, 2011) highlighted that basic standards of care for older adults are still not being met in some places.

1.6.1.3 Rationale

The research on awareness in the moderate to later stages of dementia is still in its infancy. Even less is known about how the professionals who directly care for those in the moderate to severe stages of dementia perceive awareness in their clients. Without understanding what staff observe, how they interpret their observations and how this shapes their beliefs about awareness, there may be poor integration between what is asserted on the basis of theory (concept of awareness) and how this actually translates into clinical practice (clinical phenomenon of awareness).

At this point it is important to reiterate that awareness is not a unitary construct and that the expression of awareness can be enhanced and inhibited by various environmental and care-giving factors. Furthermore, assumptions of awareness or non-awareness can have an impact on the way an individual with dementia might be responded to and ultimately, have an effect on the way the resident has their needs met, and subsequently their quality of life. Therefore, to investigate how care staff perceive awareness in residents with moderate to late stage dementia has potential applications in the clinical, research and training domains.

1.6.2 Aims

Based on a comprehensive review of the literature and in line with the evidence presented, it can be argued that as dementia progresses, people with dementia enter a phase where the objective tests (e.g. self-report scales, neuropsychological tests and neurological examinations) of awareness (across the four levels of awareness) become insensitive. It may only be via 'participant observation' that the sensitive detection of fluctuations in awareness in the later stages of dementia can be elicited. Therefore, the aim of this research is to explore if staff carers in EMI settings detect fluctuations in awareness in the residents during their routine interactions of care. To explore if there are situations when this is more likely to occur? How do staff make sense of their observations and how do they respond to any observations of awareness?

The hierarchical model of awareness proposed by Clare (2010) was used as a framework for examining staff members' perspectives on awareness at each level. The study focused on staff members who worked in EMI residential settings, as EMI nursing or residential settings are more likely to have residents with dementia. Over 60% of EMI settings offer 'specialist' services to people with dementia, and provide dementia training to staff as compared to non-EMI settings (Reilly, Abendstern & Hughes, 2006).

The interview questions were constructed to be neutral, curious and sensitive to allow both observations and beliefs held by staff to be explored. It also aims to allow insights into the process of how observations of explicit or implicit behaviours (communications, actions, etc.) associated with awareness, shape conclusions reached and beliefs held by care staff.

CHAPTER TWO: METHODOLOGY

2.1 OVERVIEW

The following chapter will describe how the research was developed and carried out. The study design will be presented along with the philosophy and rationale for choosing the qualitative methodology used. Ethical considerations and how standards for ensuring quality were adhered to will be summarised, together with the process of participant recruitment, a description of the data collection, and analysis procedures. Brief descriptions of participants' profiles will also be included in this chapter.

2.2 DESIGN

A qualitative design, guided by the principles of Grounded Theory (Glaser & Strauss, 1967) was used to explore and develop an understanding of how staff members, who provide direct care to people with moderate to severe dementia in Elderly Mentally Infirmed (EMI) settings, make sense of awareness in their clients. The research involved using semi-structured interviews with nine participants. The data from the participants' narratives was then analysed in order to elicit themes, which were then combined to generate a theory regarding staff perceptions of awareness in people with moderate to late stage dementia.

2.2.1. Rationale for a qualitative design

Qualitative methodology provides a means for pursuing an interpretative investigation of a specific issue or phenomenon (Banister, Burman & Parker, 1995). Qualitative methods are concerned with the construction of meaning about how people make sense of events in their world, and the *'quality and texture of these experiences'* (Willig, 2001 p9). It is

acknowledged that qualitative research methods enable a 'deeper' understanding of social experience and are well suited for obtaining complex information about thoughts, feelings and experiences, which would be difficult to access using quantitative methods, that traditionally attempt to measure 'variables' using statistical methods (Strauss & Corbin, 1998). Qualitative research allows the researcher to tap into participants' perspectives that may not have been anticipated or accessible through quantitative methods, thus facilitating the generation of novel insights and new understandings (Willig, 2001).

The current study aimed to explore how staff who provide direct care to people with moderate to severe dementia make sense of awareness, as displayed during their interactions with these clients. A qualitative methodology was considered to be appropriate as it would facilitate an understanding of participants' ideas of the phenomenon of awareness. Furthermore, Barker et al. (2002) suggested that quantitative approaches are the most appropriate methodology to employ when addressing limitations of the research literature. As aforementioned in Chapter One, there is a dearth of existing literature on staff carers' understandings of awareness in people with moderate to severe dementia. Therefore, a qualitative approach was thought to be an appropriate methodology to employ.

2.3 GROUNDED THEORY

2.3.1 Philosophy and rationale

Grounded Theory is one of a number of different qualitative approaches (Pigeon & Henwood, 2003). The approach was initially developed by Glaser and Strauss (1967) who argued that quantitative methods did not permit new theories to materialize from the data collected. The Grounded Theory approach to data analysis is proposed to facilitate the generation of theory that is ground within the data, as opposed to being restricted by analytical constructs, categories or variables from pre-existing theories (Willig, 2001 p.9). Since the original development of Grounded Theory (Glaser & Strauss, 1967), the authors have revised and separately conceptualised the model. The current research was guided by the Grounded Theory approach expressed by Corbin and Strauss (2008) as this recognises the role of existing theory in sensitising the researcher during the research. Grounded Theory was chosen rather than other qualitative methods such as Interpretative Phenomenological Analysis, as it is used to investigate new areas of research as a means of developing a theory and can also be used to investigate a topic in need of further development (Strauss & Corbin, 1998). Furthermore, Grounded Theory is suggested to be one of the more validated and tested qualitative methods (Ponterotto, 2002).

Limitations and criticisms of Grounded Theory generally concern the approach's epistemological foundation, in that despite being inductive in its approach it is still based upon a positivist and empiricist epistemology and the 'truth' is sought from the data (Willig, 2001 p.3). It is unlike other qualitative approaches that stem from a 'constructivist'

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epistemology, and suggests that knowledge is produced or constructed by people and within cultures, societies and historical relationships (Pidgeon, 2003). In order to aid reflexivity and transparency about how the theory has been constructed, Pidgeon and Henwood (2003) suggest that the researcher should carefully document each stage of the research process.

2.3.2 Grounded Theory Procedure

In Grounded Theory the process of data collection and analysis occur concurrently with the researcher moving between the two in an attempt to 'ground' the theory in the data as much as possible. Data analysis involves the progressive identification of categories of meaning and their integration to form an explanatory framework. Thus the term 'Grounded Theory' refers to both the method and the product of inquiry (Charmaz, 2006). Corbin and Strauss (2008) state that Grounded Theory analysis involves taking the data apart, conceptualising it and then 'developing those concepts in terms of their properties and dimensions, in order to determine what the parts tell us as a whole'.

The procedure involved using 'constant comparative analysis' to identify similarities and differences within and between categories to allow further categories or sub-categories to emerge. Thus, the researcher breaks down the data into smaller units while simultaneously merging units of data from broader categories.

The procedure involved using 'theoretical sampling' to collect further data 'in light of earlier categories that have emerged in the data' (Willig, 2001). Through theoretical sampling the researcher was able to progressively refine the emerging theory by modifying the interview questions in order to elaborate and challenge its developing constructs. Coding and sampling continued until the point 'theoretical saturation' was reached. That was, the researcher continued to sample and code the data until no new categories could be indentified and new instances of variation cease to emerge. Theoretical saturation is a goal in Grounded Theory analysis rather than a reality as modifications or changes in perspective are always possible, therefore Grounded Theory is always provisional (Willig, 2001).

A key strategy used throughout the research process was 'memo-writing', which involved the researcher keeping written memos of the development of categories, interpretations and themes evoked by the interviews and transcripts. This allowed the researcher to gain analytical distance from the data.

While the process of Grounded Theory is flexible, the method followed a broad progression from initial data collection through to increasingly refined and abstract levels of collection, finally arriving at a general analytic framework and theory (Pidgeon & Henwood, 2003).

2.3.3 Reliability and validity

The popularity of qualitative methodology over recent years has led to increased scrutiny of the quality of qualitative methodologies and guidelines to improve the credibility of

qualitative research (Pope & Mays, 2006). For instance, based upon a literature review and peer consultation, Elliott et al. (1999) proposed a set of guidelines to maximise the scientific rigour, credibility, reliability and validity of qualitative research. These are outlined below with the aim of demonstrating how quality and methodological rigour were pursued in the current research:

- *Owning one's perspective* – The researcher should specify their own values, assumptions and interests and the role that these play in the collection and interpretation of the data. This is in order to reduce the potential for the researcher to be influenced by their own philosophical stance, schools of thought, experiences, values and priorities (Pidgeon, 2003). This was achieved in the current study by the researcher outlining her background, perspective, orientation and beliefs in section 2.3.4 with the aim of being transparent about how these could influence the research process.

- *Situating the sample* – The researcher should describe the participants and their life circumstances to aid the reader in determining the generalisability of the findings. This was achieved in the current study by presenting the participants' demographic information, which was sought from them at the start of the interview process and is outlined in sections 2.5.4 and 2.5.5.

- *Grounding in examples* – The researcher should provide examples of the data to illustrate the analytical procedure utilised in the study and the understandings developed from them. In the current study, examples are used to illustrate categories and concepts taken from the data (see Results Chapter).

- *Providing credibility checks* – The researcher should check the credibility of the categories to ensure their analysis accurately reflects the data. This allows the reader to assess the fit between the data and the subsequent interpretation. This could be achieved in a number of ways (e.g. conducting a focus group). The researcher had planned to conduct a focus group but it was not possible (see section 2.6.3). However, credibility checks were achieved by triangulating the data in number of other ways (see below).

- *Triangulation* – The researcher should check the credibility of the categories to ensure their analysis accurately reflects the data. In this current study the data was triangulated by discussing the concepts and categories with both clinical and academic supervisors. Specifically, the coding of one interview was initially scrutinised with the researcher's supervisors. After the fourth interview the coding and emerging themes were reviewed again. Consideration was given to the ways in which the remaining interviews might be used to explore and elaborate on the data that had emerged so far. For instance, how participant's beliefs about awareness and dementia had been formed and how they were framing their disclosures and observations, whether the data was fitting the hierarchical theoretical framework, whether the dimensions of the illness perception model (see page 55) were applicable.

- *Coherence* – The researcher should present the data, analysis and findings in a way which fits together to form a narrative account or framework in which the phenomenon under investigation can be understood. Examples from this study can be found in the results section in diagrammatic and written form (see Chapter 3).

- *Accomplishing general versus specific research tasks* – The researcher should be explicit in their intentions to either create a general understanding of a phenomenon or a specific instance. These should be described systematically and comprehensively enough for the reader to understand the phenomenon under investigation. While the researcher acknowledges that the current research presents the views of just nine participants, it is possible that these views may reflect commonly held views of staff carers in residential EMI settings. The limitations of the design and data will be considered in the discussion chapter.

- *Resonating with the reader* – The researcher should present the report in such a way that the readers can judge it to have accurately represented the subject matter or to have clarified or expanded their appreciation of it. This was attempted throughout the thesis.

The guidelines outlined above were incorporated into the research process from design to report, as far as possible.

2.3.4 The researcher's position

As outlined in section 2.3.2 owing one's perspective is an important element in maximising the quality of qualitative research. Therefore the researcher has outlined below her own beliefs, orientation and personal interests in the subject matter.

The researcher is a 35 year old, white, single woman from a working class background in South Wales. The researcher initially became interested in working with older adults during

a placement in this specialty. Prior to this she had little personal or professional experience of being with older adults or of dementia. The only personal experience the researcher had of directly being with an individual with dementia was occasional contact with her next door neighbour Violet, who the researcher knew throughout her childhood. Violet developed Alzheimer's disease approximately 15 years ago and was cared for at home by her daughter until she eventually died in the late stage of Alzheimer's disease. The researcher always made a point of holding Violet's hand and talking to her for short periods when visiting the family next door. Despite having little understanding of dementia and stages of dementia at that time the researcher believed that it was important to continue showing Violet such respect just in case she was 'in there' and aware in some way. On rare occasions Violet would remember the researcher's name during these interactions and say her name out loud, despite her language being extremely limited.

Professionally, the researcher had clinically assessed (using neuro-psychological assessments tools) a small number of older adults who were in the early to moderate stages of dementia who were referred to the older adult specialty where she was placed. Her professional contact with older adults did not include working in EMI residential or nursing homes or with direct care staff in these settings.

2.4 ETHICAL CONSIDERATIONS

2.4.1 Ethical approval

Research proposals were submitted to the host Trust's Research and Development (R&D) committees and Local Ethics Committee (LREC) for approval. Approval was granted by the necessary committee in November 2010 (see appendix A), and by LREC in December 2010 (see appendix B).

2.4.2 Informed consent

Verbal and written consent was gained from the participants during the recruitment and data collection phases of the research. In order for the potential participants to make an informed decision about taking part in the research an information sheet, which outlined the details of the study, and consent forms were developed by the researcher. The potential participants were asked to read through the information sheet and carefully consider whether they would like to participate in the study. The researcher provided the opportunity for interested participants to ask further questions before signing a consent form. Telephone numbers were provided where the participants could gain further information about the study without obligation to take part. Participants were reminded of their right to withdraw from the study at any point without explanation at various points during the process.

2.4.3 Confidentiality and anonymity

Confidentiality was maintained in line with the Data Protection Act (1998). In order to protect the participants' confidentiality the interview transcripts were anonymised and participants were assigned pseudonyms. Each participant's contact details (e.g. telephone number, address) were destroyed following their participation in the research. Anonymised data was only viewed by the researcher and research supervisors. Following data analysis the transcripts were stored in a locked cupboard at the clinical psychology training programme (NHS premises), where they will be stored for 5 years in accordance with data storage principles.

Confidentiality is a key aspect of any research study and researchers have an obligation to take precautions to protect confidential information. The researcher of this study is bound by the British Psychological Society Code of Ethics and Conduct (BPS, 2009), and therefore participants were informed that their information would remain confidential unless issues pertaining to risk became evident during their interview. Limits of confidentiality were described in the participant information sheet and made reference to again in negotiating informed consent with participants.

2.5 PARTICIPANTS AND RECRUITMENT

2.5.1 Sampling process

In order to access participants whose work involved direct interaction with people in the moderate to late stages of dementia, EMI homes were targeted. These settings are

considered to be the most likely settings in which to find a homogeneous sample of participants fitting the research criteria. Reilly et al. (2006) suggested that EMI nursing or residential settings are significantly more likely to have residents with dementia. Over 60% offer a 'specialist' service to people with dementia, and provide dementia training to staff, as compared to non-EMI settings. Furthermore, preliminary consultation with EMI service managers and within the older adult clinical psychology service suggested that older adults with dementia tend to enter EMI settings when they are in the moderate to late stages of the disease.

All EMI settings from which staff were recruited were within one Heath Board area in South Wales.

2.5.2 Recruitment

Initially consent was sought from EMI residential and nursing setting managers to advertise for research participants. Posters advertising the research were displaying in the settings in which consent was granted. The recruitment poster (see appendix C) gave potential participants an option to either fill out their contact details on a return slip, thus consenting to the researcher contacting them directly (see appendix D), or to contact the researcher directly by telephone to register their interest and request more information about the study.

Twelve participants responded to the recruitment advert, nine of whom met the inclusion criteria (see below). As will be outlined below, the participants provided a reasonably representative sample of the dementia care profession in age, gender, experience, and training. The participants were also recruited from five different EMI residential homes, in order to reduce the likelihood that the care culture in a single setting could bias the results.

2.5.3 Inclusion and exclusion criteria

Inclusion criteria

- Qualified and unqualified professionals who were employed in an EMI setting and provided direct care for people aged 65 years and over, who were in the moderate to severe stages of dementia.
- Staff who had at least one year of experience in providing care for people over 65 years with moderate to severe dementia.
- Staff who were able to commit to an interview that may last up to 90 minutes and consent to being contacted again to be invited to a focus group.
- Staff who were able to communicate well in English and did not require the support of an interpreter.

Exclusion criteria

- Staff who did not work in an EMI setting.
- Non-professionals who provide care for people over 65 years with moderate to severe stages dementia (e.g. volunteers, family members).

- Staff who had less than one year experience of working with this population.

- Staff who had worked with people predominantly in the early to moderate stages of dementia.

- Staff without a functional level of English language such that they would have required the support of an interpreter.

2.5.4 Participants group demographics

Nine individuals participated in the interviews, eight females, and one male. Participants ranged from 24-63 years of age (mean age of 37 years). All participants described themselves as white, Welsh. Participants' experience of providing direct care to people with moderate to late stage dementia, ranged between 14 months and 25 years (mean of approximately 6.8 years experience). Eight out of nine participants reported having attended dementia training. Six of the nine participants reported having personal experience of someone with dementia in their family.

2.5.5 Participants profiles

Participant one: Elizabeth

Elizabeth was a 62 year old, white Welsh woman who had been working as an auxiliary nurse in dementia care settings for 25 years. Elizabeth had worked with people across a range of severities of dementia throughout her time nursing. At the time of the research interview she was employed in a ten bed EMI residential setting. She estimated 50% of the residents to be in the moderate to late stages of dementia and she observed that increasingly residents were admitted to the facility in the moderate stages already.

Participant two: Jayne

Jayne was a 34 year old, white Welsh woman, who had been working for 14 years with people across different stages of dementia. She was currently employed as a deputy manager in an EMI residential setting, which was the home to 8 people with dementia. She estimated that approximately 50% of the residents were in the moderate to late stages of dementia.

Participant three: Sally

Sally was a 36 year old, white Welsh female who worked as a senior care assistant in an EMI residential home. Sally had 2 years experience of working with older adults at different stages of dementia. She estimated that approximately 50% of the 16 residents in the home had moderate to later stage dementia.

Participant four: Steve

Steve was a 41 year old, white Welsh man who had worked as a care assistant for 16 months with older adults in an EMI residential home. Steve estimated that approximately 60% of the individuals he cared for were in the moderate to late stages of dementia.

Participant five: Louise

Louise was a 28 year old white, Welsh woman, who had held the position as a senior care assistant in an EMI residential home for the past 4 years. She estimated that 50% of the people she cared for were in the moderate to late stages of dementia.

Participant six: Joan

Joan was a 63 year old white, Welsh woman who had worked as a care assistant in the EMI home for the past 8 years. She estimated that 50% of the people she cared for were in the moderate to late stages of dementia.

Participant seven: Laura

Laura was a 43 year old white, Welsh woman who had worked as a care assistant for the past 3 years. She estimated that all of the residents in the EMI home were in the moderate to late stage of dementia.

Participant eight: Shirley

Shirley was a 57 year old white, Welsh, woman who had worked as a care assistant for the past 20 years and cared for people with all levels of dementia during this period. She estimated that 8 of the 9 residents she cared for were in the moderate to late stage of dementia.

Participant nine: Mim

Mim was a 53 year old white, Welsh, woman who had worked as a care assistant for the past 10 years with experience of providing care for people in all stages of dementia. Mim estimated that 50% of the residents she provided care for were in the moderate to severe stages of dementia.

2.6 INTERVIEWS AND PROCEDURE

2.6.1 Individual interviews

Individual interviews were carried out with nine participants. Grounded Theory typically involved one-to-one semi-structured interviews in which the interview schedule is used as a framework to guide and prompt the research interview, rather than to dictate its specific wording. This enabled the researcher to use prompts to explore areas of interest and relevance. The non-directive and open ended nature of a semi-structured interview also allows participants to expand on ideas that are pertinent to them, thus guiding and shaping how the interview unfolded.

In the current study the semi-structured interview schedule (see appendix E) was developed in consultation with the researcher's clinical and academic supervisors, who had extensive clinical experience of working with older adults. The questions were initially refined through discussion with the researcher's academic supervisor, before discussing the clinical resonance and sensitivity of the questions with the clinical supervisor. Finally, a staff carer who fitted the research criteria was asked to comment on the questions. As a result of this

process and in order to enhance the accessibility of the questions, changes were made to the wording of some questions, which were thought to be too complicated.

The development of the interview questions were influenced by the available evidence regarding awareness in the moderate to severe stages of dementia. In particular, Clare (2010) proposed a conceptual framework in which awareness in the moderate to late stages of dementia could be understood and researched. Clare's framework suggests that the expression of awareness operates hierarchically, at different levels of complexity. The literature also suggests that awareness and opportunities to observe its expression, could be promoted and inhibited by factors such as care interactions (Elliott, Coleman & Shiel, 2005; Ballard et al., 2001).

The illness perception model (Leventhal, Benyamini & Brownlee, 1997), which is a well established model that provides a framework for explaining how individuals make sense of components of illness (e.g., symptoms, cause, control, timeline, consequences), was also used to inform and shape the questions.

2.6.2 Individual interview procedure

The interviews were arranged at a time and location most convenient to the participants, in order to minimise inconvenience. At the start of the interview participants were reminded of their right to withdraw from the study at any time, without needing to provide an

explanation. Participants were asked if they had read the information sheet (see appendix F) and were given the opportunity to have any queries about the study addressed. Finally, the participants were asked to sign the consent form (see appendix G).

All interviews were audio-taped and transcribed for analysis. The interviews were varied in duration, ranging from 40 minutes to 65 minutes. After the interviews participants were given the opportunity to discuss the personal impact of the interview. Measures were in place to provide support for participants in the event that they were to become distressed. However, this situation did not arise.

2.6.3 Focus group interview

Focus groups are organised group discussions around a central theme (Krueger, 1988). Focus groups aim to elicit participant's feedback on the preliminary analysis of the data as a way of validating the categories and concepts from the individual interviews. This can potentially add richness to the data by allowing participants to explore and jointly construct meanings of the themes that emerged through the analysis of the data. Willig (2001) suggested that a focus group can act as a credibility check and add validity to a study by ensuring that the researcher's analysis accurately reflects the participant's experiences. Through group discussion participants have the opportunity to listen to and reflect on other participants (Marshall & Rossman, 2006). It is acknowledged that within a focus group not all concepts will apply to every participant but the theory should at least be recognisable to them (Strauss & Corbin, 1998).

All participants consented to being contacted with an invitation to attend a focus group. However, due to restrictions of different shift patterns and other commitments, only two participants were able to attend one of the several dates set. As these particular participants held similar views regarding awareness, it would not have been possible for them to validate the other perspectives that emerged in the data; therefore, a focus group was not conducted and the data was validated as outlined in section 2.3.2.

2.7 DISSEMINATION OF RESULTS

Following the completion of the research study a summary of the results was forwarded to the participants who had indicated on the consent form (signed at interview) that they would like a copy. The summary provided a brief précis of the main findings and an outline of the clinical and service implications. It is anticipated that the study will be written up and submitted for publication in a relevant journal. The findings may also be presented to local older adult services and relevant professional meetings.

2.8 DATA ANALYSIS

Data analysis were achieved by the researcher following the Grounded Theory procedure as outlined in section 2.3.1.

2.8.1 Categories and coding

The early stage of data analysis is referred to as 'open coding', a process which is largely descriptive (see appendix G). Concepts are identified and labelled in a way that captures the essence of a section of the interview, which will allow other sections of data with similar meaning to be grouped together (Willig, 2001). As the research progresses 'axial coding' is used to integrate lower level concepts into higher level units of meaning or categories (Willig, 2001). Categories refer to groups of data that share central features or characteristics with each other, which could be either descriptive or more analytical in nature, where sections of data are interpreted rather than purely labelling a particular phenomenon. Categories are not specified prior to data analysis (as in content analysis) but emerge and evolve throughout the research process. 'Selective' coding is then used to obtain *core* categories to which all other concepts, categories and subcategories could be related and understood. Selective coding involves incorporating and refining categories and organising them around a central explanatory framework. As aforementioned memo writing is an important part of the grounded theory process. An extract from the memo writing process can be seen in Appendix I.

In Grounded Theory the researcher 'interacts with the data' by moving from descriptive to analytical coding, asking questions of the data and making constant comparisons, which helps to elaborate and modify the original construct. This process is referred to as 'theoretical sensitivity' (Willig, 2001 p.35). Theoretical sensitivity is derived through what the researcher 'brings to the study' and through 'immersion in the data' from data collection to analysis (Corbin & Strauss, 2008). The researcher's theoretical sensitivity may

influence the ways in which categories are linked to each other, which is referred to as 'theoretical coding' (Willig, 2001). Debate exists within the literature regarding whether this theoretical coding is appropriate or places a restriction on the analytic process (e.g. Glaser, 1992).

CHAPTER THREE: RESULTS

3.1 OVERVIEW

This chapter presents the results of the data collected from the nine participants' narratives. The key themes that emerged from the data analysis will be outlined. These themes are arranged into core categories, sub-categories, and concepts. For ease of reading the results will be presented60 in the following convention, both within the text and the figures; **CORE CATEGORIES** will be written in uppercase bold print, **sub-categories** with be written in lowercase bold print, and <u>concepts</u> will be underlined in lower case print. Each core category is presented in a figure showing its associated sub-categories and related concepts.

Three core categories emerged from the participants' narratives including; **'SENSITIVITY TO FLUCTUATIONS IN AWARENESS'**, **'SENSE MAKING'** and **'CONSEQUENCES FOR CARING'**. These will be presented in turn below, and include a definition of each category and concept, followed by comments and illustrative quotes. Following a detailed description of the results, a diagrammatic model will be presented in Figure 3.15 to demonstrate how the core categories are linked. Further explanation of the model will be provided at that point.

3.2 CORE CATEGORY: SENSITIVITY TO FLUCTUATIONS IN AWARENESS

The category **'SENSITIVITY TO FLUCTUATIONS IN AWARENESS'** refers to staff carers' observations of expressions of awareness or behaviours in relation to an object (e.g. internal states, performance of behaviours directed toward an external object). All of the

participants reported fluctuations in awareness, even if they did not recognise the moments of lucidity as awareness. These observations represent the participants' sensitivity to fluctuations in awareness, and the fleeting nature of awareness that was not simply related to an ongoing deterioration.

This core category is largely in support of the framework proposed by Clare (2010) in Chapter One, in that all of the participants shared observations of awareness at each level Clare outlined. These included observations of sensory and perceptual awareness, on-line monitoring, evaluative judgements and meta-representations. Due to this, the sub-categories use the same terms as Clare (2010). A sub-category emerged in the data that was not in support of Clare's findings regarding awareness in the moderate to late stages of dementia. This was that the participants did not necessarily view awareness as operating hierarchically.

All of the participants made distinctions between the moderate and late stages of dementia and how the expression of awareness is different at these two stages. Six out of nine participants believed that residents were able to retain some capacity for awareness until the end of the disease, while three participants believed that residents in the later stage of dementia did not retain awareness. These participants suggested that people in the late stages of dementia lost awareness even at the fundamental level of sensory or perceptual awareness (e.g. lost the capacity to experience pain, emotions, hunger). Those participants,

who had concluded awareness was retained, suggested that it fluctuated as it interacted

with other factors such as lack of stimulation, medication, infection, or degree of dysphasia.

Figure 3.1 Diagrammatic summary of the core category 'SENSITIVITY TO FLUCTUATIONS IN AWARENESS and its sub-categories, and related concepts
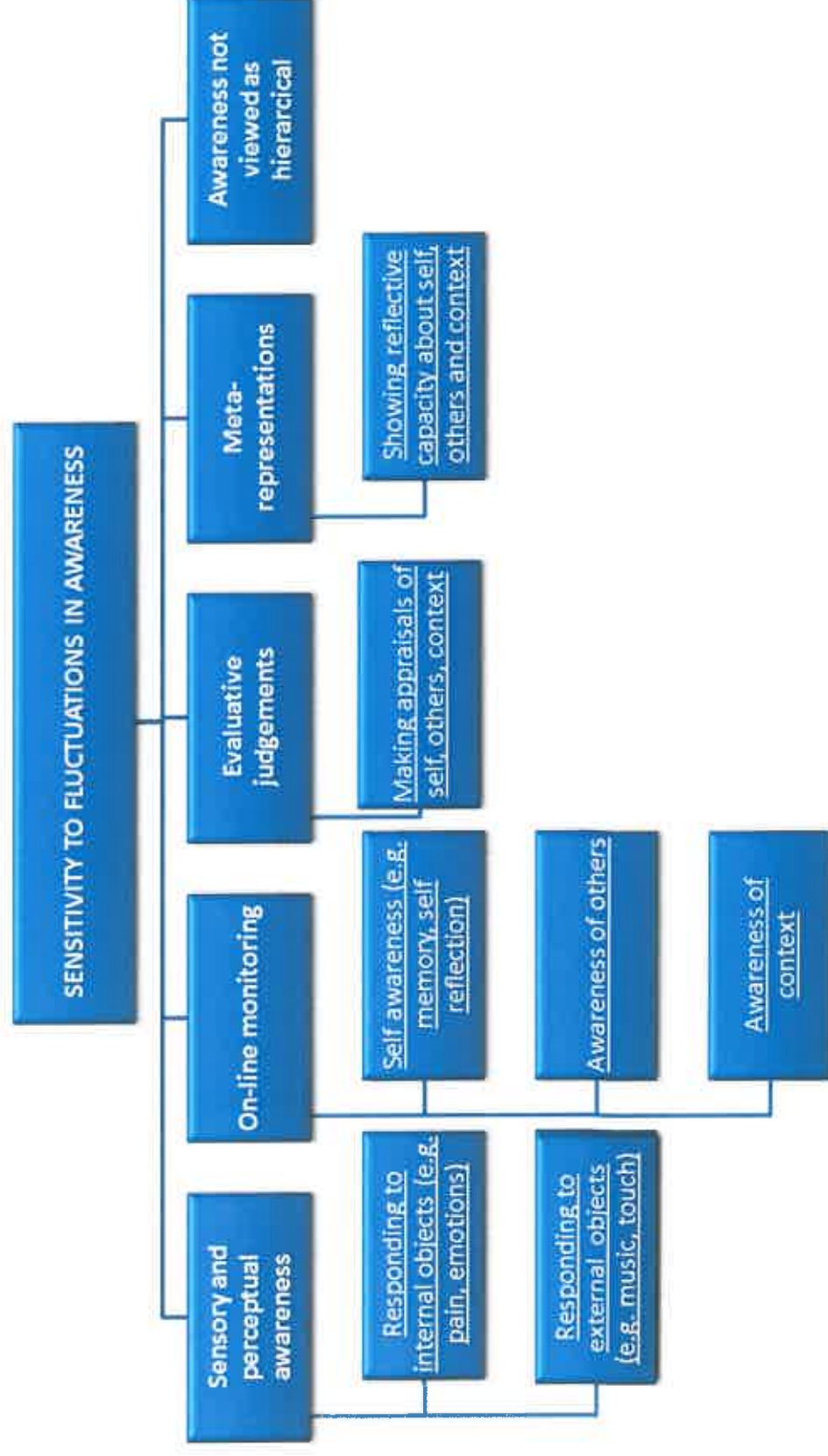
3.2.1 Sub-category (1) 'Sensory and perceptual awareness'

Figure 3.2 Diagrammatic summary of sub-category one
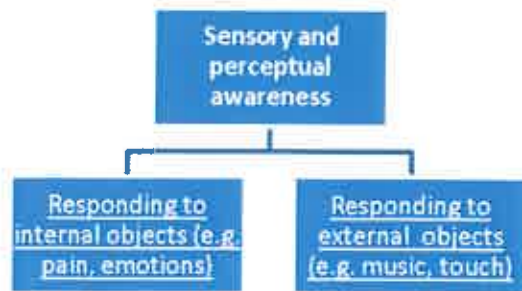
The sub-category **'sensory and perceptual awareness'** refers to observations made by participants relating to residents' responses to internal objects (e.g. pain, hunger, and emotion) and to external objects (e.g. music and touch). The majority of staff members talked about these factors:

Concept one, <u>responding to internal objects (e.g. pain, emotions)</u>

> *"Lilly who I was talking about with the late stages of dementia who can't speak; she had blisters on her body and her husband said 'she's ok, she's not in any pain with them, she's fine'. Well, she has a shower here; her husband doesn't shower her at all in the home and when we put the shower head on her the water hit the blisters and she actually grimaced and went 'ooosh' and you know so obviously to me that indicates that she still feels pain..."* (Jayne)

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"I see that when their families go they get really distraught. It starts

them off again remembering that they should be with them and all

things like that". (Elizabeth)

Concept two, <u>responding to external objects (e.g. music, touch)</u>

"We had artists here a couple of days ago for one gentleman's 90th

birthday and the songs that this artist was singing got every one of

them clapping their hand or their feet were moving. It fetches it back,

the memories back of years ago. They were singing along to pit songs

and they were clapping and their feet were moving. So I do think they

have...it did come back. It may have only been for a second or two but

it did come back". (Sally)

"I think all of our clients whether it's the middle stages or later do

respond to touch. They do, I think so anyway...and sometimes music.

One of our ladies will say 'put Apple blossom time on'. She is in the

moderate stages. Toward the end stages I do think they respond to

touch because they sometimes just put their hand on yours". (Joan)

3.2.2 Sub-category (2) On-line monitoring

Figure 3.3 Diagrammatic summary of sub-category two

The sub-category **'on-line monitoring'** refers to the observations made by participants relating to the residents expressing awareness of events occurring in the 'here and now', such as awareness of self, others and their context. The majority of participants reported situations in which residents showed awareness in the three concepts outlined below.

Concept one, <u>self awareness (e.g. self-reflection)</u>

> *"We've got a lift out there with a big mirror and some of the residents*
> *stand looking in it and say 'look at my hair'. But then you fetch them*
> *out of the lift and they don't know where they are...and they go down*
> *to that big lounge every day and they swear that they have never*
> *been down there before".* (Sally)

> *"Our Ethel, she goes up to the toilet, but doesn't go to the toilet, but*
> *she will look in and tidy her hair. We say 'oo that looks nice Ethel, do*
> *you want to go to the toilet now?' and she says 'no'. She just grabs a*

handful of tissues, shoves them up her sleeves and does not think about going to the loo". (Joan)

Concept two, <u>awareness of others</u>

"They recognise if someone is sitting there and they say "where's my friend gone?"....and perhaps the person has gone to another EMI..."where's that lady gone"...and then they follow each other sometimes, the ones that can walk". (Elizabeth)

"What we have a lot is people saying, 'I'm not staying here, they are mental' about other people. So they've got awareness that those around them have got some kind of mental problem for want of a better word, but not necessarily aware that they've got the same as those around them". (Jayne)

Concept three, <u>awareness of context</u>

"I wouldn't say so much [awareness of] hunger and thirst but as for the snow and things like that, I would outside visual things then, yeah definitely". (Louise)

"Well, when she is crying and asking to go home, she is aware that she is not in her house and she is somewhere where she shouldn't be, or where she thinks she shouldn't be. And some of them do blame their families as well. We have got one lady upstairs that says 'I'm going to kill my husband, I'm going to kill my son for putting me in a home'. So, some of them do have some sort of awareness that they are in a home, but like I said ten minutes later then have forgotten again". (Sally)

3.2.3 Sub-category (3) 'Evaluative judgements'

Figure 3.4 Diagrammatic summary of sub-category three

The sub-category **'evaluative judgements'** refers to the participants' observations of residents making judgments between the past and future in relation to their current situation. This was either in relation to their own performance, judgements about others or their context.

Concept one, <u>making appraisals of self, others, context</u>

> "They're aware that they're different, that their body or whatever is changing, their needs are changing, um, a lot of them will say 'I'm like a baby', 'You've got to do everything for me, I'm like a child again'". (Jayne)

> "The other gentleman that I told you about Fred, with the tears.... in [residential home], it's a glass fronted building and across the road there was a garage where a man always worked on his car. Fred used to think that it was a betting office, so we had to go and put bets on for him. He'd give us two and three pence and say "you know go and put this on". We'd have to actually walk out of the building and go across the road. I came back from doing it the one day and he said, "I dunno who's duller, you or me?", "Why?" I said. He said "that is a garage, it's not [the betting office], I'm in [residential home]". So, you know, on occasions he did have that awareness and on other occasions he would quite happily wave to you and say "go on, put it on" out of the window". (Jayne)

> "It's when I go to [town] shopping, like I used to". You get that scenario but I've never had anyone go forward and say "but when I'm here no". But then again you might have that little spark thing "when I get better, when I go out of here". So you have got that "when I

start walking again the doctor has said I can go home". So yeah, they

do see forward as well as backwards yeah yeah". (Louise)

"We've got a lady just up the corridor here and on times there's a

vast, vast confusion but on times it could be something on the telly, it

could be the rugby that triggers her off and she goes back to a day

when she's in the pub and then she comes through and realises that

she's not actually in the pub and she will say to you, 'I'm in a nursing

home aren't I'. So there is recognition definitely there. Just needs that

little trigger point, just something to dig deep within the brain, yeah

definitely". (Louise)

3.2.4 Sub-category (4) 'meta-representations'

Figure 3.5 Diagrammatic summary of sub-category four

The sub-category **'meta-representations'** refers to the participants' observations of residents' demonstrating thoughtful reflections about their own future, others or their situation.

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┌─────────────────┐
│ Meta-           │
│ representations │
└────────┬────────┘
         │
┌────────┴────────┐
│ Showing reflective │
│ capacity about self, │
│ others and context │
└─────────────────┘
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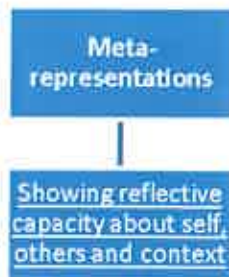
Concept one, <u>showing reflective capacity about self, others and context</u>

"Sometimes we used to be sat there and the telly would be on and you know all the news and there'd be research into this that and the other condition and somebody would say "I think I've got something like that coz that's exactly how I'm feeling". So sometimes what they see in the news and that will prompt them". (Jayne)

"I don't know if it's because they're aware of general deterioration that they feel they're unable to walk like they used to or, they're unable to go to the toilet on their own, when you're bathing them is a prime example, they sometimes say, "I wish I was dead. I'd rather be dead than have this happening to me". (Jayne)

"...it was during a bath and she was washing herself and I was sat there you know, generally just talking to her and washing her hair and things and she said 'I never thought in all my life that I would result to

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this' and she said 'the worst part about it all is I'm going to get worse'

she said 'obviously I'm not going to get any better" (Jayne)

As aforementioned, observations of meta-representations were reported far less often than the other levels of awareness.

3.2.5 Sub-category (5) 'awareness not viewed as hierarchical'

Figure 3.6 Diagrammatic summary of sub-category five

"I wouldn't say so much [awareness of] hunger and thirst but as for the snow and things like that I would outside visual things then yeah, definitely". (Louise)

The researcher prompted all participants about their observations at each level of awareness. One participant repeatedly expressed the view that residents were unaware yet he gave an example of a resident expressing awareness at an evaluative judgement level.

Researcher: "So do you think they are aware of those things such as hunger, pain, anger"?

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Steve: "I don't think so to be honest. That's my opinion, but I don't think so"

Researcher: "Have you ever noticed residents having moments of awareness about themselves or their surroundings, or their reflection in the mirror"?

Steve: "No, no, I haven't, no".

Researcher: "Some other people have described that in what seems to be unawareness a resident may have a moment of clarity when they suddenly become aware that they are in an EMI home away from their family for instance, have you ever experienced anything like that"?

Steve: "No, no I haven't".

Researcher: "Have you ever noticed anyone ever commenting on how they are now in comparison to how they used to be or how they might be in the future"?

Steve: "No, I haven't. Oh yes actually, one lady said 'I used to like mushrooms and black pudding years ago but I don't eat them any more now'. So I think she was comparing herself to what she used to do years ago".

Researcher: "So, what do you make of that example in terms of awareness? What do you think that means about awareness"?

Steve: "I don't think they are aware. I don't think they are aware of

what they used to do. I don't think they are aware, not from what I

have seen".

Another participant gave an example of a resident that did not recognise her pain for much of the time, yet was able to express an opinion at an evaluative judgement level.

"We looked after a lady who had her fingers broken by another

resident. Um, we took her up the hospital who said it's quite a bad

break. They sent her home with very strong pain killers, within 20

minutes she had taken the bandages off, 'ooh I'm alright, I'm alright,

nothing wrong with these' and she was bending her fingers. But, sort

of, when she got up in the morning she used to sleep with her hand in

a closed position, the only time she would feel pain would be first

thing in the morning and she would straighten her hands like this and

we would say "Gertie, you've broken your fingers", "ah nothing wrong

with them". (Jayne)

3.3 CORE CATEGORY: SENSE MAKING

The category **'SENSE MAKING'** refers to the process that staff carers went through in order to determine whether a resident had the capacity for awareness, or not, based on their observations. A number of key sub-categories emerged in the data as to what helped the

participants make sense of their observations (see Figure 3.7). These will be outlined in turn

below along with their related concepts.

Figure 3.7 Diagrammatic summary of the core category **'SENSE MAKING'**, its sub-categories and related concepts
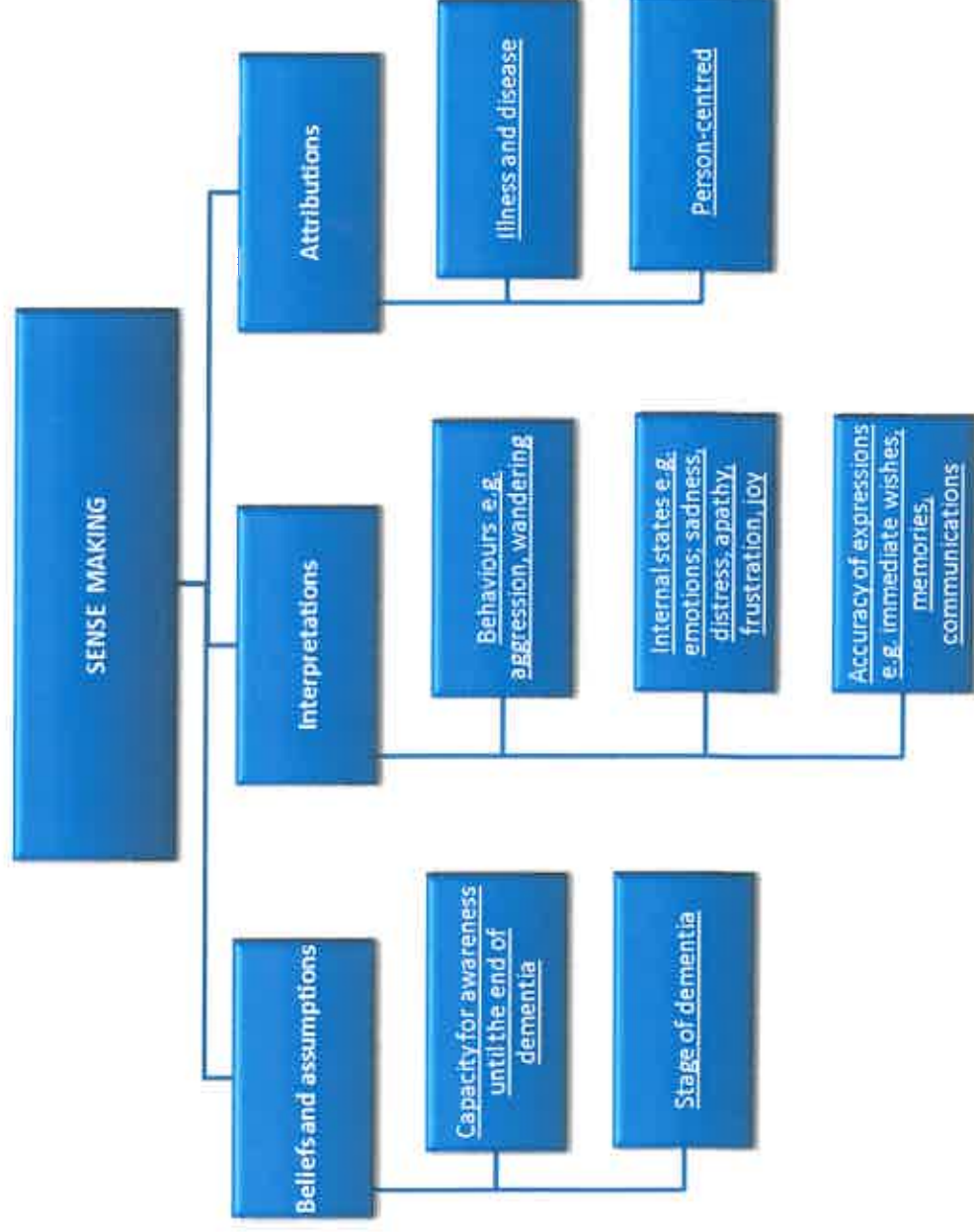
3.3.1 Sub-category (1) Beliefs and assumptions

Figure 3.8 Diagrammatic summary of sub-category one
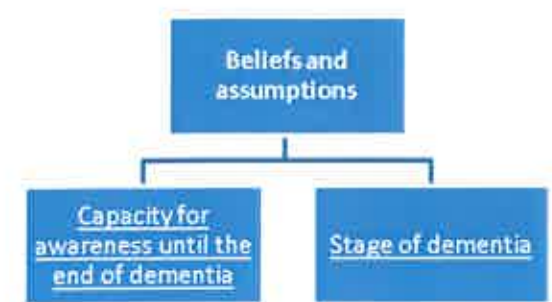
The sub-category **'beliefs and assumptions'** refers to the ideas the participants held about awareness. This appeared to be a fundamentally important starting point, as this initial belief about whether residents <u>retained a capacity for awareness</u> or not, appeared to affect the staff carers' consequent thoughts and behaviours. All participants referred to the <u>stage of dementia</u> as being significant in relation to the expression of awareness, in that they all made a distinction between the moderate to late stage of dementia. Some participants thought awareness declined to nothing, while others thought awareness was present to some degree but was unable to be expressed due to factors such as limited language capacity. These concepts will be illustrated with quotes below:

Concept one, <u>'capacity for awareness until the end-stage of dementia'</u>

The majority of participants disclosed they held a belief that people retain awareness until the 'end of their time' with dementia.

"I looked after a gentleman again in [residential home] and he was in the very late stages and towards the end he was bed ridden. He couldn't eat, drink, talk, anything and I suppose the misconception is because he was lying there almost asleep you think that they're not hearing or not taking anything on board. Me and his wife were sat there the one day and his wife was telling me all about where they used to go on holidays when the children were young, all the experiences that they'd had and when we turned around to look at this gentleman he was actually crying. So, obviously he knew what we were talking about you know". (Jayne)

"I've had many a patient who has been in the last stages and I've nursed them until they've gone. It's the voice I think. Yes. I think it's the voice. I've seen them turn at voices [particular nurses] and they'll laugh. They can't say anything... but I remember one lady, she knew and as soon as she seen you she'd laugh but she couldn't say anything. Their eyes, they'll turn their head when they hear the voices. That's in the latter part and I've seen it over and over and over. Especially say if I'd been off on my holidays and I'll come back and they know, there is still that awareness of my voice. Yes and I've seen it for years like that, they just know and if they see you they'll laugh or smile. They can't speak but they have still got something there".
(Elizabeth)

However, some participants believed that people did not retain awareness and that particularly in the late stage awareness was lost.

"To be honest I don't think that people who have got dementia have got awareness, you know in the later stages. Because the thing is they don't know where they are, what time of day it is, and they don't know their surroundings". (Sally)

"Moderate to severe, I don't think there is anything there at all. I don't think so, no. That's my experience". (Steve)

"Well, you find a little old lady is coming at you punching and kicking, I don't think she'd be like that, because when you're talking [to her family] you'll find out that she was a lot nicer in past. So as for awareness I wouldn't say that they're aware, no". (Louise)

Concept two, <u>stage of dementia</u>

All participants made distinctions between moderate and late dementia:

"Moderate, maybe they might have that recognition, that flashback. But later stages, I wouldn't say they have any awareness at all". (Louise)

"I would say like in the moderate stages, they would be more likely to express their awareness than at the end stages". (Mim)

"Self image, you've got the middle stages of dementia still, I've got a lady up the corridor Dolly, she likes to go out, put her make up on, have her hair set by the hairdresser, um, but as for, let's take it into the later stages, personally myself I wouldn't say there's much awareness there at all". (Louise)

3.3.2 Sub-category (2) Interpreting signs

Figure 3.9 Diagrammatic summary of sub-category two
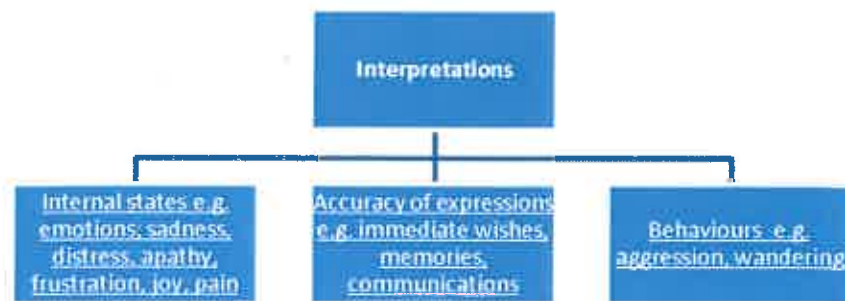
The sub-category **'interpretations'** refers to how the participants described themselves as being vigilant for evidence of awareness and what mediated expressions of awareness. This vigilance appeared to interact with their beliefs about awareness, because participants sought evidence to support their hypotheses about awareness capacity. The majority of participants held a belief about a retained capacity of awareness. However, a minority of participants appeared to interpret discrepancies in the accuracy of expressions and behaviours as evidence of the residents' unawareness. These participants appeared more likely to consider internal states as meaningless or not existing. These concepts will be illustrated with quotes below:

Concept one, internal states (e.g. emotions; sadness, distress, apathy, frustration, joy, pain)

"When you're sat by the side of her, you can talk to her, you hold her hand and you rub her hand and things, you speak about her husband and she'll smile and she'll laugh and you know she'll express sort of joy then for want of a better word". (Jayne)

"They might be frustrated that they can't get to you what they want. They know the words but it doesn't come out. Yeah, yeah, that type of thing. Something isn't right. Perhaps they're thinking, you know they're feeling lost. They're feeling something isn't quite right and they just want that little bit of human contact, a bit of reassurance. That's what I think and that's what I hope is right for them". (Laura)

"Well it's sad really because she probably wants to be at home with her husband but obviously she can't because he can't look after her. So it's sad because they can't be together and they have been married for 70 odd years. It's upsetting for her as well because she thinks they [the other residents] are trespassing". (Shirley)

Concept two, accuracy of expressions (e.g. immediate wishes, memories, communications)

These participants suggested that because the residents' expressions were inaccurate or inconsistent then they could not be aware.

> *"One lady we've got here calls everyone Johnny because that's her husband's name...so I don't know if she is aware... well, I don't think so to be honest with you. She calls me Johnny and I don't look anything like a man".* (Sally)

Below Steve is reporting examples of when residents make observations demonstrating awareness (online monitoring) but draw inaccurate conclusions based on these observations (evaluative judgements). When carers came across such inconsistencies they tended to conclude that residents were unaware. Carers appeared to struggle to identify inferred awareness in the context of inaccurate expressions of evaluative judgement.

> *"Well, I know when certain family members come that some of them may say 'that's my daughter, what's she doing here?', but it's not her daughter. Or 'my daughter is coming tomorrow', but she isn't coming. I think she is aware of other people coming in, yes, they are aware of other people coming in and think it's their daughter or their son, or their mother. They might say 'my mother is coming later', but when*

someone is 98 years old I don't think her mother will be coming. We do try to explain to them. So I don't think they are aware of the environment as an EMI. I don't think so, no". (Steve)

Concept three, <u>behaviours (e.g. aggression, wandering)</u>

"If the doctor comes, because she has got a hernia and sometimes it comes out, and obviously they won't operate because of her age, the doctor has to come sometimes to push the hernia back in. She doesn't know what he is doing. Even though she doesn't know, we have got to be there to make sure she doesn't hit out at the doctor and take her mind off it. We have got to stand there talking to her, so she doesn't actually know then what the doctor is doing. She doesn't even know what the doctor is to be honest with you, she just knows that there's a man there trying to make her belly better". (Sally)

"As for their awareness, I wouldn't say...I'd say no on that. If we were talking about aggression things like that then I would say yes because we've got the sun down period from about 4.30pm to 6pm. I just don't know what it is people just get agitated. Aggression wise, I would say yeah, you could actually pin point a certain time of the day, but as for the awareness no". (Louise)

"We have one lady who goes around taking other people's food. She never would have done that ten years ago so we've got to try and encourage her from that person because obviously she is pinching his food. And then we have got to sit her on her own...But the ones who have moderate dementia wouldn't do that". (Sally)

3.3.3 Sub-category (3) Attributions

Figure 3.10 Diagrammatic summary of sub-category three

The sub-category **'attributions'** refers to what the participants attribute their interpretations to. These attributions can be captured under two concepts, either that the resident is behaving in a particular way due to illness and disease, or the residents' behaviours and expressions are empathetically attributed to an internal state (e.g. sadness or confusion). The latter is referred to as person-centred due to the manner in which the participants considered the whole person in their interpretations and attributions.

Concept one, _Illness and disease_

"He doesn't know what he is doing now. The CPN was here and he actually was incontinent of urine and he didn't know he had done it, he didn't even know he was wet. Before he would have said 'I'm wet". (Sally)

"You learn that from when you're having the conversation with them when your reminiscing and all of a sudden a UTI starts and you've got this person who you left yesterday who is this lovely old little dear and you come back in tomorrow and they've got a UTI, the anti-biotics haven't come up and they just got this raging aggression and you can't do anything with them. But as soon as the anti-biotics kick in and start working then that subsides but as for awareness at the peak of that UTI I wouldn't say that they've got any awareness of their behaviour whatsoever. Because you've got this lovely old lady who's so nice when she hasn't got a UTI then up here awareness is totally out the window and as soon as the anti-biotics and that work she's back to normal, she's back to this lovely little old lady". (Louise)

"I think it is where more of the brain has been overtaken with dementia, the brain cells die don't they so their awareness of perhaps what they did yesterday is not there today. Dementia takes over doesn't it; it takes away awareness of everything. It's awful". (Joan)

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Concept two, person-centred

"I think people can be sort of labelled, that they've got dementia so they sort of look at the dementia rather than the person. So I think that's a little bit sad. Instead of looking at the lady before, they just see what's there now. I think they know that they've got that need but they're not supposed to quite be here. They used to live somewhere else and this doesn't feel right to them". (Laura)

"They might be frustrated that they can't get to you what they want. They know the words but it doesn't come out. Yeah, yeah, that type of thing. Something isn't right. Perhaps they're thinking, you know their feeling lost. They're feeling something isn't quite right and they just want that little bit of human contact, a bit of reassurance. That's what I think and that's what I hope is right for them". (Laura)

"They might just want a drink or show signs of being thirsty; it might just be something trivial. Perhaps just the touch of a hand...they like contact, I think they like contact. It is bound to make them feel better, whether they are aware that we are there, or it could just be anybody....a family member. I don't think they would like to be on their own. I don't think I'd like to be on my own [laughs]. Just the presence I think". (Joan)

3.4 'CONSEQUENCES FOR CARING' refers to the participants' interactions with the residents based on their beliefs and assumptions about awareness. A number of key sub-categories emerged in the data regarding ways in which the participants cared for residents based on their perceptions of awareness (see Figure 3.11). These are outlined in turn below along with their related concepts.

Figure 3.11 Diagrammatic summary of the core category 'CONSEQUENCES FOR CARING' and its sub-categories and related concepts
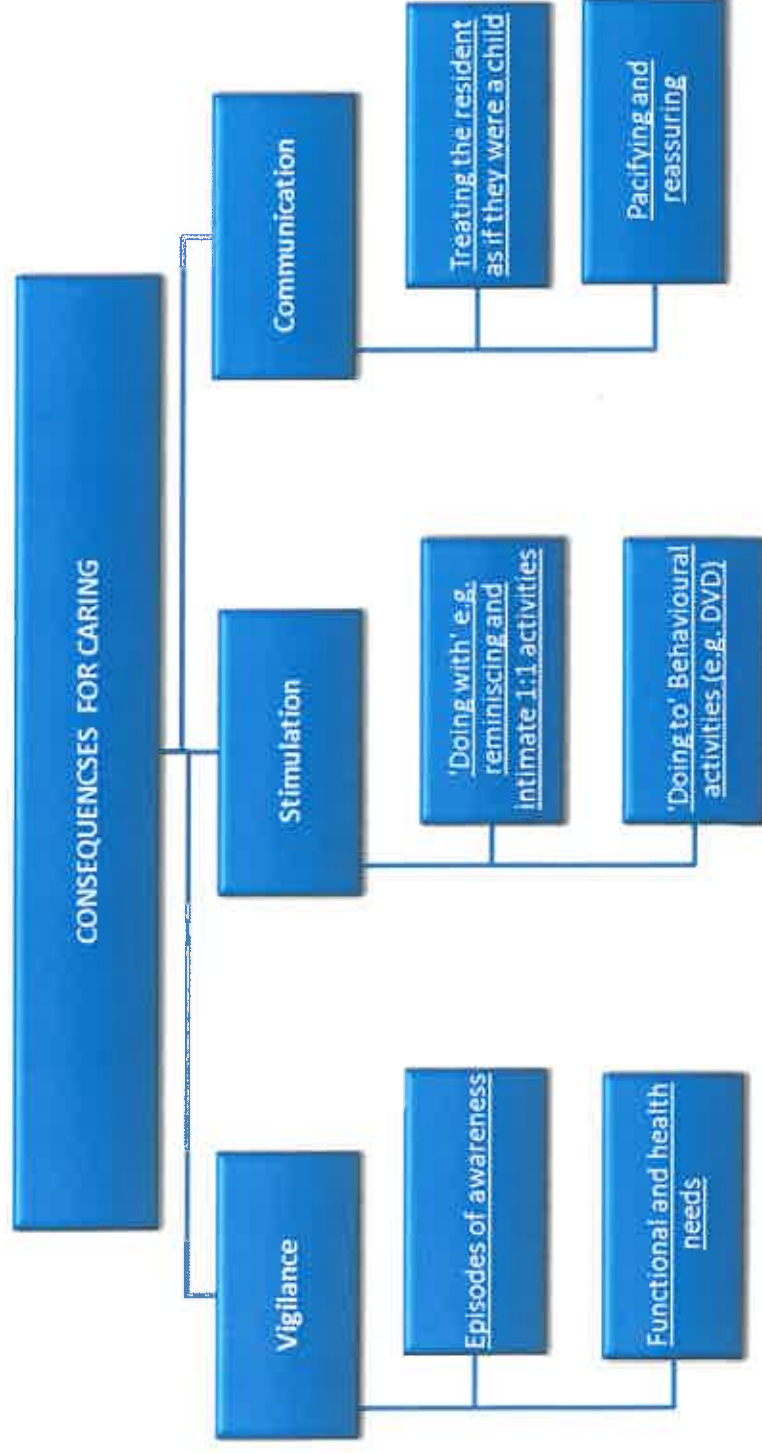
3.4.1 Sub-category (1) Vigilance

Figure 3.12 Diagrammatic summary of sub-category one

The sub-category **'vigilance'** refers to the signs that participants were more or less likely to look out for based on their initial beliefs about the capacity for retained awareness. The majority of participants with a belief that residents retained a capacity for awareness were more likely to detect <u>episodes of awareness</u>. In contrast, participants who did not believe in the capacity for retained awareness were more likely to be vigilant for the residents' <u>functional and health needs</u> and not detect episodes of awareness.

Concept one, <u>episodes of awareness</u>

> *"I think when they get use to us it's like they are talking to their family, they'll tell us everything...and it comes out, they are talking about their family and telling us everything. But sometimes it just stops then and you can't get anything out of them. They are aware of what they are telling us so I always make a point of asking more questions and they tell us as much as they can".* (Elizabeth)

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"Sometimes they may say a full sentence talking to you and then the next day they don't know the full sentence. One day you can have a full conversation with someone and the next day, or an hour or two later you just can't have a conversation with them because they can't string a sentence together". (Steve)

"It does come in little waves, they do get aware of...we have one lady who does not remember her family members and then all of a sudden they are aware then of 'can you phone my son/daughter'. Sometimes they will visit and they are not sure of the one family member, and yet they will remember the daughter in this case. But sometimes when her son comes she doesn't remember". (Joan)

Concept two, <u>functional and health needs</u>

"I think we just take it for granted and decide for them in a way because we'll sort of encourage fluids then. We need to have a good fluid intake so we sort of say 'are you thirsty?' If were feeding, or helping with fluids, we offer and if they accept we take it then they're thirsty. Still now some can push you or push you away". (Laura)

"They can't express it. No, no, I don't think they are aware of what is wrong, because we go in and we wet their mouth. We have nursed a couple here really, that have passed away. And we just do the basics

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for them that you think they need because they are not aware of what

it is". (Joan)

"We toilet them on a regular basis [residents in the later stages], so if

they can't ask us we always try to make sure they are well fed and

toileted. Because a lot of them just forget that they want to go to the

toilet or forgotten that they have eaten and had their lunch. They will

say ten minutes later 'are we going to have any food today or what?'

They have forgotten they have eaten their food. One lady does it

regular, she did it this morning, she had her breakfast, went to the

toilet, came back and saw everyone else by the table and went 'where

is my breakfast then?' She had already eaten it but had forgotten".

(Shirley)

3.4.2 Sub-category (2) Stimulation

Figure 3.13 Diagrammatic summary of sub-category two

The sub-category **'stimulation'** refers to the type of stimulating activities the participants were more likely to use with the residents, which appeared to be influenced by their belief about the capacity for retained awareness. The majority of participants were most likely to **engage** in activities that involved 'doing with' the resident (e.g. 1:1 person-centred activities). This appeared to enable a level of intimacy and connection with the resident. Due to these participants holding a belief that the residents held a capacity for awareness, they were more likely to be vigilant for, and therefore, detect episodes of lucidity. In contrast, participants who did not believe there was a retained capacity for awareness were less likely to prioritise the value of stimulating activities and would be more likely to engage in 'doing for' the resident (e.g. playing a DVD). As a consequence of not believing awareness, these participants were not vigilant for lucid moments and even when they reported clear examples of lucidity (in line with Clare's (2010) definition) they did not attribute this to awareness.

Concept one, 'Doing with'

> *"And sometimes it does [1:1] bring out awareness in people and they will say 'I've got something wrong with me and it's really worrying me now coz I can't remember nothing, you know I've lost this that and the other".* (Jayne)

> *"One to one is lovely. We do try, even though we have a group and we try different activities, if you can spend time with the person, if it's only 5 minutes and you can give that little bit of one to one you can*

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bring that person sort of a little bit forward. Whether it's a song they like, one lady, I don't know why it's special to her but she clings to this one song, perhaps you'll have a little sing with her and you can see on her face that it's made her happy because she's remembered that song. Hopefully, if you sort of spark that little memory it might bring on a little bit of conversation, or you might see them attempt to sort of eat something if they haven't been eating you know, because they feel nice and they feel happy you might be able to encourage something else". (Laura)

"you wouldn't like to see somebody unhappy would you. They're not aware that they're unhappy but you could sit with them, make them feel aware and it gives them a feeling of ease. You know like, 'this is your wife, your wife is Val', 'oh yes, I remember that.' It calms them somehow; I don't know what it is". (Mim)

Concept two, 'Doing for'

"I think you could put a DVD on or something like that. I think you would have to do something for them like put a DVD on, sing to them or something like that". (Steve)

*"We've been asked to do activities to try to stimulate but we can't do
it here because they pinch the stuff, because their awareness is not
there"* (Sally)

*"Sometimes they work, sometimes they don't; the activities and the
stimulating thing. We do things for the board, like at Christmas time,
we get resident involved with colouring and things like that. We stick
them all on the board and within ten minutes of us putting them up
they are all ripped down. And like I said, they run off with the pens and
pencils and jigsaw puzzles and everything, so half of our stuff is
missing".* (Sally)

3.4.3 Sub-category (3) Communication

Figure 3.14 Diagrammatic summary of sub-category three
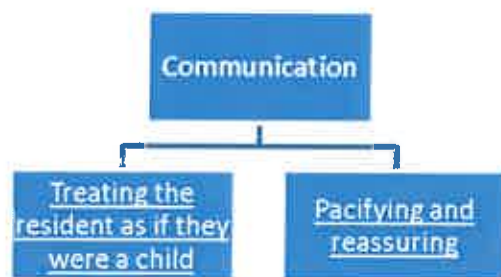
The sub-category **'communication'** refers to themes that emerged in the narratives about
the different ways the participants communicated with the residents. The majority of
participants reported adapting their communication and <u>treating the resident as if they
were a child</u> and <u>pacifying and reassuring</u> the resident at times of distress or confusion. This
sometimes included the participant telling the residents mistruths in order to pacify them.

These factors appeared to occur regardless of the belief about the capacity for retained awareness.

Concept one, treating the resident as if they were a child

> "This is probably going to sound awful now but you talk to them and you don't mean to treat them like children but you talk to them on a level that you would a child. You speak slower, you seem to define things more, you seem to put it in simpler terms, so I think it does sort of make you change your way of caring for somebody". (Jayne)

> "you prompt them to feed or to go to the toilet...you know, she is jigging, she knows but she can't tell us. So we say 'wee wee', that's something that gets through sometimes. Not all the time but sometimes". (Joan)

Concept two, pacifying and reassuring

> "We have got to really reassure them all the time. I think more reassurance helps them then by the time...I give them a couple of days and then they're quite happy". (Elizabeth)

"You can see someone is confused, they're saying their off to the shops to buy new TV. You try not to show that's not right, you sort of try and explain well maybe 'not today but because today is Monday and today we'll do this and I don't know try and get them back on the right track". (Louise)

"Reassurance mostly for them because they can get upset if they don't know where they are and they want to know where their family are and why they have been brought in here. So it's mostly reassuring that person that everything is fine because they will get really upset. 'Why am I in here?' they will say. 'Where is my family?' they will say. They think they have just been left here. They don't realise that the family is still in contact. When some families come they don't remember them. But then most of the families visit quite regular, so they are aware that the family is coming. Then you have one or two that don't come here, so then they are a bit upset when they see others having visitors. So, you just go over to them then and have a little chat to them". (Shirley)

Pacifying by reassuring explanation or mistruth

"I've heard them say "there's something wrong, I can't remember". It's strange to hear them say that. I don't like to say that they're ill, so

I say "perhaps it's the short term memory, we all have short term memory" I say to them". (Elizabeth)

"The families tend to stay for the first hour or two, the families tend to stay with them and, this is going to sound awful I know but they tend to sneak out so that they're not aware that they are going, then after half an hour an hour period, a lot of people do tend to say, 'well, where am I?'. And, you try and explain that you're in [residential home] residential home, you're staying in, we always used to say for a holiday". (Jayne)

"We explain that her husband will be up next week and that he is at home and she is here because she has broken her arm, because she did break her arm originally coming in, then say once your arm has healed maybe things will get better and you'll be able to stay with Bill again. And it will pacify her then". (Shirley)

3.5 STAFF PERCEPTIONS OF AWARENESS IN THE MODERATE TO LATE STAGES OF DEMENTIA: A GROUNDED THEORY

Figure 3.15 presents a grounded theory of the factors that the data suggested may determine how staff make sense of awareness in residents with moderate to late dementia. Also, some of the ways they may respond in their caring roles as a result. The core categories 'SENSE MAKING' and 'CONSEQUENCES FOR CARING' are suggested to interact. The core category 'sensitivity to fluctuations in awareness' will not be included in the model, as there is already a grounded theory which gives insight into levels of awareness (i.e. Clare's (2010) model. The findings of this study merely provided further support for that framework. Therefore, the two categories that provide new insights into the perceptions of awareness are illustrated without repetition of Clare's framework.

The model below proposes that staff who have at least one year experience of caring for residents in the moderate to late stages of dementia will have particular beliefs about residents' retained capacity for awareness. The staff carers' initial belief about awareness influences the subsequent way in which they provide care for the residents. That is, if staff do not believe there is a potential for retained awareness, they are more likely to focus on the fact that the residents appear unaware for much of the time. They are more likely to interpret the residents' behaviours and use discrepancies in the residents' accuracy as evidence to reinforce their beliefs of unawareness. As a consequence, these staff members are more likely to be vigilant for behavioural and explicit cues that the resident may display. The care provided by staff members with a belief in unawareness tends to focus on providing care in a way that meets the residents' physical and functional needs. It has an

emphasis on 'doing to' the resident (e.g. putting on a DVD rather than sitting next to them holding their hand). Due to this, the staff carer is less likely to detect episodes of awareness, and when they observe episodes of awareness, they are likely to either not recognise it or simply dismiss it.

In contrast, staff members who hold a belief that residents retain a capacity for awareness are more likely to interpret to residents' internal world (as well as behavioural cues) and be vigilant for episodes of awareness. The person-centred manner in which these staff members care for the residents make it more likely that they will engage in activities which involve intimacy (e.g. holding the clients hand, and reminiscing about their life with them). This type of engagement coupled with vigilance for lucid moments, makes it more likely that they observe awareness, thus reinforcing their initial belief about a retained capacity for awareness.

It should be noted that some participants' understanding of awareness appeared to develop as they thought about awareness in depth for the first time. Therefore, the model is advanced tentatively recognising that for some participants the views elicited may have been in the process of revision even as they were expressed. However, IPA is a useful methodology for facilitating participants to disclose beliefs and assumptions which, although they shape thoughts, feelings and behaviour, may not previously have been disclosed or articulated.

Figure 3.15

SENSE MAKING

No awareness retained → Interpret behaviour →

Awareness retained → Interpretation of behaviour and internal world →

CONSEQUENCES FOR CARING - Increased vigilance for;

Behavioural cues, illness and explicit signs → More task-focused and less likely to engage in stimulating activities that involves intimacy

Behavioural cues plus episodes of lucidity and opportunities to connect → More likely to engage in stimulating activities that involve intimacy

Increase likelihood of detecting

Increase likelihood of detecting

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CHAPTER FOUR: DISCUSSION

4.1 OVERVIEW

This research aimed to explore staff perceptions of awareness in people with moderate to late stages of dementia. More specifically its aim was to gain an understanding of the factors that influenced how staff members made sense of awareness in their interactions with the people for whom they cared. This is important given that people are now living longer (Knapp & Prince, 2007) which means it is likely that more people will experience dementia and enter care settings in the future. Moreover, there has been limited research into awareness in the moderate to late stages of dementia, so improving understanding of staff carers' perceptions, could potentially improve care practices and therefore the quality of life of people with dementia.

This chapter will provide a summary of the main findings of the research and will set these in the context of existing literature. Theoretical considerations and implications for clinical practice will also be discussed. In addition, a critique of the research methodology will be undertaken. Suggestions for further research will be made and conclusions about the significance of the findings will be drawn.

4.2 RESEARCH FINDINGS: THEIR RELATION TO THE EXISTING LITERATURE AND CLINICAL IMPLICATIONS

Rich data were gathered during the research interviews with nine participants. The application of a grounded theory analysis led to a number of core categories, sub-categories and concepts. A summary of these will be provided emphasising the interactions between the main findings and their clinical implications.

4.2.1 SENSITIVITY TO FLUCTUATIONS IN AWARENESS

Firstly, it is important to acknowledge that the findings of this study are in support of Clare's levels of awareness framework (Clare, 2010). The majority of participants provided observations of sensory and perceptual awareness, on-line monitoring, evaluative judgements and meta-representations. Discussed below are findings that emerged, which could add to Clare's framework by offering new insights into awareness from a carers' perspective.

The participants' narratives showed that they recognised dementia is associated with a steep decline in many cognitive functions that might support the expression of awareness (e.g. memory, language skills) and that in the later stages of the condition residents expressed awareness less frequently. Nevertheless, many of the participants' narratives illustrated **SENSITIVITY TO FLUCTUATIONS IN AWARENESS** at each of the levels proposed in Clare's framework. Six out of nine participants believed that residents were able to retain some capacity for awareness until the end of the disease, while three participants believed

that residents in the later stage of dementia did not retain awareness. These participants suggested that people in the late stages of dementia lost awareness even at the fundamental level of sensory or perceptual awareness, that is, lost the capacity to experience pain, emotions, hunger etc. All of the participants made distinctions between the moderate and late stages of dementia and suggested that the expression of awareness is different at these two stages.

Narratives about **sensory and perceptual awareness** elicited the largest set of illustrations of fluctuations in awareness. The participants reported observations of awareness in relation to internal (e.g. pain, emotions, self) and external objects (e.g. touch, music, others, context). The most striking examples were in relation to pain. The majority of participants, despite being vigilant to signs of pain in the residents and knowing when fluctuations in pain were more likely to occur (e.g. during a urine infection or following an observable injury), reported that they struggled because residents were often unable to communicate their pain. Five of the participants made reference to believing the residents no longer experienced pain or that they just forgot their pain. These beliefs were related to the residents who were unable to verbally express pain or who refused medication when offered by the staff carer.

These findings have important and serious implications for training, clinical practice, service development and care standards (see clinical implications). However, unfortunately these findings are not uncommon. There is a large literature regarding the assessment of pain in

the people with severe dementia (Cohen-Mansfield & Creedon, 2002; Chen, Lin & Watson, 2010). Many government polices and campaigns highlight that pain in people with dementia is under-detected, under-reported and under-treated (McAuliffe, Nay & O'Donnell, 2009). Furthermore, there is a lack of adequate measures to assess pain (Zwakhalen, Hamers & Abu-Saad, 2006). Literature points to the effectiveness of training caregivers in residential and nursing homes to develop sensitivity to non-verbal communication in individuals with moderate to late stage dementia (Magai, Cohen & Gomberg, 2002).

The finding that some participants held a belief that people with later stage dementia cease to experience pain, helped to inform the idea that **awareness is not viewed as hierarchical**, as proposed by Clare (2010) and Stuss et al. (2001). Some narratives suggested that some residents might be observed to show a lack of sensory awareness and others might show the full range of awareness. For instance some participants who held this belief that people did not retain sensory and perceptual awareness later gave examples of the same residents expressing episodes of awareness at other, more complex levels. This emerged in the narrative despite the researcher not asking whether the participants believed an individual resident could lack sensory awareness and retain 'higher' awareness. The idea that staff carers might not view awareness as operating hierarchically has important implications for the development of training. It may also highlight the difference between what is understood about awareness from a conceptual perspective and what is encountered clinically. Making a distinction between the concept and phenomenon of awareness was an important issues highlighted by Clare (2010).

The majority of participants made observations relating to the residents expressing awareness at an **on-line monitoring** level. These observations included examples of residents monitoring events in the 'here and now'. Participants were easily able to call on examples of residents talking about aspects of self, others or their context and often spoke of how a resident showed 'fleeting moments' of knowing what is going on. While the majority of participants considered this to be a significant and special moment, other participants did not always consider this to indicate the residents' awareness. When the researcher attempted to explore what these fleeting moments meant in terms of the residents' awareness, some participants would discount their example by giving another example of how the resident quickly returned to being confused. Often episodes of awareness at an on-line monitoring level would be emotionally fuelled (e.g. when the resident temporarily became aware of being in a nursing home, or wanting their husband). This appeared to be distressing for the resident and would lead the participant to engage in a number of different strategies to pacify the resident (e.g. telling them a mistruth). This will be discussed in more detail later.

There is emerging literature in the field of neuropsychology that could further our understanding of awareness at an online-monitoring level. For instance, Martyr et al. (2011) are currently using Stroop like tasks to dissociate implicit and explicit awareness. It is argued that people with cognitive deficits (and those without) make continuous implicit judgements (appraisals) about their performance (e.g. I said that the wrong way (verbal performance), I did that clumsily (motor performance), I can't make out what that object is

(visual performance)), but they only explicitly express or demonstrate that awareness infrequently.

Martyr et al. (2011) argue that expressions of explicit awareness are observed less frequently in dementia because patients have a disease that damages their cognitive functioning. They have a deficit in error detection (problems in fine tuning their performance to a personally held 'gold standard'). They have problems in cumulative error detection (memory problems) and problems in relating errors to personal standards of performance (autobiographical memory deficits). Therefore, their 'personal database' regarding awareness of their performance and ability to make judgements or comparisons against it is diminished or impaired. They show emotional and behavioural signs (e.g. frustration, aggression) that they are implicitly aware of their impairments. However, their ability to make accurate explicit self-referential statements or to demonstrate behaviourally that they are explicitly aware of their errors, deficits, illness and circumstances will be compromised. This is due damage to their ability to set a meaningful threshold for their overall performance.

In terms of **evaluative judgements** participants were able to draw on examples of awareness at this level. Yet there was again a dichotomy in the beliefs held about whether their examples represented awareness in the residents. One participant gave a clear illustration of a resident making a comparison between how they were now compared to how they had been in the past, yet held the belief that because the resident had dementia

and resided in a residential home they were unaware. The same participant called on another example and discounted its meaning as awareness due to the details of the example being inaccurate according to a visiting family member. Thus, this participant seemed to search for evidence that would reinforce their own belief about unawareness.

Alternatively, it could be argued that participants were being 'scientific' in their observations. Thus, if their daily interactions involved observing evidence that people with dementia are unaware (e.g. inaccurate in making evaluative judgements) then they could be concluding that the majority of people with dementia in residential homes are unable to demonstrate awareness at the level of evaluative judgement. Their narratives may then be thought of as showing that they take this baseline into account. Thus when staff observe a phenomenon that they think could be an illustration of awareness they need to interrogated it more closely (e.g. by checking details with relatives) before they conclude it was evidence of awareness or unawareness.

Clare (2008a) highlights that residential care settings may provide limited opportunities for residents to test their skills and obtain feedback; therefore residents may be more likely to draw on past experiences when making appraisals, resulting in inaccurate judgements. If staff members are not trained to understand this then it could easily lead them to make the kind of judgements that have just been discussed.

Interesting issues exist when considering awareness at an evaluative judgement level. For instance, the person with dementia will have impaired cognitive abilities, which will compromise their ability to always accurately draw on and express their experiences. This may be compounded by them continually receiving further inaccurate communications. For instance, many participants reported telling the residents mistruths, such as that the resident was only in the home for a holiday, or that they will be going home when they get better. It is questionable how people with deteriorating cognitive functions, can be expected to make accurate and informed evaluated judgements when they are not presented with accurate information by staff carers. A growing number of specialists in dementia care are arguing in favour of early disclosure of diagnostic information to patients and their relatives, in order to help them to develop strategies to cope with the consequences of the disease (Post & Whitehouse, 1995; Pinner & Bouman, 2002). In particular, Hertogha, Theb and Miesenc, (2004) provide an interesting discussion on truth telling and truthfulness in care for patients with advanced dementia.

It is important to note that the intentions behind the participants telling the residents mistruths, was in order to reduce the residents' distress. This practice implies the need for more clarity in training. There are suggestions in the literature that misinforming a person with dementia can be disempowering for them (Hertogha et al., 2004). Despite this it would be unfair to criticise staff for attempting to pacify residents in distress, particularly since guidance, for instance that provided by the World Health Organisation (2006 p.44), recommends that caregivers "must not alarm people in the early stages of dementia by giving them too much information" [about the progression of the disease]. Similarly,

communication of prognosis with people with dementia has been found to be influenced by concerns regarding distress in the presence of uncertain illness trajectories, family concerns about disclosure and by lack of guidance as to end of life care (Birch and Draper, 2008).

Participants' were also able to draw on examples of awareness of **meta-representations,** although these examples were much less easily accessible than observations of sensory and perceptual awareness. This is consistent with Clare's (2010) suggestion that awareness at a meta-representative level is less easy to express, due to the necessity of higher cognitive and language functioning. Despite this a number of participants reported that some residents expressed a wish to die rather than be in the situation they were in. It could be argued that death is a difficult concept for many people to confront (Firestone, Firestone & Joyce, 2003); therefore closing down opportunities for the residents to reflect on this may be a coping mechanism which allows the staff carer to defend themselves from attending to anxieties about their own mortality.

Clare (2008a) suggests that a more open awareness context in residential and nursing settings that provides opportunities for residents to reflect on fears and anxieties (e.g. reflective psychotherapeutic sessions) might help to mitigate residents' concerns. The development of groups could draw on the literature and experience from palliative care settings.

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4.2.2 SENSE MAKING

It appeared that participants had not actively thought about the concept of awareness in the residents prior to the interviews. Many participants commented that they 'hadn't thought about that before'. Therefore, their **SENSE MAKING** process appeared to be unfolding in the moment, which led to raw and rich insights about what contributed to their **beliefs and assumptions** about awareness. As stated in the results section the participants' beliefs about the residents' retained capacity for awareness were strongly linked to staff carer attitudes towards caring, and appeared to shape their interactions with the residents. The majority of participants reported that residents retained a capacity for awareness but that it deteriorated somewhat by the end of dementia.

Nevertheless, some participants reported moving examples of residents in the end stages of dementia, who were bedridden and could no longer talk, yet expressed awareness about their situation through a touch of the hand, turning their head, or quietly crying in relation to something specific. The participants who reported these examples expressed empathy about the residents' individuality, and value as a human being with a rich history. Some participants disclosed that they were motivated to care in an empathetic way due to placing themselves in the residents' shoes and imaging what it might be like for them. These participants stated 'if that was me, I'd want someone to come and talk to me or hold my hand'.

These narratives were in contrast to participants who did not believe in a retained capacity for awareness, and instead drew upon their observations of the residents' confusion,

inaccuracies and aggressive behaviour to conclude that the residents 'would not be that way if they were aware'. Participants' beliefs appeared to filter what they looked for in the residents (e.g. episodes of awareness, or episodes of confusions and inaccuracy), leading them to **interpret signs** that would consequently reinforce their beliefs.

It could be argued that some participants understanding of 'sense making' developed during the interview process and that the interview questions acted as an intervention which facilitated some participants to think about the residents' capacity for awareness in greater depth. Indeed, there were instances during the interviews when the participants would give contradictory statements about a residents' awareness (e.g. Steve, page 83). However, in general, the participants' narratives appeared to follow a particular path, in that those who believed in retained awareness would make **attributions** about the residents' expressed awareness in relation to their internal world (e.g. emotional state relating to their situation). In contrast, other participants who did not believe in retained awareness would attribute the residents' behaviours to the disease process and to the disease causing them not to be aware of what was happening to them.

We could speculate here as to how the participants developed their beliefs and attributions, and make theoretical links with the literature base (e.g. cognitive theory, attribution theory) to support these speculations. For instance, it could be argued that if the participants were formulating their beliefs and conclusions 'in the room', then these could be a 'snapshot' of their beliefs in evolution, rather than a strongly held and defended standpoint on the issue

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of awareness. Therefore, it is possible that the beliefs held by participants could be impressionable and a good target for training. However, this research did not explicitly study this process so this will not be elaborated on. The consequences for care are discussed next.

4.2.3 CONSEQUENCES FOR CARING

The participants' beliefs and assumptions about the residents retained capacity for awareness appeared to make them more or less likely to behave in certain ways, which had direct **CONSEQUENCES FOR CARING.** A strong theme through all of the participants' narratives was their **vigilance** for signs of the residents' needs (e.g. toileting, changing, feeding, pain). However, it appeared that participants who were sceptical about the capacity for retained awareness, were more likely to be vigilant for the residents' functional and health needs. In contrast the participants who held a belief about retained awareness were likely to look out for episodes of awareness and to attend to the residents' emotional states and internal world, as well as to their physical healthcare needs. Furthermore, the value participants placed on **stimulation** and the type of stimulating activity they were likely to engage in with residents, also appeared to differ depending on the beliefs about retained awareness. Some participants were likely to dismiss the value of stimulating activities or do them only because they were directed to. Other participants viewed stimulation as meaningful and described how they took opportunities to sit with residents. For example, to hold their hand and reminisce with them, hoping that it would make the resident feel happy. Research suggests that staff attitudes about dementia and person-centred care, and

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their confidence in addressing fundamental care needs can impact on quality of life for residents in long-term care (Winzelberg, Williams & Preisser, 2005).

Themes of **communication** emerged in the narrative that did not appear to be linked with beliefs about retained awareness. Nevertheless, some of these are linked with other issues outlined above and have important clinical implications; therefore they will briefly be highlighted here. The majority of participants referred to the need to adapt their communication to talk with the resident, this included needing to talk to them as if they were a child again. There is a literature that suggests scaffolding the person with dementia's utterances when they are struggling to communicate, can aid the person in being able to express themselves (Normann et al., 1998). Therefore, in the absence of a better way to explain it, it appeared that the participants were actually describing this process in talking to the resident as if they were a child.

O'Connor and McFadden (2010) have attempted to understand this matter more fully and have developed an 'attitude toward dementia scale'. The scale is designed to assess the attitudes of family caregivers, professionals and college students. Some of the items posed questions and statements such as, "It is okay to redirect people with Alzheimer's disease by telling small fibs"? "I would talk to someone with Alzheimer's disease the way I would talk to a child" and "People with Alzheimer's disease are child-like". The scale encompasses other themes of communication that emerged in the current research regarding telling the

residents mistruths in order to reassure and pacify them. This has been discussed in relation to evaluative judgements above.

4.3 CLINICAL IMPLICATIONS

This section will highlight and discuss the implications for service delivery and development, and clinical practice. This will be illustrated through the example of awareness of pain, as this is a particularly salient issue.

This research has uncovered evidence that some staff members in specialist EMI settings hold a belief that some residents in the late stage of dementia are no longer aware at a sensory and perceptual level, and some no longer experience pain. Despite this they also disclosed that they continued to be vigilant to verbal and non-verbal signs of pain and to provide pain relief.

The finding that some staff carers held a belief that people with dementia do not experience pain is not new. There is a large literature base which suggests that pain in this population is under-detected, under-reported and under-treatment, also that adequate measures to assess pain are lacking (Zwakhalen et al., 2006; McAuliffe et al., 2009). The evidence base reports that pain among nursing home residents is a common and major problem, with statistics indicate that pain is twice as likely to occur in individuals aged 60 years and older, than in younger people (Zwakhalen et al., 2006). Also that the prevalence of

pain in elderly nursing home residents was 40–80% (Marzinski, 1991; Blomqvist & Hallberg, 2001), thus showing that they are at greater risk of experiencing pain.

Inadequate detection of pain can lead to various problems for the resident, such as cognitive (e.g. concentration problems) and behavioural symptoms (e.g. aggression or depression), as well as greater care demands on staff carers and increased costs at an organizational level. Perceived barriers to successful pain assessment in people with dementia included a lack of staff recognition of pain, lack of sufficient education and training, misdiagnosis or late diagnosis of pain, and non-use of assessment tools. Research has indicated that staff carers have identified factors such as knowing the person, intuitive perception, education and training, and use of adequate pain assessment tools as a means of overcoming these barriers (McAuliffe et al., 2009).

Clearly, these findings imply a need to develop specialist training for people who provide care in EMI dementia services. There is research to show the effectiveness of training that has aimed to increase staff detections of pain in people with later stages of dementia, which have found that detection can increase the quality of life for the person with dementia (Cohen-Mansfield & Creedon, 2002). In addition there is evidence that increasing carers' sensitivity to non-verbal emotional signals in people with moderate to severe dementia (Magai et al., 2002) can enhance residents' mood and improved the psychological well being of the staff carers.

Staff training in EMI services could include discussion of what is currently understood about awareness at the different levels. This would assist staff carers to adopt a more informed position in detecting and appropriately responding to episodes of awareness. The findings of this study show that the majority of carers interact with their clients with sufficient sensitivity to detect instances of awareness, at least in the domains on which this research has focussed. Therefore such a training process could build on existing staff skills and empathy.

The need for more training regarding dementia and its challenges is already acknowledged via numerous government campaigns such as *"Forget Me Not"* (Audit Commission, 2000), *"Dignity for care"* (SCIE, 2007), *"Home from Home"* (Alzheimer's Society, 2008), *"See Me, Not Just the Dementia"* (Commission for Social Care Inspection, 2008). The Care Standards Inspectorate for Wales requires a minimum level of training to be completed by staff working with individuals with dementia (WAG, 2009). Yet, repeatedly reports express concern that basic standards of care are not being met for older adults (Ombudsman report) (Care and Compassion, 2011). Furthermore, in practice, regular dementia care training is inconsistent and not provided to all home care staff. In a National Survey of Care Workers (Skills for Care, 2007), 41% of 502 respondents said they had attended a dementia training course provided by their employer, while 23% had achieved either a Care or Health and Social Care NVQ level 2. However, little detail was given of the nature of the training, whether it was delivering on an ongoing basis, or whether this was reflective of the situation across the UK.

Clare (2010b) provided an interventional framework that could be used to inform the development of formulation and intervention, which could be also be utilised to develop training (see Table 1 below).

Table 1. A framework to assist in formulating awareness based interventions (Clare, 2010b)

		Level of awareness and operations involved	Possible interventions
Increasing complexity		Meta-representation. Reflection on one's situation and changes experienced, self-reflection, considering the perspective of others.	Provide a context where complex and difficult issues can be reflected upon and shared; as in support of psychotherapy groups.
	Complex awareness	Evaluative judgement. Judgements about symptoms, changes or impairments, or specific aspects of one's own abilities, performance, functioning or situation	Manage discrepancies between people with dementia and carers through negotiating common ground and shared view points; provide support to facilitate possible developments in coping style.
		On-line monitoring. Monitoring ongoing task performance as it occurs, and identifying errors	Improve accuracy of performance monitoring in everyday situations to support coping, reduce risk and maintain independence.
	Fundamental awareness	Perceptual and sensory. Registration of basic sensory and perceptual information	Increase sensitivity to signs of retrained awareness, train staff to support the expression of awareness, provide environmental stimuli.

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Government policies could be making use of the research evidence available to make education and training more comprehensive. For instance, Birch and Draper (2008) identify particular barriers in supporting people at the end stage of dementia and make recommendations for increased resources, staff training and further research in their paper. Service managers could be trained and could disseminate these findings at organisational and service levels, while residential and nursing home managers could ensure that their staff are trained to identify awareness and pain with appropriate pain assessment tools.

Clinical psychologists working within older adult services could play an important role in leading service development and delivery. There is an emphasis on leadership for clinical psychologists, which highlights the unique skill set that clinical training provides them with and would enable them to fulfil such roles (BPS, 2007). Clinical psychologists could contribute to training packages, facilitate training and provide advice and consultation regarding awareness in dementia. Clinical psychologists would be able to provide insights into the complexity of awareness as they have been trained to consider how issues are influenced from a biopsychosocial perspective. Furthermore, clinical psychologists could utilise their research skills to aid further understanding in subject areas relating to awareness and pain. A realistic issue that may present barriers to these suggestions being implemented is the current financial climate in which the National Health Service is operating in and the cut backs being made to services.

4.4 METHODOLOGICAL CRITIQUE

The following section will consider the suitability of the methodology employed in this study and examine the strengths and limitations of the study.

4.4.1 Suitability of methodology

The qualitative methodology used in this research was suitable for obtaining rich and in-depth accounts of staff experiences of awareness in the moderate to late stages of dementia. The methodology employed was particularly valuable as there is a scarcity of literature from staff perspectives of awareness. It is felt that the depth and richness of the participant's subjective experiences would not have been able to been captured with a quantitative methodology. The researcher chose to utilise a grounded theory methodology over other qualitative methods (e.g. IPA), as it was important to be able to generate substantive theory regarding the perceptions of staff carers, as opposed to looking at the nuances of each individuals' experiences.

4.4.2 Reliability and validity

The researcher attempted to maximise the rigor of the study by adhering to the guidelines proposed by Elliot et al. (1999), which are outlined in Chapter Two, section 2.3.3, and by attending to the other authors' concerns regarding rigor in qualitative methodology (e.g. Willig, 2001; Yardley, 2000). An important aspect of qualitative research is acknowledging how the researcher's own perspective can influence and bias the interpretation of the data.

Therefore the research took steps to reduce the extent of this and to ensure that neutrality was maintained as much as possible. Furthermore, neutrality was ensured by using (and repeatedly acknowledging) the use of Clare's framework (2010) and of the Illness Perceptions model (Leventhal et al., 1997) to structure the interview and to inform the process of analysis. This helped to counter subjectivity and provide restraint for the concepts being examined. It could be argued that the use of a largely untested and emergent theory (Clare's framework) to inform the grounded theory procedure might be appropriate for the development and refinement of the ideas on which the framework is based.

The process of analysis included an element of checking the logic and resonance of the findings with this theoretical framework. This was achieved by sharing the anonymised transcripts and coding with the researcher's academic and clinical supervisors, as well as regular meetings with both supervisors to ensure the emergent grounded theory was logical and resonated with their clinical experiences of working with staff in dementia settings. Additionally, the core-categories, corresponding sub-categories and concepts were presented to a fellow trainee psychologist to comment on for coherence. Feedback from all of these sources was taken into account in the process of developing the grounded theory model.

4.4.3 Strengths of the study

The researcher employed Grounded Theory, a robust qualitative method (Ponterotto, 2006), to investigate an area of research that was in need of development. The open, discursive nature of the Grounded Theory approach appeared to allow the researcher to put the participants at ease, which facilitated disclosure of rich and contextual information. The participants engaged well with the researcher and some reflected that their perspectives and opinions were not often sought. Therefore, as the researcher was interested in staff carers' experiences and opinions this may have enhanced their feelings of well being and made them think more about a topic which they had previously not given much thought to.

The researcher and the ethics panel were concerned that the study had the potential to act as an intervention, in that staff might be affected emotionally or become upset if they were facilitated to think more deeply about the experiences of those for whom they cared. The participants interviewed appeared to appreciate the opportunity to share their thoughts about awareness and did not express distress.

Grounded Theory can be used to explore areas of research that need further development. It could be argued that a strength of the study was having a theoretical framework to guide the development of the research as it helped to inform thinking in the development of the interview questions. However, the researcher remained aware that this could potentially lead to the position of the researcher's focus being too close to the theory and therefore potentially to theoretical saturation being reached prematurely. Being aware of this meant

that the researcher was able to utilise the framework by reflecting on the data and its consistency and inconsistency with the theory and framework. At the same time the researcher was able to remain neutral and inquisitive enough to sensitively follow up both perspectives of awareness and unawareness in the participants' narratives.

Spencer, Ritchie and Lewis (2003) stated that in addition to rigor, qualitative research should contribute to the wider knowledge and understanding about policy, practice and theory. It is felt that the current research has addressed some of theoretical and clinical implications, which can contribute to a developing understanding of awareness.

4.4.4 Methodological limitations

While the researcher attempted to maximise the rigor of the current research, there are noteworthy methodological limitations to acknowledge, which could hopefully aid improvement of research designs in further studies.

The participants that took part in this research responded to a poster advertisement which requested volunteers for the study. Therefore, the 'opting in' to the study may have led to a biased sample, in that the participants may have had a particular interest in the subject and in sharing their experience. It may have been that staff members with more negative experiences or different kinds of experiences may not have volunteered for the research.

Apart from the information on the poster advertisement and information sheets, participants appeared not to have actively thought about the meaning of awareness prior to the interview. This became evident in the interviews when participants either commented that they had not thought about what was being asked before, or by openly reflecting on their thoughts in the moment. Therefore, their perceptions were called upon in the moment and not necessarily thought. It could be argued that this might have also been an advantage in that it enabled dialogue with experienced staff that were bringing their ideas about awareness freshly into the room. It could be argued that their ideas were spontaneous and raw, that they were not uninformed given the length of time the participants had worked in this specialty and their experience and training in EMI. However, it could be that the participants were sharing their hypotheses with the researcher to make sense of their observations, not necessarily their well constructed and tested 'theories'. Perhaps this also means that they have not interrogated their own logic as yet. It may have been that interviewing participants who had received training on awareness or had well formed ideas about awareness may have produced very different findings.

It is important to critique the heterogeneity of the sample, in that the sample included a diverse range of experiences. For instance, the sample ranged in length of experience of working with people (between 14 months to 25 years), and with a range of dementia presentations. The participants varied in gender, personal experiences of dementia in their own families, and training. In addition, the sample was recruited from five different service settings. It could be argued that such a diverse range of variables could make it complicated to draw out comparisons across the sample, however, it could also be argued that the

generalisability of the findings are actually enhanced in contrast to a more homogenous sample. For instance, a sample recruited from a single setting may be biased by having the same training or a set of organisational cultural beliefs particular to that home.

A limitation of the sample is that the inclusion criteria required staff who were able to communicate well in English and who did not require the support of an interpreter. It could be that care staff from different ethnic and cultural backgrounds whose first language was not English, may not have come forward as they may have considered themselves not to have a good level of spoken language. Research suggests that 30-50% of care workers are from non-English speaking backgrounds (Skills for Care, 2007). Indeed, the sample in this current study included all white, Welsh participants, which does not represent the work force that care for people with dementia.

The time constraints of the study meant that it was not possible to gain feedback from the participants regarding the themes that emerged and the theory that developed from their narratives. The researcher did attempt to organise a focus group, however, it was not possible to gather any more than two participants at any one time. It was felt that the research would have benefited from including a focus group in order to add further rigor to the research process. However, given that the findings were relatively dichotomous, it may have felt revealing for participants to openly discuss their private beliefs in front of the other participants.

Further critique to the generalisability of the findings could be considered in relation to the size of the sample. Although small sample sizes are typical and acceptable for a Grounded

Theory approach (Straus & Corbin, 1998), this study only considered the experiences of nine participants. Therefore, some might question the generalisability of data from such a limited sample. However, qualitative theory argues that it is the pursuit of theoretical saturation that drives rigour, not numbers of participants, as in quantitative studies. Despite this, Thomas and Magilvy (2011) argue that the aim of qualitative research is not to generalise findings but to produce findings that have the potential to be explored with a wider range of people and to act as a starting pointing for further research. Due to the limited research looking at staff perspectives of awareness in the moderate to late stages of dementia, it is felt that the current study has produced interesting preliminary findings that raise ideas for further inquiry, which have implications for clinical practice and improving the care for people with dementia.

4.5 RECOMMENDATIONS FOR FURTHER RESEARCH

Due to the scarcity of research in this area a number of recommendations are made for further research. The findings highlighted a strong distinction between the moderate and late stages of dementia. Some participants suggested that people in the end stages of dementia are often bedridden in nursing settings. Therefore, it would be valuable to conduct a study exploring the perspectives of staff carers solely regarding individuals in the late or end stages of dementia.

While this study elicited examples of awareness in people in the moderate to late stages of dementia, it appeared easier for participants to give accounts of people who were in the

moderate stages, this may have been due to having accessible accounts of residents who were still able to express themselves verbally and show some level of independence. Such research might benefit from considering the emotional impact on staff of caring for people at the end stages of dementia and the coping strategies that they utilise to deal with this. Goodman, Evans and Wilcock (2010) acknowledge that research on end-of-life care for people with dementia is in its infancy and that there is need for investigation into end-of-life care in these settings where the majority of this population live and die. This should include the emotional impact and coping strategies used by staff who provide that care. Research could look to the general literature on coping (e.g. Lazarus & Folkman, 1984) to inform research in this area.

Further research may explore the interaction between staff perceptions of awareness and their stated reasons for choosing to work with people with dementia. In this study staff disclosed differing motivations for wanting to provide care for people with dementia. Further research might examine staff choices. For instance, is it simply a job? Is it motivated by losing a loved one to dementia and wanting to 'give something back'? These were two perspectives that were elicited during the current research, and which may be an important factor in the type of understanding and care provided to the residents.

Another interesting area of research might be to re-examine 'sense making', to improve understanding of the reasons staff carers form the conclusion that people do or do not retain the capacity for awareness (e.g. could this simply be a matter of training? Could it be a form of psychological protection or a defensive process consistent with believing that it is

better if a resident displays unawareness of what is happening to them?). Finally, there is a need to develop assessment methods that are sensitive to awareness in the later stages of dementia. This work has already has begun (Clare et al., 2002a). Furthermore other work in neuropsychology (e.g. Martyr et al., 2011) and psychiatry (e.g. Markova & Berrios, 2006) may have relevance to this process.

4.6 CONCLUSIONS

The current study used a qualitative methodology to explore the observations and beliefs staff carers disclosed regarding awareness in people with moderate to late stage dementia. The findings illustrated that participants held a belief about the retained capacity of awareness in the individuals that they provided care for. Their beliefs were formed by a sense making process whereby they drew conclusions about their observations of the residents' expressions and behaviours.

It is hoped that the current research will add to the literature base and help to inform a greater understand of awareness in dementia and of how it is perceived by the staff who provide care for people with dementia. It is also hoped that this research will help to inform further research in this area, as well as training, with the aim of improving clinical practice, and ultimately securing an enhanced quality of life for those who are affected by dementia.

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LIST OF APPENDICES

Appendix A - Research and Development (R&D) approval letter

Appendix B - Local Ethics Committee approval letter

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Appendix H- Extract from transcript with open coding

Appendix I – Extract from memo writing

Appendix A – R&D Approval letter

Debbie Cooke
South Wales Doctoral Programme
Archway House
77 Ty Glas Avenue
Llanishen
Cardiff
CF14 5DX

Ref: RSC.42.10
3rd November 2010

Dear Debbie,

Staff perceptions of awareness in people with moderate to severe dementia
Reg: RD/906/10

The Research Scrutiny Committee reviewed the amendments to your project received via email dated the 3rd November 2010.

It was agreed the amendments were satisfactory and the project be approved.

I wish you every success with this project.

Please note that no substantial changes or amendments can be made to the protocol without notifying the Trust Research & Development Office.

Kind regards

Professor Sue Bale
Chairman
Research Scrutiny Committee

Appendix B – LREC Approval Letter

GIG
CYMRU
NHS
WALES

Canolfan Gwasanaethau
Busnes

Business Services
Centre

South East Wales Research Ethics Committee Panel B

Telephone: 02920 376823
Facsimile: 02920 376835
Email: Carl.phillips@wales.nhs.uk

Miss Deborah Cooke
Trainee Clinical Psychologist
Cardiff and Vale University Health Board
Archway House
77 Ty Glas Avenue
Llanishen, Cardiff
CF14 5DX

13 December 2010

Dear Miss Cooke

Study Title:	**Staff perceptions of awareness in people with moderate to severe dementia**
REC reference number:	**10/WSE02/70**

Thank you for your letter of 10 December 2010, responding to the Committee's request for further information on the above research, and for submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Canolfan Gwasanaethau Busnes
Ty Churchill
17 Ffordd Churchill
Caerdydd, CF10 2TW
Ffôn: 029 20 376820 WHTN: 1809
Ffacs: 029 20 376826

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Cardiff, CF10 2TW
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rhan o Bwrdd Iechyd Lleol Addysgu Powys / part of Powys Teaching Local Health Board

- For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

- Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

- Sponsors are not required to notify the Committee of approvals from host organisations.

- It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Investigator CV	D Cooke	09 November 2010
Investigator CV	J Moses	23 November 2010
Protocol	2	02 November 2010
REC application	IRAS 3.0	30 August 2010
Covering Letter	D Cooke	09 November 2010
Covering Letter	D Cooke	10 December 2010
Interview Schedules/Topic Guides	1	28 August 2010
Advertisement	1	28 August 2010
Letter of invitation to participant	1	28 August 2010
Participant Consent Form: Consent Form 1	1	28 August 2010
Response to Request for Further Information	D Cooke	10 December 2010
Participant Information Sheet	3	10 December 2010
Participant Consent Form: Consent Form 2	1	28 August 2010
Referees or other scientific critique report	Anuerin Bevan Research Risk Review Committee	08 October 2010
Referees or other scientific critique report	Aneurin Bevan Research Scrutiny Committee	03 November 2010
Referees or other scientific critique report	CaRRS	29 September 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.
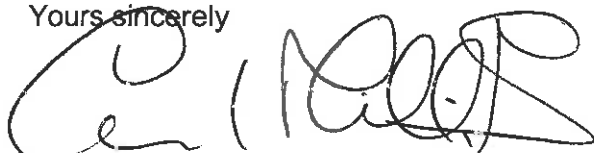
We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/WSE02/70	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Mrs A Dowden
Chair, Panel B
South East Wales Research Ethics Committees

Enclosures: "After ethical review – guidance for researchers" SL- AR2

Copy to: R&D office for Cardiff & Vale University Health Board

R&D office for Aneurin Bevan Health Board

Dr J Moses, South Wales Doctoral Programme in Clinical Psychology, Archway House - 77 Ty Glas Avenue, Llanishen, Cardiff, **CF14 5DX**

Appendix C – Recruitment poster

Staff volunteers needed for research exploring experiences of awareness/unawareness in clients with moderate to severe dementia

What is the purpose of the study?

Research suggests that awareness changes as the dementia progresses. The beginning stages of dementia are said to start with a painful awareness of what is ahead, which declines by the end of the disease to a lack of awareness. Despite this recent evidence suggests that people in the moderate to severe stages of dementia can retain some capacity for awareness. The purpose of this study is to learn about what people who provide direct care for people in the moderate stages of dementia think about awareness/unawareness.

This study invites you to share your experiences and contribute to developing what is understood about awareness/unawareness in this population. This may aid our understanding of knowing how best to respond to individuals with dementia and develop better services for people throughout the course of the disease.

Who can take part?

To take part you must have one year or more experience of providing direct care to individuals in the moderate to severe stages of dementia.

What does it involve?

You will be asked to take part in an individual interview that lasts between 60-90 minutes. The interviews can take place at a date and location convenient to you. Everything you share will be confidential. You will be invited to join a focus group at a later date to discuss the themes that have emerged during the interviews this will last approximately 90 minutes at a venue in Aneurin Bevan Health Board. Your travel expenses will be paid to and from the focus group.

How can you take part?

For further information about the study, please contact Debbie Cooke (Trainee Clinical Psychologist) on 07966 270839.

Appendix D – Consent form 1

South Wales Doctoral Programme In Clinical Psychology
Cwrs Doctoriaeth De Cymru mewn Seicoleg Clinigol

Version 1 – 28/08/10
<u>CONSENT FORM 1</u>

Study Title: Staff perceptions of awareness in people with moderate to severe dementia

Name of research: Debbie Cooke

Please initial the

boxes below if

By providing my details below, I agree that the Researcher can contact me in order to discuss the project in more detail. My details will be sealed in an envelope and stored in a locked cabinet until the Research collect them on [DATE].

I understand that my participation is voluntary and I am free to withdraw at any point without giving any explanation.

Alternatively you can contact the Researcher directly to express your interest on: 07966 270839

My name is:_____

My contact number is:_____

_____   _____

(Participants signature) (Date)

Appendix E - Interview schedule

Firstly, thank you for taking an interest in my research. Are there any questions you have after reading the information sheet?

I am going to ask you questions about working with people in the moderate to severe stages of dementia and your thoughts about awareness in these patients. There are about 20 questions, which are just there to loosely guide us.

I'd like to say that I am not looking for any particular answers because there are no right or wrong answers. I do not have experience of working with people in the moderate-severe stages of dementia, so I am interesting in learning from your experiences.

Part 1 – Experiences of working with people in the moderate to late stages of awareness

What proportion of people in this ward/unit/facility do you think have moderate to severe dementia?

Does your job involve working with those clients with moderate to severe dementia – Prompt: on every shift/only occasionally/not at all?

Just to make sure that we are talking about the same thing, what does awareness mean to you?

Do you think a person has awareness in the moderate-severe stages of dementia?

What examples can you think of?

How do you think dementia affects awareness?

If you think that someone has less awareness does this change the way you work with them? If so how?

> *Prompt:* personally, in how you see your job

Part 2 – Perceptions of levels of awareness in moderate to severe dementia

Have there been times when someone has shown they are in touch with their basic bodily functions or emotions?

Prompt: showing emotions (anger, sadness, pleasure), pain, hunger, thirst, cold

What do you make of this in terms of what it says about their awareness?

Have you noticed patients having moments of awareness about themselves or their surroundings?

Prompt: seeing their reflection in a mirror, commenting on not being able to find the right words to express themselves, responding to music, the weather?

What do you make of that in terms of what it says about their awareness?

Have there been times when you have noticed someone one day recognise that they have managed to do or say something that they usually can't do/say?

        Prompt: comment on how they are now by comparison with how they were in the past, or about how they will be in the future?

What do you make of this in terms of what it means about their awareness?

Have there been times when a patient has been able to show they are thinking about their situation

Prompt: what it's like moving to an EMI home, being separated from friends and family, living with new people many of them with impairments, death, understanding that others think differently about their situation or problem to themselves.

What do you make of this in terms of what it says about their awareness?

Part 3 – Wider concepts of awareness

What do you think causes changes in awareness in the later stages of dementia?

Prompt: the disease itself, medication, denial, the person withdrawing/giving up on life?

Do you think that levels of awareness change over time? If so how?

Prompt: does it stay stable, vary, always get worse or does it depend on other reasons?

Do you think this is the same for every person?

Are there certain times or situations which seem to make it more likely that a person with dementia will show awareness?

Are there certain times or situations which seem to make it more likely that a person with dementia will show a lack of awareness?

Do you think that the individual has any control over when, where or how they experience awareness?

Do you think there is anything that could encourage or increase awareness?

Prompt: stimulating activities, communication, medication

In your view what are the consequences of being aware/unaware for the person with dementia?

        Prompt: e.g. distressing, a good thing, of no significance?

We have come to the end of the questions. Thank you for sharing your ideas and experiences. Is there anything else you would like to add about awareness and working with people in the later stages of dementia?

Appendix F Information sheet
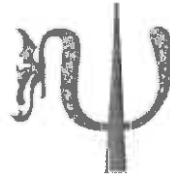
SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Version 3 – 10/12/10

<u>PARTICIPANT INFORMATION SHEET</u>

Study Title: Staff perceptions of awareness in people with moderate to severe dementia

Thank you for considering taking part in this research study. This information sheet aims to explain why the study is being carried out and what your participation will involve. Please read the information carefully before you decide whether you would like to take part. If you would like further information then please contact me via the address, email or telephone number below.

Who is carrying out the research?

My name is Debbie Cooke and I am a trainee clinical psychologist on the South Wales Doctoral Programme in Clinical Psychology. I am doing this research as a part of my qualification to become a clinical psychologist. I am interested in what staff think about awareness in the moderate to later stages of dementia.

What is the purpose of this study?

The literature on dementia has suggested that awareness changes as the disease progresses. The beginning stages are said to start with an awareness of what is ahead, which declines by the end of the disease to a lack of awareness. Despite this recent evidence suggests that people in the later stages of dementia can retain some capacity for awareness. Learning more from the observations of those who provide direct care for people in the moderate to severe stages of dementia is an important part of understanding awareness and knowing how best to respond to individuals with dementia.

Why have I been invited to participate?

You have been invited to participate in this research because you have at least one year experience of providing direct care to individuals in the moderate to severe stages of dementia. While there is a large body of research looking at awareness in the early to moderate stages of dementia, there is very little looking at awareness in the moderate to severe stages of dementia. Your participation will contribute to the evidence base of what is currently understood about dementia at these stages and what is learned will hopefully improve service provision in the future.

Do I have to take part?

No. It is entirely up to you if you decide to take part or not. If you do decide to take part in the study you will be asked to sign a consent form. If you decide to take part and then change your mind later, you will be free to withdraw from the study without any explanation.

What am I being asked to do?

If you decide to take part in the study you will be asked to sign a consent form which will provide the Researcher with your contact details. The Researcher will then contact you to explain more about the study and to answer any queries you may have. You will be asked to sign another consent form at the interview to say that you agree to be interviewed and fully understand what the study involves. You will be able to withdraw at any stage.

During the interview the Researcher (Debbie Cooke) will talk to you about ideas/theories regarding awareness in people with moderate to severe dementia. You do not need any prior knowledge of these ideas. The interview will be carried out by the Researcher at a time and place that is convenient for you. The interview will last between 60-90 minutes and will be audio-taped, transcribed and analysed. The tapes will be given a code and stored safely in order to maintain anonymity.

Following analysis of all of the interviews you will be invited to join a focus group at a location within the Aneurin Bevan Health Board, which should last up to 90 minutes. The aim of this group will be to discuss the main themes that have emerged during the interviews and to see whether these ideas fit with your experiences of awareness when caring for people with moderate to severe dementia. To illustrate how the main themes were reached direct quotes from earlier interviews will be used. This information will be anonymised in order to maintain your confidentiality. Once the study is complete the tapes will be wiped. The group will be audio-taped, transcribed and analysed.

Expenses

You will be paid travel expenses to and from the interview focus group location from your home address.

Are there any benefits to taking part in this study?

There will be no direct benefits to you personally in taking part in the study. However, there is not much known about awareness in the moderate to later stages of dementia. Therefore, this is an opportunity to share your experiences and contribute to our understanding of this subject.

Are there any disadvantages to taking part in the study?

It is possible that some participants may find this topic sensitive, and given that the interview is designed to be exploratory, it is possible that themes may emerge which cause upset (e.g. if you have personal experiences of a loved one with dementia or if you begin to think about clients in a different way).

If this situation occurred during the interview and you did not wish to continue with the interview, I would stop immediately and provide support. There would also be a person independent of the Researcher who you could speak with, if you wished to (e.g. a qualified Clinical Psychologist). There would be no obligation for you to continue, and you could either rearrange the interview to another day or withdraw from the study altogether.

Will my views and comments be anonymous and confidential?

Yes. As already mentioned, I have to follow a strict ethical and professional code of conduct that require all the information and data I receive to be kept anonymous and confidential. This means that your name, or any other information that might identify you, will not be included in the questionnaire, the interview transcripts, in the thesis, during any presentations or in any publications. This confidentiality would only be broken if the Research became aware of risk to another person.

What will happen to the findings of the study?

The study will be written up as a doctoral thesis and submitted to Cardiff University for examination in May 2011. Upon completion of the study a summary sheet outlining the main findings will be sent to the participants who have indicated that they would like a copy of the research outcome. I may also be required to present the findings to local older adult services and professional meetings. It is anticipated that the study will also be written up for publication in a relevant journal.

Who has reviewed this study?

All research carried out by the NHS is scrutinised by an independent panel called the Research Ethics Committee. This is to ensure the safety, rights and welfare of anyone who participates in a research project. This study has been reviewed by [R&D] and been given ethical approval by the NHS Research Ethics Committee.

What if I have more questions?

If you would like any further information about this study, please contact:

Debbie Cooke
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South Wales Doctoral Programme in Clinical Psychology
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Llanishen,
Cardiff
CF14 5DX

Tel: 07966 270839   Email: Debbie.Cooke2@wales.nhs.uk

If you are unhappy with any aspect of this study, please contact: Dr Jenny Moses on the address above or on 02920 206464.

THANK YOU FOR YOUR INTEREST IN MY STUDY AND FOR TAKING TIME TO READ THIS INFORMATION SHEET

Appendix G – Consent form 2

SOUTH WALES DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY
CWRS DOCTORIAETH DE CYMRU MEWN SEICOLEG CLINIGOL

Version 1 – 28/08/10

<u>CONSENT FORM 2</u>

Study Title: Staff perceptions of awareness in people with moderate to severe dementia

If you decide to take part in this study, all of the information you provide will be kept confidential. You are under no obligation to participate and have the right to withdraw at any time.

Name of researcher: Debbie Cooke

Please initial the boxes below if you agree

I confirm that I have read and understand the information sheet for the above study.

I have been given the opportunity to consider the information and have any questions answered adequately.

I understand that my participation is voluntary and I am free to withdraw at any point without giving any explanation.

I understand how my confidentiality will be ensured.

I agree to take part in the above study and consent to the interview and focus group to be audio-taped.

I would like a summary of the research findings on completion of the study. Please circle YES NO

If you have indicated 'yes' to the above question please provide details of where you would like the summary sent (i.e. email or address).

Contact details: _____

_____   _____   _____
Participant's name (printed)   Signature   Date

Appendix H – Extract from interview schedule with open coding

they go over and cwtch them and things like that. But one lady we've got here calls everyone William because that's her husband's name...so I don't know if she is aware... well, I don't know to be honest with you. She calls me William and I don't look anything like a man.

[margin notes: → clients helping each other / inaccuracy as evidence / unawareness]

R: So, do you think that levels of awareness change over time?

P: Yes.

R: How?

P: Well due to medication, lack of activities...because activities sort of stimulate. We've been asked to do activities to try to stimulate but we can't do it here because they pinch the stuff, because their awareness is not there. Some of them just don't want to know with the activities and they start taking the stuff or breaking the stuff. So to be honest with you we have lost half of the activity stuff. It's either gone down the toilet of gone in the bin, because that's what they do. If they've got something in their hand, because they can't define what it is, it goes in paper [shows action of scrumpling up paper] or goes in their pocket and goes through the wash then.

[margin notes: – activities + stimulation / – residents breaking activities / – residents inaccuracy of object recognition]

R: So how do you think awareness levels change? **Prompt:** do you think it stays stable, varies, gets worse or does it depends?

P: I think it gets worse. Once they got dementia it just goes down. I can stabilise for a couple of months, it could be moderate for a good two years but then I think it can slightly go down.

[margin notes: – deterioration / – distinction of mod + late]

R: You don't think there is ever a fluctuation...?

P: It all depends if they are on mediation. If they are taken off their medication there is a drastic drop.

[margin notes: – medications impact on resident]

R: Do you think this the same for every person?

P: No, no, because if they are taken off the dementia medication you will just see deterioration, but some of them are not on medication.

[margin notes: – medication / – deterioration]

R: So with the people who are not on medication....

P: I think they are stable...but in the end they are going to go downhill because they have dementia and it will never get better.

[margin notes: – deterioration / – no hope.]

R: So, do you think it is the same pattern for every person?

P: No, it all depends on the individual I think. I've known someone to have gone downhill and a couple of days later pick back up because they've had a urine infection, and that's the reason why they

[margin notes: – fluctuation related to illness.]

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Appendix I – Extract from memo writing

STIMULATION

Memo: any kind of stimulation that prompts or arouses awareness

Memo: prompting is linked to promoting independence and stimulation....keeping the brain active and awareness flowing

Memo: Stimulating activities often involve one to one, intimate interactions, which are easier for some staff that others and dependent on staff member's beliefs about awareness ie if the staff member doesn't truly believe in awareness (Ps: 3&4) then not only is there less motivation to do the activities but the non believing staff members are less likely to witness moments of lucidity and miss attempts of the resident to initiate communication, and express awareness. Non believers might so 'stimulating activities' like put a DVD on which cuts the opportunity for connection and intimacy. Staff who believe in awareness may do activities like trying to talk to the resident, holding their hand, singing to them.