Support groups for individuals with early stage dementia: an exploration of group experiences and processes

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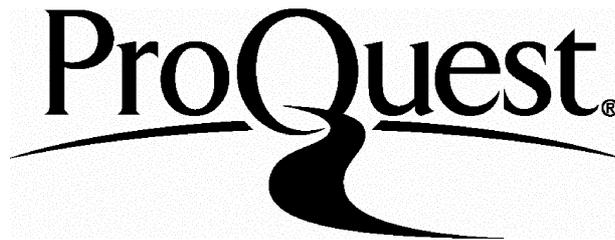
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ABSTRACT

Participation in a support group is increasingly offered to those diagnosed with early-stage dementia; however, empirical data about such groups for this population remain scarce. This study aimed to investigate the mutual support processes that occur in dementia support groups and how members perceive the groups. Eleven individuals from two support groups participated; three sessions of each group were videotaped and semi-structured interviews were conducted with individual members. Quantitative analysis of the videotapes indicated that only a minority of responses were classified as helping behaviours, and that facilitators played a highly active role in the group interactions. The interview data were analysed qualitatively; the themes identified related to aspects of the group that participants found helpful and unhelpful, and their perceptions of how the group operated. The findings have theoretical implications regarding the role of support groups in creating and maintaining social identities, as well as practical implications for how professionals might facilitate these groups.

ACKNOWLEDGEMENTS

CHAPTER ONE

INTRODUCTION

OVERVIEW

Why study support groups for people with early stage dementia?

This study aimed to investigate the mutual support processes that occur in support groups for individuals with early stage dementia, and the nature of the experience of those groups for older adults with dementia who attend. Professionally facilitated support groups increasingly constitute a major component of the formal support offered to individuals recently diagnosed with Alzheimer's disease or a related dementia in the early stages (Cheston, 1998; Yale, 1995; 1999), yet despite 'countless anecdotes' (Yale, 1999) about the usefulness of these groups for their members they are sparsely represented in the literature in terms of systematic description and evaluation (Cheston, 1998; Cheston & Jones, 1998; Kasl-Godley & Gatz, 2000; Yale, 1999). Moreover, very little is known about the views of the individuals attending such groups regarding this aspect of their care.

People with dementia who are in the early stages of the illness face a series of losses as their cognitive and adaptive functioning declines. The emotional impact of this experience has been described by Keady (1996) as 'feelings of uncertainty and panic which slowly evolve into a state of resignation and helplessness' (p. 279). Bender and Cheston (1997) describe this experience more strongly, as encompassing anxiety, depression, grief and despair. In recent years, it has been suggested that offering within a professionally-led support group a forum for mutual and professional support, sharing of information, and exploration of fears and emotions can lead to a 'working through' of these reactions and a better understanding and acceptance of the inevitable changes in functioning, role and identity. Furthermore, it can provide members with opportunities to make plans for the future (Davies, Robinson, & Bevill, 1995; Hawkins & Eagger, 1999; Jones, Cheston, & Gilliard, 2002; Yale, 1995; 1999). Within this context, it is important to ask what helping and support

processes actually take place in such support groups, and what aspects (if any) of the groups members attending them find helpful.

A decade ago Cottrell and Schulz (1993) noted that the views of individuals with dementia were excluded from research about the illness. Sperlinger and McAuslane (1994) likewise observed that few studies have sought the views of this client group on any aspect of the services they receive, while finding in their own research that people in the early stages of the illness were able to report concerns about their care and their experience of using dementia services. More recently, the British government's National Service Framework (DOH, 2001) set out in its second standard for the healthcare of older people, including those with dementia, the stipulation that service users should be enabled to make choices about the services they receive and to be more involved in their own care. A systematic study of the experience of individuals with dementia who attend support groups may enable such groups to develop in ways that are informed by users' views regarding this aspect of their care, and will advance knowledge about a relatively new area of service provision. Detailed investigation of the processes operative in these groups may further inform professional and clinical practice in this area.

Outline of chapter one

This chapter reviews the literature relevant to understanding the processes involved in support groups for people with early stage dementia and the experience of those attending them. The conceptualisation of dementia in different areas of the literature is discussed, and the impact of these different understandings on the provision of dementia care is reviewed. Empirical studies of the subjective experience of people with dementia are described, with particular emphasis given to the experience of those in the early stages of the disease and how it informs the process of assessment and diagnosis and the subsequent provision of psychological interventions, including support groups. The chapter then goes on to review the literature conceptualising mutual support and its relevance to helping processes in mutual support groups, before considering what is known about these processes in support groups for people with dementia. The implications of the literature for the present study are

discussed, and the chapter concludes by setting out the rationale for the study's methodology and research questions.

DISEASE MODELS OF DEMENTIA

What is dementia?

Dementia is defined as an organic brain disease, characterised by gradual deterioration in intellectual and adaptive functioning, for which there is currently no cure. It is predominantly a disease of old age, affecting approximately 5% of people over the age of 65 and 20% of people over the age of 80 (Lyman, 1989). A widely accepted definition of the disease is that given in the World Health Organisation report:

> Dementia is the global impairment of higher cortical functions, including memory, the capacity to solve problems of day to day living, the performance of learned perceptuo-motor skills, the correct use of social skills and control of emotional reactions in the absence of gross clouding of consciousness. The condition is often irreversible and progressive.
>
> (WHO, 1986, cited in Jones and Miesen, 1992, p. 9)

Dementia of the Alzheimer's type, also known as Alzheimer's disease (AD), and the vascular dementias, including multi-infarct dementia (MID), represent the most common dementia syndromes (Cummings & Benson, 1992). In AD the damage is believed to be caused by senile plaques, neurofibrillary tangles and granulovascular degeneration (Esiri, 1991, cited in Morris, 1996), while in MID damage is caused by the failure of blood supply to parts of the brain. The clinical picture varies between the different conditions; in AD deterioration is most often steady and progressive, while in MID a step-wise deterioration is observed (DSM IV: American Psychiatric Association, 1994; NINCDS-ADRDA: McKhan et al., 1984). However, there is some debate about the utility of these diagnostic categories as the syndromes often

co-exist and their symptoms overlap. Furthermore, despite accounting for approximately 50% of all dementias, unequivocal diagnosis of AD can only be made post-mortem.

The terms early, middle and late stage are commonly used to describe approximate points in the progression of dementia over time, and correspond to mild, moderate and severe degrees of impairment respectively. The terms are somewhat imprecise and overlapping, and relate to a continuum of functioning that varies within as well as between stages (Yale, 1995; 1999). The concept of a staged progression through dementia has been questioned by some authors, who regard it as an artificial attempt to impose order and predictability on variable and changing clinical symptoms in a way that decontextualises people from their own lived experience (Kitwood, 1993; Lyman, 1989). However, the terms have utility for describing an approximate range of functioning, and will be used here as a short-hand to denote approximate points in the progression of dementia with the assumption of some commonalities in the functioning and experience of people with dementia at each stage. Within this categorisation, the term 'early stage dementia' is used to identify individuals with only mild impairments. These are characterised by significant impairment in episodic memory, often with some difficulties in executive function, attention and working memory, and in expressive language function (Clare, 2002a). The individual is still able to carry out personal care and maintain some of his or her daily activities and activities in the home, and retains awareness of time and place (Keady & Nolan, 1995a). The term 'early stage' should not be confused with that of 'early onset', which refers to the acquisition of the symptoms of dementia prior to the age of 65 (APA, 1994).

Disease constructions of dementia

The disease model has been, and remains, dominant in the conceptualisation of dementia, and holds that the pathological changes that occur in the brain tissue throughout the process of dementia lead directly to the cognitive, emotional and behavioural changes observed. This model of linear causation is paramount, with progressive and inevitable neurological degeneration seen to correspond in a one to one relationship with an inexorable process of

cognitive and behavioural decline, until the complete disintegration of personality is reached before the point of death.

The disease model has been challenged, however, by those who point to inconsistencies between pre- and post-mortem data of individuals diagnosed with AD that appear to refute a direct association between neuropathology and cognitive impairment (Kitwood, 1997). Critics also argue that the model does not account for the variability and complexity of individuals' experience of dementia (e.g. Cotrell & Schulz, 1993; Kitwood & Bredin, 1992b; Lyman, 1989). Kitwood (1997) points out that it is unable to account for the variability of symptoms that are witnessed between individuals who share a diagnosis, nor can it explain variable presentations within an individual, including 'rementia' where lost cognitive and functional abilities are apparently regained. Early on in his work he noted such periods of rapid improvement and decline that appeared to be associated with different social environments. In particular, swift deterioration occurred when individuals with dementia moved from their homes to residential settings (Kitwood, 1989). Similarly, in one of the few systematic studies in this area, Sixsmith, Stilwell and Copeland (1993) found that a number of residents showed a decrease in dependency following admission to a residential unit which aimed to promote independence, well-being and high functioning (see also Sabat, 1994). These reports that refute the picture of irreversible, progressive decline appear to conflict with the model of linear causation.

To summarise, the medical model has been dominant in explaining the symptoms of dementia and paints a picture of inevitable progressive decline, resulting in an absolute and final loss of selfhood. However, there is a body of literature that questions the validity of this model, in view of its inability to account for all the features of dementia. Over the last ten years there has been an increase in empirical research offering a radically different conceptualisation of the processes underlying the development and maintenance of the symptoms of the disease. This body of research argues that to understand dementia we must consider not only the neuropathological, but also the social and psychological factors that influence its course.

PSYCHOSOCIAL MODELS OF DEMENTIA

As recently as 1993, Cotrell and Schulz stated that professionals largely ignore 'the personal and psychosocial needs of those who experience a dementing illness' and have continued to objectify the person with dementia as a 'disease entity' (p. 205). They argued that this had led both to a narrow treatment focus, namely the management of undesirable behaviours through pharmacological and behavioural interventions, and to a narrow psychosocial research focus on the impact of the disease on the individual's carers. However, the last decade has seen new approaches to dementia emerging that take a different view. These approaches have grown out of the problems identified with the disease model, as well as reflecting a broader trend that considers the contribution of psychosocial factors to the development and maintenance of illness more generally (see e.g. Charmaz, 1983). They offer an alternative conceptualisation of dementia, with significant implications for the provision of dementia care services.

The person-centred model of dementia

An influential contributor to the growth of psychological approaches within the area of dementia is the late Tom Kitwood (1989; 1990; 1993; 1995; 1996; 1997; Kitwood & Bredin, 1992b). Kitwood rejected the linear causal relationship between neuropathology and the symptoms of dementia postulated by the disease model, which he termed the 'standard paradigm'. Instead, he considered how the social and personal world of the person with dementia bears on the emotional and behavioural difficulties he or she may experience. Central to the approach is the conceptualisation of 'personhood', which is essentially a social rather than an individual construct:

> Personhood is essentially social: it refers to the human being in relation to others. But also it carries essentially ethical connotations: to be a person is to have a certain status, to be worthy of respect.
>
> (Kitwood & Bredin, 1992b, p. 275)

Kitwood thus proposed a person-centred model of dementia, focusing on the 'dialectical interplay' between neurological and social-psychological factors 'with special emphasis on the aspects of the latter which deprive a neurologically impaired individual of his or her personhood' (Kitwood, 1990, p. 177). While acknowledging an upper limit of functioning given a particular level of brain pathology, rather than ascribing the symptoms of dementia to the extent of brain pathology alone he saw them as reactions to the (inter) personal and social environment in which the person with dementia is situated. Those aspects of these environments that diminish an individual's personhood were termed by Kitwood 'malignant social psychology' (MSP). Kitwood (1990) gave ten examples of MSP, including disempowerment (doing things for the person that they are able to do themselves, albeit slowly) and invalidation (failure to attempt to understand the subjective experience of dementia). He theorised that when present in the environment, MSP can have a profoundly detrimental influence on the behaviour and affect of the person with dementia, beyond the effects of their neuropathology.

Some evidence for Kitwood's approach has been provided by a small number of research studies that found the behaviour of individuals with dementia to be affected not only by brain pathology but also by their social environment (Sabat, 1994; Sixsmith, Stilwell, & Copeland, 1993). The implications for those caring for persons with dementia are detailed by Kitwood and Bredin (1992b), who propose that the key psychological task of dementia care should be the maintenance of an individual's personhood. They list a number of indications of 'well-being' that they argue can be observed when personhood is present: 1) a sense of personal worth, 2) a sense of agency, 3) social confidence, and 4) hope. These constructs have been operationalised in an evaluation tool called Dementia Care Mapping (DCM: Kitwood & Bredin, 1992a). Unlike previous measures used in dementia care that tend to focus on activity levels, DCM aims to measure the relative well-being of people with dementia who may not be able to communicate verbally about the quality of their care. The person with dementia is observed in successive time frames of 5 minutes, during which time his or her behaviour is categorised and assessed for signs of well-being or ill-being. In addition, any

personal detractors (examples of malignant social psychology) are recorded. The information collected provides a rich source of quantitative and qualitative data.

Kitwood's approach appears to offer a radical change to the conceptualisation of dementia by placing the person with dementia at the centre of its model. It calls for a 'new culture of dementia care' (Kitwood & Benson, 1995) that deals not only with the progressive neurological difficulties but also with the personal and social consequences, in accordance with an understanding of dementia that includes the psychosocial as well as the neurological aspects of the illness. Moreover, the concept of personhood implies an entitlement to social inclusion, empowerment and involvement of the person with dementia.

The approach is open, however, to a number of criticisms. First, in being largely based on research with persons with dementia and dementia care within institutions, it does not necessarily address the experience of those in the earlier stages of the illness or those still living at home, and is informed by the perspectives of researchers and carers to the exclusion of persons who themselves are living with dementia. Within this context it is understandable but significant that the evaluative tool it has generated is based entirely on inferences about individual well-being and contains no mechanism for hearing the voice of the persons with dementia themselves. Second, it could be argued that the theory fails to address the emotional experience of dementia and presents the individual in a relatively mechanistic way, as a passive agent responding to external forces. In excluding the level of individual psychology and focusing instead on the social and neurological domains, this account is silent about the ways in which persons with dementia actively engage with their cognitive difficulties and social environment in a way that is uniquely their own (Clare, in press; Clare, 2002b; Pearce, Clare, & Pistrang, 2002). Third, the conceptualisation of personhood as a 'status' based on notions of autonomy and individual agency can be seen as ignoring the ways in which personhood is 'created (or diminished) in social relationships' (Nolan, Ryan, Enderby, & Reid, 2002, p. 183). Such an individualistic view of personhood ignores the ways in which the self exists within a matrix of interdependent and reciprocal relationships. Issues of selfhood and identity as created and experienced in the

intrapersonal and social domains are at the foreground of further approaches to understanding dementia within a psychosocial conceptual framework, with implications for dementia care.

Psychosocial models of selfhood and identity

Some of those subscribing to the disease model take a nihilistic view of the possibilities for continued subjectivity in the person with dementia, seeing the diagnosis as equating to a devastating 'loss of self' (Cohen & Eisdorfer, 1986). This perspective relates at the theoretical level to a cognitive account of selfhood, where the self is seen as a cognitive structure and dependent on at least some aspects of cognitive functioning. Such a view of identity clearly has important implications in the context of the memory loss that is an integral feature of the experience of dementia. If identity is internal to the individual and stable over time, then to lose your memory is to lose 'the glue the holds the self together' (Killick & Allan, 2001, p. 110) and has catastrophic consequences for the maintenance of self. In this context, acting as if the person has a coherent self might be important and helpful, but requires an 'act of faith' (p. 110).

Some authors writing from within a psychological or psychosocial framework question this understanding of subjectivity and its implications for identity in people living with dementia. First, social constructionist accounts of identity reject the view of a stable, internal, subjective self and instead see selfhood as comprising multiple selves in an ongoing process of co-construction in the social domain. While it is acknowledged that people may feel and act as if there is a stable and enduring 'self', a distinction is made between this subjective experience and the processes by which the self is seen to be constructed. Writing from within this framework, Sabat and Harré (1992) argue that the primary cause of the loss of self in the person with dementia is to be found in the ways in which he or she is viewed and treated by others. When the person with dementia is positioned as helpless, confused and impaired, their carers and others cease relating to them in a manner that facilitates the process of co-construction. From within a social constructionist model, the loss of self is therefore not an inevitable but only a possible indirect effect of dementia, and where it occurs it is related only

to the ways in which the person is viewed and treated by others. This perspective has informed recent innovations in dementia care, as the social arena in general and interpersonal communication in particular are seen as media through which the social identities of people with dementia can be established and maintained (Cheston, 1996).

Authors that situate the self within a continuing subjectivity also refute those that postulate an inevitable and catastrophic loss of self in people diagnosed with dementia. Thus Bender and Cheston (1997) draw on frameworks from clinical and social psychology to present a tripartite model of the subjective experience of dementia. Their model stresses the interdependence of internal emotion states and the social stage on which they are enacted, and presents the experience of dementia as incorporating anxiety, depression, grief and despair; the behavioural response to these emotions; and the social nature of the expression of these behaviours. Within this model certain symptoms seen within the disease paradigm as occurring in response to neurological decline, such as aggression or withdrawal, are instead regarded as indicative of psychological processes as the individual attempts to cope with and adapt to the experience of dementia. As is discussed further below, such a conceptualisation of the subjective experience of the person with dementia has significant implications for service provision, indicating the need to intervene 'at the level of minds and selves and not at the level of brains' (Cheston & Bender, 1999, p. 202).

Summary

Psychological models of dementia and dementia care have done much to reconceptualise the person with dementia from being 'a disease entity' to being someone whose experiential and social world can be explored and understood in a similar way to that of the person without the illness. It has been noted by several authors, however (see e.g. Bryden, 2002; Cheston & Bender, 1999), that to the extent that dementia care over the past decade has been informed by Kitwood's research and approach, it has predominantly been concerned with those living with dementia in the moderate to severe stages, most often in institutionalised care. Moreover, it has been informed by proxy reports and observational studies based on an assumption that 'the subjective world of the demented patient is not

directly accessible' (Albert, Del Castillo-Castaneda, & Sano, 1996). More recently, this assumption has been shown to be incorrect, as researchers in the field have begun increasingly to demonstrate that individuals with early stage dementia in particular are well able to articulate the experience and to argue for their voices to be heard (Cotrell & Schulz, 1993; Goldsmith, 1996; Keady, Nolan, & Gilliard, 1995; Russell, 1996). As this literature has become more extensive, it has become evident that people in the early stages of the illness have particular experiences and care needs that have not been addressed in either clinical practice or research and work has begun to address this gap. This work will be reviewed in the next section.

THE EXPERIENCE OF THE INDIVIDUAL WITH EARLY STAGE DEMENTIA

As developments in the fields of neuropsychology and neuroimaging have led to the identification of increasing numbers of people in the early stages of dementia, so research and clinical interest in the experience of this client group has increased, alongside the range of psychological interventions available to them (Clare, Baddeley, Moniz-Cook, & Woods, 2003). This section will review empirical work that offers a greater understanding of how people in the early stages of dementia experience their illness, and then consider the issues this raises for the process of assessment and diagnosis. Developments in psychological interventions used with this client group will then be reviewed, including a consideration of one specific intervention that is increasingly being offered to newly diagnosed people who are in the early stages of dementia: the professionally facilitated support group.

Hearing the voice of individuals in the early stages of dementia

As clinical interest in the early stages of dementia grows, a number of studies have begun to delineate the subjective experience of the person with dementia at the onset of the illness. However, few studies have sought to include the perspective of the person with dementia directly. Some accounts of the experience of early stage dementia are based on caregiver reports (Cotrell & Lein, 1993), while others are based on clinical observations of patients

(Bahro, Silber, & Sunderland, 1995). These proxy reports represent a significant step in investigating emotional and behavioural responses to a diagnosis of dementia, but do not heed the call made by Cotrell and Schulz (1993) for 'systematic study of patients' views regarding their illness and care' (p. 205).

More recently, a small number of qualitative studies based on semi-structured interviews with people in the early stages of dementia have furthered our understanding of the subjective experience of dementia, and demonstrated that those in the early stages of the illness are able to describe their experience and employ strategies for adaptation. Such work from a phenomenological perspective shows that, for many people, receiving a diagnosis of dementia requires an extended period of psychological adjustment. In a series of such interviews (Keady et al., 1995), individuals coping with the onset of the illness cited a range of emotions including fear, resentment and a feeling of being out of control. They described frustration at not being able to undertake tasks they had always taken for granted, anxiety about how they might be viewed by others, and anger towards the illness that was gradually undermining their hold on reality. However, these individuals also showed a marked resilience in the face of these losses, describing a significant degree of acceptance and adaptation to the difficulties they were experiencing. Such emotional and practical adaptations included making the most of the available time, and employing positive coping strategies to preserve existing functioning.

Accounts of the phenomenology of the early stages of dementia have frequently postulated a stage model of the experience, with individuals consistently progressing through sequential points in their behavioural and emotional adaptation to the diagnosis (Cohen, 1991; Keady & Nolan, 1994; 1995a; 1995b). Keady and Nolan suggest a longitudinal model of individuals' gradual process of acknowledgement of their illness, as they move through beginning to notice that they are not functioning as usual, to trying to cover up slips and lapses in memory, and finally admitting to themselves and then others that something is wrong. Such stage models do not appear, however, to be able to account for the variability seen in people's reactions to the diagnosis of dementia and the coping strategies they

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engage in. More recently, phenomenological research with individuals with dementia is beginning to focus on differences between individuals in an attempt to arrive at a broader conceptualisation of possible reactions and adaptations to the illness. This research suggests that the process of coping with and adapting to dementia is rather an ongoing, circular process as people try to balance the need to construct a new self in the face of the illness with a need to hold on to their existing sense of self (Pearce et al., 2002). Clare (2002b) similarly describes a continuum of adaptation and coping, with individuals occupying varying positions between attempting to maintain an existing sense of self and normality and developing 'a fighting spirit' as challenges are met head on and changes integrated within the self.

Such strategies for adaptation and coping and the variability in individual response represent, however, a new avenue of research in a body of literature that has sought to describe the potentially catastrophic reactions that can be experienced by persons who have recently received a diagnosis of dementia. This experience has been described as 'a profound, existential sense of emptiness and absence which is related to the actual or anticipated damage to their sense of self' (Bender & Cheston, 1997, p. 518). Unsurprisingly, social withdrawal and catastrophisation have been found to be common in the early stages of the illness (Husband, 1999; 2000). It is unclear, however, to what extent these descriptions reflect the particular kinds of reactions that are represented in a clinical caseload, and so may be representative only of a particular sub-group of people with dementia. The cyclical models of adjustment and coping outlined above begin to offer a conceptualisation of the subjective experience of early stage dementia that allows for variability in emotional response and coping style, both between and within individuals at different times.

Awareness of the potentially difficult emotions and reactions engendered in people with dementia who are in the early stages of the illness and who are aware both of their diagnosis and that there is no possibility of cure, has led some to argue against disclosing to the person with dementia their diagnosis and prognosis, and others to view this as 'an

ethical problem' (Midence & Cunliffe, 1996). These debates around assessment and diagnosis and their relevance to the emotional well-being of the individual with early stage dementia are considered below.

Sharing the diagnosis: an opportunity for intervention

British government guidelines on diagnostic disclosure in the case of individuals with dementia are unequivocal. Treatment of dementia 'always involves explaining the diagnosis to the older person and any carers and where possible giving relevant information about sources of help and support' (DOH, 2001, p. 98). Downs, Clibbens, Rae, Cook and Woods (2002) note that the National Service Framework for Older Adults further identifies the importance of early diagnosis in enabling people and their families to come to terms with the prognosis of dementia, and note the onus placed on the early identification of the disease by recent National Institute for Clinical Excellence guidelines stating that acetylchol inesterase-inhibiting drugs should be available on the NHS as a component of care for people with dementia in the mild to moderate stages. Pinner (2000) outlines further important reasons for diagnostic disclosure, including the individual's right to know, enabling them to make use of precious time, providing the opportunity to plan for the future, and allowing a process of psychological adjustment. However, others have questioned the motivation behind early diagnosis, citing the pharmaceutical companies as the main beneficiaries and suggesting that a medical diagnosis is not a prerequisite for the help needed by people with practical difficulties (Heller & Heller, 2003).

In view of these debates, consensus in the field of dementia research and practice is increasingly in favour of the patient deciding where possible whether to be given the diagnosis of dementia, if it is found to apply (Downs et al, 2002; Husband, 2000; Meyers, 1997; Pearce et al, 2002; Rice & Warner, 1994). However, numerous research studies indicate that the practice of clinicians with regards to sharing the diagnosis with the person involved is far more equivocal. Results of surveys of the attitudes and practice of healthcare practitioners have been largely consistent, with only around 50% of clinicians regularly telling patients with dementia their diagnosis (Downs et al, 2002; Holroyd, Turnbull, & Wolf, 2002;

Pinner, 2000; Pinner & Bouman, 2002; Rice & Warner, 1994). Moreover, in a sample of General Practitioners that did share the diagnosis with the person with dementia, more than one third used only euphemistic terms such as 'memory problems' or 'confusion' (Downs, Clibbens, Rae, Cook, & Woods, 2002).

Several authors note that this discrepancy between professional opinion and guidelines and actual clinical practice is most likely the result of assumptions about the distress disclosure might cause or judgements that people are too impaired to understand (Husband, 1999; Meyers, 1997; Pinner, 2000). This ambivalence is reflected in the process of giving a diagnosis where it does occur; it is unclear what a person will understand by 'memory problems,' or indeed by terms such as Alzheimer's disease or dementia where these are used, without sufficient support and time for explanation. The practice of dementia assessment often falls short of the consensual, considered process recommended in the literature, and those at the forefront of diagnosis and prognosis have been the subject of criticism for failing to address the psychosocial and emotional issues involved (Keady, 1996; Moniz-Cook & Woods, 1997).

Cheston (1998) raises this issue when he urges providers of dementia services to consider 'how the broad scope of dementia care can be made more psychotherapeutic' (p. 221), and gives as an example the carrying out of neuropsychological assessments in a way that attempts to meet the emotional needs as well as the practical requirements of individuals. The notion of assessment and diagnosis as a therapeutic process is further considered by Pinner (2000), who argues that disclosure of a diagnosis should not be a one-off event but 'an ongoing, dynamic process and fundamental part of the care of a patient with dementia' (p. 515). Acknowledging the range of positive and negative emotions expressed by people with dementia in the early stages, she argues that possible negative reactions should not be viewed as a reason for withholding the diagnosis from the patient. Instead she points out that the expression of distress is not necessarily a negative outcome, and insists that as in other therapeutic contexts 'it is part of [the clinician's] role to work with distress' (p. 515).

The debates and dilemmas surrounding the issue of diagnostic disclosure should therefore be understood within the context of a still evolving understanding of the subjective experience and needs of the person with dementia at the time of diagnosis and beyond, and the service provision that should be available in response. However, diagnostic disclosure is increasingly seen as both an individual's right and an opportunity for therapeutic intervention: with the increasing interest in diagnosis and disclosure has come increased clinical interest in psychosocial interventions that can be provided to individuals in the early stages of dementia.

Psychological interventions for individuals with early stage dementia

Caring for the emotional needs of people following diagnosis with early stage dementia is still a relatively new area of clinical practice. In the United States a movement is underway to establish a service infrastructure for this client group (Yale, 1999); however, in the United Kingdom, Keady and Nolan's (1995b) vision of distinct and separate services for people in the early stages of dementia remains to be realised. This paucity of support contrasts sharply with that offered within health and social care provision to those with other forms of illness such as HIV or cancer (Bender & Cheston, 1997).

However, interest in the area is growing rapidly, with increasing reports in the literature of a wide range of psychosocial work with people in the early stages of dementia. These include memory rehabilitation (Clare et al., 2000; Clare, Wilson, Carter, & Hodges, 2003), psychosocial interventions in memory clinics (Moniz-Cook, Agar, Gibson, Win, & Wang, 1998), a range of group therapies (Scott & Clare, in press), counselling and support at the time of diagnosis (Husband, 2000; Pinner, 2000), and the use of specific therapeutic approaches. These latter include cognitive behavioural therapy for depression in people with mild to moderate dementia (Teri, Logsdon, Umoto, & McCurry, 1997), and psychodynamic psychotherapy (Sinason, 1992).

An area that remains problematic with regard to psychological interventions for this population, however, is the delineation of people's support needs in the period following a

diagnosis of dementia as distinct from their need for psychotherapeutic intervention. The focus on the emotional and behavioural difficulties that can be experienced as individuals face current and anticipated losses and changes in functioning, reviewed above, in conjunction with the tendency for service provision for people with dementia to be professionally organised and facilitated, appears to have resulted in a perceived need on the part of clinicians to provide services without always distinguishing between a need for therapeutic intervention and a need for more general support. Thus Bender and Cheston (1997) go so far as to argue that all people newly diagnosed with dementia should have access to therapeutic forums within which the implications of the diagnosis could be explored. By acknowledging issues of loss and grief, they believe, the person with dementia may be able to move on and begin to make sense of their losses. Other authors concur that psychotherapeutic intervention could be seen as essential for those facing the losses and changes incumbent with the early stages of a dementing illness. In this view the grief, anxiety and anger described in phenomenological reports of the experience of dementia are adaptive responses that can and should be modified by counselling and psychotherapy (Jones, Cheston, & Gilliard, 2002). It is, however, unclear whether all those living with the early stages of dementia would perceive a need for such psychotherapeutic intervention, with its emphasis on therapeutic change and 'working through.' The research on the phenomenology of individuals with dementia reviewed above suggests that, while some struggle in the early stages of the illness and may welcome therapeutic support, others are able to employ a range of emotional and practical coping strategies and show a remarkable degree of acceptance and adjustment. Such individuals might however benefit from opportunities to receive more general support from professionals and/or peers to bolster and help mobilise their existing practical and emotional resources.

One forum that has traditionally been utilised by other populations as an opportunity for such supportive transactions is the support group, where individuals who share the same difficulty or experience meet together in a mutually supportive exchange. Such support groups, professionally facilitated, in fact represent a recent and innovative form of intervention for individuals with early stage dementia. Informed both by discourses around mutual support

and those of psychotherapeutic change, the professionally facilitated support group is gaining increasing recognition as a potentially helpful intervention to offer to people with dementia in the period following diagnosis. This is discussed further below.

Support groups for individuals with early stage dementia

Noting that the support group has long been established as a means of supporting carers for people with dementia (see for example Monini, Tognetti, Cinque, Di Franco, & Bartorelli, 2001; Morris, Woods, Davies, Berry, & Morris, 1992), one clinician in the field of dementia published a book in which she provided a framework for setting up, facilitating and evaluating a support group for the individuals with early stage dementia themselves (Yale, 1995). Since its publication, there has been an increasing number of reports of such groups in the literature (see e.g. Cheston & Jones, 1998; Hawkins & Eagger, 1999; Jones et al., 2002; LaBarge & Trtanj, 1995; 1998). These groups are variously described as providing a space for people to share experiences, share coping strategies, process the emotional responses to the diagnosis, and discuss shared issues and concerns. Caron (1997) describes one such support group. He reports that members spoke freely about a range of topics. They talked about their changing relationships with family and friends, and how they felt patronised by them. They discussed how they felt they had to cover mistakes or lapses in memory in order to 'pass', and how they feared letting people know they had dementia in case they withdrew or treated them like they had gone crazy. They shared their frustrations about the constraints that had been imposed on their lives by dementia, and talked about how unprepared they had been for the effects of the illness. They felt that they 'were having to work out how to cope with the disease alone' (p. 320). Such descriptions and accounts of these support groups are beginning to build a rationale for their further provision within dementia services.

These hopes and expectations of support groups for individuals with early stage dementia draw on notions of emotional support, giving and receiving help, and receiving guidance and information as mechanisms through which the hoped for outcomes will be achieved. In other areas of the literature, these mechanisms have been conceptualised as important

components of mutual support. Before further considering the literature on support groups for individuals with early stage dementia, the literature on mutual support and support groups more generally will be reviewed as it pertains to understanding the mechanisms for achieving personal change in support groups for individuals facing a crisis or coping with a chronic stressful situation.

SUPPORT GROUPS AND MUTUAL SUPPORT

In recent decades increasing numbers of people have been turning to various forms of mutual support groups and organisations to help them cope with a variety of life crises, transitions and chronic stressors. Yet there is a lack of consensus in the literature about what actually constitutes a support group, and it has been suggested that such groups lack a solid theoretical foundation (Helgeson & Gottlieb, 2000). This section will consider current definitions of support groups and the theoretical rationale for their existence, before providing a brief overview of empirical support for their functioning and effectiveness.

What is a support group?

Support groups are commonly understood to be forums where individuals with a common experience or concern come together with the intention of providing and receiving mutually beneficial helpful transactions. Such mutual help has been defined by Borkman (1999) as referring to 'individuals joining together to assist one another emotionally, socially, or materially' (p. 4). The group context for such transactions has variously been termed in the literature 'self-help group,' 'mutual aid', 'mutual support group' and 'support group'.

One distinguishing feature of these groups that repeatedly emerges in the literature is the presence or absence of professional facilitators. Numerous authors point to the clash between the 'grass roots ethos' of the self-help movement and facilitation by a professional whose expertise resides in theoretical rather than experiential knowledge, and who is invested with an authority and power sanctioned by the State (Humphreys & Rappaport,

1994; Powell, 1997; Rappaport, 1993). Borkman (1999) views the incursion of professional power into the mutual support group as being highly detrimental, as it introduces a powerful hierarchy that positions the 'patient' as subordinate and disempowered. Likewise, Schubert and Borkman (1991) consider professional involvement to alter the essential characteristics of mutual support to such a degree that they exclude professionally-led groups from their typology of self-help groups. Support for this view is provided by research that found that professionally facilitated support groups had a more formal, psychologically directed approach than those that were peer-led, and that their members adopted a passive, dependent 'patient role' (Toro et al., 1988). However, even strong advocates of the 'grass roots' model of self-help argue that under some circumstances skilled professional facilitation will be required, such as where individuals are very damaged, weak or frail to the extent that they need professionals to intervene in and maintain the group (Borkman, 1999).

In the light of these debates certain authors have adopted different terminology for peer-led versus professionally-led groups, with the term 'support group' used for professionally facilitated groups only (see Borkman, 1999; Helgeson & Gottlieb, 2000). This terminology will be used from here on. Within this conceptualisation support groups have recently been defined as follows:

> Typically ... 6 to 12 people who 1) share a similar life stressor, transition, affliction or noxious habit, and 2) receive expert information and/or training and engage in mutual aid to foster improved coping and adjustment.
>
> (Helgeson & Gottlieb, 2000, p. 222)

Support groups thus typically combine education and the fostering of coping skills with provision of mutual support, with no necessary clear distinction between facilitators and group members as to who performs each function. They differ from psychotherapeutic groups in that the leader does not engage in clinical practices such as diagnostic assessment or psychological interpretation, and from self-help groups in that as well as involving expert leaders, they do not usually engage in advocacy. However, they share a

number of features with self-help groups, as they are founded on the practice of mutual support and sharing that is fostered by a sense of identification based on shared life events and experiences (Helgeson & Gottlieb, 2000).

In summary, while there is a lack of consistency and consensus in the mutual help literature as a whole, the term 'support group' has increasingly been used to refer to those small group interactions where people with a shared experience come together in the presence of one or more professional facilitators with the purpose of providing and receiving mutually beneficial forms of support. There is some evidence that the nature of these transactions may differ to those in groups that are peer-led. However, there are also many commonalities between the nature of the support offered in support and self-help groups. The different forms this support can take is considered in the next section, which considers the theoretical rationale for this form of supportive intervention.

The theoretical underpinnings of support groups

Conceptualisations of the mediating processes through which support group interventions are deemed to have their effect are drawn from a wide range of literature in the fields of clinical and social psychology. Here they will be summarised under the headings of provision of social support, bi-directional helping, and social comparison and social learning theories. A brief overview will be provided of each, in addition to a consideration of their possible limitations.

Social support

Gottlieb (2000) posits that a key difference between the support group and other psychological interventions is that in the former it is the supportive interactions between members that act as the mediating process through which change occurs, rather than the insights or modelling offered by the professional practitioner. He views the social support offered within the group setting as supplementing the resources available within an individual's existing social support network, which may be depleted or unable to offer support due to being drained by the stresses of their caregiving responsibilities towards the

individual. Alternatively, there may be no 'similar others' within their network who have experienced the same life event or stressful circumstance, making it harder for the individual to find emotional support and information about ways of coping. In this context, the assumption is that members of a support group will provide a level of social support that will compensate for these deficits.

Three main types of supportive interactions have been described: emotional, informational and instrumental (Hogan, Linden, & Najarian, 2002). Emotional support includes the expression of caring and concern and the communication of empathy. It is believed to reduce distress by enhancing self-esteem, decreasing feelings of isolation and stigma, and encouraging the expression of feelings. These processes are consistent with those highlighted in the group psychotherapy literature, notably Yalom's (1975) notions of universality - the process of learning that that one's problems are not unique - group cohesiveness and catharsis as curative factors in the group experience. Informational support includes the sharing of experiential knowledge in order to provide guidance or advice, and is thought to increase the recipient's coping skills and sense of mastery and control. Instrumental support involves the provision of material goods or practical help. Emotional and informational support have been operationalised behaviourally within the support group setting by Paine, Suarez-Balcazar, Fawcett and Borck-Jameson (1992) as reflecting feelings and making brief statements of encouragement, sharing similar experiences, offering suggestions to solve a problem, and offering information about alternatives.

The literature suggests that support group members view social support as one of the most helpful features of a support group. In one study, when asked why their group was effective, 83% of members cited the supportive and accepting environment it provided (Knight, Wollert, Levy, Frame, & Padgett, 1980). Similarly, Maton (1988) found that activities relating to social support such as receiving empathy, sharing personal experiences and problem solving were related to reported satisfaction and benefits by group members.

Bi-directional helping

The value of demonstrating altruism was highlighted by Yalom (1975) in the context of psychotherapy groups, and support groups perhaps provide even greater opportunities to offer help to others. Although not as widely explored in the literature as the benefits of receiving support, the process of providing support is also thought to confer considerable benefits. These were first conceptualised in Riessman's (1965) 'helper-therapy' principle, where the helper role is seen as providing an opportunity to gain a sense of empowerment and competence, increase feelings of self-efficacy and so enhance self-esteem. Recent empirical support for the principle has been provided by an observational behavioural measurement of the helping transactions that occur in self-help group meetings for people with serious mental health problems, where giving help to others predicted psychosocial adjustment (Roberts, Luke, Rappaport, Seidman, Toro & Reischl, 1999).

The 'bi-directional support hypothesis' (Maton, 1988) states, however, that people who both provide and receive support will experience greater well-being that those involved in only one of the two processes. Evidence for this hypothesis was provided by Maton's finding that group members who both gave and received support had lower levels of depression, higher self-esteem and reported higher levels of satisfaction that those who either predominantly gave or predominantly received support. Maton posited three possible theories for this finding. The 'additive benefits explanation' hypothesises that both receiving and giving support impart benefits, and the individual who is involved in both processes accumulates the benefits from both. 'Balance theory' states that there are costs in both giving help (not getting one's own needs met) and receiving help (feelings of dependency, inferiority and indebtedness) that cancel each other out in bi-directional helping. The 'needs/resource theory' acknowledges, however, that higher levels of well-being could be a prerequisite rather than a consequence of bi-directional support.

Social comparison and social learning theories

Social comparison theory (Festinger, 1954) states that in times of uncertainty or stress, people evaluate themselves through comparisons with others. Helgeson and Gottlieb (2000) suggest that diversity among support group members can provide opportunities for such social comparison. They argue that upward comparison with better-off members can provide motivation and useful information; comparison with similar members can be a normalising experience; and comparison with members who are worse off can enhance self-esteem.

Stewart (1990) cites the applicability of social learning theory to understanding the mechanisms by which members' self-efficacy is increased in self-help groups. Other members of the group may function as 'role models' to increase an individual's repertoire of coping strategies, and through providing alternative ways of perceiving a problems increase the range of possible solutions.

Possible hindrances to helping processes in support groups

The processes outlined above that are thought to mediate the effectiveness of support groups for those who attend them may not always do so in a straightforward and unequivocal manner, however. Helgeson and Gottlieb (2000) outline a number of ways in which the assumptions and theories on which support group interventions are based may not hold for particular members or in particular contexts. First, peers may not always provide the reciprocal emotional support thought to be essential to the successful functioning of a support group. This may be because the particular experience being described may not in fact be shared by other members of the group, or people may not respond to the experience with the same level of distress. Alternatively, emotional support may be offered but not perceived. Helgeson and Gottlieb point to literature that suggests that the perception of emotional support is more strongly related to emotional well-being than actual received support. They suggest that support group members may be so different on variables such as age, gender, and occupation that the stressor is all they have in common and so group interactions are not perceived as supportive.

Helgeson and Gottlieb also question the assumption that expressing negative feelings will reduce distress. They point out that for members unused to expressing feelings the encouragement to do so may well increase rather than decrease their levels of stress. In addition, focusing on emotional expression may lead to a downward spiral if it causes the individual to become more aware of his or her negative feelings. Finally, they suggest that expressing feelings may not on its own lead to cognitive or behavioural change, and indeed may lead the individual to focus on the problem rather than on solutions to the problem.

Evaluation of support groups

Empirical evaluations of support groups have provided some evidence for their usefulness in terms of enhancing people's level of psychological functioning and positive health outcomes (Hogan et al., 2002). The methodological difficulties faced by such studies are, however, well-documented, and limit the conclusions that can be drawn (Goldklang, 1991; Helgeson & Gottlieb, 2000; Powell, 1997). There is some converging evidence, however, that short-term groups of 8-10 sessions are not as effective as groups that continue over the longer-term, especially where they concern chronic or ongoing stress (Gottlieb, 2000). The literature also suggests that interventions that include an education component alongside the provision of mutual support achieve better outcomes than groups based on peer discussion and support alone (Helgeson & Cohen, 1996; Helgeson & Gottlieb, 2000). However, some authors have noted that the outcome literature in this area is based on assessments of a group's effectiveness according to the researcher's and not the group members' criteria, and point to the discrepancy that frequently exists between the two (see Goldklang, 1991; Helgeson & Gottlieb, 2000). In this respect, literature on support groups is in line with that on therapeutic helping more generally, where the importance of clients' subjective experience in construing the therapeutic experience has been emphasised, and research undertaken to investigate the helpful and unhelpful aspects of therapy as perceived by both clients and therapists (Llewleyn, 1988).

Similar to research that aimed to identify the crucial therapeutic factors in psychotherapy groups (Bloch, Reibstein, Crouch, Holroyd & Themen, 1979), a small amount of research

has begun to address the observation by Roberts et al. (1991, p. 716) that 'although establishing the effectiveness of mutual help is important, researchers cannot ignore the task of adequately describing the activities, helping behaviours and interaction processes that characterize the groups'. Roberts et al. point out that in order to understand which aspects of the mutual help experience produce positive change we must investigate and measure the process variables involved, and note that currently the few attempts to do this almost all rely on members' retrospective reports.

In an attempt to document 'in vivo' group support and interaction processes, Roberts et al. devised a 'behavioural observational system' to systematically describe and document the activities and interactions that occur in group meetings. This coding system operationalised the processes hypothesised to be operative in the mutual support setting, enabling investigation of social support 'as a behavioural act between a provider of support and a recipient' (p. 717). Studies using this and other such coding systems to observe support group processes have documented a range of helping behaviours such as offering emotional support and information, and sharing similar experiences (Paine, Suarez-Balcazar, Fawcett, & Borck-Jameson, 1992; Roberts et al., 1991; Toro et al., 1988). More recently attempts have been made to link the occurrence of helping processes within a group to group outcome (Roberts et al., 1999). This research found that providing help to others predicted improvements in psychosocial adjustment, but that for recipients of help better adjustment depended on the type of assistance received. Objective study of transactions operative in support groups remains however a developing area in the literature.

SUPPORT GROUPS FOR INDIVIDUALS WITH EARLY STAGE DEMENTIA: WHAT WE KNOW FROM CURRENT RESEARCH

The provision of support groups for individuals with early stage dementia is predicated on the assertion that 'people with [early stage dementia] can participate in and benefit from support groups just like people in any other support group in which the goal is to adjust to and cope

with an illness or crisis in one's life' (Yale, 1999, p. 58). The rationale for such groups is thus based on notions of the provision of the kind of emotional and informational support that is thought to mediate the effectiveness of support groups more generally:

> The basis for using support groups as a psychosocial intervention [with people with early stage dementia] is the assumption that the group supplies: a) emotional bonding that creates closeness and reduces feelings of isolation; b) enhanced self-esteem in having information to share about current coping strategies; and c) information exchange that creates a sense of hope and efficacy.
>
> (Kasl-Godley & Gatz, 2000, p. 763)

This assumption is not yet, however, backed up by empirical observation and research. Current literature on the use of support groups with this client group provides little systematic description or investigation into the support processes and helping transactions thought to operate. Descriptive reports of such groups in which facilitators describe their impressions of the group (Caron, 1997; Hawkins & Eagger, 1999; Jones et al., 2002) indicate, however, that the characteristics and processes of these groups may in fact be different to those discussed in the wider mutual support literature. Thus Caron (1997) portrays vividly in his description of an early stage dementia support group the impact of the members' impairments on the group's functioning:

> No-one could remember what the main topic was, so content was free-flowing and shifted quickly. Repeated stories were the norm ... Persons in the group showed a high degree of acceptance. Competition was pointless; in the face of shared impairment, humility was the rule. Repetitious questions or lapses in understanding were accepted as group members recognised their own foibles and foibles yet to come.
>
> (Caron, 1997, p. 320)

It is unclear to what extent the particular nature of the interactions between individuals with early stage dementia impact on the processes theorised to be important change mechanisms in support groups. It may be that both the provision and the perception of emotional support and bi-directional helping are decreased in exchanges between impaired individuals, particularly where these are heavily mediated by professional facilitation. Processes of social comparison may similarly function quite differently where one has no possibility of attaining the levels of cognitive functioning of those better off than oneself, and where those worse off present a lived example of 'foibles yet to come.'

Furthermore, it is widely argued that the nature of the impairments and emotional distress faced by people with early stage dementia necessitates facilitation by professionals with knowledge and experience both of the needs of individuals with dementia and of group processes (Jones et al., 2002; Keady et al., 1995; LaBarge & Trtanj, 1995; Yale, 1995; 1999). This view would appear to be supported by facilitators' reports that indicate that they take a much more active and directive role than in support groups with other client populations (Cheston, Jones, & Gilliard, 2003; LaBarge & Trtanj, 1995). It is also suggested by facilitators that in these support groups they take on an additional role as a 'group memory', holding on to members' memory, knowledge and words for them as they struggle to remember (Cheston, 1996; 1998). As described above, research within the area of mutual support suggests that this increased need for, and reliance on, a group facilitator will have implications for the nature of group interactions and processes.

An additional consequence of the predominance of professional involvement in these groups, and the concomitant 'professional's eye view' (Nolan et al., 2002, p. 194) of their aims and activities, can perhaps also be seen to be the potential conflation of therapy and support functions observed above in relation to other psychosocial interventions. Thus Bender and Cheston (1997, p. 526) cite Yale's and other support groups as 'helping [the person with dementia] to change psychotherapeutically' (p. 526), while Cheston (1999) calls them a 'psychotherapeutic intervention'. Jones, Cheston and Gilliard (Jones et al., 2002) use the terms 'psychotherapy' and 'support' interchangeably and do not differentiate between

their own 'group psychotherapy project' and support groups described in the literature. It is unclear to what extent the processes and experience of groups that are envisioned to be both supportive and therapeutic differ from groups that have a purely supportive function. In view of all the above issues, it is not yet clear how far we can extrapolate from the generic mutual support literature to inform the theory and practice of early stage dementia support groups.

Evaluations of support groups for individuals with early stage dementia

Within the developing clinical literature on the provision of support groups to these clients there are few evaluative studies of groups that aim to provide a forum for emotional and practical support, rather than being purely psychoeducational or activity-based. The few studies that do exist suggest that support groups are appreciated by people with early stage dementia. LaBarge and Trtanj (1995) used a 'satisfaction questionnaire' consisting of eleven closed and three open questions to evaluate the response to a ten week 'support group for people with mild dementia' in which they aimed to help members to share thoughts and feelings and to provide emotional support. Eighty-six percent of replies were positive. In an earlier study (Peach & Duff, 1991), the facilitators of a 'mutual support group' that ran weekly over a one-year period contacted members at one year follow-up to ask their opinions of the group. Five of the six members who responded thought the group was 'very helpful'. Yale (1995) likewise cites the participants of her support group as reporting high satisfaction, with reduced feelings of isolation and a number of additional benefits, including being more able to acknowledge their diagnosis and discuss problems. However, these accounts rely on brief 'satisfaction questionnaires' and facilitator reports and so provide very limited and possibly biased information. It is also unclear how much of the group experience the participants in the early study were able to recall after the period of one year. A more systematic evaluation of participant views was offered in a recent qualitative study of two time-limited support groups that investigated the group experience from a phenomenological perspective (Morhardt, & Menne, 2001). Themes that emerged from the participant interviews suggested that members benefited from opportunities to meet with others who were experiencing similar difficulties, having information to share that increased their feelings of being useful,

and being able to gather information about the dementia process. This study provides useful information on possible elements of the group experience that need to be explored further.

Studies have also attempted to shed light on the types of themes discussed in such groups and the support processes that occur. LaBarge and Trtanj (1995) wrote detailed notes at the end of each session they facilitated, providing a qualitative 'audit trail' of themes discussed and group processes such as bonding and acceptance of decline. More recently LaBarge, Van-Dras and Wingbermuehle (1998) reported a content analysis of transcripts from an eight session support group for eleven individuals diagnosed with Alzheimer's disease. This suggested that group members voiced concerns about their fluctuating memory and difficulties with daily activities, and the effects these had on their relationships. They also sought information about the illness and shared coping strategies. However, the reliance in the former study on facilitators' post-hoc session notes as the basis for evaluation, and the conflation of the facilitator and researcher roles in both, impact on the confidence that can be placed in the themes and processes they report. Retrospective accounts are vulnerable to selection of what is remembered according to the needs, values and preoccupations of the individual doing the recalling. Moreover, strong personal commitment to the intervention and optimism about its usefulness may lead to the 'observation' of positive outcomes that are not apparent to others, including possibly the person with dementia (Kitwood, 1997; 1995).

Outcome research in the area of support groups for this population is at a very early stage and thus far few conclusions can be drawn about the possible outcomes for the individuals who attend. In a quasi-experimental study into an 'early dementia support group' conducted by Yale (1995; 1999), thirteen patients were allocated to a treatment-as-usual control group or an eight-week support group offering education and emotional support. Pre-, post- and follow-up interviews showed no significant differences on a range of outcome measures either between the two groups or over the course of the intervention. Yale herself points out, however, that the conclusions that can be drawn from this are limited by the small number of participants and the use of measures that may have been too insensitive to pick up the changes likely to be seen in the group over the time available. A further evaluation has

recently been conducted of six 10-week long 'psychotherapeutic support groups' for people with early stage dementia (Cheston, Jones & Gilliard, in press). Levels of anxiety and depression were measured before, during and after the intervention, and the participants' use of coping strategies was assessed at the same points. The study found a reduction in depression and anxiety during the intervention and at follow-up, but with no change in the use of coping strategies. This study appears to offer evidence of the effectiveness of support groups for individuals with early stage dementia. However, the description of the groups as 'psychotherapeutic' raises questions about the nature of the interactions and helping transactions and how these were related to the outcomes observed. It may be that this study offers evidence of the effectiveness of psychotherapy groups for this population rather than of support group interventions. Indeed, Cheston (personal communication) has more recently described the groups as psychotherapy groups rather than support groups.

IMPLICATIONS OF THE LITERATURE FOR THE CURRENT STUDY

A need for further research

The studies detailed above indicate that support groups may be a helpful and appreciated intervention for individuals in the early stages of a progressive dementia, for whom there otherwise remains very little service provision. However, the studies are very few in number and much of the groups' support processes, helping behaviours, content and outcomes remain unknown. In addition, apart from one systematic study, the reports rely almost exclusively on facilitators' impressions, post-hoc case notes and brief 'satisfaction questionnaires'. This means that the information they provide is limited and may be biased or incomplete. Further systematic study of the support group processes and experience is therefore needed to clarify and extend our understanding in this area. Most importantly, as regards support groups for people with early stage dementia, there is virtually nowhere in the literature that provides 'systematic study of patients' views regarding their ... care' (Cotrell & Schulz, 1993, p. 210). While not undermining the value of professional expertise, the absence of accounts that elicit the perspective of the person with dementia directly means

that currently our knowledge is based solely on professionals' representations of that perspective, translated into a language and conceptual framework of their own.

Rationale for the current study

This study aims to explore the support processes and helping transactions that occur in support groups for individuals with early stage dementia, and to discover and describe the views and experiences of the individuals who attend. As such it is discovery-oriented, using qualitative methodology (semi-structured interviewing and interpretative phenomenological analysis, described below) in combination with a quantitative, observational approach to describing the processes and transactions in the group.

Knowledge about the processes and outcomes of early stage dementia support groups remains underdeveloped, and theory-generating research is therefore appropriate (Henwood & Pidgeon, 1992). Thus Cotrell and Schulz (1993) suggest that large quantitative studies may be premature, Cheston (1998) argues for the need for greater attention to be paid not just to therapeutic outcomes but to therapeutic processes, and Cheston and Jones (1998) conclude that 'a qualitative evaluation of group processes, involving the videotaping, transcription and analysis of data may be of more use at this point in the development of...clinical ideas.' In the generic literature on support groups there is also a call for an emphasis on discovery and description, with Goldklang (1991) recommending more descriptive, formative and process focused research (see also Maton, 1988; Powell, 1997; Powell & Cameron, 1991; Roberts et al., 1991; 1999).

An empirical investigation into the behaviours and interaction processes that are operative at the group will increase our understanding of the functioning of these groups, while providing an additional perspective on the information gained from group members' self-report about their experience.

Rationale for the study's approach and method of analysis

The above review of the literature indicates that at present we lack any phenomenological perspective on the experience of attending a support group for people with early stages dementia, and there is scarcely any observational data on the interactions and support processes that actually occur. This study therefore sought to elicit directly the perspective of individuals with early stage dementia who attend such a group, and to provide an observational description of the group processes.

In accordance with these aims, the study took a phenomenological approach to the study of the participants' experience and views, seeking to elicit, engage with and represent their accounts of their experience using semi-structured interviews and interpretative phenomenological analysis (IPA). IPA is a qualitative method of analysis that works with texts generated by participants, most often with transcripts of semi-structured interviews, to generate a thematic account of the phenomenon in question (see Smith, 1995). Smith, Jarman and Osborn (1999) describe IPA as being 'concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself' (p. 218). IPA is thus an approach to research that is informed by the philosophical framework of phenomenology, focusing on the content of individual subjectivity and how the individual experiences the world (Willig, 2001). Semi-structured interviews can elicit direct accounts of individual experience that allow both the researcher and participant flexibility in the research process, and create a more collaborative research activity.

The coding of processes in therapeutic transactions has a long history in the literature. In adopting this approach to the discovery and description of group interactions and support processes the study followed in the footsteps of recent attempts to extend this tradition to the area of mutual support.

Self-report and direct observation represent two different kinds of information and make different contributions to our understanding of a phenomenon. In using both methodologies

the study sought to elicit different but complementary perspectives that would enhance our understanding of dementia support groups.

RESEARCH QUESTIONS

This is a study of the experiences and processes of support groups for individuals with early stage dementia. It combines qualitative methodology with quantitative coding of group processes to obtain a rich understanding both of the actual transactions and interactions that occur in the groups, and the perception of the group experience of the individuals who attend. The study asks the following specific questions:

1) What is the nature of the support processes and interactions that occur in support groups for individuals with early stage dementia?

2) What is the experience of the individuals who attend such groups?

CHAPTER TWO

METHOD

This study uses qualitative and quantitative methods to look at processes and interactions in support groups for individuals who are in the early stages of dementia, and the views of those individuals about the experience of attending such a group. This chapter outlines the recruitment of the participants and describes their characteristics, and also the characteristics of the two participating support groups. It then considers the ethical considerations inherent in the study, before going on to describe the procedure used for data collection. Finally, the methods of data analysis are described, with an overview both of the behavioural observation system used to record the group interaction and of interpretative phenomenological analysis (IPA).

RECRUITING THE PARTICIPANTS

The participants in this study were individuals with a diagnosis of possible or probable dementia who were in the early stages of the illness, and who were ongoing members of a support group for individuals with early stage dementia. Recruitment to the study was undertaken on a group rather than individual basis, as all members of a group needed to be willing to participate in the study if that group was to take part. The target population was members of all support groups for individuals with early stage dementia in the London area in early 2002.

I contacted psychologists working in older adult services and/or memory clinics in and around London to identify existing support groups which might be interested in participating in the study. As a result of these enquiries it became evident that there was only one existing support group in this area for individuals with a diagnosis of early dementia. Further enquiries through the Alzheimer's Society confirmed that while there were many support groups in the area for families and carers of people with dementia, this was indeed the only

support group for the individuals themselves. At this stage of enquiry, however, psychologists in a further three services expressed an interest in setting up such a support group and in participating in the study. Of these, one service did set up a group within the time frame of the study and expressed a continued interest in taking part. The actual target population therefore consisted of all members of the two identified support groups in existence at the time of the study.

I followed up these initial contacts with a meeting with the facilitators of each group. At these meetings I outlined the aims, objectives and potential usefulness of the study and described what would be required of the participants and of the facilitators themselves. The facilitators also had an opportunity to ask me questions and to raise any concerns. The facilitators of both groups indicated at this stage that they were willing in principle to invite their groups to participate in the study, and agreed to discuss the project with their group members to gauge their interest.

The group facilitators introduced the aims and methods of the study to their respective group members over two to three sessions, each week re-visiting the information provided the week before. In this way the idea of the study was introduced to the participants by someone they already knew, and with whom it was hoped they would feel able to raise questions if they did not understand what was being proposed or had forgotten a detail that had already been explained. It was hoped that this would also enable them to raise any doubts or objections to taking part in the study, and to state whether they were in any way unhappy with what they were being invited to do. The facilitators stressed that the members did not have to agree to take part in the study at all, even if everyone else in the group was happy to, or could agree to the group being videoed but not take part in the interviews. It was also stressed that (non-) participation would not affect their membership of the group or any other aspect of their treatment. All participants indicated at this stage that they would be willing to participate in the study.

I then provided the facilitators with information sheets outlining the aims and methods of the study, and consent forms for each group member (see Appendices 2 and 3). The facilitators used a further group session to go through each item on the information sheet with the group members, answer any questions and complete the consent forms individually.

THE PARTICIPANTS

In order to be included in the study participants were required to be currently attending one of the two identified support groups for individuals with early stage dementia taking part in the study. Here the basic features of those groups are described, followed by the characteristics of the participating individuals. Further contextual information about the groups is then provided in the form of the group facilitators' characterisation of their group's aims, expected benefits and style of facilitation.

Participating groups

Group A

This group had existed for approximately four years, and was run as part of the programme of activities offered by a day hospital that catered for older adults who had recently been diagnosed with possible or probable dementia. All group members were therefore also members of the day hospital, though for some their attendance at the hospital comprised only their participation in the group. Others also attended other groups and activities provided at the hospital. Membership of the group was open-ended, and continued until the individuals themselves no longer wished to attend or in the judgement of the group facilitators their illness had progressed to a point where they were no longer able to benefit from attending the group. During the period of data collection for this study there were seven members in this group, comprising six women and one man. The group met weekly for one hour, in a room at the day hospital.

The group was facilitated at any one time by two health professionals, rotating on approximately a three-month basis and drawn from a pool of professionals connected with the day hospital including a psychiatrist, psychologist, assistant psychologist and admiral nurse. At the time of the study the group was facilitated by an admiral nurse and assistant psychologist.

Group B

This group was set up approximately nine weeks prior to the period of data collection for this study. It also operated as part of the programme of activities offered by a day hospital attended by older adults with a variety of functional and organic difficulties, and met for one hour weekly in one of the rooms at the hospital. Membership of the group was accessed via the memory clinic attached to the hospital. The group was set up to be open-ended, with the intention that members would leave and join the group as appropriate to their needs. At the time of the study its membership comprised two men and two women.

The group was facilitated by a consultant psychologist and assistant psychologist who were members of staff at the day hospital.

Inclusion criteria for individuals

The inclusion criteria for the study were equivalent to the criteria used by the two participating groups to determine their membership.

Both groups required their members to be over the age of 65, to have been diagnosed as meeting the diagnostic criteria for probable or possible dementia of any type, and to have been categorised as having mild cognitive impairments. Scores of 18 or above on the Mini Mental State Examination (MMSE: Folstein, Folstein, & McHugh, 1975) were taken as an approximate indication of mild impairment, in conjunction with the clinical judgement of the assessing clinician. All members needed to have been told that they probably had dementia, and to acknowledge at least some degree of memory loss. In addition, in the judgement of the referring clinician and the group facilitators, potential members were required to be able

to participate in a group setting and to be potentially able to communicate something of their experience of dementia. Finally, all members had to be willing and able to give their informed consent to participate in the group.

Participating individuals

The combined group membership of eleven participants took part in the study, comprising eight women and three men. Of these, one participant decided later on in the study to take part in the video recording of the group sessions but not the interviews. Therefore a total of eleven participants from two support groups took part in the recording of group sessions, and ten of these were interviewed about their experiences in the group.

The participants ranged in age from 72 to 86 years old, with a mean of 79 years. Eight described themselves as 'English' or 'British', two as 'Irish', and one as 'Jamaican'. Six of the participants lived alone, four lived with their spouse and one person lived with her son. Four people had been in a professional occupation prior to retirement, four had been in a skilled occupation, three in a semi-skilled occupation, and one person described her previous occupation as 'housewife'.

Seven participants had been diagnosed with possible or probable vascular dementia, and four with probable Alzheimer's disease. Their MMSE scores ranged from 19 to 29, with a mean of 24. For seven participants these scores had been recorded within the six months prior to the start of the study, for two participants within the previous year and for two participants within the previous two years. None of the participants had any other major psychiatric diagnoses, but five people were described in their day hospital files as suffering from 'depression.' One person had received brief individual therapy for her depression, lasting for ten sessions. This had been provided by the assistant psychologist who also facilitated the support group, but was not ongoing during her membership of the group.

The length of time for which participants in Group A had been members of the group ranged from eight weeks to two years, with a mean of fifteen weeks. All four participants in Group B had been members of the group since it began, nine weeks prior to the start of the study.

Two members of Group A and three members of Group B had pre-existing relationships with one of the facilitators of the group, in that the facilitator had carried out their neuropsychological assessment as part of the process of diagnosis. This was in addition to the pre-existing therapeutic relationship specified above. In addition, one member of Group A was receiving couple therapy from one of the group facilitators, concurrent with his attendance at the group.

Further contextual information about participating groups

Further contextual information about each group was gathered by way of a semi-structured interview conducted with each individual facilitator. The interview sought to elicit information about the groups' aims, expected benefits and style of facilitation, as perceived by the group facilitators, and included the following questions:

> What are the aims of the group?
>
> What happens in the group?
>
> What do you think it is about the group that is helpful for the group members?
>
> How do you think the group members make use of these factors?
>
> What is it like facilitating the group?
>
> Has facilitating the group, or the group itself, been different to what you expected? In what way?

Aims of the support groups

Each group was characterised by its facilitators as being discussion-based and member-led. The facilitators of Group A described the primary aim of their group as being to enable people to talk in a safe and supportive environment about the experience of living with dementia, and to discover that others shared their difficulties – 'sharing common problems

and themes, so that they don't feel that they're alone.' More specifically, the aim for this group was for the members to have the opportunity to explore the emotions they experienced as a result of their diagnosis, which they might not feel able to discuss with friends and family outside of the group. An additional aim was to enable group members to gather information about their diagnosis, illness and suggested coping strategies.

The facilitators of Group B similarly described a primary aim of their group as being the sharing of common experiences, allowing the members to discover that they were not alone in their experience. However, the emphasis in this group was on reducing members' sense of social isolation and creating an informal environment where 'people feel like they fit in and there's a place for them where they can actually relax.' These facilitators did not see exploring feelings to be a primary aim of the group, although they could be talked about if they 'came up.' Similarly, providing information about dementia and about coping strategies was not an explicit aim in this group, although the facilitators expressed some unease about this and felt that the absence of more directive goals such as cognitive rehabilitation was 'a bit neglectful.'

Expected benefits of the group

For all the facilitators an expected benefit of attending the support group was that the members would feel less unique in the difficulties they were experiencing and would be able to talk about their experience with others who shared their difficulties. The facilitators of Group A further alluded to the aim of providing information about dementia in the hope that this would 'alleviate any worries or misconceptions that [the members] have about the illness,' but felt that perhaps the most helpful aspect of the group for the members was being able to share the frustrations and difficulties inherent in living with dementia.

A further benefit cited by each of the facilitators was the provision of a tolerant and non-judgemental environment, where members felt accepted. An important aspect of this was the tolerance of communication difficulties and assistance with communication where this was needed and wanted by members. The facilitators of Group A saw this as being a universal

feature of both the group facilitators and members, with group members 'only ever responding with empathy' towards those exhibiting dementia-related difficulties. The facilitators of Group B however felt this was a more problematic area, and specifically that the group could potentially be unhelpful for members if there was too wide a range of abilities.

Style of facilitation

Each of the facilitators described their group as being member-led, but with some direction provided by the facilitators. The facilitators of Group A suggested topics for discussion or generated dementia-related topics from members' more general discussion about their week. They described an active role in the group, 'constantly bringing in every member, and constantly keeping a check on how everyone's feeling.' These facilitators saw an important aspect of their role to be to bring the discussion back to members' feelings when members 'insist on reminiscing' or 'change the subject.'

The facilitators of Group B also ensured all members were brought into the discussion, but described themselves as being less directive in determining the focus of discussion, saying rather that they 'just helped it to run along.' They described a more interpretative style of facilitation, reflecting on what they understand to be going on in the conversation between members and drawing out the themes and preoccupations.

ETHICAL CONSIDERATIONS

Ethical approval for the study was granted by the Barking and Havering Local Research Ethics Committee and the St Mary's Local Research Ethics Committee (see Appendix 1).

There is increasing recognition in the field of dementia research that people in the early stages of dementia are frequently able to give informed consent, and are often pleased to be invited to participate (Bartlett & Martin, 2002). I was concerned, however, about the ability of

the participants to understand the aims and objectives of the study and exactly what their involvement would entail. A further concern was that the group context of the study could lead to social pressure on the participants to take part.

These concerns were addressed through providing repeated opportunities to discuss the study in surroundings and with people who were familiar to the participants, in accordance with the view that seeking consent from individuals with dementia should be a process rather than a one-off event (Bartlett & Martin, 2002; Dewing, 2002). Initially this involved the study being introduced in the group setting by the group facilitators, who over a number of weeks re-visited the information provided. This was done both orally and in writing, using the information sheets provided. As discussed above, it was hoped this would increase the likelihood that participants would feel able to raise questions or concerns about the study or decline to participate, and would facilitate their retention of the information provided. Furthermore, the group facilitators, and later I, emphasised to the participants that they could decline to participate even if other members of the group wished to take part, that they could do this once the study had started even if they had originally given their consent, and that they could consent to be videoed but not take part in the interviews. This issue of consent was re-visited on several occasions as the study progressed, and in fact one participant did decide later on in the study not to take part in the interviews.

It was anticipated that some participants might find the process of being interviewed demanding, and the interview schedule was consequently designed to ensure flexibility in the interview and to enable participants to go at their own pace. In addition, it was emphasised to participants that they could take a break whenever they needed and could end the interview at any time. Again, two participants did choose to end the interview part-way through. Finally, the participants were made aware that their group facilitators were available to discuss with them any issues raised in the interview or to speak with them if they had found the experience in any way distressing.

DATA COLLECTION

Initial meeting with group members

Once all members of each group had given their formal consent to take part in the study I contacted each group to set up an informal meeting. This took place at the usual venue for the support group, shortly before or just after a weekly meeting, and lasted approximately 20 minutes. I described again the aims and process of the study with the group members, and answered any questions or concerns they raised. This meeting also provided an opportunity for the participants and me to become acquainted with each other. All participants indicated again at this stage their willingness, and in some cases their eagerness, to be involved in the study.

Recording group meetings

Following the initial meeting, data collection began with the video-recording of the group sessions. In the case of Group A, I video-recorded three group sessions over a period of five weeks. In the case of Group B, six sessions over a period of thirteen weeks were video-recorded by one of the group facilitators. Three of these were selected for analysis on the basis of the full attendance of the group members and the optimal sound quality of the videos.

Interviews with group members

The participant interviews took place after all three group sessions had been recorded (Group A), or after the first three sessions had been recorded (Group B). Members of Group A were interviewed immediately following a group session, in order to facilitate their memory of the group. Transport arrangements precluded this happening for members of Group B, who were interviewed in place of a group session that had been cancelled. In both cases all interviews with the participants were carried out by me.

In order to further aid people's memory of the group, it had been intended to conduct the interviews in the room in which people met for the support group. Unfortunately, this was not possible in either case. As a substitute prompt, people were therefore either actually shown the room before moving to an alternative place where the interview was conducted, or else where this was not possible the room was described to them verbally and prompts provided about the set-up and seating of that morning's meeting.

The interviews lasted between 10 and 45 minutes, with an average length of approximately 25 minutes. All the interviews followed a semi-structured format, allowing the participants some flexibility in how they responded to my questions and what information they conveyed. The interview schedule was prepared following guidelines suggested by qualitative researchers (Smith, 1995; Willig, 2001), and informed by themes and issues raised in previous studies of support groups for this client group (Morhardt, Menne, & Sherrell, 2002; Yale, 1995). All interviews thus broadly encompassed the following questions:

How do you find going to the group?

Why do you like/dislike going to the group?

What do you do in the group?

What do you find helpful?

Is there anything you find unhelpful?

Would things be different if you didn't go to the group?

A written version of these questions was placed in front of the participant during the interview as a physical prompt to help orient them to the interview topics during the interview, should this be needed.

Following the interview I talked to the participants about the experience of being interviewed and responded to any further concerns or queries.

ANALYSIS OF THE VIDEO RECORDINGS OF GROUP SESSIONS

Each video recorded session was analysed using the Behavioural Interaction Codes (BIC) (Roberts et al., 1991). This is a 'behavioural observation system' previously used for coding the processes in both professionally facilitated and peer-led groups for adults with enduring mental health problems. The BIC Manual was obtained from one of the authors, and the analysis of the group sessions was carried out in accordance with its detailed instructions.

Overview of the procedure

For each individual group meeting the units of analysis were numbered sequentially, with each unit corresponding to a single 'talking turn' of either a group member or facilitator. This was defined as the entire content of an individual's speech from the moment he or she started speaking until the moment another individual began to speak. The person who was speaking during the unit in question was noted, and each group member was allocated a unique letter, while each facilitator was allocated the designator F1 or F2 for this purpose. One of thirteen Interaction Codes was then recorded for each unit (see overview of BIC categories below). Finally, a record was made of to whom the speaker's response was directed, using M, F or G to indicate another individual member, the facilitator(s) or the group respectively. Each of these steps is described in more detail below and an example of a completed record sheet is presented in Appendix 4.

Overview of the BIC

The BIC is used to record and analyse verbal responses within a group setting; it does not capture elements of non-verbal behaviour. The codes and their definitions are presented in Table 1. Two codes represent the sharing of information, with a distinction made between personal and revealing disclosures (Self Disclosure) and the sharing of superficial, factual or impersonal information (Information Giving). A similar distinction is made between comments aimed at eliciting such information or disclosures (Personal Question and Impersonal Question). Requests for Feedback are questions that explicitly ask for help or support. Three

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of the codes (Support, Interpretation and Direct Guidance) represent helping responses offered from one individual to another individual or to the group as a whole. Two codes indicate individuals' reactions to comments or suggestions that had been offered to them (Agree and Negative), while a further two relate to the task orientation of the group. These latter either represent responses that explicitly sought to direct the conversation (Group Process) or which were not directly relevant to the current content of the conversation and did not meet the criteria for any of the above codes; these comments were often humorous (Talk). A further code was added to represent responses that purely re-stated or summarised an earlier statement made by an individual or individuals, without adding any element of interpretation or explanation. This code (Reflection) was not included in the system devised by Roberts et al. for mutual help meetings, but was felt to be required to capture a number of the interventions made by the support group facilitators. Responses that were inaudible were recorded as such (Inaudible).

One other adaptation was made to the BIC as originally laid out in the manual. Significantly, a broader definition of Self Disclosure was used in this study than in the original research carried out by Roberts et al. The original definition of this code required the speaker to discuss feelings, desires or expectations that were 'generally non-public, not ordinarily readily volunteered, and psychologically or emotionally meaningful.' After reviewing the videotapes of the support group sessions and discussing them with a second researcher, it was felt that this definition would exclude members' comments that were personally relevant and appeared to be psychologically or emotionally meaningful, but which could not be generally regarded as non-public. Indeed, the members often shared information with each other that appeared to be personal and meaningful to them, and which they might be hesitant to share in other contexts due to others' disinterest or impatience with their speech and language difficulties, but which would not necessarily be considered to be private. It was therefore decided to code as Self Disclosure all comments that gave specific personal information about the speaker or about someone in the personal life of the speaker, regardless of whether or not that information would generally be considered non-public.

Table 1: BIC categories[a]

Category	Definition
Disclosure	
Self Disclosure	Comments that give specific personal information about the speaker or someone in the personal life of the speaker.
Information Giving	Comments that give clarification of previous comments or general, impersonal, trivial, vague or abstract information about the world, the speaker or other individuals.
Questioning	
Personal Question	Comments that request revealing information about an individual's feelings, motivations, opinions, or actions.
Impersonal Question	Comments that ask for orientation, clarification, repetition, general factual information about the world, or impersonal (factual or superficial) information about another member.
Request for Feedback	Comments that directly request the group or a particular member of the group or a facilitator to provide the speaker with an evaluation, interpretation, suggestion, information, or guidance about the speaker's feelings, actions or personal life.
Helping behaviour	
Support	Comments that have the aim or effect of raising or enhancing another group member's status; are nurturing, encouraging, or approving of another group member; or offer tangible assistance.
Interpretation	Comments that interpret, analyse, evaluate, redefine, reconceptualise, challenge, summarise or explain another group member's comments or behaviour.
Direct Guidance	Comments that give concrete, direct and specific suggestions, direction or guidance about possible courses of action.
Affective response	
Agree	Comments that show agreement with an opinion or interpretation previously stated, show acceptance or acknowledgement of support or feedback, or verbally indicate that the speaker will comply with a suggestion or guidance.
Negative	Comments that explicitly disagree with a previously stated opinion or interpretation; are resistant, closed or defensive; or indicate disapproval of another group member, or the speaker him or herself.
Task Orientation	
Group Process	Comments that have the aim or effect of altering or reflecting on the immediate group process.
Talk	Comments that are not relevant to the group's current task; humorous comments that cannot be coded as any of the above.
Reflection	Comments that re-state a member's earlier statement without adding to or going beyond its original meaning.

[a] Taken from Roberts et al. (1991), with minor adaptations

Thus, for example, the comments of an individual who spent some time reminiscing about happy times that occurred in her childhood would have been coded as Self Disclosure.

Allocation of BIC categories to speaker responses

Both the group members' and facilitators' responses were coded as described above. False starts and 'conversation oilers' that signalled attentiveness or encouragement to continue were not recorded. The latter were most often verbalisations such as 'uh-huh', simple repetitions of the speaker's words, or brief sentence completions. Where these occurred, the original speaker's comment was treated as one unit, as if the conversation oiler had not been uttered.

Sometimes it happened that two or more codes could be seen to apply to a single talking turn. In these cases, two principles determined which BIC category was used, in accordance with the guidelines used by Roberts et al. and set out in the BIC manual: offering or seeking personal information took precedence over providing or enquiring about factual or impersonal information, and disclosures took precedence over questions. Where neither of these principles applied, the BIC category used was that which, in the judgement of the coder, represented the dominant codeable meaning of that comment.

Coding the direction of interaction

As described above, for each response the speaker was recorded using a unique letter for each group member and the designators F1 or F2 for the facilitators, and the individual(s) to whom the comment was directed noted using M, F or G to indicate another individual member, the facilitator(s) or the group respectively.

The direction of the comment was recorded as 'F' where the speaker appeared to address his or her comment exclusively to one or both of the facilitators. Where the speaker appeared to address a comment to two or more individuals this was considered to be directed at the group and was coded as 'G', with the exception of where the two individuals

were both facilitators. In all other cases the direction of the response was recorded as having been addressed to an individual member (M). Decisions about the intended direction of a comment were informed by the speaker's head and facial movements and the direction of their eye contact, as well as the content of their speech.

Inter-rater reliability

A total of 208 talking turns were coded by a second rater, both for the BIC categories and the direction of interaction. The talking turns were taken from different time points across four group sessions, two from each group. There were no instances of either Requests for Feedback or Reflection. For the remaining eleven BIC categories, Cohen's kappa ranged from .75 (Group Process, Negative and Support) to .93 (Self Disclosure), with an overall kappa of .84. For the direction of interaction, Cohen's kappa ranged from .76 (comments directed at a facilitator) to .81 (comments directed at the group), with a mean of .78. Tables 2 and 3 present the kappas for each BIC category and direction of interaction.

Table 2: Cohen's kappas for each of the BIC categories

BIC category	Kappa
Self-disclosure	.93
Information Giving	.76
Personal Question	.90
Impersonal Question	.82
Request for Guidance	Not identified in sample
Interpretation	.83
Support	.75
Guidance	.83
Agree	.80
Negative	.75
Group Process	.75
Talk	.90
Reflection	Not identified in sample
Overall kappa	.84

Table 3: Cohen's kappas for each of the directional categories

Direction	Kappa
Member	.78
Facilitator	.76
Group	.81
Overall kappa	.78

ANALYSIS OF THE INTERVIEWS

Each interview was tape recorded, and then transcribed verbatim with all identifying details excluded in order to ensure confidentiality. In accordance with the aims of the study, the transcription was undertaken in a way that paid careful attention to participants' language and meaning but not to the linguistic features of their speech, such as repetitions or pauses. A sample section of two transcripts can be found in Appendix 5. The transcripts were then analysed using interpretative phenomenological analysis (IPA: Smith & Osborn, 2003; Willig, 2001), a method of analysis that has been used in previous research with individuals with early stage dementia (see e.g. Clare, 2002; in press; Pearce et al., 2002).

IPA works with texts generated by participants, most often with transcripts of semi-structured interviews (see Smith, 1995). It takes an idiographic approach, engaging in detailed and exhaustive analysis of each individual case (i.e. transcript) before integrating these at a later stage into an overarching thematic representation that reflects the experience of the group of participants as a whole. The analysis involves the identification, clustering and integration of themes in individual transcripts in an ongoing and cyclical process. This continues until a full integration of themes from the entire set of data results is reached (Smith et al., 1999; Willig, 2001). Here I will describe the details of each step of the IPA analysis as it was conducted in this study, with examples illustrating each of the steps provided in the appendices.

The first step of the analysis aimed to identify in each individual transcript the main ideas, concerns and experiences expressed by that particular participant. This involved reading and re-reading each individual transcript, following the guidance of Smith et al. (1999) to note down in the margin 'anything that strikes you as interesting or significant about what the respondent is saying' (p. 220). At this initial stage no attempt was made to further conceptualise, summarise or group these notes, and in making them I remained as close as possible to the participant's own words. An example of this stage of the analysis is shown in Appendix 6.

The second step of the analysis involved collating the notes made for an individual transcript, and considering how they related to each other. This process aimed to identify possible connections between the ideas and experiences identified in step 1, and to begin to group the notes into tentative themes and sub-themes. This was done for each individual interview and is illustrated in Appendix 7.

Once steps 1 and 2 had been carried out with each individual transcript, the third stage of the analysis began a process of cross-case analysis which sought to integrate the themes and sub-themes identified for each participant into an overarching structure that represented the experience of the group as a whole. I began this process by writing out the identified themes from each individual transcript onto separate sheets of paper and seeking to tentatively group together those that appeared to express similar ideas. Some of the themes from across the transcripts clearly expressed a common idea or preoccupation and were easy to cluster together into a 'master theme.' Other themes were less readily grouped together and required careful thought about how they might be related, and often a return to the transcripts from which they had emerged to re-examine the participant's meaning. Gradually these themes too were then clustered together according to my interpretation of their shared meaning. During this process certain themes were identified that were shared by a number of individual transcripts, and these were grouped together. Others were wholly subsumed into new master themes, or their sub-themes divided between emerging master themes that appeared to more closely relate to their individual meanings. This stage of analysis was thus cyclical and moved between emerging themes and the verbatim transcripts, ensuring that the themes identified were grounded in the data from which they were derived.

During this cross-case analysis a small number of themes that were identified in only one or two participants' transcripts and which did not appear to be related to any other identified themes were dropped from the analysis. The remaining list of themes thus constituted a 'master list' that reflected the experience of the group of participants as a whole, and

consisted of the 'major themes which seem[ed] to capture more strongly the respondents' concerns on this particular topic' (Smith et al., 1999, p. 223). This master list of themes and sub-themes is presented in Chapter 3.

Finally, a complete set of quotations for each master theme and sub-theme was gathered by returning to the transcripts and re-analysing them using the themes and sub-themes identified in the master list (see Appendix 8). These quotations were then listed in full in a final master table of themes and quotations, which provided the basis for the narrative account given in chapter three.

Credibility checks

While IPA recognises that an individual's experience cannot be directly accessed but can only be mediated through the researcher's own interpretation of the data, the credibility of the analysis can be enhanced by the engagement of more than one researcher with the text (Elliott, Fischer, & Rennie, 1999).

In this case, a second researcher with extensive experience of IPA and specialising in dementia studies read a selection of the interviews and examined a selected number for emerging themes. These were then cross-checked with the themes originally identified, and suggestions made about where the analysis could be extended. The second researcher then examined the completed list of themes for each individual participant and later the master list of themes, each time suggesting points where the analysis might be improved in terms of its comprehensiveness or clarity. She further checked the final master list of themes to ensure that it was internally coherent and meaningful, and that the themes identified reflected the original transcript data. Feedback from this researcher was incorporated at each stage into the cyclical process of analysis.

Researcher's perspective

The influence of the researcher's own phenomenology on the sense he or she makes of individuals' accounts of their experience is integral to IPA. Guidelines for qualitative research

also stress the importance of researchers clearly setting out their own values, assumptions and framework of understanding that they bring to the research in order that readers can more readily evaluate the study and its findings and consider possible alternatives (Elliott et al., 1999; see Chapter 4 for further discussion).

I am a white British trainee clinical psychologist in my early thirties, and was conducting the project to fulfil the research requirements of a Doctorate in Clinical Psychology. I have some limited experience of conducting neuropsychological assessments of people with suspected dementia, but do not have any further experience in my capacity as a psychologist of working with older adults. However, in previous employment I have worked as a support worker for adults with severe and enduring mental health problems and/or a learning disability, some of whom were older adults who had also been diagnosed with dementia.

In my clinical work I employ a broadly social constructionist and systemic framework of understanding. I believe that mutual support can enhance, or in some cases preclude the need for, professional support and this belief informed my interest in the current topic of research. I approached the study with an expectation that the participants would find the support groups they attended a positive and useful experience, and that the findings would affirm that support groups can be a helpful aspect of service provision for this client group.

CHAPTER THREE

RESULTS

This study gathered quantitative and qualitative data pertaining to two main research questions: 'What is the nature of the interactions and support processes that occur in support groups for individuals with early stage dementia?' and 'What is the experience of the individuals who attend such groups?'

This chapter first describes the quantitative data pertaining to the first of these questions, comprising the results of using the Behavioural Interaction Coding scheme (BIC) to analyse the verbal interactions between individuals participating in the videotaped support group sessions. An interpretative phenomenological analysis (IPA) of the transcripts of the semi-structured interviews carried out with the support group members is then presented, giving details of eight main themes identified across the interview transcripts.

Group themes and content

It was not the purpose of this study to give a detailed account and analysis of the content of the group discussions. However, in order to provide a context for the findings that follow, a brief description of the kinds of topics raised within each group is given below.

Group A

As the facilitators' description of the aims of this group and their role within it may suggest, the conversation within Group A often centred on the practical and emotional consequences of the members' diagnosis of dementia, with topics such as the experience of loss, coping strategies for dealing with memory difficulties, and letting friends and family know about the diagnosis. Members also spoke about the past, telling of their distant childhoods and about their spouses, children and grandchildren. Some mourned family members who had died or a way of life that no longer existed, while on other occasions the stories and anecdotes seemed to recollect happy times that the speaker remembered well. Members also spoke about current events and activities in their lives, and these were often used by the facilitators

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to illustrate or explore an aspect of the experience of dementia and to bring in other members of the group.

Group B

The conversation in Group B appeared to consist largely of stories and anecdotes told by the members about their lives, past and present, but perhaps most often and vividly about their childhoods. The group members would often comment on how well they could remember the story they were relating, in contrast to their difficulty remembering the simplest things in the present. The events and preoccupations in the present that they spoke about often explicitly related to their difficulties with memory, or reflected themes of threat and loss. At other times they would directly talk about their memory difficulties and the experiences they had in common, and share ideas about ways of coping.

THE NATURE OF THE INTERACTIONS AND SUPPORT PROCESSES THAT OCCUR IN SUPPORT GROUPS FOR INDIVIDUALS WITH EARLY-STAGE DEMENTIA

The results presented here first address the frequencies of responses, both within the group as a whole and as they pertain to group members and facilitators. Data on the process of interaction within the group, in terms of the direction of responses between group members and facilitators, are then presented.

The main aim of the research was to investigate support processes and interactions as they occurred in the groups, rather than to compare these processes across the two groups. Accordingly, no formal comparison of the results obtained from each group is made. However, data for Group A and B are presented separately, as the differences in the group interaction and style of facilitation are such that to amalgamate the results would obscure the actual nature of the group processes.

Frequencies of verbal responses

Tables 4 and 5 present the frequencies and percentages of occurrence of the thirteen BIC categories across the three group sessions for Group A and B, reported in each case both for the group as a whole and for group members and facilitators.

Overall frequencies of the BIC categories

The data show that a fifth of the verbal responses in Group A were categorised as Self Disclosure, while in Group B approximately one quarter of responses were categorised in this way. In both groups disclosure behaviours (Self Disclosure and Information Giving) together accounted for approximately one half of all interactions that occurred during the three group meetings, with questioning behaviours (Personal Question, Impersonal Question) accounting for approximately a further quarter. Nine per cent of the interactions in the Group A meetings and 14% of those in Group B meetings were characterised as helping behaviours (Support, Interpretation and Direct Guidance). Comments that were otherwise uncodable (Talk) accounted for 6% of interactions in Group B and 2% in Group A. In both groups affective responses (Agree, Negative), Requests for Guidance, Group Process and Reflections each accounted for 7% or less of comments.

Frequencies of the BIC categories for group members and facilitators

In both Group A and Group B over one third of responses made by group members were characterised as Self Disclosure. Information Giving accounted for a further 42% and 28% of members' responses in Group A and B respectively, with the result that disclosure behaviours together accounted for 77% and 66% of members' total responses. 10% or less of members' responses in both groups were characterised as questions, and 5% as helping behaviours. The remaining responses were characterised as affective responses and otherwise uncodable comments, with 8% of responses or less accorded to each of these categories in each group. No responses by group members in either group were characterised as Group Process or Reflections, and 1% or less were characterised as Requests for Feedback.

In both groups approximately 50% of all facilitator responses were characterised as questions, with Personal Questions accounting for approximately one third. In Group A the next most frequent type of facilitator intervention was Information Giving (22%); in Group B it was Interpretation (28%). Together, helping behaviours accounted for 16% of facilitator responses in Group A and 36% in Group B. In each group the remaining categories (affective responses, Group Process, Talk and Reflections) each accounted for 4% or less of facilitator responses. There were no instances of Self Disclosure or Requests for Feedback by group facilitators.

Significantly, in Group B half of all responses characterised as Support and two thirds of those characterised as Direct Guidance originated from the group members. In Group A approximately one third of responses in each of these two categories originated from the group members. In both groups the third type of helping behaviour, Interpretation, originated in the great majority of cases from the facilitators.

The great majority of disclosures that occurred in both groups originated from the group members, while the majority of questions originated from the group facilitators. However, there were notable group differences: in Group B members were as likely to ask Impersonal Questions as the facilitators, while in Group A only one quarter of Impersonal Questions were asked by group members.

Table 4. Frequency of verbal responses across three group sessions – Group A

	Members		Facilitators		Total	
	Frequency	**(%)**	**Frequency**	**(%)**	**Frequency**	**(%)**
Self disclosure	153	(35)	0	(0)	153	(20)
Information giving	185	(42)	72	(22)	257	(33)
Personal question	7	(2)	107	(33)	114	(15)
Impersonal question	19	(4)	60	(18)	79	(10)
Request for feedback	6	(1)	0	(0)	6	(1)
Support	7	(2)	16	(5)	23	(3)
Interpretation	2	(<1)	20	(6)	22	(3)
Direct guidance	8	(2)	16	(5)	24	(3)
Agree	31	(7)	12	(4)	43	(6)
Negative	7	(2)	2	(1)	9	(1)
Reflection	0	(0)	12	(4)	12	(2)
Group process	0	(0)	7	(2)	7	(1)
Talk	13	(3)	3	(1)	16	(2)
Inaudible	3	(<1)	0	(0)	3	(<1)
Total	441	(100)	327	(100)	768	(100)

Table 5. Frequency of verbal responses across three group sessions – Group B

	Members		Facilitators		Total	
	Frequency	**(%)**	**Frequency**	**(%)**	**Frequency**	**(%)**
Self disclosure	174	(38)	0	(0)	174	(26)
Information giving	126	(28)	17	(8)	143	(22)
Personal question	12	(3)	64	(31)	76	(12)
Impersonal question	33	(7)	32	(15)	65	(10)
Request for feedback	2	(<1)	0	(0)	2	(<1)
Support	15	(3)	14	(7)	29	(4)
Interpretation	4	(1)	58	(28)	62	(9)
Direct guidance	5	(1)	3	(1)	8	(1)
Agree	38	(8)	6	(3)	44	(7)
Negative	5	(1)	1	(1)	6	(1)
Reflection	0	(0)	1	(1)	1	(<1)
Group process	0	(0)	3	(1)	3	(1)
Talk	32	(7)	9	(4)	41	(6)
Inaudible	7	(2)	0	(0)	7	(1)
Total	453	(100)	208	(100)	661	(100)

Direction of group interactions

More than half of all verbal responses in Group A and over two thirds of those in Group B were made by group members, with a corresponding 43% and 32% of responses made by the facilitators (see Tables 4 and 5). Tables 6 and 7 indicate to whom the responses were directed, with clear differences in the nature of the interaction apparent between the two groups.

Interactions between an individual member and a facilitator account for almost three quarters of all verbal responses that occurred during the three videotaped sessions of Group A, with 39% originating from a group member. A further 19% of responses were directed from a group member either to another member or to the group, with the remaining 9% being directed from a facilitator to the group.

In contrast, almost half of all interactions in Group B were directed between group members, with 22% being directed from one member to another and 25% from a member to the group. A further 46% of interactions occurred between an individual member and a facilitator, with 21% originating from the group member and 25% from the facilitator. The remaining 7% of responses originated from a group facilitator and were directed towards the group. In neither group were there any interactions between facilitators.

It is notable that 68% of responses made by members in Group A were directed towards a facilitator, while in Group B member responses were approximately equally directed towards a facilitator, another group member, or the group as a whole. In both groups 78% of facilitator responses were directed towards an individual group member, with the remainder directed towards the group. Overall, the majority of interactions in the groups involved a facilitator, and most of these occurred between a facilitator and an individual member.

Table 6. Direction of interactions across three group sessions – Group A

	Frequency	(%)	% of total responses
Member to member	67	(15)	9
Member to facilitator	300	(68)	39
Member to group	74	(17)	10
Total member	441	(100)	57
Facilitator to member	256	(78)	33
Facilitator to facilitator	0	(0)	0
Facilitator to group	71	(22)	9
Total facilitator	327	(100)	43

Table 7. Direction of interactions across three group sessions – Group B

	Frequency	(%)	% of total responses
Member to member	147	(33)	22
Member to facilitator	140	(31)	21
Member to group	165	(36)	25
Total member	452	(100)	68
Facilitator to member	162	(78)	25
Facilitator to facilitator	0	(0)	0
Facilitator to group	47	(22)	7
Total facilitator	209	(100)	32

THE EXPERIENCE OF THE INDIVIDUALS WHO ATTEND SUPPORT GROUPS FOR PEOPLE WITH EARLY STAGE DEMENTIA

This section describes the themes that were identified across the transcripts of the interviews carried out with the members of the two support groups. A total of eight main themes were identified, with seven of them incorporating up to six sub-themes. These are defined and elaborated below, and are illustrated with quotations from the participants. Such verbatim reports are presented in quotation marks or in separate italicised paragraphs, and cite the identity number of the participant quoted. Table 8 presents each of the themes with their sub-themes, and their prevalence across the participant interviews.

Table 8: Themes and sub-themes identified across participant interviews

Themes and their sub-themes	Prevalence[a]
A useful group	**Frequent**
• A terrific boon	• Frequent
• People in the same boat	• Frequent
• Meeting people	• Frequent
• A learning process	• Moderate
• An anchor	• Moderate
• Help with speaking up	• Moderate
I do find it difficult	**Frequent**
• It doesn't always come easy	• Moderate
• Going on and on	• Moderate
• I didn't really want to come	• Moderate
• Coming here hasn't made me any better	• Moderate
All talking together	**Frequent**
• How dementia affects day-to-day living	• Frequent
• Talk about the early days	• Infrequent
• Normal everyday things	• Moderate
• Chatting around	• Moderate
Keeping the pot boiling	**Frequent**
• We all like the facilitators very much	• Moderate
• Keeping the conversation going	• Moderate
• Running it	• Moderate
• Breaking the string	• Infrequent
Attending to see if you can get it	**Frequent**
• Joining in in your mind	• Moderate
• I'm not very entertaining	• Moderate
There isn't one that's like another	**Frequent**
Outside, on your own	**Frequent**
• That feeling of isolation	• Frequent
• Reluctant to talk	• Frequent
The business of dementia	**Frequent**
• Difficulty remembering the group	• Infrequent
• This dreadful short term memory	• Frequent
• Why I lost my memory	• Moderate
• What am I going to be like later on?	• Moderate
• Being the boss-man	• Moderate

[a] Prevalence is categorised as: frequent when identified in more than two thirds of participant interviews; moderate when identified in between one and two thirds of interviews; and infrequent when identified in less than one third of participant interviews.

A useful group

This theme refers to the overall perception that attending the support group had been a positive and helpful experience. All the participants expressed a general sense of having benefited from the group, and all made further reference to specific ways in which the group had been helpful to them. These encompassed meeting other people with dementia who shared the same difficulties and experiences; having the opportunity for social interaction; learning more about dementia and strategies for coping; feeling sustained outside the group

by the support provided within it; and being helped to communicate, where this was difficult. Each of these is elaborated further below.

A terrific boon

All the participants echoed the sentiment expressed by participant 1 that 'it's a useful group - serves a marvellous purpose.' Many stated that they 'enjoy coming here' and 'look forward' to attending each week, saying that coming to the group had been 'a terrific boon' (9). This expression of overall satisfaction with the group and the benefits gained can be summed up in comments made by many of the participants about how much they would miss the group were it to end. For one participant the group served as a weekly dose of medicine, with significant and immediate benefits:

> *The group is a dose of making me feel a bit more happier about myself*
> *and I go out feeling a bit lighter than I came in. (P9)*

People in the same boat

Meeting people in the same situation as themselves appeared to be one of the most helpful aspects of attending the group: 'it's good to know that other people are in the same boat as yourself, that other people have the same kind of difficulties that you do' (P4). For some participants this was most helpful in that they felt understood by 'likewise kin' (P6), whose shared experience obviated the need for lengthy explanation about the difficulties caused by dementia:

> *It's like, you know, when you go into prison and you find everybody else*
> *there knows what it's like. So you don't have to do any explanations*
> *to them. (P1)*

For others, the experience was most meaningful in reducing the sense of being alone in coping with dementia, as meeting others who shared their difficulties 'gives you a feeling that you're not the only one' (P8). Meeting others with the illness reduced the stigma that is attached to having dementia and which participants had themselves internalised. They

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described themselves as feeling 'less ashamed' (P6) and realising that 'it's not a wicked thing to have' (P7).

Finally, meeting others with dementia was useful in the opportunity it provided to offer help and support to others. It appears that such opportunities raised participants' self-esteem and gave meaning to the difficulties they were struggling with: 'If I tell them my experience it helps people' (P1).

Meeting people

For many participants the group was useful simply in providing the opportunity for social interaction, in an environment where other people were accepting and welcoming:

It's other people to say hello to. (P2)

It takes you out of yourself. (P3)

You meet other people and you're able to talk. (P6)

A learning process

Several of the participants referred to attending the group as an opportunity to learn more about dementia and strategies for coping, where you can 'ask questions' and 'get to understand what is happening' (P5). Significantly, however, two of the participants stressed that the group was a 'learning process' not just for the members but also for the facilitators, who are 'still learning' about dementia and 'trying to find out more about it' (P1). For one of these participants, attending the group and sharing his experience was a way of contributing to this accumulation of knowledge and benefiting others in the future: 'More will be learnt about dementia as time goes by and people will benefit' (P1).

An anchor

An important function of the group was to provide a stable sense of support that participants were able to draw on at times outside of the group when they were feeling vulnerable or overwhelmed. Participants described the group as 'an anchor' (P9) or as 'something to hang

on to' (Ps 1 and 8). It was important for them to be able to think back to what had been shared and discussed in the group, and to take the other group members as a reference when encountering difficulties themselves:

> *If I do sort of get a bit het up at home I tend to think back: they're like*
> *it, you know. They cope. So if you're hitting a low you think of the*
> *others, and that helps. (P9)*

Help with speaking up

Finally, for those participants who found it hard to communicate due to their language or memory difficulties, a vital feature of the group was the presence of an environment where all communication is accepted and facilitated. For some, the knowledge that their speech would be accepted and not ridiculed was enough to enable them to speak out: 'You can talk without making yourself look silly' (P8). Others with a greater level of difficulty, however, stressed the importance of the group as a place where they were helped to communicate, citing it as a place where 'you get some sort of consolation [help] with speaking up' (P6). These participants stressed too the importance of the atmosphere of empathy and understanding for their speech and communication difficulties, and explained how the patience and encouragement they experienced in the group enabled them to communicate beyond the point at which they would normally have given up:

> *I make a mistake and I don't want to say anything again. But people say,*
> *'What is she saying?' And when I answer they hold my head. So that's*
> *why I say what I have to say. (P5)*

I do find it difficult

Despite overall satisfaction with the group, participants described times when 'it doesn't help' (P9). This theme refers to those aspects of the group that participants found difficult or uncomfortable, or that they were otherwise not happy with. The majority of the participants indicated that they found at least one aspect of the group experience difficult. For many it was hard to speak out within the group, while others found it irritating to be in a group of

people whose memory problems led them frequently to repeat themselves. For some even the idea of joining such a group was daunting, and attending the group initially uncomfortable. Finally, for a few participants the group had not met their expectations and attending had failed to deliver the hoped for benefits. These are all elaborated further below.

It doesn't always come easy

Many participants reported that they found it difficult to talk within the group. For some this was due to a general shyness when speaking in front of a group of people, and these individuals described how they 'find it difficult,' 'get nervous' or 'clam up' when they try to speak (Ps 3,4 and 7). Others were aware of the difficulties their fellow group members were experiencing in this area, and reported that 'you can see people in the group that want to hold back' (P8). Such reticence appeared to be potentially problematic for the whole group, with some participants castigating themselves for it ('it's really silly for a woman my age' P4), and others finding it difficult to respond to ('I don't like it when it [the conversation] dies away' P8).

For other participants it was the subject of the discussion that made them uncomfortable, specifically when the focus of the group was on participants' emotions and the individual perceived a pressure to contribute: 'We have to try and explain our feelings a lot and it doesn't always come easy' (P1). Again, it seems that fellow group members were aware of others' reluctance to talk where painful emotions were involved: 'Very often you've got somebody have a very poor thing, that she doesn't want to mention' (P7).

Going on and on

It clearly emerged from the interviews that having a diagnosis of dementia oneself does not necessarily make one tolerant of the effects of the illness in others. While acknowledging that certain difficulties will be inevitable in a group of individuals with dementia - 'Being such a group, people go off the point quite easily' (P1) - members nevertheless stressed that, for them, the repetitions and lack of clarity caused by people's memory loss were one of the most difficult aspects of the group. One participant felt it necessary to couch his observation

in hypothetical terms ('Say a person like me started on one piece and you go on and on about it, that would make others fed up' P9); another was very direct: 'I'm not too old to suffer – you know when someone is talking nonsense … it's irritating when someone repeats the same thing three times' (P1). While acknowledging the need 'to be very understanding and tolerant' (P1), for some participants a drawback of the group was that 'we're doing too much talking which we've already talked about' (P8).

I didn't really want to come

Despite their descriptions of the support group as somewhere they looked forward to coming to and enjoyed attending, for some participants it was clear that this had not always been the case. These participants indicated that attending such a group can initially be a very threatening and uncomfortable experience, to the extent that their attendance is perhaps coerced:

> *When I first came I didn't come happily. I said I would do it, then I got*
> *home and thought, Oh hell. I really didn't want to come. (P9)*

For some this initial anxiety and discomfort was a result of a false perception of what the group would entail, such as the participant who 'felt [she] was going to be an idiot amongst other people who knew what they were talking about' (P9). However, it appears that such anxiety does not immediately dispel on joining the group, and that for the first few weeks the group can be an uncomfortable place to be. This may have been the case for one new member who, one participant reported, 'sat next to me and didn't talk for a good few weeks' (P8). Certainly it would appear that participant 6 spoke not only for herself when she said that she liked attending the support group only 'once I had got used to it.'

Coming here hasn't made me any better

Finally, a few participants expressed dissatisfaction with the group due to it not having met their initial expectations. These expectations were mostly concerned with 'improving things' (P9), most notably participants' memory functioning, and appear to be based on a misapprehension about the group's purpose:

*Coming to the classes hasn't made me any better. I don't feel I've got
my memory back. (P10)*

*I just want to be my old self – and I'm not sure it [the group] is helping
me to do it. (P9)*

All talking together

This theme refers to what is talked about in the group, and the nature of this group talk. The

perceived topics of group discussion fell into three main areas: living with dementia,

reminiscing about the distant past, and talking about ordinary happenings in the present. All

who raised the subject characterised the discussion as 'chatting.'

How dementia affects day-to-day living

Issues to do with dementia were one of the foremost topics of discussion in the support

groups:

We talk about how dementia affects day-to-day living (P1)

How your memory is and how it isn't (P4)

*We all talk together about it – how we lost that memory and how it's
affecting us (P10)*

It is interesting to note, however, that all but two of the participants did not use terms such as

'dementia' or 'Alzheimer's' at this or any other point in their interviews, but instead seemed to

prefer symptom-based descriptions of their difficulties, most notably around memory

problems (e.g. 'loss of memory' P10).

In the perception of most participants, much of this discussion focused on talking about

strategies for coping with the difficulties caused by the illness: 'How you would save yourself

from your memory' (P7). Here, the exchange of experiences and strategies between group

members seemed to be important, as members shared with each other 'what's been helpful

or not' (P7) and '[told] what worked marvellously' (P5). More directive guidance appeared at times to come from the group facilitators, as one member recollected clearly:

> *We talked about passing on responsibility for your affairs to others ... it's*
> *quite useful in serious matters of your income particularly ... if there's*
> *somebody else who knows and who'll take responsibility for them. (P1)*

Talk about the early days

For members of Group B an equally important focus for their discussion was recollections of 'the early days' (P10). This involved talking with each other about 'different things that happened to us when we were young,' often things that happened during 'the war years' such as when '[another group member] was evacuated' (Ps 8 and 10). Such reminiscence appeared to be a means by which members could talk with authority and confidence about a topic to others who were interested, in contrast with the unreliability of their memory and conversation on more day-to-day topics: 'I can remember everything back, but I can't tell you what day it is' (P10).

Normal everyday things

Not all the conversation was so highly focused, however, rather group talk also encompassed the seemingly more inconsequential happenings in life: 'what you do when you're not at this place – normal everyday things' (P3); 'whatever you've been doing this week' (P8). However, there was some indication that such talk was not itself inconsequential, rather that in acting as an audience to these everyday experiences the group accorded them a new focus and sense of meaning. Thus one participant told how she lives her week with the group in mind, trying to notice 'something that would fit in nicely' that she can relate at the next group meeting with the rest of her 'week's experience' (P5).

Chatting around

Group discussion was described as being like a chat, with the implication of informality and lack of structure: 'we usually chat around' (P9). Some participants were more specific about how such a conversation worked: 'You'll talk about something and someone else will pick up'

(P8), with the result that the interaction 'just ties up as some sort of chat' (P9). This way of

proceeding met with participants' approval:

> *It's got to be free and easy – you don't want to come and sort of, 'What*
> *do you do and do you? (P9)*

Keeping the pot boiling

This theme refers to participants' appraisal of the facilitators and the role they played in the

group. Although the topic of facilitation was not included in the interview schedule,

participants raised it in their interviews and indicated that, for them, the facilitators were one

of the most important factors in the group experience. Their overall appraisal of the group

facilitators was overwhelmingly positive, with their most important role being perceived to be

to facilitate communication within the group. It was notable that the facilitators were regarded

by the participants as being incontrovertibly in charge of the group, with a minority

expressing strong feelings of dependency.

We all like the facilitators very much

The participants who addressed the topic of the group facilitators expressed universal

approval for the individuals facilitating their particular group: 'we all like [the facilitators] very

much' (P9); 'they are extremely good' (P6). They were attributed with a range of positive

qualities: a facilitator is someone who 'cares and is trying to improve your circumstances'

(P1); who 'doesn't ignore you and who answers' (P6); and is a person 'that seems to

understand what you're talking about' (P8). One individual stated that he felt welcomed and

accepted by the facilitators, and stressed the importance of their professional role in feeling

enabled to open up and use their support: 'I don't feel I'm an onus [burden] on them because

they're professionals...you're not putting anybody out, it's their job' (P1).

Keeping the conversation going

The facilitators' assistance with communication within the support groups appeared to be key

both to the role of the facilitators and to the functioning of the group. One aspect of this key

task was facilitating the flow of conversation within the group: 'trying to extract something from each of the members' (P9) in order to 'keep the pot boiling' (P1). Such efforts to keep the conversation moving were seen as vital, 'because otherwise everybody would just sit there' (P8).

It was recognised that members' dementia-related difficulties presented challenges to the group interaction that facilitators had to 'manoeuvre around' (P9). This was recognised as not always being easy; for example, when members wandered off the point the facilitators had to 'bring them back without insulting them' (P1). When the challenges of structuring the group's interaction were negotiated successfully, however, this enabled members to join with the conversation in ways they may otherwise have been unable to do: 'while the leaders keep the conversation going people can be expressing themselves and showing more of themselves' (P1). Participants were highly aware of the techniques used by the facilitators to ensure this flow of conversation, citing 'prompting' (P8) or 'coming in with the right questions' (P9). Indeed, the tendency of the facilitators to ask questions and the importance of their doing so for members' ability to join the conversation was noted by several participants: 'they ask a question and I'm able to put the words together' (P5).

Participants also highlighted the importance of the role played by facilitators in assisting individual members' communication where this was hindered by speech or memory problems. As one participant noted, 'trying to remember things yourself over a period of time is quite tricky – it's important to have somebody to remember for you what you're talking about' (P1). Another participant with impaired language noted the importance of being helped with her speech: 'They get my voice and put it in those words that I have said' (P5). Others who were less impaired also noticed and appreciated the assistance provided by the facilitators to other group members: 'You can see when she wants to pull someone through' (P8).

Running it

It was apparent, however, that the participants viewed the professionals in the group as not so much facilitating the group interaction as controlling it. In some participants' perception they were 'the people running it,' who might 'stop it,' and who 'allow[ed]' the group members to talk in certain ways about certain topics. In this participant's mind, her role in the group was simply to be 'here with these people, listening to ['the facilitators]' (P9). Another participant put it more plainly: 'They take the lead' (P5).

Breaking the string

The reliance within the group on the facilitators was sometimes experienced as a more pervasive sense of dependency, which, while not widespread among the participants, was a strong theme for those for whom it was an issue. One such participant, when asked hypothetically about the group ending, found it 'difficult to talk about' and said that her 'stomach really went over' just thinking about it. This individual felt that '[the facilitators] would always have to be there for a while' if she were to stop attending the group, but although she had been worrying about this for some time she felt more secure 'now I know they're not going to break the string' (P9). A minority of others echoed her fears: 'I'd feel lost [if the group ended and the facilitators left]. I wouldn't know what to do' (P10).

Attending to see if you can get it

This theme refers to individuals' awareness of their own participation in the group. This includes participants' descriptions of how they contributed to the group, including the strategies they used to overcome barriers to participation, and their evaluation of these contributions.

Joining in in your mind

Several participants indicated that their contribution to the group varied according to the level of difficulty they were experiencing, and that their participation was not always a vocal one:

> *You can join in in your mind if your memory allows you, which it has done on and off. (P9)*

> *You listen to what they're saying... They're saying something and I think, 'Oh, I never thought of that.' Yes. And then I'm going on that story myself. (P7)*

> *Until you find yourself words that strike you to say, you just carry on. (P5)*

As these comments indicate, for many participants the memory and language difficulties caused by their dementia meant that joining in with the group conversation was not always easy. These individuals described how they listened to others' contributions with great care, 'attending to see if you can get it' (P7). For them, participation required a determination and concentration that was perhaps belied by their quiet demeanour in the group: 'you try again, and then you try it two, three times, you start to fit yourself in a position where you can make a sense out of it' (P5).

Others whose difficulties were less pronounced described a more active contribution to the group: 'I usually just try and get something going' (P8).

I'm not very entertaining

Interestingly, both participants who were quieter in their participation and those who were more active were critical when evaluating their contribution to the group. The former worried that they were 'not very entertaining' (P6) or 'haven't got much to talk about' (P3), and one participant found that 'it's hard to put up with when you know you're not contributing or people are being patient with you all the time' (P1). Those who were more vocal were conversely concerned that they were 'talking too much and stopping someone else talking' (P8). Some, however, valued their own individual contribution: 'I'm a good listener' (P4).

There isn't one that's like another

Participants were struck by the diversity of the individuals attending the group: 'There isn't one that's like another' (P6); 'Everybody has their interest in different directions' (P5). There was some apparent ambivalence about the coming together of a group of people who

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potentially had only their diagnosis in common: 'Someone else might be something else entirely unlike anything I would go for' (P7). Most participants were interested in the others' differences, however, regarding the diversity of the group as a benefit rather than a drawback: 'Always interesting to have a little peep into somebody else's life' (P6); 'a little collaboration between everyone who's different' (P9).

It was evident that the development of relationships between group members was mediated by the difficulties they experienced as a group of individuals with dementia, most notably the difficulty in building a deepening knowledge of their fellow members over the weeks that they met: 'First we say who we are [at the start of each meeting], because not all of us know each other' (P5). The extent to which this was an issue for particular individuals varied considerably; however, as a group it appears that building a sense of familiarity and rapport was a slow process; even those who were most able to hold their fellow group members in mind ('we're beginning to find out a bit more about one another over the weeks') felt after eight group meetings that 'it's still early days' (P8).

While developing individual relationships within the group may have been a slow and difficult process, this did not detract from the importance participants appeared to accord to the task. Awareness of, and interest in, other group members was a theme identified in the majority of participant interviews, with participants indicating the attention they paid to other members of the group and their significance to the group experience. One individual with significant memory problems recounted observations of others from the session immediately preceding her interview ('the one where the husband's died' P7), while another whose memory was more intact told of his concern over time for another group member:

> *She sat next to me and she didn't talk for a couple of weeks. I says to*
> *her one day, 'It's not that bad, is it?' (P8)*

Overall, participants expressed a sense of appreciation for the others in the group, even where they could not recollect them individually: 'It's really nice people' (P7); 'We do seem to gel' (P9). Their comments suggest that even where participants did not (yet) have a sense of

relationship with individual members of the group, a kind of collective relationship existed that was perceived as both helpful and significant:

> *If there's any sort of problem I've got or might get – I'm quite sure there's somebody there who would want to help me if I told them. I get that feeling. So that's a comfort in itself. (P6)*

Outside, on your own

The lack of wider relationships in participants' lives, and the problematic nature of the relationships they did have, emerged strongly from the interviews. This theme refers to this absence of social contact and support. Participants spoke of this predominantly in terms either of an overwhelming sense of social isolation, or of feeling unable to turn to the people in their lives for support with the practical and emotional difficulties they experienced as a result of dementia. In both cases a comparison, either implicit or explicit, was often made with participants' experience within the group.

That feeling of isolation

Many participants contrasted the companionship and support received within the group with the social isolation experienced outside of it. These individuals described a sense of appalling loneliness, of 'not going out at all' (P2), of feeling 'horribly stuck out on my own' (P9) and 'completely alone' (P6). They explained how this had not always been the case: one recalled that she 'used to have a friend' (P6), another that he had watched his friends 'buzz off' (P1), and a third that living with dementia had 'taken it [her social life] away' (P7). The emotional experience of this poverty of relationships was described by one participant as 'that feeling of isolation' (P6). Another expressed relief at the social interaction provided by the group, 'otherwise I wouldn't be talking very much at all' (P4).

Reluctant to talk

Even when participants did have contact with others outside the group, they often expressed an inability or unwillingness to reveal their diagnosis of dementia or to talk about the practical

and emotional difficulties they were experiencing. This reticence was summed up by the individual who professed herself to be 'reluctant to talk to people who haven't got it or don't know much about it' (P3). Some were anxious about how others would react, not wanting to 'be labelled' (P1) and worried that people would think 'they were going off their heads' (P1) or were 'mental patients' (P6). One participant stated that 'when you tell people you've got dementia it sounds like you're making excuses for yourself' and felt that in any case 'people don't want to know' (P1). Others believed that people would find it difficult to cope if they knew the full extent of their difficulties, and did not want to burden their family or friends. Thus one participant insisted that there was 'no way' she would ever tell her children she had dementia because 'they would feel awful about it' (P6), while another said simply that she 'felt [she'd] better not talk it over, because it's something nobody else is worrying about' (P7).

For all these participants the group clearly offered an opportunity to share experiences with people who did have and know about dementia, in a safe environment that contrasted sharply with 'outside, on your own' where 'you've got to be careful what you say' (P5).

The business of dementia

This final theme refers to the difficulties, emotional responses and preoccupations experienced by an individual living with dementia, which were extensively described by all but one individual. Participants described their difficulties and emotional reactions to them in stark and concrete terms, with some indicating how these difficulties impacted on their ability to make use of the group. Common preoccupations were trying to understand the reasons for their memory loss, and ruminating on the possibility of further deterioration. A few, however, retained a sense of continuity with their past personal and professional identities and indicated that they felt able to bring these into their current experience in the group.

Difficulty remembering the group

A loss of memory functioning was the predominant focus for all participants in their descriptions of their difficulties, and a subject to which they returned throughout their

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interviews. Not surprisingly, some specifically mentioned its impact on their ability to recall the support group experience itself: 'It's frustrating – I was paying attention but now I'm struggling to get at the gist of it' (P1); 'I couldn't say what was discussed – can't even quite remember going there' (P2). It is significant, then, that despite this inability to recall the detail of the group experience participants were still able to give their thoughts, opinions and impressions of the group. One participant herself observed that it was not apparently necessary to be able to retain details of the content of a group meeting to be able to derive benefit from it: 'By the time you get out you don't know what was said, but you're calmer' (P9).

This dreadful short term memory

Participants described the difficulties they experienced as a result of dementia in straightforward terms that contrasted sharply with their reported reticence on the subject with others. The problems they described struggling with were varied, perhaps most strongly summed up in one participant's exasperation with 'this dreadful short term memory' (P6), but encompassing the different areas of decline in functioning associated with a diagnosis of dementia:

> *I put things down and I can't go back to find it. (P4)*
>
> *I am interested in what [friends say], to get the words from what they are saying, but I can't. (P5)*
>
> *I'm suffering from one side of the sentence to the other to join it together. (P9)*

Participants were highly critical of themselves in their struggle to cope with these difficulties, describing their 'thrashing around in difficulty' as 'pathetic' or 'idiotic' (Ps 1, 6 and 9). One participant forcefully summed up the emotional impact of living with dementia: 'The business of dementia – it's appalling really' (P1). Others described equally strong emotions in response to the diagnosis and ongoing experience of the disease: feeling 'ashamed' (P3), 'painful and cross' (P4), 'embarrassed' (P8) and 'very frightened' (P10). Another described 'getting in a bit of a mess' and 'feeling chewed up' (P9). The diagnosis itself came to one

participant as 'a big shock' (P7). It is not surprising then that 'first of all you don't admit to yourself that there's anything wrong' (P8). For these participants living with dementia was an all-pervasive and frightening experience, one they were well able to articulate but felt unable to share with others.

Why I lost my memory

Many of the participants were preoccupied with trying to understand the cause of their memory loss. Some acknowledged it as being the result of an organic illness, others saw it as an inevitable result of the aging process, while yet others sought an explanation in a specific event or experience. Often participants presented competing explanations in the course of one interview; it was clear that despite a clear group focus on dementia as an organic illness, for the group members this was not unproblematic:

> *It's an illness all right. P1*
>
> *If you live long enough that's what happens to you, I suppose. (P1)*
>
> *I think it's because I've had a terrific amount of worry. (P6)*
>
> *I still blame it on a fall on the head. (P9)*

Several of the participants expressed some hope that their memory functioning would improve, a few expressing some frustration that the group would not supply direct answers about their illness:

> *I wanted to find out from the group why I lost my memory. It would be helpful [if the group would tell you] if your mind is going to get worse. (P10)*

What am I going to be like later on?

Participants' preoccupation with their memory loss was also expressed in their fears about a future decline in functioning: 'My God, what am I going to be like later on?' (P3). Here it appeared that some knowledge of the inevitable course of dementia existed alongside an alternative state of not-knowing, with one participant simultaneously expressing a hope that she 'might get [her] memory back' and envisioning a future of total dependency:

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> *like someone who has no mind at all, who's born handicapped and*
> *has to be fed and washed. I'd feel like a cabbage. (P10)*

Being the boss-man

Participants described a sense of disjunction between past, present and possible future functioning yet, significantly, a few participants appeared to hold on to a sense of continuous identity linking past and present experience. Thus one participant explained her current sense of unease in the group in terms of previously leading tutorials as a university lecturer, and her continued need to communicate expertise:

> *The only way I feel it is easy in a group is if I am the boss-man. If I*
> *am giving them something that I know then I feel quite happy. (P9)*

Another felt that, 'being a nurse' (P6), she had knowledge about the brain's inability to repair itself that perhaps was not shared by all members of the group. Finally, it seemed that a stable sense of personal characteristics as well as professional role could remain constant in the person with dementia. Despite all the difficulties highlighted by participant 8 and his fears for his future functioning, it seemed that not a lot had changed when he found himself part of a group:

> *It goes back to when I was at work – I was always the one that would*
> *start it off.*

Thus is seems that the group provided a context in which members could experience some continuity in their sense of self, and that, conversely, this constant thread of identity aided members in making sense of the group experience.

Summary

The participants' accounts of their experience of the group and which aspects of that experience they found helpful or difficult can be seen to have a number of common threads.

Some participants were anxious about the group prior to joining and during the first few sessions. Gradually, however, group members found out that they were with people in the same boat as themselves who understood their experiences and difficulties, and that the group was a place where their memory and language difficulties were accepted and where they were encouraged and helped to communicate.

Over time, the group appeared to become a positive experience that participants contrasted with the isolation they experienced outside of the group and with their inability to talk about dementia with friends and family. They felt able to talk in the group about their everyday experiences of dementia as well other aspects of their past and present lives, and felt too that the group provided them with an opportunity for social contact. The facilitators as well as the other group members were an important part of the group experience for many participants, who expressed a sense of reliance on them for the group to work. A minority of participants expressed a deeper level of dependency.

All participants found a number of aspects of the group difficult, however, notably talking in front of a group of people or about certain topics such as emotions, and being together with other people whose contributions may be repetitive or vague. The difficulties related to living with dementia remained, and participants expressed worries about these and about how their future functioning might deteriorate. Some mentioned how these difficulties impacted on their ability to participate and make use of the group.

Overall, however, the support group was a weekly experience that these participants looked forward to, experiencing it as a relief from the difficulties and challenges of their life on the 'outside':

> *Without [the group] it's a seven day job – whereas now it's*
> *only a six day. (P6)*

CHAPTER FOUR

DISCUSSION

This chapter first reviews the aims, methods and main findings of this study. These findings are then discussed in the context of existing literature on the experience of individuals with early stage dementia and on mutual support as presented in Chapter 1, as well as other areas of psychological literature that are relevant to the study's findings. My reflections on the research process are then presented, followed by a discussion of methodological issues raised by the study and some suggestions for further research. Finally, the implications of the study for clinical practice are considered.

SUMMARY OF THE RESEARCH AIMS, METHODS AND FINDINGS

This study aimed to investigate the mutual support processes that occur in support groups for older people with early stage dementia, and to discover and describe the views and experiences of the individuals who attend. The study was formative in nature, with an emphasis on discovery and description in order to illuminate an area about which little is currently known. Eleven individuals who attended one of two support groups for people with early stage dementia participated; semi-structured interviews were conducted with individual members and three sessions of each of the support groups were videotaped. The interview transcripts were analysed using a qualitative method of analysis, and the videotapes were analysed to provide quantitative data about the group processes and transactions.

Analysis of support processes and interactions within the groups indicated that between approximately 10 and 15 % of all responses could be characterised as helping behaviours with support accounting for 5 %. One third of all transactions characterised as support originated from group members. The majority of the member responses were characterised as disclosures, with members sharing personal information in over one third of their responses.

The facilitators played a significant role in the group interactions, contributing almost one half and one third of all responses in Group A and B respectively. Their dominant role was to ask questions of individual members or the group, followed by providing information to the group members (Group A) or providing guidance, support and reflections on the group experience (Group B). Three quarters of all interactions in Group A took place between an individual member and a facilitator, while in Group B almost half the interactions occurred between group members.

Participants found much about their groups that was helpful, citing benefits such as meeting people in a similar situation, increasing social contact and being helped to communicate in an environment where difficulties with memory and speech are accepted. They described their groups as a place where they could talk about the experience of living with dementia, but also where they could chat about normal, everyday things or about the past. Participants also described a number of aspects of the group that were unhelpful or difficult, for example feeling pressured to talk about emotions in front of others and having to cope with the manifestations of dementia in other group members. The group facilitators were perceived as being integral to the smooth running of the group, with participants regarding them as the leaders of the group with responsibility for ensuring and directing the flow of conversation.

INTERPRETING THE FINDINGS

In this section the findings are reviewed as they relate to existing literature on mutual support and dementia generally, and support groups for individuals with dementia in particular. I then draw out three aspects that appear to be significant for our understanding of the provision of support groups for this population: the support group as an opportunity for social contact; the importance of the group for constructing an identity; and the role of professional facilitation.

Research on support groups for individuals with early stage dementia

The tendency for the emerging themes to reflect positively on the group experience is consistent with the findings of the few studies of dementia support groups, which indicate that members find such groups to be a positive and useful experience (see Morhardt & Menne, 2001; Yale, 1995). They also echo the positive outcomes suggested in this relatively new area of research: Morhardt & Menne reported that their group members expressed appreciation of others who are in the same boat, reliance on the group and/or the leaders, and a sense of purpose gained through contributing to other group members. The sampling bias noted elsewhere in the literature as being inherent in support group research (e.g. Goldklang, 1991) – the propensity for dissatisfied members to 'vote with their feet' and evaluations therefore to be weighted in favour of the satisfied members who stay – is less likely to have been a factor here, where individuals were placed in a group by professionals involved in their care and might therefore be considered less likely to exercise their choice to leave. The overall positive quality of the themes that emerged in this study thus contribute to the developing evidence that such groups might be of benefit to individuals with early stage dementia.

The difficult or aversive aspects of the group experience identified in this study, such as having to talk about emotions within the group or putting up with the dementia-related difficulties of other group members, do not, however, feature in the empirical studies cited above or in facilitator accounts of support groups for individuals with dementia (see Caron, 1997; Hawkins & Eagger, 1999; Yale, 1995). It could be speculated that group members are perhaps more willing to discuss negative as well as positive experiences of the group when the researcher is not also a group leader. It is certainly interesting to consider whether the absence of these difficulties from facilitator accounts of dementia support groups reflects a more general discrepancy between facilitator and member perceptions of the group experience. Further participatory research with individuals who attend such groups would clarify this further.

Support groups and the emotional impact of living with dementia

The findings here, in particular those contained in the theme 'The business of dementia', support those sections of the literature that highlight the emotional impact of receiving a diagnosis of dementia (see Chapter 1). In the wider literature this impact is often situated within a sequential, staged model of the experience of dementia, with individuals progressing from an awareness that something is wrong, through a period of secrecy, and arriving eventually at a position of wanting to make sense of the symptoms (see e.g. Keady & Nolan, 1995a; 1995b). It is a model that informs the view that support groups facilitate a process of working through the emotions and difficulties that arise with a diagnosis of dementia, once individuals have reached the stage where they need to engage with these (Keady et al., 1995; Yale, 1995).

There is some evidence, however, that the experience of dementia is not as staged and sequential as such models would suggest, rather that individuals move between a number of different strategies for engagement and coping in accordance with their current needs, past experiences, and personality (Clare, 2002, in press; Pearce et al., 2002). Such a variation between and within individuals over time in their engagement on an emotional and practical level with the implications of the diagnosis has significant implications for the functions and processes of support groups for this population. Certainly in this research, although participants indicated in their interviews that they were struggling with many fears and difficult emotions associated with their illness, the qualitative data suggest that working through these was not among the most valued aspects of the group experience. This is supported by the observational data, which likewise indicate that seeking support for these difficulties might not have been a significant element of the group process. If this is more widely the case, then it would suggest that the focus in the literature on psychotherapeutic change in the context of support groups for individuals with early stage dementia does not always reflect the processes and preoccupations of the groups themselves. In addition, it suggests that receiving and providing emotional support, as defined in the literature, might not be a significant component of the support group experience. This is explored further below.

The occurrence and perception of support in the groups

An interesting aspect of the findings of this study was the discrepancy between participants' perception of the groups as being supportive and caring, and the observational data suggesting that the actual incidence of supportive transactions in the group was low. This is the one area in which the observational and qualitative data obtained in this study diverged. Research suggests that the perception of emotional support is more strongly correlated with emotional well-being than actual received support (Helgeson & Gottlieb, 2000; Roberts et al., 1999). In light of this evidence, the findings of this study that group members appear to retain an emotional memory of being contained, supported and understood within the group, even where the actual frequency of supportive transactions seems to be low and members' ability to recall them in detail is limited, is significant.

The reasons for the apparent low incidence of supportive transactions in the group is however important, given the argument that one of the features that differentiate support groups from group psychotherapy is that in the former it is the supportive interactions between members that are the important ingredients rather than the modelling or insights provided by the facilitators (Helgeson & Gottlieb, 2000). It is therefore important to consider the reasons why only 5% of all transactions that occurred in both support groups studied here were judged to contain elements of a supportive exchange, with only a third of these involving support offered by a fellow group member.

One explanation for the low incidence of supportive responses observed could be that the processes thought to be instrumental in support are hindered by the cognitive impairments experienced by people with dementia. For example, Roberts et al. (1999) cite the provision of informational support and emotional support as being integral to the support group experience. However, it might be surmised that the former is likely to be hindered if an individual finds it hard to solve problems or remember information because of difficulties with memory or executive functioning, while the second is less likely to occur if he or she cannot remember fellow members or has a reduced capacity for empathy. Even if the cognitive

difficulties do not hinder these processes fully, it may be that the group members require more time to build up the sense of familiarity and trust that is a prerequisite for open sharing and support. The participants' comments, described in Chapter 3, that the group was still in its 'early days' would suggest that this may have been the case; if so, a higher proportion of support transactions may have been recorded had the study been conducted at a later point in the life of the group.

It may also be the case that the constellation of individuals in the groups adversely affected the opportunities for support. The reasons set out by Helgeson and Gottlieb (2000) as to why a group may not be conducive to supportive exchanges, for example because the members have nothing in common except their shared problem, may be particularly pertinent here, where members had been placed in the group by healthcare professionals rather than seeking it out themselves. Similarly, individuals whose impairment is more advanced may represent for other members a despairing picture of what they might themselves become rather than be the source of enhanced self-esteem predicted by social comparison theory (Festinger, 1954). Aspects of the themes that emerged from the participant interviews, for example the diversity of the people attending the group, including those that participants 'wouldn't normally go for', and the difficulties posed by members whose dementia was more advanced, suggest that these considerations might be pertinent to the current study.

The active role played by the group facilitators could be a further factor in these findings. With the majority of transactions occurring between group members and facilitators, it could be that opportunities for members to offer support to each other were restricted. In addition, it could be that the participants derived support largely from their interactions with the facilitators rather than from each other. Certainly the theme concerning the facilitators that emerged from the participant interviews indicates that they were integral to the members' experience of feeling contained, supported and understood.

The findings must be interpreted, however, in the context of the similarly low level of supportive responses that was found when the BIC was used to investigate processes in

mental health support groups (Roberts et al., 1991). It may be that they reflect limitations of the coding system rather than characteristics of the group process. A further consideration when attempting to explain the low incidence of supportive responses, particularly when this is contrasted with the themes of being understood and contained that emerged in the participant interviews, is therefore the definition of support used by the BIC. Support is quite narrowly operationalised within the system, for example requiring responses to demonstrate nurturing and encouragement, or to offer assistance to another member. If the definition is widened to include other responses defined in the BIC as helping responses, for example those which offer guidance or which seek to summarise or explain another person's comments or behaviour, the incidence of supportive transactions within the group increases two- or three-fold.

However, even with this extended definition of support, it may be that the BIC did not capture all the support activities that occurred within the groups, either because they were too subtle or because they took a form that fell outside its narrowly-defined version of helping behaviours. For example, Paine et al. (1992) consider personal disclosure itself to be a form of support, an activity that constituted much of the interaction within the groups here but was not categorised by the BIC as an instance of support. Similarly, an aspect of support groups considered by Levine (1988) to be integral to their supportive function is the psychological sense of community that they provide. This is interesting in the context of this research for two reasons. First, because the sense of belonging to a group of individuals with similar experiences and difficulties was one of the main themes to emerge from the participant interviews; and second, because supportive transactions as defined by the BIC might not necessarily be required for such a sense of shared experience to emerge. This explanation for the relatively low frequency of support and helping responses in the groups would suggest that support needs to be conceptualised more widely for this client group.

Finally, the possibility of differing generational norms should be considered in connection with how support is operationalised in the BIC. It is likely that those who attend such groups will be drawn from a generation that often prohibited the public display of emotion, and

where people perhaps dealt with their personal difficulties through means other than sharing them openly and exploring them with others. A definition of support that requires a nurturing response to an original emotional disclosure may not therefore be appropriate. In this case it may be that the gap between what professionals believe to be appropriate to the support group setting and what is actually observed reflects the different generational norms of the facilitators/researchers and the group members.

The overall findings of this study are that support groups can offer a valued experience in the aftermath of a diagnosis of dementia and provide an environment in which members feel contained and supported. However, both the data on group processes and the qualitative data derived from the participant interviews suggest two significant discrepancies: first, between perceived support and the actual supportive responses recorded using the BIC; and second, between the conceptualisation in the dementia literature, echoed by some of the group facilitators, of support groups as enabling members to work through difficult emotions and experiences, and what is actually occurring within the groups and valued by the individuals who attend them. These findings suggest the need to clarify the possible support versus the therapeutic functions of such support groups, as discussed in Chapter 1. They also suggest the need to offer a different idea about what is useful about the groups for the individuals who attend, and to develop an alternative conceptualisation of support for this client group. Two ideas about what such a conceptualisation might be are offered below.

Opportunities for social contact

The current findings suggest that one function of the support groups studied here that is highly valued by their members is the opportunities they provide for social contact. The importance of people who share a common illness or stressor coming together not just for emotional support or to share their difficulties and ways of coping, but to seek friendship and social exchange, is documented in other contexts (Maton, 1988). The dementia support groups so far reported in the literature, however, appear to prioritise the exploration of the practical and emotional sequelae of receiving a diagnosis of dementia and mention little about their role as a forum for social contact. While it is recognised that the provision of

social contact may be needed and wanted by people with dementia, this tends to be viewed as an alternative activity to that offered by a support group (see e.g., Yale, 1995).

The findings here would suggest, however, that particularly in the case of dementia, where people's cognitive difficulties may hinder them from participating in the social networks previously available to them, a support group can play a particular role in establishing social contacts and building an identity based on social ties with others rather than on the difficulties associated with dementia. The particular characteristics of a support group may situate it as a forum where members are enabled to build relationships in which they can negotiate such difficulties as speech and memory problems, rather than these purely being the focus of a shared experience. It may also be that talking about those aspects of their experience that draw on individuals' relatively intact long-term memory provides them with a sense of mastery that enhances their self-esteem, and thus their ability to form social relationships. This accords with the value placed by the participants on 'just chatting' and would suggest it is important for support groups to facilitate social contact that allows the individual with dementia to talk about aspects of their lives that are *unrelated* to their experience of dementia, including everyday happenings and the past, as well as issues to do with their illness.

This element of the results is in accordance with existing generic knowledge about support groups. Many researchers writing within this domain note the discrepancy between professional and member criteria for successful outcomes of support groups, with the former focusing on elements of personal and therapeutic change and the latter concentrating on the social support and relationships that evolve (Goldklang, 1991; Helgeson & Gottlieb, 2000; Knight et al., 1980; Maton, 1988). In his study of support groups Maton found that members saw support groups as an opportunity to develop friendships and reconstruct social networks. His findings echoed those of Knight et al. in an earlier study, namely that members judged social support to be the most important factor provided in support groups. When asked how the group helped them, the response given most frequently by members was that it provided social involvement, and that social contact was the most helpful aspect of the

group experience. In their appreciation of the opportunities provided by their support group to meet people and interact socially and 'just chat', the participants in this study were thus echoing the benefits of support group membership cited by members of different support group populations over the last twenty years.

Such a function of the support group would also appear to fit with the wider literature on dementia and dementia services. Certainly in providing social engagement and meaningful activity in a context where the individual with dementia is listened to and their views respected, the support group can be seen as an example of the 'new culture of dementia care' (Kitwood, 1997). Moreover, there is some evidence that the improvements seen with certain interventions for people with dementia, for example reminiscence groups, are due to the social contact they provide rather than specific elements of the intervention (see Kasl-Godley & Gatz, 2000). It is also in accordance with emerging literature on the view of the person with dementia on the services they receive, which suggests that at least some individuals are clear that they do not want specific 'interventions' so much as the facilitation of opportunities for social interaction (Scott & Clare, in press).

In asking in more detail what it means to listen to the person with dementia, Reid, Ryan and Enderby (2001) stress the importance of providing companionship and friendship, and fostering a feeling of helping and supporting others. Sifton, cited in Nolan et al. (2000), likewise emphasises the quality of the experience of taking part rather than defined therapeutic or practical goals, when she insists that the ultimate aim of interventions in dementia care is 'to enhance, enliven and enrich the present' (p. 202). While this is not incompatible with emotional exploration and psychotherapeutic change, it can be an important end in itself. It could be argued that the provision of generic social contact is an aspect of support groups for people with dementia that is neglected in the theory and practice of dementia support groups. The findings from this study appear to suggest that it requires further investigation.

Social identity

Nolan et al. (2002) argue that personhood is 'created (or diminished) in social relationships' (p. 183). This argument is made specifically with reference to people with dementia and their carers, however it could also be seen to encompass relationships between individuals with dementia, and to have specific relevance to the ways in which support groups operate in the social domain. The findings of this study would appear to fit with aspects of the literature that argue such groups can also intervene at the level of the social self. The prevalence of story-telling within the groups, the importance accorded by the group members to the business of 'chatting' about the past or about present-day happenings, and the predominance of personal disclosure amongst the group processes observed, can all be seen as examples of the creation of a social identity constructed through discursive practices within the group. Such a view accords with social constructionist ideas about the construction of a self through talk, outlined in Chapter 1. Such a view poses a very different conception of the functions and purposes of a support group.

It has been suggested that reminiscence functions as a discursive practice in which personal identity and selfhood are constructed through the recounting of lived experience (van Langenhove & Harré, 1993, cited in Cheston, 1996). Sabat and Harré (1992) argue that in the individual with dementia selfhood can be lost, not directly as a result of the disease process itself, but rather indirectly as a result of the restricted range of opportunities available to individuals to establish their identity through talk. From this perspective, support groups can provide a means by which selfhood can be constructed and maintained as past and present lives are told and re-told between members (Cheston, 1996). The groups observed here can be seen as a facilitative context for members' stories about the past and seemingly inconsequential 'chat' about the present, thus enabling the talk through which members' social selves are established and held.

The value of reminiscence for older people more generally and the role of narrative in making sense of past and current experience has long been recognised as an important component of life review in the older adult population. However, the ideas outlined above

suggest that support groups can perhaps be seen as also facilitating a cohesive sense of identity for their members, when opportunities for the individual with dementia to create and maintain a social self in other contexts are impoverished. Perhaps, in the emphasis on talking about the past and 'everyday things', we see the importance of creating a self as other than that of a person with dementia; a temporary web of stories told and lives lived (White, 1991) apart from the diagnosis that has come to dominate identity in other contexts. Such a view of the possibility of creating or sustaining an identity that is not subsumed by the diagnosis of dementia would also accord with models that emphasise the personhood of the individual with dementia, with their emphasis on identity and emotional experience (see e.g. Kitwood, 1997). In this context support groups could be seen to be a forum in which personal experience can be validated and explored and an identity can be constructed, and where these processes are not necessarily and inextricably bound up with the person's memory loss. If this is the case, then support groups can be seen as being qualitatively different from other interventions, for example cognitive stimulation groups, in that they not only provide a forum in which the experience of dementia can be explored, but also exist as a place where individuals can construct a self apart from their identity as a person with dementia. Such an idea raises wider questions about how services for people with dementia in general enable them to construct and maintain an identity separate from their dementia-related difficulties, and how this can be managed successfully in the support group setting.

The role of facilitators

It has been suggested in the dementia literature that support groups can be a forum that give people with dementia a voice, where they are otherwise disenfranchised and disempowered (Cheston et al., 2003). It is unclear, however, to what extent this is the case with the support groups studied here, given the frequency of facilitator intervention and the participants' perception that the facilitators set the agenda and controlled the group process. Up to three quarters of all interactions involved a facilitator, and despite questions about facilitation not being included in the interview schedule, the role of the facilitators emerged as a rich theme in the participant interviews.

The existing literature assumes the need for facilitators in support groups for individuals with dementia (Cheston et al., 2003; Hawkins & Eagger, 1999; LaBarge & Trtanj, 1995; Yale, 1995, 1999). The reasons for this assumption are rarely made explicit, but when they are they tend to make general reference to members' perceived vulnerability. For example, there is the assumption that 'counselling skills are needed to protect the vulnerable and guide group process as necessary' (LaBarge & Trtanj, 1995, p. 291), and Cheston et al. similarly assume the need for directive facilitation and professional support. Such assumptions may be justified, given the authors' stated aim of working through the difficult emotions associated with the experience of dementia and effecting therapeutic change. The need for professional facilitation becomes less clear, however, once the therapeutic and support functions of the groups are disentangled. Do we see support groups intervening primarily in the emotional or the social domain? What are the hoped for goals or outcomes? And is the mechanism through which it is intended these should be achieved therapeutic intervention or social support? These questions appear to be as yet unresolved in the area of support groups for individuals with early stage dementia. If certain support groups were to have different aims, for example providing opportunities for social contact and 'chatting about normal things', would the facilitation needs be the same?

Such a question becomes pertinent when one reviews the empirical literature on professional facilitation and support groups considered in Chapter 1. Thus Toro et al. (1988) found that professionals change the atmosphere and process of support groups when they lead them, with member-led groups perceived to be higher in cohesion, expressiveness and self-discovery. They suggest that members in professionally-led groups take on a passive, patient role. Borkman (1999) cites this and other evidence that professionally-led support groups are more structured and hierarchical than their member-led counterparts, with the members being disempowered and the professionals empowered. She cites research that indicates that in professionally facilitated support groups the members tend to become dependent on the professionals, whom they regard as experts. The current study would appear to be consistent with much of these findings. It is for these reasons that proponents of mutual support such as Borkman regard the incursion of professional power into support

groups as being detrimental to their members, disempowering them and positioning them as subordinate.

However, even strong proponents of independence from professional power raise the possibility that professional facilitation may be required in support groups for more vulnerable people (Levine, 1988). It is possible that the cognitive difficulties experienced by individuals with dementia will always necessitate professional involvement; for example, the participants in this study cited a need for a 'group memory,' and this is also referred to elsewhere in the literature (Cheston, 1996; 1998). Similarly, Killick and Allan (2001) note the role played by asking questions of people with dementia in enabling them to speak and share their experience, and Maton (1988) points to the increased satisfaction in groups where the leader is perceived as being capable. Both these positive aspects of group facilitation are reflected in the qualitative and the quantitative data obtained in this study. Morhardt & Menne (2001) saw the dependency of their participants on the group leader as a positive aspect of the group, and linked it with Yalom's description of high levels of accurate empathy, non-possessive warmth and genuineness. Participants in this study certainly attested to their appreciation of the facilitators, the usefulness of their interventions, and their belief that without them the support group would not function successfully. Facilitators appeared to function for the participants as an anchor in the group, able to facilitate coherence both of speech and experience and offer a sense of stability against a background of threat and change. The hierarchy that existed between facilitators and members in the groups appeared to be welcomed by the participants, perhaps resonating with this particular age cohort's previous expectations and experiences of professionals.

There are undoubted challenges posed within support groups for people with dementia by the cognitive difficulties of those who attend them. There are also undoubted tensions between the possible benefits of professional facilitation and the potentially subordinating effect on group members. The question of how to offer useful facilitation without encouraging members to adopt a patient role remains an area to be explored in research and clinical practice in this area. Certainly we have not heeded Levine's assertion that, while it may be

the case that those with fewer personal and psychological resources will fare less well without professional facilitation, 'we should not accept that proposition until it is thoroughly tested' (1988, p. 181). Perhaps a conflation of therapy and support in this area hinders us from exploring the potentially different facilitation needs of groups based on mutual support and those envisioning psychotherapeutic change. Perhaps the apparent reluctance thus far to test the assumption that we as professionals are indispensable to the support group process for this client group is linked to our eagerness to offer the skills and knowledge we possess, and our need to be needed. There are some indications that alternative models of support group leadership are possible: a web-based support group run by and for individuals with early stage dementia has created an alternative depository of 'group memory' in the documents and contributions posted on the site, thus enabling members to hold and access their contributions in a textual form (www.dasni.org). Anderson and Goolishan (1999) suggest that the challenge for professionals is to adopt a 'not knowing' position in which they lay aside their assumptions and are truly curious about what their clients are telling them about their lives and about what they need and want. In the field of support groups for individuals with dementia we perhaps have yet to see where this would take us.

REFLECTIONS ON THE RESEARCH PROCESS

Impact of my role as researcher

As a trainee clinical psychologist, I was situated in the professional realm also occupied by the group facilitators. There is therefore a great likelihood that I will have been identified with the facilitators in the minds of the participants, and indeed there was much evidence in the interviews that this was the case. For example, one participant assured me that 'you and [one of the facilitators] are just the right people for us.' Such an identification will likely have had a significant influence on the content and process of the participant interviews, particularly given the participants' positioning of themselves as grateful receivers of the help offered by the 'expert' facilitators, and the concerns expressed about the power of the facilitators to end their membership of the group. In addition, it appeared that some

participants confused me with the facilitators for at least part of the interview: many referred to 'you' when talking about the facilitators. Again, this raises similar issues with regard to how this may have influenced the accounts participants gave of their experience of the group.

Research process

Wilkinson (2002) points out that when disempowered people participate in research, their marginalized position in society can be reflected in the relationship between researcher and researched. As a result, she argues, while it is essential to include the views of individuals with dementia when undertaking research, it is important to recognise the potential for these inherent power inequalities to be played out. It is important, therefore, to consider ways in which the powerlessness of the participants in this study relative to myself could have been replicated in the research relationship, and the potential impact of this on the research process and findings.

My possible identification with the facilitators who had the power to grant or withhold membership of the group, discussed above, may be regarded as one aspect of this unequal relationship. Given the power differential between the participants and me, consideration should be given to the degree to which the participants felt able and were enabled to express their views and concerns in my interviews with them. This may have been impacted on further by the influence of social desirability and the tendency for people receiving help to evaluate that help positively (Solomon et al, 2001). Both these factors may have been further mediated by participants' difficulties with speech and memory. Yet there is evidence in the interviews that the process was a positive experience for the participants, in which they felt listened to and empowered to speak. One participant likened the experience of being heard in the group with her experience of being interviewed: 'the same thing you are doing to me here now – to get my voice and to put it in those words that I have said.' Another thanked me 'for listening.' However, there is also evidence of the participants wanting to flatter and reassure me. I was assured by one participant who had confused me with the facilitator that I

'was doing a marvellous thing.' Each of these aspects of the research process should be held in mind when interpreting the study's findings.

The issues regarding inequalities of power have implications for all research with individuals with dementia. However, they are perhaps particularly an issue in research that is inherently and explicitly linked to service provision and therefore to the professionals providing the service. It could be considered whether participants would have felt more empowered to be critical had they been attending a group that was not professionally-led, and where there was therefore no confounding of the facilitator and researcher roles and the power relationships inherent in them. However, a number of participants did express some difficulties and frustrations with the group experience. There is therefore evidence that it was possible for at least some of the participants to be critical at least some of the time.

Finally, it is important when considering the research process to return to the issue of consent. Despite the care taken during the consent process, described in Chapter 2, it could be argued that the degree to which participants actually gave their consent to participate in this study entirely freely remains open to question. Given certain participants' feelings of dependency on the facilitators and their concern that they may curtail their membership of the group, it may be that they felt pressured to take part in the study when invited to by the facilitators. In this case, it might have been better for me, as a person unrelated to the group, to carry out the consent process. The original decision that the facilitators should obtain consent from their group members was made on the assumption, however, that familiarity with the person seeking their consent would make it easier for participants to raise objections or ask questions. It is unclear in this case how the relative benefits and disadvantages of the consent process used influenced members' participation in the study and thus the results obtained.

METHODOLOGICAL ISSUES

The methodological issues raised by this research can be discussed in terms of the study's generalisability, its research design, the process of data collection, and the methods of data analysis used.

Generalisability

The findings of this study should be considered in the context of some limitations regarding the degree to which they can be used to draw conclusions about the wider support group population. First, they are based on only two groups and a total of eleven participants. Given that no further groups were identified as being in existence at the time in the geographical area of the study, this number does include all possible members of a service provision whose relative newness and rarity constituted part of the rationale for the study. The number of participants also corresponds to those in comparable qualitative studies (e.g. Clare, 2002; Morhardt & Menne, 2001). However, the limited number of participants does have implications for the extent to which the findings can be generalised to the wider population of dementia support groups. This is particularly so if one considers the marked contrasts in terms of style of facilitation and interaction between the two groups studied here; it is likely that support groups for this population differ considerably and findings based on one such group cannot be assumed to apply equally to others.

A second limitation concerns sampling bias. In using naturally occurring support groups the study was able to examine the group processes and experiences as they actually occurred in two established services. However, as a result the group members, and thus the research participants, were selected by the facilitators and/or assessing clinicians and in addition to the explicit criteria set out in Chapter 2 it is likely that idiosyncratic criteria were used in these decisions about which clients should be offered the group. Furthermore, survey evidence suggests that only a small proportion of people with dementia, especially with mild impairments, are in contact with services (Cooper & Fearn, 1998). As the route of referral for both groups identified for this study was diagnosis via a memory clinic, the participants in this

research will have been drawn only from this small and possibly unrepresentative population. Certainly their demographic data reveal a number of biases: all but one of the participants were white British or Irish, and all but three were women. Further research drawing on a greater number of groups from a wider geographical area, incorporating a range of formats and styles of facilitation, and including groups that accept self-referrals from the community, could begin to illuminate the limits of the generalisability of the findings of this study.

It is also significant that both groups studied here were professionally facilitated. As is discussed above, support groups that are facilitated by professionals can differ from those that are member-led in terms of content and process. This study can therefore more accurately be described as investigating professionally facilitated support groups for individuals with early stage dementia. Research using member-led support groups, were they to be founded, could clarify the extent to which the findings are relevant to groups using a different source of facilitation.

Research design

A further consequence of recruiting existing support groups, which themselves had recruited members referred to a local memory clinic, is that it was not possible to ensure that all participants were actually experiencing the mild level of cognitive impairment that would be expected in the early stages of dementia. There is some evidence to suggest that, despite the stated aim of such services, individuals' dementia has often advanced beyond the very early stages by the time they come into contact with memory clinics (Woods, 1995). As the degree of the cognitive impairment experienced by the participants in this study was evidently such that either they or their family sought help and diagnosis from services, it may be that their impairments were at the more severe end of the range found in early stage dementia. Although the MMSE was used as an approximate indicator of mild impairment, this is only a screening instrument and does not reliably indicate the specific deficits and level of difficulty experienced by a given individual (Hodges, 1994). Moreover, for some participants their most recent MMSE score pre-dated their entry to the study by up to two years (see Chapter 2).

Had the time and resources been available, a neuropsychological assessment of all individuals by myself at the time of the study would have clarified the extent of impairment each was experiencing and the stage of dementia this was likely to indicate. However, this would likely have been an aversive experience for the participants and therefore not ethically justifiable. Moreover, a strength of this study is its ecological validity; it investigated the processes and experiences in naturally existing support groups. Given the current propensity for support groups to be linked to memory clinics and other dementia services, it is likely that any variation in the level of impairment experienced by participants at the time of this study will reflect a similar phenomenon in other support groups for individuals with early stage dementia.

Researchers have pointed out that individuals' experience of support groups is dynamic and changes over time (Solomon et al., 2001). This study could have been improved by using a longitudinal design or follow-up interviews, in order to investigate how the group processes and members' experiences of the group changed with increasing familiarity. The time constraints of the study, however, meant that this was not possible. For the same reason it was not possible to wait until the groups were more established before conducting the research, although it would perhaps have been preferable if participants had been attending the group for a longer period at the start of the study, particularly given their own description of it still being 'early days.'

Finally, it is noted in Chapter 2 that a therapeutic or assessment relationship existed between a small number of participants and their facilitators either prior to, or concurrent with, their membership of the group. This may have complicated the interactions and relationships within the group, and certainly for one participant it did influence her feelings of dependency on the group facilitator. Such dual relationships may be typical of support groups facilitated by professionals working in the memory clinics to which they are attached; however, in this case they should be borne in mind as a possible confounding factor in the findings of the study.

Data collection

Video-recording of group sessions

The reactivity of participants to the process of being observed is well-documented in observational research (Banister et al., 1994). The possibility cannot be discounted that the participants in this study behaved differently in the group sessions that were being video-recorded, and that the process of video-recording therefore affected the group processes and interactions. In addition, the observational data was based on only three group meetings for each of the two support groups. It might be that the sessions recorded were in some way untypical of the group meetings, and that the data obtained is therefore unrepresentative. However, there was no indication from the facilitators of either group that the content of the sessions that were video-recorded, or the interactions of the members, differed significantly from the usual group meetings.

Participant interviews

A number of factors may have affected the quality of the interview data obtained in the study. First, conducting a single interview with participants may have gathered less rich data than if multiple interviews had been conducted, as the latter would have increased the participants' familiarity with me and with the interview process, and would have allowed for any fluctuating ability or willingness to engage. Pratt (2002) recommends conducting multiple interviews over time to increase participants' familiarity and to 'get them on a good day'. She reports that in her study she obtained a higher quality of data during the second interview, even where the individual with dementia could not remember the first interview or the interviewer.

Second, it was unfortunate that it was not possible to cue participants' recall of the group by conducting the interviews in the room where the group took place. Although, as explained in Chapter 2, this was unavoidable, if I were to replicate this research I would ensure that additional cues were provided prior to the interviews. A clip of the video-recording of a previous group meeting would be one possibility that might increase recall. Third, again due to the time constraints within which the study was conducted, there were limited

opportunities for the participants to meet me prior to the interviews. Ideally, more time would have been allowed for the group members to get to know me, as greater familiarity would have been desirable both on ethical grounds and because it might have increased participants' willingness to be open about their experience of the group.

However, the variety of the themes identified and the quality and quantity of the textual illustrations, drawn from across the transcripts, indicate that despite these limitations the data obtained were of sufficient quality to provide valid information about participants' experience of the support groups they attended. The interview protocol appeared to work well, facilitating a structured and coherent interview yet allowing enough flexibility for participants to raise the views and experiences that were pertinent to them. The strong theme that emerged concerning the participants' experience of the group facilitation, unforeseen by me and not present as a topic on the interview schedule, attests to this flexibility.

Methods of data analysis

The methods of data analysis can be discussed in terms of the strengths and limitations both of the BIC and of IPA, and with reference to the criteria set out by qualitative researchers against which the quality and credibility of qualitative research can be judged.

The BIC

In using an existing observational coding scheme that had been utilised in published research on support group processes, this study was able to draw on a measure with known validity and reliability to investigate group processes and interactions that had not previously been researched with this client group. Given the previously stated time and resource constraints of the study, it would most likely not have been possible to undertake this aspect of the investigation had there been the need to develop a new observational measure. The observational data obtained through the use of the BIC provides interesting information on the group processes and interactions that enhances the data obtained from the participant interviews, and can inform future practice in this area.

However, adapting an existing measure for use with this client population does have a number of drawbacks. These are mainly concerned with the issues, discussed at the start of this chapter, regarding the appropriateness of the definition of 'support' and the consequent ability of the measure to describe the support activities occurring in the group. It may be that, given the nature of the impairments caused by dementia and their impact on the group interactions, a wider conception of supportive transactions is needed when investigating groups for individuals with dementia. Alternatively, given the low percentage of supportive transactions also observed in published studies using the BIC with other support group populations (Roberts et al., 1991), it may be that this measure more generally fails to capture the full range of helping behaviours that occur in a support group setting. In either case, future research in this area could usefully develop a customised observational measure informed by a wider-ranging conceptualisation of support.

A further limitation of the BIC is the absence of any consideration of non-verbal behaviour. Consequently, the group processes and interactions investigated in this study were limited to those of a verbal nature, and it was not possible to incorporate information provided by group members' and facilitators' non-verbal behaviours. In addition, the coding scheme as used in the current study looked only at the categorisation of different verbal behaviours and did not consider issues concerning the sequence of these behaviours within the group. While the study therefore provides useful initial information about the kinds of group processes and interactions that occur in support groups for individuals with early stage dementia, it is not able to consider how these may be related to each other or how particular verbal behaviours may encourage or impede others. Study designs that included both verbal and non-verbal transactions, and considered issues of their sequencing, would extend the findings of the current study and could usefully be incorporated into future research.

A more general limitation of any observational coding scheme is that allocation of the data to particular coding categories will inevitably require an element of the individual observer's own judgement. In this case I tried to ensure adequate reliability of the results through

enlisting a second researcher to independently rate a section of each video-recording. The inter-rater reliability statistics obtained, reported in Chapter 2, suggest that sufficient agreement was achieved for the results to be regarded as reliable and useful.

Interpretative Phenomenological Analysis

IPA is concerned with individuals' experience and the meanings they attach to them. It investigates phenomena as they are perceived by the individuals experiencing them, and offers a clear and systematic method to the researcher by which he or she can organise and integrate the emerging data. For these reasons it offered clear benefits to this study that sought to elicit and describe people's views on the support group they attended.

However, the method can be criticised for failing to acknowledge the constitutive nature of language: in equating an individual's account of their experience with the experience itself, it can be said to fail to recognise the ways in which language constructs rather than describes experience (Willig, 2001). Such a criticism emerges from a social constructionist standpoint that can be seen to be at odds with the assumptions of the phenomenological approach that informs IPA. However, it is relevant to question the extent to which the participants' accounts reflect a particular construction of their experience for a particular purpose in a particular context – perhaps to convey appreciation of the group in the context of a research project they may have perceived to have a bearing on whether the service would continue, and to a researcher they may have identified with the facilitators providing it. Such a possibility was considered in the 'Reflections on the research process' section above and should be borne in mind when interpreting the study's findings.

The beliefs, assumptions and framework of understanding that I brought to the study (see Chapter 2) may also have informed the course and outcome of the research. The influence of the researcher's own phenomenology on the sense he or she makes of individuals' accounts of their experience is integral to IPA. My own identity as a trainee clinical psychologist, my belief that mutual support can enhance or exist outside of the benefits obtained from professional support, and my own social constructionist and systemic

framework of understanding, will all have informed this research project and the emergent themes identified in it. In setting these out explicitly, this research conforms to guidelines that stress the importance of researchers clearly stating the values and assumptions that have informed their work, in order that readers can more readily interpret the analysis and consider possible alternatives. These guidelines, and their relevance to this research, are further considered below.

Credibility

Qualitative researchers (see Elliott et al., 1999; Henwood & Pidgeon, 1992) have set out guidelines, which they argue are pertinent to the particular characteristics of qualitative research and can be used as criteria against which the quality and credibility of such research reports can be evaluated. One such criterion is the need for the researcher to own his or her perspective, discussed above. Another is that the analysis and interpretations made should be grounded in specific examples from the data, in order that the reader can follow the procedures used to arrive at the results and can assess for themselves the fit between the data and the researcher's interpretations of them. In this study I provided a detailed account of the procedure used to generate emergent themes from the data, and illustrated this with actual examples in the appendices. Each of the themes is illustrated with a number of direct quotations from the interview transcripts, and the themes themselves are named using the participants' own words.

Elliott et al. further describe a number of checks that qualitative researchers can employ to ensure that their accounts are credible, such as referring to others' interpretations of the data or comparing the results with other sources of data or perspective. In this case, a second researcher checked the coherence and credibility of the themes at various points in the analysis, as described in Chapter 2. In addition, the qualitative data generated by the participants were compared with the data obtained from the observational coding scheme. The extent to which the data from these different sources suggest similar findings, for example with regards to the significance of facilitator intervention, provides strong support for the credibility of the analysis.

The study could have been improved by seeking the views of the participants and facilitators on the findings, as any confirmation that the findings seemed valid and resonated with their experience would have increased the credibility of the research. However, it was not possible within the time constraints of the study to carry out this desirable credibility check. In addition, the length of time between data collection and a written presentation of the findings being available was such that participants may not have been sufficiently able to recall taking part in the research. An alternative method of obtaining such validation may be to seek the views on the findings of individuals with dementia who are currently members of a support group. This is planned in the near future with the current members of the support groups studied here.

Another criterion for the quality of a qualitative research report is that it should resonate with readers, such that they feel it has clarified or expanded their understanding of the topic. It is up to readers to judge whether this has been achieved.

SUGGESTIONS FOR FURTHER RESEARCH

I have suggested possible extensions or improvements of this study at various points in the discussion so far; here I aim to draw these together and highlight those that seem to offer the most useful avenues for future research.

Support groups are heterogeneous in terms of their format, facilitation and style of interaction, and the differences observed between the two groups in this study suggest that this diversity will likewise be a feature of support groups offered for individuals with dementia. Replication of this study across a larger number of groups would help to discover the extent to which the findings generated by these participating groups and individuals can be generalised to the wider dementia support group population. Inclusion of groups from a

wider geographical area and with a diverse socio-economic and cultural membership would help to further illuminate the boundaries of that generalisability.

The interaction processes of dementia support groups and the group characteristics that members find helpful are likely to vary according to the degree of impairment experienced by those attending the group. As noted above, in the current study the fact that the route of referral to the groups was in both cases diagnosis via an attached memory clinic may mean that individuals were already experiencing considerable dementia-related difficulties by the time they were offered participation in the group. Research conducted with groups set up in the community, rather than attached to dementia services in the NHS, may clarify the different needs of those at varying points along the phase of the illness that is encompassed by the term 'early stage dementia.'

The current study can more accurately be described as research into the experience of support groups for individuals with dementia that are professionally-led. Existing literature on support groups and the findings of this study both indicate that professionals can have a profound impact on the content and process of the groups that they facilitate. Furthermore, research indicates that the style of facilitation is significant in terms of these outcomes. Additional research that looked at both member-led and professionally facilitated support groups, and incorporated a research design that was sensitive to different facilitation aims and characteristics, could usefully explore how different sources and styles of facilitation are related to particular group processes and experiences in the early stage dementia population.

This study's findings from fairly newly established groups could also be further usefully developed using a longitudinal design that gathered data from groups and individuals over multiple time points. This could take account of observations of other support group populations that the way in which people use support groups and their experience of them changes over the course of their participation in a group (Solomon et al., 2001), and explore how this applies to groups for individuals with dementia. Such research would enrich the

data collected here concerning the processes and experiences that emerge in the early stages of a group.

Finally, as is discussed in Chapter 1, research in the area of support groups for people experiencing mental health problems has begun to examine particular aspects of support transactions and to relate such processes to group outcome (Roberts et al., 1999). Similar research designs could be utilised in the field of groups for individuals with dementia to delineate and further explore particular issues of support processes, for example the occurrence and impact of bi-directional helping (Maton, 1988). Such research would increase our understanding of the helping processes that can occur in groups catering for people in the early stages of dementia, and enable us to begin to relate the processes observed to different outcomes for the individuals who attend.

IMPLICATIONS FOR CLINICAL PRACTICE

The findings of this study have a number of implications for the provision of support groups for individuals with early stage dementia, and for the role of clinical psychologists and other professionals in particular. These implications relate to three broad areas discussed earlier in this chapter: the provision of social contact as an important function of the group, the role and nature of professional facilitation, and a consideration of the characteristics that appear to contribute to a useful and enjoyable group experience. Each of these sets of implications are discussed below.

Dementia support groups as an opportunity for social contact

The significance of the support group as a means to facilitate social contact for and between individuals with early stage dementia is a finding of this study that has considerable service implications. It implies that support groups for individuals with early stage dementia should validate and facilitate the provision of social contact as one of their core functions, alongside the provision of emotional support and a forum to discuss dementia-related difficulties.

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Integral to this function would be the opportunity to talk about events and experiences unrelated to the diagnosis of dementia, such as 'everyday things' or the past, and for these to be seen as a valid topic for discussion in themselves. Opportunities for informal social support could be provided as an adjunct to the main support group meeting, or could be integral to the group interaction. Alternatively, groups could be offered where informal social contact, rather than emotional support or exploration, is a more central component. Such an approach has been taken by a new service set up within the London area since the start of this study, which incorporates informal social contact and a user-led discussion forum (Pratt, Clare, & Aggarwal, in press). Such an approach allows for flexibility in service provision in accordance with individuals' differing needs and preferences, as is further discussed below.

Nature of the group facilitation

The questions and issues raised by this study concerning the facilitation of support groups for individuals with early stage dementia imply that this aspect of group provision requires careful consideration. Clearly there is a role for professional involvement in such groups, and particularly in groups that are envisioned to be psychotherapeutic or exploratory in nature. However, as is argued above, the current lack of clarity concerning the therapeutic versus the support functions of such groups has led to an assumption of the necessity for professional facilitation that would appear to be untested in either clinical or research contexts. Given the lack of alternative models of support group provision, it is unclear whether professionals may usefully occupy roles other than that of facilitator, such as assisting individuals with dementia to set up their own group or co-ordinating referrals. It is likewise unclear whether it is most helpful for professional facilitation, where it does occur, to be directive or purely to follow members' own agendas.

Evidence that professionally-led support groups, compared to those that are member-led, tend to be more structured and formal and encourage their members to adopt a patient role, suggests the need for future clinical practice to explore the boundaries of professional involvement required for the effective running of groups for those with early stage dementia. Experimentation with different degrees and styles of professional and member-led facilitation

would clarify this issue and potentially lead to the development of different types of support groups that would cater for the different needs of diverse individuals. It could be, for example, that a group could be member-led with some organisational support. The Dementia Advocacy and Support Network International, the web-based self-help group run for and by people with dementia, can be seen as one recent example of this.

The support group literature has noted in the context of other client populations that professionals can have a vested interest in being needed (Borkman, 1999). While not losing sight of the particular requirements of individuals with cognitive and other dementia-related difficulties, as professionals we need to be clear about the needs and agendas that are informing the development of support groups for this client population.

Group characteristics

The findings of this study suggest some possible issues for consideration when planning future groups. First, it was evident from the participant accounts that there can be tension between the benefits of being together with people who share the same difficulties and experiences and so can offer understanding and support, and the frustrations of being with a group of people who are all exhibiting the difficulties associated with a diagnosis of dementia. While this tension can never be totally resolved, it should be borne in mind that individuals with early stage dementia can find the outward signs of the illness as difficult to cope with in others as can people without dementia. For this reason, it may be advisable to ensure as far as possible that groups are homogeneous in terms of their members' level of cognitive and behavioural functioning.

The study's findings also suggest that the cognitive difficulties experienced by group members can mean that a longer time is required for members to establish a sense of familiarity and trust with each other, such that the support functions of the group are able to develop. This would suggest that it may be helpful for groups to be long-term or open-ended rather than offering a fixed number of sessions over the short term.

Finally, the views and themes that emerged from this study attest to the varying preferences of individuals for different ways of talking about the difficulties and experiences that arise from a diagnosis of dementia. With the literature increasingly exploring the range of possible coping styles adopted by individuals living with dementia and how these are influenced by their different personalities, backgrounds and experiences, it would seem evident that some individuals may not wish to use an approach that is based around talking at all. It is therefore important that we do not assume that everyone can or wishes to benefit from a dementia support group, and to develop a variety of approaches that can facilitate social contact and support. Given the concerns raised in this study about the degree to which the group members actually exercised a choice in attending the groups, offering a number of possible options to the individual newly diagnosed with dementia may also facilitate him or her making an active decision about the services s/he receives.

SUMMARY AND CONCLUSION

The findings of this study fit with much of what we know about the workings of mutual support groups generally, and as these relate more specifically to people with dementia. The overall experience of the groups was positive, and they provided a forum for processes of personal disclosure, story-telling and informal social exchange. Certain assumptions about the ways in which such groups may be helpful to those who attend them were challenged by the findings here: there was not as much evidence as perhaps predicted by the literature of an exploration and working through of emotional reactions to the illness, and members were not found to be as mutually patient with each other's dementia-related difficulties as expected. Particularly significant was the apparent low incidence of, and importance attached to, specific supportive interactions in the group. There are several potential reasons for this, including the possibility that the support functions of such groups operate differently to how they were originally conceived on the basis of existing literature. It also contrasts with the perception of understanding and support that are evident in the themes that emerged from the participant interviews. Two alternative conceptualisations of the supportive functions

of these groups were discussed that appear to be suggested by the findings here: the support group as an opportunity for informal social contact, and the support group as a forum for the creation and maintenance of a social identity.

The findings also raised issues concerning how such groups can best be facilitated, with unanswered questions about possible tensions between the need for the groups to be professionally facilitated and the potential subordinating effects of this facilitation on the group membership, and between the desire of professionals to offer help and the need to empower the individual with dementia. Perhaps this study ultimately offers the basis for further questions that can be usefully asked, rather than the beginnings of potential answers. It would, however, seem to underline the importance of choice in the provision of support groups to people with early stage dementia: there is evidence that there is a need for groups that are professionally facilitated and groups that are member-led; for some that offer informal social contact and others that are focused on the exploration of emotions and therapeutic change. As is recognised in all aspects of dementia care, the challenge in this aspect of service development is to increase the diversity of services available and facilitate the individual with dementia in making a truly active and informed choice between the options open to him or her.

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APPENDIX 1

Letters confirming ethical approval

North East London **NHS**
Health Authority
The Clock House East Street BARKING IG11 8EY

Tel: 0208 532 6221 (direct line) (If I am unavailable please leave message

Ms. L. Mason
26 Grange road
HOVE
BN3 5HU

5th July 2002

Dear Ms. Mason

Re: **LREC (B&H) 2002/5**
Support groups for individuals with early stage dementia: An investigation into group experiences and processes

Thank you for your letter of the 27th May 2002 responding to points raised by the Barking & Havering Local Research Ethics Committee.   The Committee is now able to approve the commencement of this study and looks forward to receiving a final report of your research findings in due course.

Yours sincerely

Mrs. J Irwin-Hunt
Chair LREC

St Mary's **NHS**

NHS Trust
Local Research Ethics Committee, R&D Office
Mailbox 121, St Mary's Hospital, Praed Street, London, W2 1NY

Tel No: 020 7886 6514:   Fax No: 020 7886 1529
Email: Ros.Cooke@st-marys.nhs.uk

Ms Lis Mason
Sub Department of Clinical Health Psychology
University College London
Gower Street
London WC1E 6BT

26/02/02

Dear Ms Mason

Support groups for individuals with early stage dementia: an investigation into group experiences and processes.
Lis Mason, Psychology, UCL WC1E 6BT

Ethics No:01.132
R&D No: 01/X0188E

On behalf of the members I am pleased to say that St Mary's Local Research Ethics Committee (LREC) has now approved this project, which was reviewed on 25 February 2002 taking into account the answers you have provided. The grid below shows those documents approved in accordance with the ICH Good Clinical Practice Guidelines. This approval is given on the understanding that the research team will observe strict confidentiality over the medical and personal records of the participants. It is suggested that this be achieved by avoidance of the subject's name or initials in the communication data. In the case of hospital patients, using the hospital record number can do this; in general practice, the National Insurance number or a code agreed with the relevant GP.

Research documents approved	Original date	Date of approval
LREC form revised to include questions 11c to 15a	20.2.02	25.2.02
Patient information sheet revised: printed in larger font and to include statement that the video & audio tapes will be destroyed/erased after data has been analysed/written up	20.2.02	25.2.02
Cvs: Nancy Pistrang, Dr Linda Clare	11.2.02	25.2.02

Chairman's initials
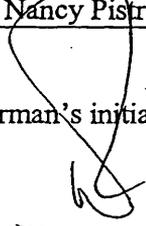
APPENDIX 2 – Information sheet for participants

Sub-Department of Clinical Health Psychology

UNIVERSITY COLLEGE LONDON

GOWER STREET LONDON WC1E 6BT

RESEARCH PROJECT

WHAT ARE PEOPLE'S EXPERIENCES OF DEMENTIA SUPPORT GROUPS?

Lis Mason
Nancy Pistrang, Ph.D.
Linda Clare, Ph.D.

Tel.: 020 7679 5962

INFORMATION FOR PARTICIPANTS

You are invited to take part in this study which will look at people's experience of attending a support group for people with dementia, and examines the interactions between people in such support groups. Dementia support groups are relatively new in the UK, and not much is known about what happens in them or what people who attend the groups find helpful or unhelpful about them. This study aims to find out what people's experiences are of attending a dementia support group, and to investigate some of the interactions that occur between people in the group. We hope that the information obtained will enable us to better understand how to provide support groups for people with dementia that people find useful and helpful.

PROCEDURE

The study will take place in two stages. First, we would like to videotape two or three sessions of your support group over a 4 to 8 week period. After this, you will be invited to take part in an interview about your experiences in the support group. You will be asked what you find helpful and unhelpful about the group, and about what happens in the group. The discussion will be tape recorded and should last about 30 minutes.

CONFIDENTIALITY

All material will be held in confidence, and will only be used for research purposes. All conversations will be anonymous, and information given will be treated confidentially. Information gained from the videotapes of the group session will also be treated confidentially, and group members will remain

anonymous. No one who agrees to take part in the study will be identifiable in any research report, including the final report if the study is published. The tapes and videotapes will be erased at the end of the study.

TAKING PART IN THE STUDY

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without giving a reason. You can also decide not to participate on any particular day if you do not want to, but still participate at a later stage. If you do decide not to take part, or withdraw at a later stage, this will in no way effect your membership of the support group or your attendance at the Day Hospital or any other aspect of your care.

EFFECTS OF TAKING PART IN THE STUDY

It is expected that taking part in the study should be a pleasant experience. However, should you find any part of the experience distressing the facilitators of the support group will be available to talk with you and provide support.

FURTHER INFORMATION

You will be given a copy of this information sheet and, if you decide to take part, a signed consent form to keep. If you would like to know more about the research project, or would like to contact the researchers for any other reason, they can be reached at the address and phone number above.

Thank you for considering taking part in this project.

APPENDIX 3

Consent Forms

Sub-Department of Clinical Health Psychology

UNIVERSITY COLLEGE LONDON

GOWER STREET LONDON WC1E 6BT

**KENSINGTON & CHELSEA AND WESTMINSTER HEALTH AUTHORITY
ST MARY'S LOCAL RESEARCH ETHICS COMMITTEE**

CONSENT FORM

AGREEMENT TO PARTICIPATE IN RESEARCH PROJECT

I, (name of subject) ....

Of (address)   ....

Agree to take part in the research project:

Support groups for individuals with early stage dementia: an exploration of group experiences and processes

I confirm that the nature and demands of the research have been explained to me and I understand and accept them. I understand that my consent is entirely voluntary and that I may withdraw from the research project if I find that I am unable to continue for any reason and this will not affect my medical care.

Signed: .... Print Name: ....

Witness: .... Print Name: ....

Date: ....

Investigator's Statement:

I have explained the nature, demands and foreseeable risks of the above research to the subject:

Signature: .... Date: ....

Sub-Department of Clinical Health Psychology

UNIVERSITY COLLEGE LONDON

GOWER STREET LONDON WC1E 6BT

BARKING AND HAVERING
LOCAL RESEARCH ETHICS COMMITTEE

CONSENT FORM

AGREEMENT TO PARTICIPATE IN RESEARCH PROJECT

I, (name of subject) ....

Of (address)   ....

Agree to take part in the research project:

Support groups for individuals with early stage dementia: an investigation into group experiences and processes

I confirm that the nature and demands of the research have been explained to me and I understand and accept them. I understand that my consent is entirely voluntary and that I may withdraw from the research project if I find that I am unable to continue for any reason and this will not affect my medical care.

Signed: .... Print Name: ....

Witness: .... Print Name: ....

Date: ....

Investigator's Statement:

I have explained the nature, demands and foreseeable risks of the above research to the subject:

Signature: .... Date: ....

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APPENDIX 4

Sample response coding sheet

Coder: Lis
Group: A   **Session:**   **11/6/2002**

Unit	Speaker	Code	Direction
1	F2	F	G
2	F2	Q	M
3	A	D	F
4	F2	Q	M
5	A	D	F
6	F2	S	M
7	A	D	F
8	F1	S	M
9	F2	S	M
10	A	D	F
11	F1	S	M
12	F2	Q	G
13	D	D	F
14	F2	Q	M
15	G	F	F
16	F2	?	M
17	G	F	F
18	F1	?	G
19	G	F	F
20	F2	Q	M
21	E	F	F
22	D	F	M
23	E	F	G
24	F2	F	G
25	D	F	G

Unit	Speaker	Code	Direction
26	E	F	F
27	F2	?	G
28	B	F	F
29	E	F	F
30	F2	Q	M
31	B	F	F
32	B	inaudible	F
33	E	F	G
34	F1	S	M
35	E	D	F
36	F2	S	M
37	E	D	F
38	F2	S	M
39	E	D	F
40	F1	Q	G
41	C	D	G
42	F1	I	M
43	C	D	G
44	F1	F	M
45	C	D	F
46	F2	?	G
47	G	D	F
48	F2	Q	M
49	G	D	F
50	F2	?	M

APPENDIX 5

Sample sections of transcript

Participant 4

EM: [Introduces interview.] Can you tell me first of all about what happens in the group on Tuesday mornings. What do you do when you meet together?

P4:   Well I think we talk about Alzheimer's you know. Not being able to think very much. Um...[coughs] and, uh, yes I'm sure that's what we think about – Alzheimer's.

EM: Uh-huh. So you meet together and talk about Alzheimer's //

P4:   Yeah, how you...how your memory is. And how it isn't. Yeah...

EM: And...and what do you talk about when you talk about Alzheimer's and your memory. Do you, do you //

P4:   We talk about each other's experience, you know. How it affects us in...in some way...

EM: Right. So you, you talk about what it's like to have Alzheimer's and how other people //

P4:   That's right, yes. It affects people in a different way, you know, different ways ...yes. Loss of memory, you know. My memory's not too good.

EM: Yeah. And that's why you go to the group.

P4:   That's right, yes.

EM: So everyone in the group then has got Alzheimer's or...a dementia like that [P: Yes, something like that, yes] or have difficulties with their memory.

P4:   Mm-hmm. Yes.

EM: Yeah...

P4:   And...you know...It's good to know that other people are in the same situation as you are yourself. Yeah...and that helps really.

EM: So it helps to go to the group [P: That's right] and to know that other people have the same kind of difficulties that you do.

P4:   Yes, that's right. Otherwise if you don't know about these things you think, Oh, you're the only one, sort of thing... You know what other people are going through and you think, Oh, well, somebody else is the same as me, you know, hasn't got a good – you know, hasn't got a very good memory at all. It's...it's really not very nice not to be able to remember what happened yesterday. And till somebody reminds me, I'm like that, you see.

EM: Yes... So you're relying on other people really to [P: That's right, yes] remember for you.

P4:   Yes, yes.

EM: Yeah...

P4:   So, it's...a bit awkward.

EM: So what's it like going to the group – what's it like being in the group?

P4:   Oh, I like it very much. 'Cos you feel, well after all there's other people in the same boat as you are... [3 second silence]. Um, I clam up when I'm talking.

EM: I know, it's a bit difficult, isn't it [P: Yes, mmm] You don't know me either...

P4:   Yes, and I get a tiredness in my throat.

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EM: Uh-huh, so it's difficult to talk because your throat gets tired...yeah.

P4 :   Yeah. [5 second silence]

Participant 9

EM: If you could just tell a bit about what happens in the group, when you meet here on Thursday mornings...

P9:   Um, apart from a little friendly chat you know, to start it off with...um... This, this is going to be a bit odd because we just sort of...ask [facilitator] questions individually...it just ties up as a sort of chat in its way. Which I find pleasant. And I also find it pleasant simply because I can hear that other people are in the same boat as me so I don't feel so horribly stuck out on my own. And several times they've mentioned exactly a thing...that had happened to you with your memory. They've had it. So I, I just walk out quite sort of at peace when I leave here. And I think [facilitator] has a very good way of...er, setting it all up with us, you know. We all seem to get on very well with her. So, uh...yeah, I think it's good.

EM: So when you say it's good because you find out you're in the same boat as everyone //

P9:   You hear how one person is affected and another and sometimes how we cope with it. Yeah, I think I have learned things. Don't sort of ask me exactly what, I don't quite, I can't quite tell you. But I go out feeling a bit lighter than I came in. So...and I just think [facilitator] seems to lead it the right way.

EM: Right...So it sounds like having someone there who's able to lead the group is quite important.

P9:   Yes, it is. Yes. Because we would all chatter about heaven-knows-what that really wasn't helping. We've been doing that out there. Um...and... But [facilitator] does seem to...come in with the right questions now and again, you know, that we all sort of talk about. Yes, I find it good.

EM: So she kind of guides the conversation in some way //

P9:   Yes. She makes you feel... 'cos I kept feeling an idiot. Because I couldn't think of things and I'd gone //

EM: In the group you felt like that?

P9:   No, at home.

EM: At home, right.

P9:   And, uh, when I was speaking to people, you know. And I'd forget everything and... But coming here, it's settled me a lot more, as I say, to see other people who are like it. But [facilitator] just has a good way. I never feel, um, I've got somebody bossy to answer questions or anything. It all goes in a lovely chatty way.

EM: Right... And when you say that you feel more settled...is that more settled just in the group, or has it made you feel more settled outside the group as well?

P9:   Well, yes, because if I do sort of, er, get a bit het up at home I tend to think back, um, you know – Well, they're like it. You know. They cope. That sort of feeling, it is. So...[5 second silence]]

EM: So you can kind of draw on what you've talked about in the group and reassure yourself.

P9:   Yes. Well I was getting a bit of a wreck before I came, I kept thinking it was only me. And er...my God, when am I going to be, what am I going to be like later on. I always hoped I'd be good for being around for [daughter] and things like that. But now I feel much more settled about that sort of thing. So yes, it has been good for me.

EM: It's been a positive experience.

P9:   Absolutely.

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APPENDIX 6

Interpretive phenomenological analysis (stage 1): initial notes in margin

Extract from interview with participant 4

P4: Yes, that's right. Otherwise if you don't know about these things you think, Oh, you're the only one, sort of thing... You know what other people are going through and you think, Oh, well, somebody else is the same as me, you know, hasn't got a good – you know, hasn't got a very good memory at all. It's...it's really not very nice not to be able to remember what happened yesterday. And till somebody reminds me, I'm like that, you see.	otherwise you think you're the only one you know what other people are going through you think, Somebody else is the same as me – hasn't got a good memory it's not very nice not being able to remember what happened yesterday

Extract from interview with participant 9

P9: Um, apart from a little friendly chat you know, to start it off with...um... This, this is going to be a bit odd because we just sort of...ask [facilitator] questions individually...it just ties up as a sort of chat in its way. Which I find pleasant. And I also find it pleasant simply because I can hear that other people are in the same boat as me so I don't feel so horribly stuck out on my own. And several times they've mentioned exactly a thing that had happened to you with your memory. They've had it. So I, I just walk out quite sort of at peace when I leave here. And I think [facilitator] has a very good way of...er, setting it all up with us, you know. We all seem to get on very well with her. So, uh...yeah, I think it's good.	a little friendly chat to start it off with we ask facilitator questions we ask F questions individually – just ties up as some sort of chat other people in same boat – don't feel so horribly stuck out on my own they've mentioned exactly a thing that had happened to you with your memory walk out quite at peace when I leave F has a very good way of setting it all up We all seem to get on well with F

APPENDIX 7

Interpretive phenomenological analysis (stage 2): analysis of themes within interviews

Example themes initially identified in interview with participant 4

1.   We talk about Alzheimer's

This refers to what the participant says is talked about in the group

we talk about Alzheimer's
not being able to think very much
how your memory is and how it isn't
talk about each other's experience
how it affects us

2.   Other people in the same boat

The benefits of being with people who are in the same situation

it's good to know that other people are in the same situation as yourself
otherwise you think you're the only one
you think, Somebody else is the same as me – hasn't got a very good memory
you feel there's other people in the same boat
don't feel so bad in myself when you know that other people are suffering the same sort of thing

3.   Sit and listen quite happily

What the participant perceives to be helpful about the group

3.1   I can associate myself with them [being able to identify with other people]

you know what other people are going through
I always think I'm worse off than other people
I can associate myself with them
I can listen and think, I'm like that

3.2   I can listen - and say my piece when I want to

I can listen
I can say my piece when I want to
I could comment on things
I'm a good listener
I can sit and listen quite happily

3.3   Otherwise, I wouldn't be talking very much at all [social isolation]

otherwise, I wouldn't be talking very much at all
my son at home – they don't talk much, men

APPENDIX 8

Interpretive phenomenological analysis (stage 3): re-analysis of interviews using master themes

Participant 4

P4: Yes, that's right. Otherwise if you don't know about these things you think, Oh, you're the only one, sort of thing... You know what other people are going through and you think, Oh, well, somebody else is the same as me, you know, hasn't got a good – you know, hasn't got a very good memory at all. It's...it's really not very nice not to be able to remember what happened yesterday. And till somebody reminds me, I'm like that, you see.	**Theme 1: It's a useful group** otherwise you think you're the only one you know what other people are going through you think, Somebody else is the same as me – hasn't got a good memory **Theme 8: The business of dementia** it's not very nice not being able to remember what happened yesterday

Participant 9

P9: Um, apart from a little friendly chat you know, to start it off with...um... This, this is going to be a bit odd because we just sort of...ask [facilitator] questions individually...it just ties up as a sort of chat in its way. Which I find pleasant. And I also find it pleasant simply because I can hear that other people are in the same boat as me so I don't feel so horribly stuck out on my own. And several times they've mentioned exactly a thing that had happened to you with your memory. They've had it. So I, I just walk out quite sort of at peace when I leave here. And I think [facilitator] has a very good way of...er, setting it all up with us, you know. We all seem to get on very well with her. So, uh...yeah, I think it's good.	**Theme 1: It's a useful group** other people in same boat – don't feel so horribly stuck out on my own they've mentioned exactly a thing that had happened to you with your memory walk out quite at peace when I leave **Theme 3: All talking together about it** a little friendly chat to start it off with **Theme 4: Keeping the pot boiling** we ask F questions individually – just ties up as some sort of chat F has a very good way of setting it all up We all seem to get on well with F