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TWICE A CHILD III

The Experiences of Asian Carers Of Older People with Dementia in Wolverhampton

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Twice a Child III: Asian Carers of Older People with Dementia

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Twice a Child III: Asian Carers of Older People with Dementia

Chapter One: Introduction to Report

A Dearth of Black and Minority Ethnic Studies

Modern Britain, in common with other advanced industrial societies, is increasingly characterised by an ageing population (Taylor and Field, 1997). Although many elderly people remain fit and active, increasing age brings with it an enhanced likelihood of ill health, dependency and use of health and social services (Tinker *et al*, 1994). Along side this general experience of ageing, statistical projections indicate a significant increase in the number of elderly who suffer from dementia (Kirby, Lehmann and Majeed, 1998). The number of carers too has increased so that there were over 6 million unpaid carers in 2001 (National Statistical Office). Such care in the community traditionally rests heavily on family members, and takes place within particular contexts of obligations, reciprocities, economic circumstances and moral identities (Finch and Mason, 1993).

Whilst there is an extensive and rich literature on family relationships, norms and negotiation of obligations within the majority White community in the UK, there remains a relative dearth of information on minority ethnic groups (Ahmad and Atkin, 1997). This relative dearth of information is perhaps less true in Wolverhampton than in other cities in the UK, for this TAC III Report is the third of a set of studies carried out in the city since 2000 under the auspices of what is now For Dementia Plus, a Wolverhampton based service development organisation working across the West Midlands, dedicated to the improvement of health and social services to sufferers of Dementia and their carers. Whilst Dementia Plus West Midlands become known as 'For Dementia Plus West Midlands' in April 2006 due to a merger with 'For Dementia', the charity best known for their Admiral nurse activities, the research carried out within report was carried out under the auspices of 'Dementia Plus West Midlands'.

Twice a Child I and II

The first research in 2000/1 to be named 'Twice a Child' was co-sponsored by the University of Wolverhampton, Wolverhampton Primary Care Trust and Wolverhampton City Social Services with Department of Health support. The research, using community based researchers, sought to document the experiences of service users from the African-Caribbean and Asian carers of older people with dementia in Wolverhampton. During this original research, carers were asked to describe their understanding of dementia. The phrase 'One a Man, Twice a Child' was used, particularly in the African-Caribbean community, to short-handedly describe the ways that older people with dementia were perceived to experience the disease. In effect, dementia was considered to cause a second childhood by the progressive stripping away of the knowledge, understandings and ways of behaving redolent of their adulthood. The metaphor 'Twice a Child' was considered apt, and consequently used as the title of the research.

In 2001, Dementiplus West Midlands published the original research in a report entitled 'Twice a Child,' (TACI). The research was updated in 2003, resulting in the Report 'Twice a Child II' (TACII). The research recounted in TACII included an updating of the experiences of health, social and voluntary services by some of the Asian and African-Caribbean carers involved in TACI as well as the experiences and perspectives of 'new' carers from each community in Wolverhampton (carers not involved in the initial research). TACII also focused upon the development of services following the publication of the initial TACI report. The research found that developments had occurred in service provision, but many carer experiences of services in TACII remained similar to those experienced in TACI. Wider developments were important here, for central government targets and directives affected service developments more than local needs (Moreland, Read, Jolley and Clark 2004).

Given the passing of time and the availability of a volunteer, it became appropriate to update TAC II by carrying out further research with carers of older people with dementia. The lack of funds meant that the new research concentrated upon the Asian

community only in Wolverhampton. As the research was managed from within Dementia Plus West Midlands, it became appropriate to entitle the (this) report 'Twice a Child III,' (TACIII), despite the earlier research being focused upon two original communities (the African-Caribbean and Asian communities in Wolverhampton). *Specifically, this particular research focuses on Asian carers from within the Punjabi, Hindu, Gujarati and Muslim community in Wolverhampton.* In total, 15 carers of Asian older people with dementia in Wolverhampton were interviewed. Five of the carers had been involved in the previous Twice a Child research projects (so-called 'old carers'), whilst ten 'new' Asian carers who had no prior involvement with any research were interviewed also.

The overall aim of the research was not only to continue to identify the impact and effectiveness of developments since TACI and TACII, but also to reveal any new or recurrent issues that exist for carers in order to suggest recommendations. An in-depth literature review was carried out too in order to reveal the current issues that needed to be addressed (See Chapter Two). Following the literature review, the carer interview schedules used in TAC II were amended and then used to collect data (See Chapter Three: Research Process and Methodology). The results of the TAC III interviews were then collated and analysed and are presented in Chapter5. Recommendations for further service development are subsequently provided.

Chapter Two: The Literature Review

Introduction

In all research, it is both important and necessary to establish a comprehensive knowledge base and locate any current issues concerned with the subject area in question. Consequently, the literature review for TACIII looked again at:

- Definitions of dementia and its general incidence;
- The prevalence of dementia in the Asian community;
- Differentiating factors for dementia in the Asian community;
- Caring issues concerned for someone who has the dementia;
- The service provision for Asian people with dementia and their carers;
and
- The health policy and social service context for Asians with dementia
and their carers.

The TACIII research assumes that readers utilise the knowledge arising from the literature as a backcloth, and relate that knowledge to the issues that arise from the interview results. Doing so allows us to consider and understand the current issues and perspectives on dementia care by the Asian carers interviewed in Wolverhampton.

What is Dementia? Definition and Known Causes

The word dementia is derived from the Latin *demens*, meaning ‘without mind’ (Cantley, 2001). Dementia is a term used to describe a group of illnesses that cause a progressive decline in the ability to remember, to learn, to think and to reason (Alzheimer’s Disease Society, 1992, O’Brien *et al*, 2000). Brotchie (1995) describes dementia as a group of symptoms that result from the destruction of brain cells, the term having been chosen by the medical profession as the least offensive and most accurate term to describe this group of illnesses (Nancy and Rabins, 1999). Dementia is commonly a chronic and progressive disorder that occurs in people aged 65 years and over.

There are many different types of dementia. This diversity makes the process of mapping and differentiating between the different types a difficult and arduous process. Stokes and Goudie (2002) state the most common types of dementia to be:

- Alzheimer's disease (AD);
- Vascular dementia (VD);
- Dementia with Lewy bodies (DLB); and
- Early onset dementia (EOD).

Less common forms of dementia are caused by other degenerative conditions, including front-temporal dementia known as Pick's disease (O'Brien *et al*, 2000). Other degenerative conditions are Parkinson's Disease and Huntington's Disease, whilst Down's syndrome which is known to lead to AD (Chapman *et al*, 2001). Infection and the effects of toxins on the brain can also lead to other forms of dementia, as well as head injuries and accidents involving loss of consciousness (Stokes and Goudie, 2002). These toxins can include alcoholic and other related dementia such as Creutzfeldt-Jakob disease and Korsakoff's syndrome (O'Brien *et al*, 2000).

The most common symptoms of dementia are:

- Memory loss, particularly initially in the short-term memory;
- Changes in personality (e.g. mood swings and uncharacteristic behaviours);
- Increasing difficulty in communicating; and
- A loss of ability to carry out tasks previously seen as easy, such as unbuttoning a shirt (Brotchie, 1995).

Cognitive functions such as memory, language use and loss, visual-spatial and perceptual abilities, thinking, and problem solving are particularly affected (Patient Plus, 2005). The prognosis and experience of dementia will however, be unique to each individual depending on the type of dementia and the characteristics of the individual concerned.

Currently, there are no cures for most types of dementias, though there is evidence that some treatments reduce the effects of dementia or delay its onset. Treatment

examples include the use of Statins (cholesterol lowering drugs) and drinking green tea on a daily basis (Jick *et al*, 2000: Alzheimer’s Disease Society, 2000). According to The British Coffee Association (2005) drinking coffee on a regular basis too can help protect against diseases such as type II diabetes, Alzheimer’s disease and Parkinson’s disease. It is clear, however, that much more research is needed before firm conclusions can be drawn.

What is the Incidence of Dementia locally and nationally?

Although dementia is relatively rare in persons under the age of 65, the prevalence of dementia roughly doubles every five years after the age of 65 (O’Brien *et al*, 2000). These rates are highlighted in the table below that provides an estimate of the numbers of people suffering from dementia according to age in Wolverhampton in the year 2001.

Table 1: The prevalence of Dementias in the Elderly in Wolverhampton

Age	No. in population	Prevalence of dementia	Estimated no. with dementia.
65 - 69 years	11,126	1.5%	167
70 – 74 years	10,381	2.5%	260
75 – 79 years	8,537	6%	512
80 – 84 years	5,610	13%	729
85 years +	4,337	25.5%	1,106
			=2,774.

(Source: Wolverhampton City Primary Care Trust, 2005. p.5).

Wolverhampton has a population of approximately 236,573 people (Health Scrutiny Review, 2004). At 22.1 % of the total population, Wolverhampton has the second largest black and minority ethnic (BME) community in the West Midlands, of which Asians (Indians, Pakistanis and Bangladeshi) comprise 14.3% (roughly two thirds the total)(Office of National Statistics, 2005).

The prevalence of dementia estimates indicated that there were 2,774 people over the age of 65 with dementia in Wolverhampton in 2001. There is clear evidence that the incidence and proportions of older people with dementia increases with age (Elliot *et al*, 1996). At the same time, although increasing age is the most important known risk factor for developing a dementia, dementia is not held generally to be part of the ageing process (Cantley, 2001); Brotchie, 1995). This is important as there are differential practical consequences for the planning of health services depending upon the extent to which dementia is considered an inevitable result of ageing or a disorder occurring within a specific age range (Riedel-Heller *et al*, 2001).

Nationally, the Alzheimer's Disease Society in 1998 predicted that over the next thirty years, about 154,000 more people in the UK will develop dementia, giving an estimated total of 752,741 people with dementia by the year 2021. Patel *et al* (1998) too predicted that in 2021 approximately 0.75 million people over the age of 40 will have AD, a statistic that is equal to 42 new cases of AD every day for the next ten years. These are disturbing forecasts, with massive implications for carers and service provision.

The prevalence of Dementia in the Asian community

Whilst the information set out above appears clear and concise, problems remain with estimating the prevalence of dementia, for dementia prevalence rates are known to vary by ethnicity and race, just as they do by gender (Yeo and Gallagher-Thompson, 1996). Ethnic differences in prevalence rates are due to a variety of factors, including shorter life expectancy and faster ageing processes within the Asian population (Anderson and Brownlie, 1997). Other factors such as socio-economic class and family history, which differ significantly amongst cultures, can also affect prevalence rates, as can geographical mobility (Age Concern, 2002). The majority of ethnic minority groups live in inner city neighbourhoods with higher levels of deprivation and poor housing conditions that, in turn, can lead to health deficiencies. The Government based Index of Deprivation, for instance, ranks Wolverhampton as the 29th most deprived local authority in England.

To date, little research has been conducted to date specifically upon the incidence of dementia in the Asian community. There are difficulties over methodologies (Reider-Heller et al, 2001), sometimes suggesting that the incidence of dementia in the Asian community is 'hidden' rather than non-existent' (Brownlie, 1991). One study, conducted by Yeo and Gallagher-Thompson (1996), however, did find that more people in the White community suffer from Alzheimer's Disease than in the Black community, and that more people from the Black and Asian community suffer from Vascular Dementia than in the White community, possibly due to the higher incidence of diabetes and hypertension in BME communities (Seabrooke and Milne, 2004). Seabrooke and Milne (2004) also suggest that increases in life span are affecting all ethnic groups, including the Asian population as the population as a whole age, so that the incidence of dementias will tend to increase. Illife and Manthorpe (2004, p. 284) propose, however, that *'there is no priori reason to believe that ethnicity itself has a major impact on the onset or course of dementia syndromes, unless: (1) the dementias have a genetic basis, or (2) are caused by exposure to environmental agents specific to particular cultures, or (3) cultural factors can protect people against the development of dementia'*. As we still do not know these things, there is still much to discover in this area of research.

Asian migrants to the UK, especially Wolverhampton, have come primarily from Punjab in India, particularly Jullunder and Hoshiapur, and central and southern Gujarat in India. The majority of immigrants from Pakistan came from the West Punjab in Pakistan, the northwest frontier area, and the Mirpur district of Kashmir. Those who came from Bangladesh come primarily from Syllet (Young and George 1991, p.25). Consequently, issues associated with language and cultural barriers as well as a high degree of stigma attached to mental illness, occurs in services dealing with the Asian communities (Patel *et al*, 1998; Seabrooke and Milne, 2004).

Religion, Language and Cultural Barriers

One of the most common issues associated with dementia and ethnic minorities concerns language (Tibbs, (2001), Ahmad and Atkin, 1997). The need to communicate with all people in a language that they understand is now accepted as important, and resources are commonly committed to translation by social services

departments and health trusts. As Tibbs clearly points out, however, there remains a lack of day-to-day involvement of staff from ethnic minorities that will ensure that minority ethnic people with dementia or their carers will always find someone with whom they can converse in their first language. This is despite there being more and more people with dementia who come from other cultures whose first language is not English (Killick and Allan, 2001). Even if a person with dementia initially knows English, the progression of the illness suggests that many minority ethnic community members will more than likely revert back to their first language, which in most cases, will be the language from their place of birth. If the carer caring for that person too cannot speak, read or write English, further difficulties arise.

In an associated issue, Leff (1973) suggests that people from non-western cultures may lack a language/vocabulary for describing the changes in states of mind associated with dementia. There is no word in Asian languages equivalent to depression; rather people might describe themselves as having a pain in their heart (Heron 2000). Neither is there an equivalent term for dementia in Asian languages, which is too considered a factor in the lack of dementia awareness amongst Asian communities in the UK (Seabrooke and Milne, 2004). Even where Asian people are bilingual, a complex web of social and political rules influence which language is spoken in what circumstances and with whom (Drakeford and Morris, 1998). As Tibbs (2001) points out, not many second and third generation Asians in today's society are fluent in their Asian language and the older generation are very aware of this.

Closely associated with language is culture, defined as a set of shared meanings, assumptions and understandings that have developed historically in a given community (Thompson, 2003). According to Rack (1982) Asians typically perceive mental health problems in terms of social dysfunction and unusual behaviours. Once the patient is functioning normally within the family and society, they are perceived as 'cured' and there is no need to explore the psychological condition further. Relatedly, dementia may be regarded as a normal part of the aging process, and thus may not require medical care. Indeed, Chiu (2001) suggests that Hindu culture prepares people for old age by a process of disengagement from society and their community. Associated with this disengagement is the tendency to give up their

authority over both their family and property so as to devote their time to self-realisation. Developing one's inner spiritual life is defined as preparation for the next phase of existence, especially where their religion such as Hinduism believes in reincarnation (Blakemore and Boneham, 1994). Consequently, behaviours in old age due to dementia may be accepted as normal within a religious community, and be managed locally by disengagement and isolation. Religious belief, consequently, can have a major influence upon community perceptions of unusual behaviours that may be caused by dementia.

For devout Asian Muslims, Islam is considered to be a 'way of life', creating a very tight knit community with important cultural differences to the majority of Asians (Sheik and Gatrad, 2000). According to Tibbs (2001), Muslims, from wherever they originate, do not feel clean unless they wash under running water, so sitting in water and having a bath would not cleanse the body. This cultural belief could indeed affect the care of the patient, especially if the home does not have the appropriate shower facilities. Tibbs (2001) notes too that body language can be very easily misinterpreted. Indian women, for instance, are not expected to make direct eye contact with a person of authority, especially males. Examples such as these make it extremely important for any person working with Asian carers to be fully aware of religious and cultural norms and for this to influence their behaviours towards the person with dementia and their carers.

A hidden problem: Stigma

Wharrad's (1998) study in Haringey, London found that there was a general lack of knowledge about dementia in the Indian Gujarati community living in Haringey. Dementia was commonly seen as mental illness or madness that carried a major stigma and resulted in people with dementia being hidden within families. This stigma effect was reiterated in their study by Seabrooke and Milne (2004) who reported that mental illness is still seen very negatively by Asian families, given their desire to portray an image of well being to those outside the immediate family. The stigma associated with acknowledging mental ill health is particularly negative for older people with dementia and adds to the family duty to care as well as to the noted resistance to seeking help from health and social services. These situations can in

turn give rise to problems of detection due to isolation and the confusion of dementia with 'normal' aging (Larson and Imai, 1996).

Asian carers thus need accessible and appropriate information and support (Watters, 1997). It is important to identify and work with and through the family and kinship networks, link persons and the broader networks of community and social service, all of which provide the community context for the ethnic patient and family (Yeo and Gallagher-Thompson, 1996.) Lonely vulnerable people in the minority ethnic communities need to know where they can get access to information, advice and help, especially the carers (Okuyiga, 1999). Okuyiga goes on to suggest that ethnic minority communities are reluctant to access mainstream health and social services due to a mistrust of the local state bureaucracy in addition to barriers created by language, culture and stigma.

Closer to home, Phillipson *et al* (2001) conducted in-depth interviews with Indians in Wolverhampton using interpreters and care workers in order to discover the impact of changes in ethnic composition on family structure and family support for older people. Two of their interviewees were men who suffered from dementia, who reported on very vibrant kinship environments whereby older people both give and receive support. At the same time, however, their research suggested concealed patterns of isolation and deprivation among ethnic minority elders, problems made more acute for those with poor physical and mental health.

Caring for someone who has dementia

In 1998, the Social Services Inspectorate published a report entitled '*They look after their own, don't they?*' The report, based upon inspectorial evidence, challenged the myth that ethnic minority families universally support dependent members and instead highlighted a number of service deficits to minority ethnic communities (Department of Health, 1998). Although Asian families are known to be extended and have tight kinship networks, research suggests that those kinship patterns of help are becoming more fragile due to more nuclear families (Redelinghys and Shah, 1997) and younger adults moving away to work (Ahmad, 1996: Moriarty and Webb, 2000).

Despite such trends, coping with a family member with a diagnosis of dementia is one of the significant and difficult roles that family caregivers adopt (Wenger, 1994). The difficulties associated with care-giving are found to be highest amongst women (Mittelman *et al*, 1995), given that, in general, there are more women who act as carers than men (Horowitz, 1985). This emphasis upon female carers is due to a number of reasons, including the dominant cultural assumption that daughters are considered to be better suited to care-giving than sons, especially in ethnic minority cultures (Jones and Mieson, 1992; Globberman, 1996). Women too tend to marry older men and on average live longer, with the result that more male dementia patients have a spouse to care for them, for Asian families in Wolverhampton tend to be of patrilineal descent and patrilocal residence (Phillipson *et al*, 2001). One consequence of this often is for formal responsibility for care to reside with a male relative whilst the actual care is delivered by female relatives, usually daughters or daughters in-law who have to manage the care alone (Seabrooke and Milne, 2004).

There is now considerable evidence that supporting a family member with dementia may have both psychological and physical effects upon the well being of the carer as well as direct and indirect financial implications (Wenger, 1994; Schulz and Williamson, 1997). Direct financial costs often include medical consultations, investigations, pharmaceuticals, the provision of personal and nursing care and, later, residential care (O'Brien *et al*, 2000). Indirect financial costs may include the loss of earnings of both the person with dementia and their carer, for many carers, particularly women, give up paid employment (Yee and Schulz, 2000) for the caring role, especially if the person suffers early-onset dementia (Chapman *et al*, 2001) or the care arrangements involve intergenerational caring (Adams & Manthorpe, 2003).

Whilst there are now schemes in place for carers to receive and handle direct payments in lieu of provided care packages, there remains a lack of awareness in the Asian community regarding such direct payments (Newbigging & Lowe, 2005). The number of people who have taken up direct payments remains low, especially in the ethnic minority groups (Commission for Social Care Inspection, 2004).

Service Provision for Asian people with dementia and their carers

Minority ethnic groups' experiences of dementia and dementia services generally have not been well documented in the UK (Adams and Manthorpe, 2003), at least partly because dementia is accepted as 'hidden' within the minority ethnic communities (Anderson and Brownlie, 1997). Blakemore and Boneham (1994, p.78) suggest that '*Asian people's social lives and priorities are often seen as 'too different' from majority norms, incomprehensible and insufficiently adapted.*' Asians may well be socially excluded as service users due in part to institutionalised racism (Patel et al, 1998), as well as the added difficulty of the stigma attached to suffering from a mental illness (The Sainsbury Centre for a Mental Health, 2002; Turner and Benbow, 2002). Where policy and service planning systems do consider the dementia related needs of Asian communities (Heer, 2001; Patel *et al*, 1998; Daker-White *et al*, 2002), there remains a dearth of specialist service provision for the Asian community, even in Wolverhampton (Moreland et al, 2004).

Health policy and social service context for Asians with dementia and their carers

The 1990 National Health Service and the Community Care Act provided the framework for major changes to the delivery of health and social care to vulnerable older people (Department of Health, 1990). Obligations were established upon Health Trusts and Social Service departments to recognise that people from different cultural backgrounds may have particular care needs and problems. It provided an opportunity for the statutory sector to engage with the independent sector and work in partnership with service users and carers to identify their needs and develop services to meet them. These goals have proved harder to achieve (Richards and Brayne, 1996; Department of Health, 1998).

After coming to power in 1997, New Labour has pursued a programme of modernisation for health and social care. 'The NHS Plan 2000' (Department of Health, 1998a), for instance, required NHS trusts and social services departments to define how they will meet the health and social care needs of local populations, with a particular emphasis on meeting the needs of marginalised and minority groups and ensuring equality of access to services. The publication of the NHS Framework for

Older People (Department of Health, 2001) set out a ten-year plan for service development in the NHS and social care services. Standard 7 of this document relates specifically to older people's mental health care, and states: '*older people from Black and ethnic minority communities need accessible and appropriate mental health services. Unfortunately, for a number of reasons, services may be neither readily accessible nor fully appropriate*' (Department of Health, 2001, p.90). The Audit Commission 'Forget-me-Not' reviews of 2000 and 2002 too highlighted considerable variations in the range and types of services as well as a lack of coherence and specialist services in dementia care (Audit Commission, 2000, 2002).

The Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004 Combined Policy Guidance (Department of Health, 2005, p.7) require local authorities to inform carers that they may be entitled to assessment of their needs. Local authorities were encouraged to develop an information strategy to ensure that carers are being told of their rights, including the large number of 'hidden' carers (those not known to local authority). Locally, the 'Strategy for Older People in Wolverhampton' was developed in 2005 with the vision to '*enable older people in Wolverhampton to live life to the full by optimising opportunities for health and participation in social, economic, cultural and civil affairs and by providing access to high quality health and social care services with respect to the individuality and lifestyles choices for those who need them.*' On 14th Nov 2005, the Care Services Improvement Partnership launched *Everybody's Business* Service Guide, detailing the next steps in improving mental health and care services for older people. *Everybody's Business* builds on the service models in the *National Service Framework for Older People* (Department of Health, 2001) and supports the principles promoted in *Securing Better Mental Health for Older Adults* (Department of Health 2005d), by describing the foundations and key elements of a comprehensive service personalised for older adults with mental health needs. For a list of the current health, social services and private sector provision for dementia patients in Wolverhampton please refer to *appendix 1*.

None the less, Kar *et al* (2005) suggest that family doctors (GPs) who are interested and knowledgeable in detail about dementia are few and far between. Consequently, family doctors have an ongoing need for such knowledge to reinforce the view that

dementia patients, *'are interesting, challenging and rewarding to treat, and that a proactive caring approach can greatly enhance the person's quality of life.'* (p. 267). According to a UK survey by the Audit Commission (2000) over 50% of General Practitioners admit that they do not know enough about dementia and only 48% of those surveyed felt that they had received sufficient training to help them diagnose and manage dementia. However, 54% recognised the importance of actively looking for early signs of dementia.

Aspects of Quality and SERVQUAL

Issues and definitions of what constitutes quality service abound as well, for there are clear moves by the Labour Government to create a health service that is 'person centred'. Standard 2 of the Older People's Service Standards, for instance, notes that the, *'standard is to ensure that older people are treated as individuals and that they receive appropriate and timely packages of care which meet their needs as individuals, regardless of health and social services boundaries'* (Department of Health, 2004). This statement has clear connections with the literature on quality, including the constituent elements of the SERVQUAL questionnaire (Parasuraman, Zeithaml, & Berry, 1988). Parasuraman et al identified five major aspects of quality in a service, which they identified as:

1. *Responsiveness*, or a willingness to help customers and provide prompt service;
2. *Tangibles*, or the appearance of physical facilities, equipment, personnel, etc.;
3. *Empathy*, the caring, individualized attention provided to the customer;
4. *Reliability*, or the ability to perform the promised service dependably; and
5. *Assurance*, conveyed by employees' knowledge and their ability to communicate trust and confidence (Parasuraman, Zeithaml, & Berry, 1985).

Though the Servqual questionnaire was not used in our research, it will be seen later that the concerns of our sample of Asian carers with aspects of service such as the speed and relevance of response as well as the sensitivity of provision echo those five dimensions of SERVQUAL.

Conclusion

This literature review has sought to synthesise a considerable amount of literature on dementia and dementia care in the Asian community. It has become apparent from the literature review that there are not only many issues currently concerned with dementia in the Asian community, but also that the issues concerned are on going from the publication of the initial TACI report in 2001. The issues raised in this literature review include:

- The lack of awareness and understanding of dementia in Asian communities including issues around the perception of mental health.
- The incidence of dementia in Asian communities.
- The personal contexts and pressure points that arise in caring for someone with dementia in Asian communities.
- The extent of community help and support.
- The experience of services including; health services (particularly family doctors), social services, voluntary and private organisations for people with dementia and their carers.
- Issues around direct payments.

To see if the situation has changed in Wolverhampton, the fieldwork for TACIII was designed to collect data on the local situation of Asian carers in Wolverhampton, and to analyse that data for the implications for local needs and provision.

Chapter Three: Research Design and Process

Due to this research being an update, the interview research design process originally conducted by Dementiplus for the TACII research in 2003/4 was updated for use in TACIII (the original interview schedules for TACI are contained in *appendix 3*). In TACII (2003/4), an interview schedule was constructed for new carers (*appendix 4*) as well as another for carers previously interviewed in TACI (*appendix 5*). The term 'new' thus is specific to this research, for 'new' carers are defined as carers not being involved in previous TACI or TACII research, and who thus are 'new' to the research, not necessarily new to caring for older people with dementia.

For TACIII, the existing TACII interview schedules were amended to address relevant current issues, such as the carer experience of, and perspectives on, Direct Payments. The interview schedules, as before, were semi structured (Hakim, 2000).

TACIII: Why The Semi Structured Interview?

Interviewing has been described as 'conversations with a purpose' (Burgess, 1984: Kvale, 1996: Cloke *et al*, 2004), specifically to make the respondent's implicit knowledge of the topic under study more explicit (Flick,2002). In all three main types of interview - unstructured, semi structured and structured (Denzin and Lincoln, 1998), the purpose is to '*give an authentic insight into peoples experiences*' (Silverman, 1993, p. 91). A semi-structured interview allows the interviewer to ensure that a list of topics are covered, though not necessarily in the same order for interviewees have a great deal of leeway on how to reply (Bryman, 2004, Dearnley, 2005).

The interview schedules used for TACIII 'old' and new' carers broadly covered the following areas, usually in the same order:

- General patient information;
- General carer information,
- The history and experiences of the person with dementia;
- The possible value of doctor's letters:

- The carer experiences of health, social and voluntary services.

A final section allowed the carers to express any further thoughts as well as their reflections on their experiences as whole.

Interviewer Bias and Interpretation

A potential difficulty in conducting interviews is interviewer bias (Hakim, 2000), which can involve unfair influence and prejudice as '*interviewers are human beings and not machines, and their manner may have an effect on respondents*' (Seltiz *et al*, 1962, p. 583). The reduction of cross-interviewer bias was assisted in the TACIII interview process by one researcher conducting all of the interviews. The interviewer, being multilingual in the main Asian languages, was able to move between the languages in order to ensure that the carers understood the questions and were able to respond appropriately.

At the same time, because the majority of interviews were conducted in an Asian language (Punjabi, Hindi and Gujarati) due to many of the older carers being non-English speaking, there was, of necessity, some condensation of the interviewee's answers as their responses to questions were written down, though all the interviews were taped, and answers checked and meanings recorded in English. Where language problems were likely to occur, the interviewer requested younger family members to be present to ensure validity of response (Patel and Mirza, 2000). Out of the fifteen interviews, younger family member involvement only occurred in two interviews. Additionally, with carer consent, the responses were shared with the CMHNM who has been supporting the carers for periods longer than 12 months and up to eight years. The CMHNM ensured that the data reflected the situations of her patients and their carers, there being no alteration necessary.

It was reported in TACI that interviewers might possibly, in their desire to note as many items as possible whilst the interview was occurring, note things down in such a way as not to completely echo the words or tenor of what was being said by the interviewees. Similarly, the collation of materials that has to occur by the report writer has an effect of perhaps bringing some items to the fore, and others being unintentionally sent into the background. Moreland (2001, p. 45) reported that '*whilst*

every effort was made to check out the existence (or hopefully not) of such potential biases, it would be wrong to give the impression either that there may not be some occurring, however good the intentions are of all concerned.' Although all attempts were made to reduce this in TACIII, it is only fair to reiterate this statement.

Data Analysis

The results of the carer interviews, once collated, were analysed using thematic analysis and coding. In thematic analysis, descriptive codings (what is this an example of?) were applied to facilitate the identification of common responses and patterns of answers (Bryman, 2004). These codings in turn allowed for the development of common themes to be developed by *'bringing together components or fragments of ideas and experiences, which are often meaningless when viewed alone'* (Leininger, 1985).

Memos were also used to assist in the development of themes. Memos are notes taken from the researcher that act as important reminders in various areas, i.e. what is meant by particular terms being used in the interviews. Memos help to crystallise and ground ideas by allowing the researcher to keep track of the responses and the development of any potential concepts. Once the themes were developed, they could be presented, but also used to facilitate a more longitudinal understanding by comparing TACIII outcomes with those of TACI and II.

Chapter Four: Service Developments following TACI and II

As the TACII Report (2004) notes, service developments since 2001 have been affected by external developments and organisational changes nationally and locally. Examples of such changes include the creation and evolution of the National Service Framework for Older People (2001), the creation of the Wolverhampton Primary Care Trust in 2002, and the publication of the single assessment framework for older people's services (2002 for implementation in 2004). Consequently, some of the issues raised by the carers in TACI came not to be addressed due to differential organisational priorities and differing degrees of commitment (Moreland, 2003. p. 43). A number of developments did take place, however, as a result, at least partly of TACI and II, though more so in health services rather than social services. Though knowledge remains incomplete due to local informal initiatives, following TACI, the following developments were noted in respect to the Asian community in Wolverhampton:

- AWAAZ and the BME Housing Association secured a safe housing facility known as 'Navjeevan' for women suffering from mental health problems including dementia.
- Social service staff received Asian language tuition, and the opportunity to visit specialist Asian facilities such as EKTA, the Asian Day Centre in Wolverhampton.
- The creation of an Asian Carers' Support Group, renamed 'DOST' in June 2006 (**D**ementia and mental health **O**lder people's **S**upport **T**eam). The group have met regularly and continues to be run successfully.
- Wide-ranging informational talks about dementia carried out in and across the Asian community.

- The creation of leaflets in the different Asian languages specifically on understanding dementia and carer issues.
- The creation of audiotapes in Hindi and Punjabi specifically on understanding dementia and carer issues. These tapes complement the videotape entitled 'Dementia Ki Hai,' meaning 'What is Dementia?' that was produced by Alzheimer's Concern Ealing in 2000, and available in Punjabi.

Developments since TACI and II occurred also for the African-Caribbean community in Wolverhampton (Moreland, 2003), though these are not detailed here as TACIII was not concerned with the experiences of the African-Caribbean community, though such research is still desirable.

Chapter Five: The TACIII Carer Interviews

Introduction to Chapter

In 2005/6, one of the two authors, in collaboration with Dementiplus, was able to carry out a further set of interviews with a number of Asian carers of older people with dementia from the Asian community in Wolverhampton. As with the previous studies in TACI and II, the aims again were to not only seek information regarding their experiences as service users, but also to draw out key issues and concerns that these carers are currently dealing with. Consequently, as in previous studies, the interviews sought to gain information in the same four broad areas used in TACI and II, and which overlap with the five areas of the SERVQUAL quality service experience questionnaire noted earlier. The four research areas were:

- Access to services
- Experiences of services
- Communication processes and understanding
- Service improvement

Logically, it was considered that, if improvements in services had occurred, then new carers ought to have a qualitatively different (and experientially better) experience of the three sectors (health, social service and voluntary sectors) in accessing services, whilst the old carers' experiences of the three service sectors should have improved too, either through their accessing new services such as Direct Payments or by a better qualitative experience of those services already utilised by the carers and the older people with dementia.

A total of fifteen carers were interviewed. Five carers were 'old' carers, four of whom had been previously interviewed in both TACI and TACII. One carer had been interviewed in TACI but did not take part in TACII. The remaining ten carers were 'new' carers who had not taken part in either of the two earlier research projects. The chapter has been divided into two parts, firstly discussing the results from the new carer interviews followed by a discussion of the results from the old carers. Carers

were declared as ‘old’ on the basis of having previously been interviewed in prior research projects.

TACIII: The New Carers

Table 2 indicates the situation and characteristics of each new carer and their patient.

Table 2: Personal characteristics of TAC III new carers and their patients.

Carer	Patient information				Carer information			
	Age (yrs)	Gender	Position in family	Lives with?	Age (yrs)	Gender	Relationship to patient	Employed Yes/No
1	75	Female	Mother	Carer and family.	46	Female	Daughter-in-law	No
2	76	Female	Mother	Carer and family.	43	Male	Son	Yes: F/T
3	78	Male	Father	Carer and family.	50	Female	Daughter-in-law	No
4	82	Male	Husband	Alone with wife, the carer.	80	Female	Wife	No
5	69	Female	Wife	Alone with husband, the carer.	70	Male	Husband	No
6	76	Female	Mother	Alone with son, the carer.	45	Male	Son	No
7	71	Female	Mother	Carer and family.	38	Female.	Daughter-in-law	Yes: P/T
8	70	Male	Father	Carer and family.	39	Female.	Daughter-in-law	No
9	71	Male	Husband	Alone with wife, the carer.	71	Female	Wife	No
10	52	Male	Husband	Alone with wife, the carer.	48	Female	Wife	No

Table 3 below provides information upon the type of dementia each patient has, the ethnic origin of the patient and the carer, and the language(s) used to conduct each interview.

From Tables 2 and 3, it can be seen that:

- The patients were five men and five women;

- The average age of the patients was 72 years, or 74 years if the one person with early onset dementia is excluded;
- The average age of the carers was 53 years.
- 7 of the 10 carers were female;
- 6 of the 10 patients lived in intergenerational family units;
- Only 2 carers were in paid employment (one full-time (son) and one part-time (daughter in law));
- The majority of patients had vascular dementia (N = 6) (Asians are at more risk of developing vascular dementia due to the increased incidence of diabetes and hypertension (Seabrooke & Milne, 2004));
- 2 of the patients were of Pakistani Muslim background, the rest coming from Indian backgrounds, being either Sikh or Hindi religions;
- 3 of the interviews were conducted in English, the rest being conducted mainly in Punjabi.

Table 3: Type of Dementia, Ethnic Origin and Main Language of Interview

Carer	Patient illness	Ethnic origin - Religion (patient and carer).	Language(s) that interview was conducted in.
1	Vascular dementia	Indian: Hindu	Hindi/English
2	Lewy bodies	Indian: Sikh	English
3	Lewy bodies	Indian: Gujarati	English/Punjabi
4	Vascular dementia	Indian: Sikh	Punjabi
5	Vascular dementia	Indian: Sikh	Punjabi
6	Old age dementia	Pakistani: Muslim	English
7	Vascular dementia	Indian: Sikh	Punjabi/English
8	Vascular dementia	Indian: Hindu	English
9	Vascular dementia	Indian: Sikh	Punjabi
10	Early on-set dementia	Pakistani: Muslim	English

As we indicated above, the results for the New Carers are discussed under the four main headings:

- Access to services.
- Experiences of services.
- Communication processes and understanding.
- Service improvement. We begin with access to services.

TACIII New Carers: Access to Services

Despite the effects of TACI and II, the TACIII new carers' experiences continue to reflect the difficulties in accessing services commonly encountered by minority ethnic older people (Patel & Mirza, 2000). The data suggests that the barriers present in Asian carers accessing services is largely due to 1) the lack of understanding of dementia which, in turn may lead to 2) failure to seek early professional help, 3) GP misdiagnosis and (or) failure to link to specialist health services. Once a diagnosis was achieved, the carers were found to continue to have 4) patchy knowledge of the range of services available and 5) patchy knowledge of any care approaches such as direct payments, or their entitlements and access thresholds.

The Lack of knowledge and understanding

It is important to remember at the outset that there is no established term or definition for dementia in any of the South Asian languages (Seabrooke & Milne, 2004). Consequently, the understanding of dementia was very dependant upon the sources of information used, including books, leaflets, tapes, videos, Internet and verbal communication. Seven out of ten new carers obtained their first information about their patient's illness from the Community Mental Health Nurse (CMHN). One carer received the bulk of their information about dementia from their General Practitioner (GP), and the remaining two carers obtained their information from their own general background reading as well as their GP. The carers gained additional information about Dementia either from listening to audiotapes provided in their own language and/or leaflets that were written in a language legible to them that were developed following TACI and II. The majority of carers were not able to attend the Asian carer's support group established after TACI due to difficulties over transport and arranging alternative care for their patient. Those carers who do attend the group stated it to be very helpful in assisting their understanding of the disease and their rights.

At the same time, despite the availability of the different sources of assistance, some carers were still ignorant about dementia. Carer 5, for instance, when asked about his understanding of dementia said ... *'I don't know what to understand. When she does*

anything, I don't know if it is her or the illness. It's like someone else is trapped in her body'. Many of the carers interviewed emphasized how talking to a professional (in most cases the CMHN) in their own language was the only way they had developed an understanding of dementia. Those carers who spoke English too found it difficult to describe the illness to other family members in an Asian language. Carer 10, who had a good understanding of dementia due to background reading in books, stated... *'I feel sorry for our people that can't read English. I say that because I have so much trouble trying to explain to my mum what's wrong with dad.'* Consequently, Asian carers' understanding of dementia remains largely low-level or commonsensical. Out of the ten carers, only one non-English speaking carer attempted to say the Asian word for 'dementia' in the interview, as it is very hard to pronounce in Asian languages. The other carers referred to dementia throughout the entire interviews as 'this illness.'

There were also issues arising from the damaging social effects of the disease and the diagnosis, for, *'I think it's the hardest illness that anyone has to deal with. When other people ask me what's wrong with her, I don't know what to say. Half the family just think she's gone crazy. It's so annoying'* (Carer 5). The continuing lack of knowledge about dementia within the community too adds to the stigmatising experience of dementia, a feature first raised in TACI (Moreland, 2001).

Failure to seek early professional help

The interviews revealed that out of ten carers interviewed, three cases of dementia had been a 'hidden' problem for a number of years. Carer 4 stated that they first noticed the older person concerned was having memory problems *'years ago.'* She continued to say... *'I thought it was natural – you know – part of growing old. It was only when he started to become violent I sought professional help'*. Carer 6 on the other hand, despite noticing the memory problems *'years and years ago'*, considered the symptoms to be associated with her diagnosed condition of depression. Only when the condition deteriorated to a level with which the carer could no longer cope was the GP informed. These and other respondents, however, did emphasise that if they had known what dementia was earlier, they would have asked for help earlier.

Misdiagnosis and (or) failure to link to specialist health services

On visiting their GP, five carers were told that it may be dementia on the first occasion and were immediately referred to a specialist. Additionally, Carer 4, whilst told that it was a ‘memory problem’ was still referred immediately to an old age psychiatrist. Of the remaining four carers:

- Carer 1** GP did not suggest that it might be dementia until they had been back for the third time.
- Carer 3** GP did not state that it might be dementia, though the patient was referred to a specialist. During the interview the carer too pointed out that even if the GP had stated that it was dementia they would not have understood what it was.
- Carer 5** When the carer first went to see the GP, no action was taken. After numerous appointments over a period of six months, the GP eventually suggested dementia and referred the patient to a specialist.
- Carer 9** Due to the person concerned being an alcoholic the initial problems were, according to the GP, alcohol related problems. This viewpoint continued for eight years until the patient’s condition deteriorated dramatically in 2004, leading to a referral to a specialist.

Due to the different symptoms and prognosis of the different dementias, ‘*early detection is difficult but not impossible*’ for GPs (Kar, Jolley, & Misra, 2005: 270). Other than the possibility of the GPs lacking knowledge and symptom recognition with regard to dementia, two of the above carers (5 and 9) stated that they had difficulty in communicating with their GPs due to language barriers. TACII revealed that having an Asian GP helped the carers to be more open to the GP, which included speaking to them in their own language when appropriate (Moreland, 2003). Carer 4 had an Asian GP, and considered this made an important factor, as the carer does not speak English.

Out of the ten new carers interviewed, there was only one definite case of initial misdiagnosis by a GP. Carer 9 first consulted the GP about the older person concerned experiencing memory problems some eight years ago, but due to alcoholism, the symptoms of dementia were construed as alcohol abuse by both the

carer and the GP. This patient was diagnosed with dementia six years after the first initial visit when the GP referred the patient to a specialist due to violent behaviour. Whilst one has to be careful with the possible bias of small samples, Wolverhampton GPs do seem to be doing better than GPs as a whole, as over 50% of General Practitioners in the UK admit that they do not know enough about dementia and only 48% of those surveyed felt that they had received sufficient training to help them diagnose and manage dementia (Audit Commission, 2000).

Incomplete knowledge of range of services available

The wider literature suggests that older people are more likely to lack awareness of service provision (Hoad, 2002), so it is not surprising that the new carers had difficulty in accessing services, for the carers not only had incomplete knowledge of the range of services available to them but also were unable to separate those services into the correct sectors of service provision. This was evident when the carers spoke of social services when asked about health services and vice versa. None of the carers accessed any voluntary sector services, though this may be due to the carers either being unaware of the voluntary services available to them, or simply not knowing what voluntary services are. Carers 4, 5 and 9 admitted that they do not know what voluntary services are, though this may be age related as these three carers were the only new carers interviewed that were themselves over 65 years of age. Five carers stated that they were unaware of any voluntary services available to them whilst the remaining two carers (carers 10 and carer 5) stated that, though they had researched voluntary organisations, they had not accessed them due to their perception that the voluntary agencies were not able to meet the patient's needs.

Incomplete knowledge of entitlements and access thresholds

The interviews revealed a number of instances where carers did not know whether they were entitled to services, particularly financial support services such as Direct Payments, nor did the carers understand access thresholds. Carer 6, for example, claimed that he was not entitled to direct payments as he already had a carer's allowance. Carer 10 claimed that receiving direct payments would not increase her financial income (see 'communication processes and understanding below').

With the exception of carer 7 who is a Carer Support Worker, and therefore aware of her entitlements, the carers operated under the assumption that they are entitled only to the services suggested to them by health professionals (GP, CMHN and Psychiatrist). This suggests that it is up to health professionals (or those that they inform) to notify carers of all the services that they are entitled to as opposed to those services that are recommended. Experientially, however, there did seem to be a hierarchy of credibility amongst the carers of which professionals know best...'*I always ask the CMHN for advice. The professionals know best after all*' (Carer 8).

TACIII New Carers: Experiences of Services

As ethnic minority experiences of services remains area in need of more research (Adams & Manthorpe, 2003), the research sought to elicit the experiences of the different services for both the carer and their patient in Wolverhampton of those services that the carers and older people with dementia were receiving. Carers were asked about their satisfaction and supportiveness of the services in general, the promptness of each service, and the overall relevance of the service to their needs and those of the people for whom they care. The interview results revealed that their experiences were dependent upon 1) the availability and range of services, 2) appropriate help and support and 3) cultural awareness and competence from the services in question.

Availability and range of services

Whilst the TACIII carer responses indicated that there is still some dissatisfaction amongst the new carers, there was a greater preponderance of satisfactory evaluations than there were in TACII. This suggests that there has been some improvement in services, though we have to be careful in claiming too much as the sample was an opportunity sample rather than a representative sample per se. None the less, there does appear to be grounds for optimism.

The majority of new carers (N = 8) were pleased with the health services that they had received. The remaining two carers were dissatisfied with their GP for not requesting

a referral earlier. The most frequently used and highly rated health service amongst the new carers, however, was the CMHN, who is *'always there when we need her'*. Carer 5 went on to say that, *'If I have any problems I just call her and leave a message; she always gets back to me by the next day'* (Carer 5). Carer 6 stated that, *'whenever I need to know anything I just call the CMHN, she's very helpful.'* The positive responses towards the Asian CMHN are similar to those revealed in TACII (Moreland, 2003. p. 35). Carers were also very positive in their evaluation of the specialist health services provided to the older person with dementia for which they care. Old age psychiatry services were rated as relevant and helpful to the patient by their carers - a positive continuation from the previous research findings in TACI and II.

The TACIII new carers stated that the availability and range of different services, particularly day care centres, allowed the carers some relief from the pressures of caring. Carer 3 stated that, *'he goes to day care for two days a week. It's nice that it's in the day because I get time alone, which is what you need as a carer.'* Carers 5, 7, 8 and 10 all stated that they are able to have time to rest whilst their patients were at day care, so much so that the services were rated as either satisfactory or very satisfactory as well as being relevant and helpful to the patient. The remaining five carers however, spoke of difficulty with social services due to service availability.

Carer 2 considered social services not to meet the needs of carers with full time jobs, for *'if you work, you get no break... no time to spend with the family alone... and difficulty with transport because you have to get to work on time. Most of these day centres do not open before 9am and that is when I have to be at work.'* Carer 9 on the other hand, considered that two days a week day care was insufficient respite for the amount of work the caring role involves. Difficulties over a holiday placement caused carer 1 to rate social services as unsatisfactory, unhelpful and not relevant to the needs of the patients due to the patient returning more distressed than before. Others, such as carers 2 and 8, experienced difficulty with day care service due to lack of transport facilities (see 'service improvement' below).

Appropriate help and support

The carers spoke of the importance of appropriate help and support for both themselves and their patient. All ten carers confirmed the specialist assessment to be very satisfying and relevant to both the patient's needs as well as their own. *'It felt like they were going to help me. For six years I had lost hope'* (Carer 9). *'Everything became a lot easier after the assessment –I was getting the help I needed'* (Carer 4). *'I was very pleased that after the assessment, she would get the appropriate help and treatment'* (Carer 5). The specialist assessment also helped carers to understand more about dementia. *'I was shocked that I had never heard of this illness before'* (Carer 3). Carers too felt that the CMHN provided the most appropriate help and support due to her being both Asian and readily available. Carer 4 emphasised the importance of the appropriate help and support from the GP... *'I struggled a long time on my own and then, just after one visit to the GP, I get all this help that I didn't even know existed.'*

It was considered by a number of carers too that certain services already available did not provide the appropriate help and support for the older person with dementia, and was not meeting their needs. Despite, for instance, EKTA being a specifically Asian Elder Day Centre in Wolverhampton, Carer 3 noted that *'He used to go to Ekta but they can't handle him anymore'*, a situation too noted by Carer 2 who said that, *'None of the services are specialised in looking after people with dementia, so how can they assure her needs are being met?'* The lack of transport too was an issue for Carer 5 as, *'I have to take her to Ekta on the buses and it gets very tiring for not just me but her too - it makes everything harder but I have to take her else she will miss out'*.

Such comments as these provided a consistent message from the carers throughout the TACIII research, which is that of the desirability of tailoring services to the needs of the person with dementia and their carers. Since at least the beginning of the new millennium, the moves towards the personalisation of services specifically to meet the needs of the carers and older people with dementia has been a central policy of the current national Labour government, who are pursuing the policy in a variety of different ways, including Direct Payments (Askheim, 2005; Department of Health, 2005c; Newbigging & Lowe, 2005). Despite such developments, and the move towards more favourable evaluations of services by the carers in TACIII, there

officially is still a long way to go to achieve a patient led health service in practice (Department of Health, 2005a).

Cultural awareness and competence

Existing research suggests that ethnic minority older people consider that the majority of services are not provided in ways that recognise their distinctive culture, beliefs and needs (e. g. Audit Commission, 2002; e. g. Bowes & Wilkinson, 2003; Department of Health, 2005b). A key need, especially for the older members of Asian communities, is the capacity to converse in their own language. For the TACIII carer, having a person of their own ethnic group able to speak the Asian languages, as the CMHN is able to do, was a major factor in their very positive evaluations of the specialist health service in Wolverhampton. Linked to this there was recognition of cultural awareness and empathy, evident from the following comments:

'I was very surprised that the CMHN was Asian, it made life so much easier,' (Carer 8).

'I'm so glad the CMHN has been coming and thank God she's Asian... that's all that's needed... It's easier for mom and me because she understands our culture' (Carer 6).

'The CMHN is Asian and I think that's great. She understands the responsibility of being a daughter-in-law and being a mother and wife. So much is expected from Asian women, we're supposed to be super women' (Carer 7).

The latter quote from Carer 7 is particularly interesting as it includes a gender specific comment indicative of traditional Asian assumptions about the role of women.

Similar cultural backgrounds, whilst important, are not necessarily sufficient to overcome other factors important in service delivery. A case in point is the evaluation of EKTA, the Asian Elder specific day centre in Wolverhampton. For Carer 2, 'EKTA' is not competent in caring for Asian elders with dementia due to a *'lack of cultural awareness, dementia awareness and respect for elders.'* Specifically, the

Asian staff of EKTA were criticised for allowing the person with dementia to wander off and go missing whilst in their care. As Carer 2 said, *'if this is what's available to Asians with dementia... it's terrible.'* He suggests, along side other carers, that there is a need for dementia awareness training for Asian staff as well as cultural awareness for non-Asian staff.

Carer 10 continued the theme of cultural competence (Cross, 1989) by emphasising the importance of service staff being aware of the different beliefs and values associated with religions other than Christianity. The absence of a specialised service for Muslims with dementia was a worry and concern for Carer 10. The example she gave concerned the eating of pork, meat forbidden to Muslims: *'my husband (the patient) has become so forgetful that he would eat pork if you gave it to him and that is really bad. I have had to make sure that these services meet his needs.'* The TACIII new carers' interview results thus reveal that cultural awareness and competence delivered by services is an area of concern and desirous in service improvement.

TACIII New Carers: Communication processes and understanding

The interview schedules sought to gather information regarding the different communication processes and the level of understanding of these processes by the TACIII new carers. The interview results raised issues in regards to two areas; firstly, the possible value of doctor's letters; and secondly, issues around direct payments. The results also raised issues around the use of interpreters.

The value of doctor's letters.

Referral and reply letters are common means by which doctors exchange information pertinent to patient care. Ensuring that letters detail the needs of letter recipients saves time for clinicians and patients, reduces unnecessary repetition of diagnostic investigations, and helps to avoid patient dissatisfaction (Tattersall *et al*, 2002). As sufferers are now entitled to copies of such letters between the GP and health services upon request, information was sought regarding the possible value of these doctor's letters.

Surprisingly, and differently to TACII, nine out of ten new carers considered that it would be unhelpful for the patient to have copies of such letters for a number of reasons, particularly the patient not being able to understand the purpose of the letters or not being able to read English. Two carers stated that the patient has full trust in their GP and did not need to see the letters whilst the remaining two carers believed that the older person concerned would be uninterested in the letters. Having copies of letters would be pointless also due to their forgetfulness. Marrow and Robson (2005) similarly found that patients declined such letters because they were uninterested in the referral process and trusted their GPs. Although the patients involved in the study by Marrow and Robson did not suffer from any cognitive impairment, their results reflect the replies of those given by the TACIII new carers.

Carers were then asked how helpful it would be for themselves (the carers) to have copies of the letters. Only two out of ten carers stated that they would find the letters helpful because they would be able to 'keep track of things.' Three out of ten carers were unsure whether they would find the letters helpful whilst the remaining carers rated them as unhelpful and very unhelpful. Three carers said that they would find the letters unhelpful because they trust their GP. One carer preferred not to know, whilst the remaining carers claimed that would not understand such letters due to not being able to read English. Those that were unsure about the letters simply did not understand the purpose of such letters.

When asked what kind of information such letters should provide at different stages including the initial assessment stage and the later stages, eight out of ten carers replied that they did not understand such stages and what each stage involved. Although the remaining two carers replied to the question, their responses were relatively passive... *'We should be notified of every liaison between our GP and health services. They should tell us what's going on really, at any stage of the illness'* (Carer 2). Carer 8 simply stated that the letters should tell *'the truth'* which suggests some mistrust of the bureaucracy associated with such provision as Okuyiga (1999) identifies in his research.

It is evident from the research that some carers and (or) their patients do not find such letters helpful due to the fact that they cannot read English. For those carers who

cannot read English and would like to receive such letters suggested that they should be sent in the language legible to them i.e. Punjabi or Hindi. For those carers that can read English and whose patients cannot, suggested that it would be of no harm to send such letters to the patients in a language legible to them. Due to the characteristics of dementia, however, carers considered that the letters would still be of no use to the patient. When asked to who the letters should be sent to primarily, only one carer replied that they should be sent to the patient. The remaining suggested that they should be sent to themselves, the carers.

Overall, there was much confusion, for many of the carers did not seem to understand about doctor's letters and what they involve. The majority of the carers asked to move on to the next section in the interviews, suggesting that copies of doctors' letters was not a source of concern to the carers.

Direct payments

According to the Department of Health website,

“Direct Payments are cash payments made in lieu of social service provisions, to individuals who have been assessed as needing services. Direct Payments can be made to disabled people aged 16 or over, to people with parental responsibility for disabled children, and to carers aged 16 or over in respect of carer services. The aim of a direct payment is to give more flexibility in how services are provided to many individuals who are assessed eligible for social services support. By giving individuals money in lieu of social care services people have greater choice and control over their lives, and are able to make their own decisions about how their care is delivered” (www.dh.gov.uk/PolicyAndGuidance/OrganisationPolicy/FinanceAndPlanning/DirectPayments/fs/en).

Despite the numbers of people with mental health needs, and Direct Payments (also known as Individual Budgets) being available since 2000, the numbers of people who have accessed the direct payments system remain low, especially in those ethnic minority groups (Commission for Social Care Inspection, 2004). Consequently, the TACIII carers were asked whether or not they were aware of direct payments. Six out of ten carers replied that they were aware of direct payments whilst the remaining four were not aware. Only one carer actually used direct payments to employ someone to

wash and dress their patient and sit with them if she (the carer) has to go anywhere, whether it's work or shopping. In her view, *'It's a very good service; I get to do much more because of it'* (Carer 7). As a working Carer Support Worker herself, Carer 7 may be considered advantaged at knowing more about services available and how to access them. All the carers not aware of direct payments indicated that they would be interested in finding out more about them. The carers suggested that someone should speak to them on a 'one-to-one' basis about direct payments because, *'the terminology on the leaflets is terrible. Someone should just come round and do everything with us, including the paperwork'* (Carer 1) Carer 1 also emphasised that having someone to talk to about direct payments would, *'make sure that me and my husband fully understand'*.

Those carers aware of direct payments were asked to state their reasons for not accessing or using them. Carer 2 stated that, *'I'm not sure whether we're entitled to it or not, or whether I would use it if we were. I need to know more about it really'* whilst Carer 4 went as far as to say that... *'It's too much paperwork and headache. I don't understand them – it's just too much hassle. I'm fine the way I am... we're fine the way we are.'* Carer 10 also emphasises that *'there's too much paperwork involved and I don't think I'm going to get much more than I already do.'* The reasons for not using direct payments were thus less a lack of knowledge of the service as a perception that accessing them was difficult and time consuming, and would not necessarily lead to any improvement in service for the person with dementia. Ridley and Jones (2003) too found in their study that in order to make direct payments work for mental health service users, what was needed was 'person-centred' assessment, access to proper support, advice and training, and direct payment schemes that were flexible to allow for different arrangements and for transitions.

The use of interpreters

Although there was not a section dedicated to the use of interpreters on the interview schedule, Carer 2 had experienced the use of a professional intermediary provided by social services and commented on the use of that service. Although there is only one carers suggestion to be discussed, it is important to record their views as mentioned earlier; each situation is unique to the individual and each individual

statement provided by carers is one step closer to service improvement. The use of interpreters is also a communication process that is in need of more research according to Tibbs (2001). Existing research suggests that providing an interpreter is not necessarily always the solution to language barrier problems (Patel and Mirza, 2000). Patel and Mirza suggest that first generation ethnic older people have a tendency to lapse into a mixture of English and their mother tongue, making it difficult for them to be understood by care workers, relatives and interpreters. They also suggest that a three way conversation causes difficulty and causes patients to feel uncomfortable. Carer 2 however, argues that interpreters merely act as ‘translators’ in that they have difficulty in interpreting what one means as opposed to what one is saying. He states... *‘there shouldn’t be an intermediary, this has caused many problems for us around meaning. On one occasion, I let my wife speak, she speaks only Punjabi. I stayed quite and listened to the interpreter and I had to correct him on so many occasions as to what my wife meant. I dread to think what would have happened if I was not there.’* It is evident that research still remains scant and piecemeal and the use of an interpreting service is an area in need of further research.

TACIII New Carers: Service Improvement

The final section of the interview schedule in TACIII sought to gather information in regards to service development proposals and additional service proposals from the carers. The analysis of the interviews identified two major themes behind carer suggestions for service improvement:

- Early detection and education; and
- Cultural awareness, sensitivity and competence.

Following this, individual carers suggested additional service improvements.

Early detection and education

As GPs are the normal first port of call for potential dementia sufferers, the carers considered that there is an ongoing need to educate GPs with regard to the symptoms of dementia. The carers too spoke of the necessity of educating the Asian community itself about dementia, not solely to reduce stigma, but more so to increase

the chances of enhanced detection by symptom recognition, prompting the seeking of professional help at an earlier stage. Carer 4, for instance, was adamant that her situation would have been better' *if the problem was addressed a lot earlier.*' She then went on to say, *'but I suppose that's my fault for not asking for help earlier'* thereby accepting that there is a role for the layperson as well. Carer 5 too stated that, *'if I knew something about the illness I could have detected it earlier. They say it can't be prevented but if I had just noticed the signs earlier it wouldn't have got this bad'*. Carer 9 pointed out that dementia can be easily mistaken for the ageing process in the Asian community, so that it is up to service providers to *'tell us before hand what this illness involves so we know what to look out for.'* Carer 3 additionally suggested that Asian men should be educated about the effects of alcoholism and the possibility of developing alcohol related dementias for, *'Asian men drink too much – it's in their culture and they do not know the consequences.'*

Kar *et al* (2005, p. 267) suggest that early diagnosis of dementia enables:

- The starting of effective treatments earlier (e.g. acetyl-cholinesterase inhibitors) in order to slow down the progression of the illness;
- Effective service planning for individuals, including treatment for non-cognitive symptoms;
- The possibility of maintaining independence via environmental manipulation using aids such as Telecare (Barlow, 2003);
- The improvement of social interaction and quality of life by activity programmes; and
- Involvement of the person with dementia and their carers in decision-making regarding their care plan in the future as well as other aspects such as advocacy, lasting power of attorney, living wills and advance health directives.

Cultural awareness and competence

A major area of concern to the TACIII new carers was the level of cultural awareness and competence within services. This is not a new proposal, for the TACII carers also stated that there ought to be 'culturally relevant and competent services for

older people with dementia and their carers' (Moreland, 2003. p. 41). Suggestions for improvement by the TACIII new carers varied from 'case specific' suggestions based on personal experiences and circumstances to, 'service generic' suggestions based upon wider perceptions of service development needs.

Carers 2 and 10 based their recommendations upon personal circumstances and experiences of services. Carer 2, because of a negative experience, where the older person with dementia for which he cares had been 'disrespected' at the Asian day centre EKTA, was adamant that he would '*definitely recommend cultural awareness training for the staff at EKTA... at the moment I would not recommend it (EKTA) to anyone... Older people should get respect...the staff there are incompetent*'. Carers 1 and 10 too stated that services should have respect for their users, for '*they are still individuals and deserve respect as elders*' (Carer 10). Carer 10 went further to suggest that social service staff should include more Urdu speaking people, Islamic staff and staff knowledgeable about Islam so that care is received in accordance with the religion. Carer 10 explained this by saying that, '*our needs are very different from other ethnic minority groups. Muslims are forbidden to eat pork. My husband's condition is so bad that he would eat it if it was given to him... he also must eat only halaal meat. Because of this he can eat only vegetarian food but I still worry, accidents happen.*' Though devout Muslims too should pray five times a day, her experience is that no service is available whereby this can take place. Carer 10 therefore suggested that there should be cultural awareness training for staff about the beliefs and values of Islam. For her part, Carer 1 also emphasised the importance of religion, for as a Sikh, '*our people believe in God – especially the elders. If I could take her to the temple I would, but I can't. If there was a (transport) service that took them to the temple I think that would be really good... they are in God's hands now after all.*' The carers also suggested that there should be basic language skills training for existing staff. Such suggestions are perfectly in tune with wider development in the theory and practice of cultural competence in social service and health practice (e.g. Hanssen, 2004).

Additional service suggestions

In addition to the common issues highlighted above, individual carers suggested the following:

- A specialised service for Asian older people with dementia that can meet the needs of not only their illness, but also their beliefs and values.
- An evening care service for those who work full time jobs and (or) wish to spend quality time with their families.
- An emergency after hour's service.
- A transport service.

TACIII: The Old Carers (Previously Interviewed in TACI and/or II)

Table 4 indicates the situation and characteristics of each old carer and the person for whom they care, whilst *table 5* provides information upon the type of dementia each patient has, the ethnic origin of the patient and the carer, and the language(s) used to conduct the interview.

From *table 4* and *table 5* it can be seen that:

- The patients were three men and two women;
- The average age of the patients was 69 years, or 72 years if the one person with early onset dementia is excluded;
- The average age of the carers was 56 years;
- 2 out of 5 patients lived in intergenerational family units;
- No carers were in paid employment;
- All carers were female;
- All patients had different types of dementia;
- 1 of the patients was of Pakistani Muslim background, the rest coming from Indian backgrounds, being either Sikh or Hindu religions;
- 1 interview was conducted in English, 1 in Gujarati, 1 in Urdu and 2 in Punjabi.

Table 4: Personal characteristics of TAC III old carers and their patients.

Carer	Patient information				Carer information			
	Age (yrs)	Gender	Position in family	Lives with?	Age (yrs)	Gender	Relationship to patient	Employed Yes/No
1	73	Female	Mother	Carer and family.	40	Female	Daughter-in-law	No
2	59	Male	Husband	Alone with Carer	58	Female	Wife	No
3	71	Male	Husband	Alone with Carer	67	Female	Wife	No
4	75	Male	Husband	Alone with Carer.	72	Female	Wife	No
5	69	Female	Wife	Carer and family.	41	Female	Daughter-in-law	No

Table 5: Type of Dementia, Ethnic Origin and Main Language of Interview for TACIII Old Carers

Carer	Patient illness	Ethnic origin - Religion (patient and carer).	Language(s) that interview was conducted in.
1	Vascular dementia	Pakistani: Muslim	Urdu
2	Early Onset Dementia	Indian: Sikh	Punjabi
3	Not Known	Indian: Gujarati	Gujarati
4	Lewy Bodies	Indian: Sikh	Punjabi
5	Alzheimer's	Indian: Sikh	English

As with the discussion on new carers, the results are under the four main headings indicated earlier; access to services, experiences of services, communication processes an understanding, and service improvement.

TACIII Old Carers: Access to Services

The rationale for interviewing carers involved in the previous TACI and/or II was the assumption that, if improvements in services had occurred, the old carers' experiences of the three service sectors should have improved too. Interestingly, after indepth analysis of the TACIII old carer interviews, it became apparent that the barriers present in accessing services for the TACIII old carers again remained 1) the

lack of understanding of dementia, 2) patchy knowledge of the range of services available and 3) patchy knowledge of entitlements, particularly Direct Payments.

Knowledge and understanding of dementia

As with the new carers, the understanding of dementia was very dependent upon the sources of information used. Four out of five old carers stated that their understanding of dementia had improved since they were last interviewed due to the sources of information that had become available to them through leaflets and audiotapes. Those that understand Punjabi also had a videotape available to watch. Carer 3 pointed out that the availability of an audiotape and video in Gujarati would help improve her understanding of dementia. Currently, the leaflets are available in all South Asian languages; the audiotapes are currently available in Hindi and Punjabi whilst the videotape is only available in Punjabi.

Interpersonal communication generally was rated highly. Carer 1 suggested that a '*...one-to-one discussion in Urdu with someone who understands our religion (Islam)*' would improve her knowledge. Language barriers, however, do affect carers' knowledge and understanding of dementia, a situation similarly found in the TACIII new carers. Carer 5, who can understand, read and write English well, said that she struggles to explain dementia to her husband in Punjabi. Instead, the CMHN was called in to provide an explanation, though the difficulties remain with explaining dementia in an Asian language (see TACIII New Carers: Lack of knowledge and understanding of dementia).

Two out of five old carers attend the Carer Support Groups and similar to the new carers, stated it was very helpful in assisting their understanding of dementia and their rights. Unlike the new carers however, the old carers too noted that the experience of caring for the person with dementia and watching the progression of the illness itself informed their understanding. Four out of five carers stated that the condition of the dementia had got worse since they were last interviewed whilst carer 3 stated that it had improved due to treatment.

Knowledge of the range of services available

Unlike the new carers, three out of five old carers used voluntary organisations, whilst the remaining two carers made no comment. The two carers making no comments were carer 4 is over the age of 65, whilst carer 5 is an intergenerational carer in her early 40's. Those carers who mentioned the use of additional services did so in the relevant sectors (health, social and voluntary) except for old carer 4 who spoke of social services when asked about voluntary services. Despite this, the data suggests that their knowledge of the range of services available to them has improved since TACI and II.

Knowledge of entitlements

Similar to the new carers, the old carer interviews revealed instances where carers did not know whether they were entitled to services, particularly Direct Payments as a financial support service. All five carers said that they were not aware of direct payments, though four of the five expressed an interest in finding about more about Direct Payments in case there is an entitlement. No other additional comments were made.

TACIII Old Carers: Experiences of Services

Carers were asked of their experiences of any additional services used either for them selves or the patient, since TAC I and II in health, social and voluntary sectors. The aim was to not only gain an understanding of the satisfaction and supportiveness of the services in general, the promptness of each service, and the overall relevance of the service to their needs and those of the people for whom they care, but also to see if their experiences have improved since TAC I and II. The TACIII old carers data revealed that overall, carers' satisfaction with services have improved since the prior research projects., The results, however, indicated that, similar to the new carers, the old carers' experiences of services were dependent upon 1) the availability and range of services, 2) appropriate help and support and 3) cultural awareness and competence from the services in question.

Availability and range of services

The main health services used by the TACIII old carers were GPs, CMHN and Specialist Psychiatrists. Although there was still some dissatisfaction amongst the carers with their GPs, though there was a greater preponderance of satisfactory evaluations since TACI and II, which indicates some improvement in the service provided by GPs. Four out of the five carers stated that their only involvement with the GP was for repeat prescriptions. Interestingly, carer 3 stated that '*...if it's something to do with the illness (dementia) we deal with the CMHN, for other things we go to the doctor.*' Old Carer 5 was the carer most dissatisfied with the GP service because '*...we always ask the GP to do home checks but they keep on telling us to bring mom (the patient) to the surgery... she can't go anywhere!*' This example stresses the importance of appropriate help and support, one of the factors causing the old carers to rate the availability and quality of the service provided to them by the CMHN as the following comments prove:

- Carer 1** *The CMHN continues to come, and she still works hard. She's very good. It would be nice to have another one, as she is so busy.*
- Carer 2** *I am very happy with the CMHN; she helps as much as she can. Whenever she comes, she always has time to listen.*
- Carer 3** *If there is anything with the illness (dementia) we ask the CMHN. She should stay longer when she comes. She could tell us more about the available services; mind you she does that most of the time.*
- Carer 4** *If there was another person like her that would be good. I feel sorry for her – she must get a lot of hassle from people like us.*
- Carer 5** *She's like family to us. I praise her for what she has done. I'm forever calling her over silly things, as she always knows what to do.*

Carers stressed the need for another CMHN for there seemed to be a sense of guilt associated with requesting her service. In discussing Specialist Psychiatrists, for instance, carer 5 stated that there needs to be '*a bit more support*' from the consultants as it causes her to be '*always bothering the CMHN.*'

Appropriate help and support

The TACIII old carers' experiences of services are largely dependent upon whether they offer the appropriate help and support for both themselves and the person for whom they care. Carer 2 stated '*... Social services cannot meet his needs as there is no day care in the area.*' Carer 2 however is the only carer out of all the TACIII carers interviewed that has the use of Telecare buzzers and a flood warning system which she states to be very useful and highly recommends for others.

Whilst the satisfaction of the specialist psychiatrists has improved hugely since TACII, carer 5 stated '*...they do their assessments and or whatever they have to do and then you never see them again*' which indicates that not only should there perhaps be more involvement from specialist psychiatrists but also perhaps education for carers as to the roles and responsibilities of the different services.

Other than the dilemma of lack of transport facilities, which will be discussed in more detail in 'service improvements', carers were thankful to day centres for they were able to '*get a break*' (carer 3) and '*get more things done*' (carer 5). There are instances however where services were causing distress to carers and the person with dementia for not providing the appropriate help and support. Carer 1 has been on the waiting list for one year at the time of the interview for an assessment from Occupational Therapy. Due to the lack of space, the person with dementia has been sleeping in the living room. Carer 1 has not only requested an extension to the house in which they reside but also for something to be done about the uneven paving outside of her house which means that carer 1 '*cannot take her (the patient) out anywhere due to the fear that she may fall.*' This can lead to significant impact upon the person with dementia both mentally and physically and can also cause unnecessary strain upon the carer.

Carer 2 when referring to 'Stretton Street Community Centre' stated that '*it was not appropriate*' due to the fact that '*it was not secure so he (the patient) could easily wander off.*' This emphasises the importance of services being able to meet the needs of dementia patients.

Cultural awareness and competence

Cultural awareness and competence is an important factor towards the carers' experiences of services. The TACIII old carers' expressed the importance and need to be heard and converse in their own language. As stated earlier, TACII revealed that having an Asian GP helped carers to be more open to the GP, which included speaking to them in their own language when appropriate (Moreland, 2003). This was also revealed in the TACIII old carers. Although the majority of carers main involvement with the GP is repeat prescriptions and physical check ups, whether or not the GP was Asian made a huge difference. Carer 1 stated due to her GP being able to speak Punjabi they '*understand each other well.*' Carer 2 on the other hand, stated '*... my GP does not speak Punjabi, but luckily I understand English although I can not speak it.*' This would result in the GP being unable to communicate with the carer effectively which can in turn lead to the problems discussed in the TACIII new carers such as misdiagnosis. Carer 4 also emphasised difficulties associated with language barriers as she has difficulty ordering repeat prescriptions due to the fact that the receptionist at her doctor's surgery cannot speak or understand Punjabi and the carer cannot speak or understand English. Due the fact that there is not a younger member of the family around to help and offer what Ahmad and Atkin (1997) call additional reciprocal services, particularly in terms of their knowledge of English and local cultures, the carer relies on CMHN to speak to the receptionist when and if necessary. Even with the help of the CMHN, carer 4 stated '*the receptionist should know Punjabi and things should be done on time.*'

In relation to the specialist psychiatrist, carer 1 stated '*if would be helpful if they could speak Urdu as the CMHN has to come and translate.*' Here the carer is not only emphasising the difficulties associated with the presence of an interpreter but also feels that she could understand things better if they were describes directly by someone who is fluent in her own language. Carer 4 also suggests that specialist psychiatrists would be more helpful if '*they could spoke our own language.*'

Interestingly, carer 1 expressed the need for more staff that understands Islam as expressed by carer 10 of the TACIII new carers. As discussed in the literature review, Islam is a 'way of life' and cannot be generalised with other Asian religions and

cultures because it is so 'different' (Sheik and Gatrad, 2000). Carer 1 also notes trends in Muslim families that she feels services should be aware of. Directly aimed at housing services, carer 1 stated that *'Asian Muslim families are known to be big families that all live together and services should be aware of this.'* This is an area that is in need of further research and deserves attention.

TACIII Old Carers: Communication Processes and Understanding

As stated, the TACIII interviews gathered information about the different communication processes and the level of understanding of these processes. The two main areas of concern are doctor's letters and Direct Payments. Direct Payments has been discussed in detail earlier (see TACIII new carers: communication processes and understanding). Due to this and the fact that the TACIII old carers made no additional comments on Direct Payments other than those mention in 'knowledge of entitlements' this section will focus solely on the possible value of doctor's letters.

The value of doctor's letters

All five carers stated that doctor's letters would either be very unhelpful (N=2) or unhelpful (N=3) to the person with dementia largely due to the fact that they cannot read English or can no longer read English. Carer 5 stated that the person with dementia for whom they care would *'not be interested.'* Similarly, all five carers stated that they would find copies of the doctor's letters very unhelpful (N=1) or unhelpful (N=4) for the same reasons; that they cannot read English. This is in exception of carer 5 who stated that she would only like copies of the letters if the condition of the patient severely deteriorates. When asked if the letters should be available in another language, four out of five carers replied that they would have copies of such letters if they were in a language legible to them. Such letters for carer 4 would be of no use due to the fact that carer 4 cannot read or write any language and thus would need someone to explain the letters to her. Interestingly, all five carers were unaware of what these letters should contain at the initial assessment and later stages which reflect the responses of the TACIII new carers and raises the question as to whether or not these carers actually understand what such letters involve or, on the contrary, what the initial assessment stage involves.

TACIII Old Carers: Service Improvement

As stated earlier, the final section of the TACIII interview schedule sought the gather information in regards to service developments and additional service proposals from the carers. There was only one carer (5) who stated the need for early detection and education as identified by the TACIII new carers. Cultural awareness training and language skills training were however recommended for staff by three out of five carers, which reflect the issues raised by the TACIII new carers. In relation to additional services, the TACIII old carers suggested the following:

- A specialised service for Asian older people with dementia that can meet the needs of not only their illness, but also their beliefs and values.
- A transport service
- Telecare for couples living alone
- More voluntary services (in Bilston)
- A housing service, especially for those people caring for someone who has dementia to ensure that the house facilities the needs of the patient.

Conclusion to chapter

The results from the TACIII carer interviews have allowed us to not only develop knowledge in regards to the situations of Asian carers caring for an older person with dementia in Wolverhampton, but also has allowed us to identify the ongoing issues that need to be addressed when considering further development. Our experience of the research makes us agree wholeheartedly with Beattie *et al* (2005), who assert that service providers should go beyond labels in order to address the support needs that individual carers and people with dementia have (Beattie, Daker-White, Gilliard, & Means, 2005). This means getting behind and beyond cultural stereotypes (Burr, 2002) to reach and address the person with real-life predicaments and needs (Illife & Manthorpe, 2004).

To summarise, the TACIII results revealed issues in two main areas:

Dementia in the Asian community:

- Lack of knowledge and understanding of dementia amongst carers and the Asian community in general which, leads to:
 - Stigmatisation.
 - Mistaking symptoms of dementia with old age.
 - Hidden problem and carers' remaining isolated.

Service Provision:

- Lack of detailed knowledge of dementia amongst GPs.
- Lack of knowledge and awareness of service provision and entitlements, including voluntary organisations.
- Lack of cultural awareness, sensitivity and competence within health and social services, including language barriers.
- Lack of understanding regarding direct payments.
- Additional service suggestions.

In order to tackle the above, the TACIII new carers feel that there is a need to:

- Improve early detection of dementia through the raising of awareness in the Asian community and in-service education for GPs.
- Develop and implement a three-level cultural competence training and development programme (cultural awareness, cultural sensitivity and cultural competence levels) for new and existing staff, to include South Asian basic language skills training.

Chapter Six: Project Recommendations

After in depth analysis of the TACIII interviews, there are a number of recommendations that we can make for future development. These recommendations are at three levels. Firstly, the Asian community in Wolverhampton, secondly, those recommendations aimed specifically at Asian carers in Wolverhampton and finally, suggestions for further development for services.

The Asian Community in Wolverhampton

At the risk of stating the blindingly obvious, social and health services, along with members of the Asian community, and organisations that serve the community, need to develop a concerted and ongoing programme of awareness raising and understanding of dementia in the Asian community. Not only is the Asian community ageing, and thus potentially likely to have increasing numbers of people with dementia, such a programme of education and guidance is necessary in order to 1) increase the possibility of early detection and thus reveal 'hidden' carers and 2) address the issues of social stigma associated with mental health. The TACIII carer results, in particular the new carers, revealed that dementia is commonly mistaken as a feature of old age.

Recommendation 1: A properly resourced Dementia awareness and education programme

Although For Dementiaplus focus provides informational talks that are open to the public, experience suggests that it is the carers that mostly attend, whose needs are different from those not yet in a caring situation. Secondly, these informational talks are not specifically focused on the Asian community, or take place within settings where the Asian generally meet. We consider it essential, therefore, to provide informational talks and other materials in places of congregation such as temples, mosques and mandirs (Hindu temples).

More lasting and focused provision of information and training might be made through other local developments. Wolverhampton City Primary Care Trust, for instance, has a Patient Advice and Liaison Service (PALS). The PAL core activities include providing information on the NHS and health-related matters, confidential help, advice and support to patients and their carers especially in regards to finding their way around the health service and the Expert Patient Programmes. That is, PALS have established a six-week training programme designed to empower patients so as to enable them to take a greater control and management of their particular illnesses, thus becoming the *experts* of their illness. This programme commenced on 28th March 2006 and Dementia carers have recently, through the carer support group, have taken part in this programme. It is recommended, therefore, that the PALS service be contacted in order to investigate the potential for expert carers giving informational talks on a general basis about dementia to their local community. PALS suggest that once this six-week programme is complete, carers caring for someone who suffers from dementia will be the ‘lay’ experts of that illness. Asian carers need to be made aware of this service and encouraged to attend and participate in such programmes.

Recommendation 2: Addressing the Stigma of Mental Illness

Seabrooke and Milne (2004) suggest that people from the Asian community need to recognise that dementia is an illness and accept too that having dementia is nothing to be ashamed of. Whilst the provision of information can contribute to the decrease in ignorance that is inextricably related to stigma and stigmatising activities, the community needs to understand that the quality of life of dementia patients and their carers can be greatly improved by the wider acceptance of dementia as an illness, as well as help and services from local providers. Seabrooke and Milne suggest that raising dementia awareness through workshops and focus groups among the community members can be effective. However, as the authors clearly note, unless there is ongoing investment in an educational cycle incorporating this type of workshop, learning and information sharing will cease, allowing a reversal to cultural norms and dementia being hidden and marginalised.

Asian carers in Wolverhampton

The majority of the TACIII carers expressed a need for further education regarding dementia to improve their understanding. In regards to the Asian carers in Wolverhampton the following suggestions are recommended.

Recommendation 3: Sources of information Available in Asian Languages

As the interview results proved, the audiotapes produced in Punjabi and Hindi have been of help to the carers that were provided with them. Those carers who do not speak these languages, however, remain at a disadvantage. Consequently, it is proposed that these tapes are produced in Urdu and Gujarati languages also. This may be achieved through the CMHN who is the Asian Link Nurse for Wolverhampton and responsible for the tapes in Punjabi and Hindi. The CMHN has confirmed that the Gujarati Association and Urdu interpreters in Wolverhampton would be willing to produce the tapes.

Recommendation 4: More Sources of information

The video on dementia has also proven to be effective, though it is available only in Punjabi. To overcome the disadvantage experienced by those who cannot understand Punjabi it is recommended, due to time constraints, that the same video be 'dubbed' over in Urdu, Hindi and Gujarati with permission from the Alzheimer's Concern Ealing who originally produced the tape in 2000. It would be useful too to produce a DVD version for those who do not have access to a video recorder. This could be achieved with help of both the facilities and students at Wolverhampton University (who Dementiplus are in association with) who can help dub the tapes and produce a DVD version using the relevant equipment. Those who produced the audiotapes in the necessary languages could also be asked to dub over the video.

Recommendation 5: A befriending service

Many carers suggested that speaking to someone on a 'one-to-one' basis in their own language would largely help improve their knowledge of dementia. As Tibbs (2001) suggests, there is clearly a shortage of people from ethnic minority communities in social services, and there is no guarantee that those who are Asian are fluent in the desired language. Currently, those who are fluent in different Asian languages, act as interpreters. However, the interpreting service in Wolverhampton is currently generic as opposed to specialised (Moreland, 2003). As mentioned earlier, according to a study conducted by Patel and Mirza (2000) using an interpreter is not always necessarily the solution to language barrier problems for they suggests that first generation ethnic minority older people have a tendency to lapse into mother tongue and English making it difficult for them to be understood by care workers, relatives and interpreters. Patel *et al* (1998) suggest that a three way conversation may well result in the carer feeling uncomfortable as well as creating many issues around translation. It could therefore be suggested that interpreters should be trained and educated in issues around dementia in order to give 'one-to-one' talks with carers. However, this would require changes to their job contracts which in deed may become a lengthy process. Other options therefore need to be explored.

Age Concern have a befriending service in Wolverhampton which consists of volunteers to visit older people who have recently been discharged from hospital or a Community Resource Centre to provide companionship and friendship on a short term basis. However, there is again, a lack of ethnic minority people involved in this service in order to meet their needs. Although many carers stated that they would like to speak with someone who is of a professional background, for example, the CMHN, this would be a hard task to achieve due to the shortage of ethnic minority staff. There is however, no current reason as to why members of the Carer Support Group can't be trained to give information talks to their peers about dementia. These people would be from the same community and will have encountered many of the problems that the carer will have encountered themselves or are about to encounter. This way, issues such as cultural and language barriers are tackled and carers shouldn't really feel that they need to conceal their problems because they are speaking with a person who also cares for a person with dementia. These people could act as a befriending service as

volunteers. Training sessions should then be provided dealing with issues around confidentiality, respect, cultural and language barriers and dementia just to ensure that carers who have volunteered are aware of the issues concerned and have the correct level of education. Once this has been achieved, appointments can be made for these volunteers to visit carers in the comfort of their own homes to discuss any issues and concerns they may have regarding the illness and help increase their understanding of dementia as well as service provision, especially regarding; voluntary organisations, the purpose of doctor's letters, what initial assessment and later stages involves and entitlements. It is important that carers receive appropriate and sufficient training in order to do this. It is the carers after all that are the *experts*. Transport will need to be provided for these volunteers which can be done through social services. Presenting information at Carer Support Groups is useful, however only for those that attend.

Service suggestions

Other than the additional service suggestions by the TACIII carers, including the need for another Asian CMHN, carers expressed a huge need for cultural awareness training and dementia training for staff.

Recommendation 6: A Three-level cultural competence training

There is a need to develop and implement a three-level cultural competence training and development programme (cultural awareness, cultural sensitivity and cultural competence levels) for new and existing staff, to include South Asian basic skills training.

Recommendation 7: Integrated Service education

Develop and implement a dementia training and development programme for those staff that are involved with dementia patients, including GPs.

Chapter Seven: Conclusion to Report

The aim of this report was to not only analyse the effectiveness of developments since TAC I and II but also reveal any current issues that exist for carers in order to suggest recommendations for future development to help better the experiences of Asian carers caring for an older person with dementia in Wolverhampton. This was done by firstly conducting an in depth literature review in order to reveal any current issues that need to be addressed. Based on these current issues, the existing interview schedules used in TAC II were amended as discussed in the research process and methodology. TAC III interviews were then analysed and discussed using thematic analysis. After in depth analysis of the information presented, recommendations for further development were then suggested.

Overall, the TACIII results revealed that there is lack of knowledge and understanding of dementia amongst carers and the Asian community in general which, leads to; stigmatisation, mistaking symptoms of dementia with old age and encourages carers to remain hidden and isolated. In relation to service provision, the results revealed that there is a lack of knowledge and awareness of service provision and entitlements, including voluntary organisations and a poor understanding regarding direct payments amongst carers. The results also revealed that there is a lack of knowledge of dementia amongst GPs and a need for cultural awareness, sensitivity and competence training within health and social services, including language barriers.

In order to tackle the above, it was felt by the TACIII carers that there is a need to improve early detection of dementia through the raising of awareness in the Asian community and in-service education for GPs. As is the need to develop and implement a three-level cultural competence training and development programme (cultural awareness, cultural sensitivity and cultural competence levels) for new and existing staff, to include South Asian basic language skills training. Of huge concern is also the issue of Direct Payments. There is an urgent need to raise awareness and improve carers understanding in regards to the service. Carers are (unknowingly) entitled to an assessment and the service could indeed benefit many of the carers (as it

does for Carer 7 of the TACIII new carers). Should a Direct Payment assessment therefore be compulsory rather than at request?

The 'Twice a Child' research projects have indeed proved themselves useful in that they have allowed us to repeat interviews at a later date to find out how individual's perspectives have changed over time in regards to a particular event or experience (Hakim, 2000) and suggest recommendations for future development that will no doubt, be re-assessed in 'Twice a Child IV' in the near future.

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Appendix 1: The Provision for Dementia Patients in Wolverhampton

Current health and social services for dementia patients in Wolverhampton:

- 40 inpatient assessment and treatment beds at Penn Hospital (Cedar and Larch wards).
- 40 continuing care beds purchased from Heatun Housing (Pennfields Court and Bushbury Court).
- A total of 21 social care respite beds (Blakenhall Resource Centre, Nelson Mandela House and Warstones Resource Centre).
- 22 OMI residential beds at Blakenhall Resource Centre.
- Memory clinic (based at Penn Hospital).
- 3 x integrated health and social care Community Mental Health Teams.
- Blakenhall Resource Centre (southeast sector) providing long stay and respite care, specialist domiciliary care, carer support and health and social day care services.
- Groves day hospital (currently covering north and south west sectors).
- The Liaison Psychiatry team provides interventions for older people at New Cross Hospital (this is a limited service).
- OMI Asian Link Service – CPN post and social worker post.
- A second resource centre is currently under development in the North of the City and is due to open in December 2005. This will provide 30 OMI long-stay residential places and 15 respite beds for individuals with dementia. The scheme will also provide health and social care day services.

Private sector provision for dementia patients in Wolverhampton:

- Newlyn Court Nursing Home – 72 beds.
- Goldthorn Court Nursing Home – 48 beds.
- Mill House (residential) – 24 beds.
- Oaks Court – 17 beds.
- Bellvue Nursing Home – 38 beds.
- Oaken Terrace – 51 beds.

Source: Redesign of Older Peoples Mental Health Services. Consultation Document: 17th October- 14th November, 2005. p. 15-16.

Appendix 2: How the TACIII interview schedules were initially constructed.

The interview schedules used for this particular piece of research were first developed in 2001 for the initial TACI research project. This was done by firstly conducting a literature review that focused around ethnic minority communities in the UK and their current understandings regarding people with dementia and their carers, as well as issues of current provision and support for these people. This was then followed by interviews with a number of community and religious figures (10 per community) in order to ascertain their current knowledge and prevalence of dementia in the communities they serve. Questions were also asked in regards to any service provision currently available to people with dementia and their carers in their organisation and their willingness to be involved in any future developments for these people. The interviews were carried out by the project officers who were themselves members of the two ethnic groups (Afro-Caribbean's and Asian's). The project co-ordinator subsequently tabulated the results, and they were then shared with the Project Action Group (PAG) that included the project officers who carried out the interviews. Arising from the analysis and discussions at the PAG, as well as those that arose from the literature review (which was also shared with the PAG and Steering Groups), action points were identified and collated.

A draft of the interview schedule was then developed by the project co-ordinator. This was then shared with the project officers and a few people from the PAG that were available and willing to review and contribute to the development of the schedule. After subsequent modifications, the interview schedules were shared with the whole of the PAG, who were invited to give both immediate comments and to add any further comments as appropriate. From these different contributions a final version of the interview schedule was collated. The interview schedules for the two samples of the community and religious figures were developed in the same way.

The research process employed in TACII in 2003 was slightly different from TACI, in that no attempt was made in this research to revisit the community organisations and interview leading people from those organisations about their knowledge, experiences

and perspectives on dementia in their respective communities. Instead, the focus was on identifying changes that had occurred since TACI, in the provision of services by Health and Social Services in the City of Wolverhampton and selected carer experiences of those services. This therefore involved returning to those carers interviewed in TACI as well as 'new' carers that had no prior involvement in the research. Using the original interview schedule in produced in TACI as a basis, two interview schedules were produced to meet the needs of the different groups being interviewed (an interview schedule for previously interviewed carers and an interview schedule for 'new' carers). These interview schedules too were validated by Dementiaplus.

Appendix 3: TACIII New Carers Interview Schedule

Interview schedule for new carers.

Thank you for allowing me the opportunity to speak with you. We are part of a Social Services and Primary Health Trust sponsored project to review the services people with Dementia and their carers need. The project is trying to identify the current and possible future needs of people with dementia and their carers in the Asian communities in Wolverhampton. Part of the project is about talking to the carers of people with dementia about their experiences.

It is important for you to understand that your responses to the questions will be anonymous.

Section One: Patient information

1. Can you tell us a little bit about the person with dementia for whom you care?

Preferred Name:

Age..... Sex: Male / Female

Ethnic Origin..... Religion
.....

Position in family?

Do they live? :

Alone With you With other family members
Other (Please Specify)
.....

How would you describe the current problems arising for (name) from the dementia (Prompt to give guidance only if needed: forgetfulness, wandering, do they recognise people sometimes/always, can they remember how to dress etc)
.....
.....
.....
.....

Section Two: Carer Information

2. Who would you describe as the main person (from family or friends) who provides the day-to-day care for (name)? Or who provided it when the person lived at home. It is likely to be the person being interviewed!

2.1 Name:

Age..... Ethnic Origin

Sex: Male / Female

Relationship to person with dementia.:.....

What sort of things does (name) need you to help with:

.....
.....
.....
.....
.....

2.2 Describe briefly your/the carer's:

Health:

Mentally.....
.....
.....
.....

Physically.....
.....
.....

Family circumstances.....
.....
.....

Work circumstances (if appropriate).....
.....
.....
.....

2.3 Are other family and friends involved in caring for (name) Yes / No

If yes list caregivers and their main involvement.

.....
.....
.....
.....

Prompt :This might include: decision- making, shopping, meals, transport, laundry personal care etc

2.4 Briefly describe what do you understand about Dementia?

.....
.....
.....
.....

2.5 How did you first get information/get to understand more about (name)'s illness?

.....
.....
.....

2.6 Is the financial support you receive sufficient and appropriate?

.....
.....
.....
.....

2.7 Are you aware of **direct payments** as a way of obtaining care? (*Explain what direct payments are*).

Yes []

No []

If yes, please go to 2.9.

2.8 If *no*, would you be interested in finding out more about them? Yes [] No []

If the answer is yes, how would you recommend this is done?

.....
.....
.....
.....

2.9 (If the carer is aware of direct payments and chooses not to use them). Are there any particular reasons as to why you do not use direct payments?

.....
.....
.....
.....

Section Three: The Possible Value of Doctors letters

I would now like to ask you about the usefulness of having copies of any letters between their GP and the health services that have dealt with the person with Dementia that you care for.

3.1 How helpful do you think it would have been for him/her to have copies of the letters?

Very helpful Helpful Not sure Unhelpful Very Unhelpful

Why do you think this is so?.....

.....
.....
.....
.....

3.2 How helpful do you think it would have been for you as the carer to have copies of any such letters?

Very helpful Helpful Not sure Unhelpful Very Unhelpful

Why do you think this is so?.....

.....
.....
.....
.....

3.3 Based upon your experiences as a carer to date, what kind of information should such letters provide at different stages of the illness?

What do you believe is needed at the initial assessment stage?.....

.....
.....

.....
.....
.....

What information would be helpful in the later stages?

.....
.....
.....
.....

3.4 What could best be done to help you understand Dementia and care for him/her?

.....
.....
.....
.....

3.5 What would happen if the letters sent to the person you care for, or yourself, were only in English?

.....
.....
.....
.....

3.6 Would you prefer the letters to be in another language? YES [] NO []

If so, what language?.....

3.7 Would it be best to send any such letters to the person for whom you care, or to you as the carer, or to someone else, or a mixture of these?

.....

Would the stage of Dementia affect this? YES [] NO [] If so, in what way?.....

.....
.....
.....

Section Four: The History and Experiences of (Name's) Dementia

4.1 Could you describe in more detail about how you came to find out that (name) had memory problems/dementia?

When did you first notice that (name) was having memory problems or other symptoms of dementia?

.....
.....
.....

What made you think that (name) was having memory problems?

.....
.....
.....
.....

When you noticed that (name) was having memory problems or other symptoms of dementia? What did you do?

.....
.....
.....
.....

4.2 Did you go and see (name)'s GP? Yes / No

If yes When did you go to see (name)'s doctor

What did they say was the illness?

.....
.....
.....

Did the GP ever suggest it may be a dementia? Yes / No

At what point

.....

And / or did they ask a specialist to see (name)

Yes / No

Comment.....

.....
.....
.....

4.3 If yes, when (person name) had that specialist assessment (or Outpatient or Home visit from the consultant) how do you feel about the promptness of that service?

Very satisfied Satisfied Dissatisfied Most dissatisfied

In your opinion was the health assessment helpful/relevant to (name)'s needs:

Very relevant Relevant Not really relevant Not helpful

Additional comments

.....
.....
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.....
.....
.....

What would have made it more helpful?

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.....

Did any of the doctors suggest or refer you on to other services/organisations which may be of help?

Yes No

Which services/organisations?

.....
.....
.....
.....

4.4 Does (name) have or did they have old age psychiatry services or treatment (this might include day hospital, a stay at Penn Hospital, home visits by a nurse or psychiatrist)

List the specialist health services currently supporting (name) e.g Psychiatrist, CPN, day hospital, hospital ,others specify

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.....
.....

How do you feel about these services? For (name) was it :

Very helpful Helpful Acceptable Not helpful

Comment.....
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.....
.....
.....

What would have made it more helpful?
.....
.....
.....
.....

4.5 Was the help and assistance right for you, the carer ?

Comment.....
.....
.....
.....

4.6 What do you think would improve these services for older people with dementia?.

Particularly for those from minority ethnic communities
.....
.....
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.....
.....

Section Five: Your Experiences of Social Services

5.1 If you and/or (name) have/had services from Social Services, what were/are they?

(List the services provided or funded by Social Services currently supporting (name): e.g home help, day care, social worker, respite stays, residential or nursing home, others (Please specify)
.....
.....
.....

.....
.....

5.2 Was the process of getting the services arranged?

Very satisfactory Satisfactory Unsatisfactory Most unsatisfactory

5.3 Were services organised promptly?

Very promptly Promptly slowly Very slowly

5.4 Were the services helpful/ relevant to (name)'s needs:

Very relevant Relevant Not really relevant Not helpful

Comments.....
.....
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.....

5.5 Was the help and assistance right for you, the carer?

Comment.....
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5.6 What do you think would improve Social Services' process or services for older people with dementia. Particularly for those from minority ethnic communities

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Section Six: Experiences with Voluntary Organisations

6.1 If you and/or (name) have /had support from community/voluntary organisations?

Please list the organisations/groups currently supporting (name) voluntary /community groups e.g Age Concern, lunch clubs, Alzheimer's Society, temples, churches, others please specify

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.....

6.2 Was the process of getting the voluntary services arranged:

Very satisfactory Satisfactory Unsatisfactory Most unsatisfactory

6.3 Were services organised promptly?

Very promptly Promptly Slowly Very slowly

6.4 Were the services helpful/relevant to (name)'s needs:

Very relevant Relevant Not really relevant Not helpful

Comments.....
.....
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.....
.....

6.5 Was the help and assistance right for you, the carer ?

Comment.....
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.....

6.6 What do you think would improve the services from voluntary agencies for older people with dementia, particularly those from ethnic minority communities?

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.....

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.....

Section Seven: Further Needs and Reflections

7.1 Are there any other services available to (name) that you know of but do not use at present? If so, what are they, and why are you not using the service?

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.....
.....
.....
.....
.....

7.2 Has the help changed over time, as difficulties increased for (name) or yourself?

Yes [] No []

Comment.....
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.....
.....
.....
.....

7.3 Are there any other ways that you think any of the services could/should change so that they would be better able to meet the needs of people like (name) or their carers?

.....
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.....

7.4 What new or additional services would you suggest might be considered to better help people with serious memory problems and/or dementia , and their carers, particularly those who come from minority ethnic communities

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.....

7.5 Are you part a carer support group? Yes [] No []

If *yes*, do you view it as helpful and why?

.....
.....
.....
.....
.....

If *no*, would a support group for carers who are caring for someone with memory problems be helpful to you?

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.....
.....
.....

7.6 Is there anything else you would like to add to what we have said already?

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.....

Thank you for allowing me to interview you.

Date:

Appendix 4: TACIII Old Carers Interview Schedule

Interview schedule for carers previously interviewed in TAC and/or TACII.

Thank you for allowing me the opportunity to speak with you again as part of another Social Services and Primary Health Trust sponsored project to review the services people with Dementia and their carers need. The project is seeking to update the current situation as well as highlight possible future needs of people with dementia and their carers in the Asian communities in Wolverhampton interviewed as part of the original 'Twice a Child' project that finished in 2001, and 'Twice a Child II' that finished in 2003. That is why we are returning to talk with carers that we interviewed before in the project.

Again, it is important for you to understand that your responses to the questions will be anonymous in any report that is written.

Section One: Patient information

Were you interviewed previously for:

Twice a Child []

Twice a Child II []

Both []

1. Can you tell us a little bit about, the person with dementia for whom you care?

1.1 How old is now?

1.2 We would like to start by asking you about, and what has changed since we last interviewed you:

1.2.1 The condition of dementia?

.....
.....
.....
.....

1.2.2 Their general behaviours?

.....
.....
.....
.....

1.2.3 Their family/carer situation.....

.....
.....
.....
.....

1.2.4 What additional problems have you had to face in caring for since we last came to see you?

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.....
.....
.....

Section Two: Information about you, the Carer

2.1 Are you still the main person (from family or friends) who provides the day-to-day care for (name)? If not, who is it? Yes [] No []

.....
.....
.....
.....

2.2.1 How would you describe your health since we last came to see you?

Mentally.....
.....
.....
.....

Physically.....
.....
.....
.....

Family circumstances.....
.....
.....
.....

.....
.....

2.4 Have you had to involve any additional family and friends in caring for (name)

Yes [] No []

If yes list them and their main involvement.

.....
.....
.....
.....

Prompt :This might include: decision- making, shopping, meals, transport, laundry personal care etc

2.6 Is the financial support you receive sufficient and appropriate?

.....
.....
.....
.....

2.7 Are you aware of **direct payments** as a way of obtaining care? (*Explain what direct payments are*).

Yes [] No []

If yes, please go to 2.9.

2.8 If *no*, would you be interested in finding out more about them? Yes [] No []

If the answer is yes, how would recommend this is done?

.....
.....
.....
.....

2.9 (*If the carer is aware of direct payments and chooses not to use them*). Are there any particular reasons as to why you do not use direct payments?

.....
.....
.....
.....

Section Three: The Recent Medical History and Experiences of (Name's) Dementia

3.1 What have been the experiences of with their GP since we last spoke to you?.....
.....
.....
.....

3.2 How do you currently feel about the service provided by’s GP??
Very satisfied Satisfied Dissatisfied Most dissatisfied

3.3 What do you think could be improved in relation to the service provided by the GP?
.....
.....
.....
.....

3.4 What have been the experiences of with the mental health services since we last spoke to you?
.....
.....
.....
.....

3.4.1 a) Specialist.....
.....
.....
.....

3.4.2 How do you currently feel about the service provided by the Specialist?
Very satisfied Satisfied Dissatisfied Most dissatisfied

3.4.3 What do you think could be improved in relation to the service provided by the Specialist?.....
.....
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.....
.....

3.5 Community Mental Health
Nurse.....
.....
.....

.....
.....

3.5.2 How do you currently feel about the service provided by the CMHM?

Very satisfied Satisfied Dissatisfied Most dissatisfied

3.5.3 What do you think could be improved in relation to the service provided by the CMHN?

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.....

3.6 Are there any other medical services are used by

.....?

(e.g. Physio, Night Nurse etc)? If so, what are they?

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.....
.....
.....
.....

3.6.1 If you do use other services, how do you feel about them?

Very satisfied Satisfied Dissatisfied Most dissatisfied

3.6.2 What do you think could be improved in relation to any other services that are used by (name)?.....

.....
.....
.....
.....

Section Four: The Possible Value of Doctors letters

I would now like to ask you about the usefulness of having copies of any letters between their GP and the health services that have dealt with the person with Dementia that you care for.

4.1 How helpful do you think it would have been for him/her to have copies of the letters?

Very helpful Helpful Not sure Unhelpful Very Unhelpful

Why do you think this is so?.....
.....
.....
.....
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.....
.....

4.2 How helpful do you think it would have been for you as the carer to have copies of any such letters?

Very helpful Helpful Not sure Unhelpful Very Unhelpful

Why do you think this is so?.....
.....
.....
.....

4.3 Based upon your experiences as a carer to date, what kind of information should such letters provide at different stages of the illness?

What do you believe is needed at the initial assessment stage?.....
.....
.....
.....

What information would be helpful in the later stages?
.....
.....
.....
.....

4.4 What could best be done to help you understand Dementia and care for him/her?
.....
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.....

4.5 What would happen if the letters sent to the person you care for, or yourself, were only in English?
.....

.....
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.....

4.6 Would you prefer the letters to be in another language? YES [] NO []

If so, what language?.....

4.7 Would it be best to send any such letters to the person for whom you care, or to you as the carer, or to someone else, or a mixture of these?.....

Would the stage of Dementia affect this? YES [] NO [] If so, in what way?.....
.....
.....
.....
.....

Section Five: Your Experiences of Social Services

5.1 Since we last spoke to you, have you had any other additional services from Social Services? YES [] NO [] If yes, what are they? (List the services provided or funded by Social Services currently supporting (name): e.g. home help, day care, social worker, respite stays, residential or nursing home, others (Please specify)

.....
.....
.....
.....
.....
.....

5.2 Was the process of getting the new services arranged?

Very satisfactory Satisfactory Unsatisfactory Most unsatisfactory

5.3 Were the new services organised promptly?

Very promptly Promptly Slowly Very slowly

5.4 Were the new services helpful/ relevant to (name)'s needs:

Very relevant Relevant Not really relevant Not helpful

Comments.....
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5.5 Was the help and assistance provided by the services right for you, the carer?

Comment.....
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5.6 What do you think would improve Social Services' process or services for older people with Dementia, particularly for those from minority ethnic communities

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Section Six: Experiences with Voluntary Organisations

6.1 If you and/or (name) received additional support from community/voluntary organisations since we last saw you? YES [] NO []

If yes, please list the organisations/groups currently supporting (name) voluntary /community groups e.g. Age Concern, lunch clubs, Alzheimer's Society, temple, church, others specify.....

.....
.....
.....
.....
.....

6.2 Was the process of getting the additional voluntary services arranged:

Very satisfactory Satisfactory Unsatisfactory Most unsatisfactory

6.3 Were the additional services organised promptly?

Very promptly Promptly Slowly Very slowly

6.4 Have the additional services been helpful/relevant to (name)'s needs:

Very relevant Relevant Not really relevant Not helpful

Comments.....
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.....
.....
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.....
.....

6.5 Was the help and assistance right for you, the carer ?

Comment.....
.....
.....
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.....
.....
.....

6.6 Have you been to a Carer's group meeting? YES [] NO []

If yes, what benefits or problems have arisen from such groups?

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.....

6.7 Based upon your new experiences since we last talked to you, what do you think would improve the services from voluntary agencies for older people with dementia, particularly those from ethnic minority communities?

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Section Seven: Further Needs and Reflections

7.1 Are there any other ways that you think any of the existing services could/should change so that they would be better able to meet the needs of people like (name) or their carers?

.....
.....
.....
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.....
.....

7.2 What new or additional services would you suggest might be considered to better help people with serious memory problems and/or dementia , and their carers, particularly those who come from minority ethnic communities

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.....
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7.3 Is there anything else you would like to add to what we have said already?

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.....
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Thank you for allowing me to interview you.

Date: