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**An Exploration of the Perceptions and Experiences of People of South Asian
Origin of Palliative Care Services in North Kirklees**

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1. INTRODUCTION

The Centre for Health and Social Care Research at The University of Huddersfield was approached by the North Kirklees Primary Care Trust to undertake an exploratory study of the perceptions and experiences of people of South Asian origin (as the largest minority ethnic group) of palliative care services in North Kirklees. The study, funded by the Department of Health will be delivered by the University of Huddersfield.

The research was conducted across the North Kirklees Primary Care Trust. Ethical advice was provided by the University of Huddersfield Human and Health Sciences School Research Ethics Panel and ethical and research governance approval for the study was given by Wakefield District Research Ethics Committee and Calderdale & Huddersfield NHS Trust Research & Development Department.

The aim of the research was to present an overview of current palliative care service provision; identify gaps in this provision; provide examples of good practice and a summary of the subjective understandings of service users, carers and community members from the South Asian community about the care of people with advanced incurable disease, at the end stages of life and their need for services.

It was furthermore anticipated that through the dissemination of the findings, this research would enhance the knowledge base of Palliative Health Care Professionals in relation to minority ethnic culture, knowledge, which may be applied to the subsequent development of culturally sensitive services.

2. RESEARCH AIM

The research aims to present an overview of current palliative care service provision; identify gaps in this provision; provide examples of good practice; and to explore the perceptions and experiences of people of South Asian origin living in North Kirklees, about the care of people with advanced incurable disease, at the end stages of life and their need for palliative care services.

2.1 Objectives

- To produce a review of existing literature with examples of best practice in palliative care services for minority ethnic groups and people from South Asia specifically
- To identify examples of best practice through direct observation and networking
- To explore the views and perceptions of palliative care service providers on current service provision for people of South Asian origin
- To explore the perceptions and experiences of palliative care services of users and non-users from the South Asian community.
- To examine the fit between service providers and users views concerning the availability and effectiveness of palliative care services for South Asian people living in North Kirklees.
- To consider the implications of the findings for Palliative Care Service development.

3. BACKGROUND

Palliative care, according to Sepulveda et al (2002p.94), is ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’

Palliative care services have developed across the United Kingdom to reflect this approach. Initially much of this development was outside of the National Health Service (NHS) resulting in regional variations in services offered. Despite an increase in NHS funding for palliative care services, such variations apparently persist. (National Council of Hospice and Specialist Palliative Care Services, 2000)

Whilst availability varies nationally, the Parliamentary Select Committee on Health (2004) notes that only a small number of referrals to available palliative care services are from black and minority ethnic groups. Having considered (albeit somewhat limited) research findings, a number of suggestions are made to explicate the low referral pattern, including:

- *Certain types of cancer are less prevalent in these populations*
- *Services are culturally insensitive*
- *A perception that palliative care services are available only for white middle class patients*
- *A lack of information provided to minority ethnic groups, and a lack of translation facilities*
- *The hospice movement grew out of the Christian charitable movement which is not always perceived to be receptive to other faiths and cultures. For example, hospices are often named after Saints*

From the above suggestions, perception and communication appear to be major factors affecting referral / uptake of palliative care services. Cultural insensitivity is referred to somewhat more explicitly as 'cultural incompetence', by O'Hagan (2001), who asserts that the two most conspicuous characteristics underpinning culturally incompetent services to ethnic minority groups include: a lack of knowledge and understanding of cultural and religious issues; and a lack of effort on the part of individual professionals and their agencies to do anything about it.

Whilst definitive research in this area is lacking, it would appear from the available literature (for example DoH 1995, Gatrad & Sheikh 2002), that there is a consensus of opinion regarding both the significance of service provider's knowledge and attitudes and user perception. A number of recommendations are made concerning further education and training and the need for better dialogue by palliative care providers with user groups from minority ethnic communities. (For example NICE and Kings College 2004).

Such recommendations were reflected in the request for this research study. North Kirklees Primary Care Trust has been funded for a research project to investigate reasons for the lack of uptake of palliative care services by the minority ethnic communities living in North Kirklees.

It is anticipated that the project will generate a number of recommendations for North Kirklees palliative care services in order to improve access / uptake for these groups.

4. RESEARCH METHODOLOGY

4.1. Literature Review

A review of existing literature was undertaken in order to:

- Produce a review of existing literature and best practice
- Explore appropriate cultural perspectives of health and illness
- Identify ethnic minority levels from demographic/census data
- Utilise relevant information from the review to inform the development of a semi structured interview schedule

4.2 Qualitative Study

In order to produce rich data for the given research objectives, a qualitative study was designed. The essence of qualitative research is for people to learn from an individual's voice and experience. Hence the study aims to explore the views and gain an understanding of the subjective meaning attached to incurable advanced disease and palliative care of South Asians in North Kirklees.

The study was divided into the following phases:

Phase One

The first phase was concerned with inviting providers of palliative care services in hospital and community settings, to take part in individual semi-structured interviews. It was anticipated that each interview would last an hour and would explore the views and perceptions of staff on the current service provision for South Asians in North Kirklees. Staff would be asked about the current situation, to identify gaps in provision and to suggest areas where progress and further action should be taken.

Sample and Recruitment of Participants for Phase One

Sampling was purposive in order to address the research objectives. It was decided that 5 community nurses, (to include MacMillan Nurses and others who provide specialist palliative care services), 5 hospital nurses and 5 hospice nurses would be recruited to the study. In the first instance an introductory letter with instructions regarding the sampling strategy, would be sent out to the main contact person, who had agreed to identify participants and to post information sheets out in the envelopes provided. Once participants had the information sheets they were asked to read them carefully and discuss with others if necessary. The information sheet gave details of the research, aims, background and information on what the subjects' participation would involve. Once they had decided to take part in the study, respondents were asked to contact the researcher who would then arrange an appointment for the semi-structured interview. It was therefore anticipated that fifteen interviews would be conducted with service providers who represented the spectrum of available palliative care services in both hospital and community.

Phase Two

The second phase of the research was concerned with the views, perceptions and experiences of ethnic minority service users and family/carers about services for people who have symptoms related to incurable advanced disease and care in the end stages of life. The interviews would also be used to obtain information on the current quality and accessibility of the palliative care services. Participants were to be invited to take part in semi-structured interviews. It was envisaged that each interview would last an hour. An interpreter who had been trained to use the interview schedule would accompany the researcher if a problem with communication had been identified. Where possible the researcher conducted the interviews which were tape recorded. Should there be language difficulties; the interpreter would conduct the interview. Following this, the researcher discussed and made notes on the main issues arising from the interview with the interpreter. Transcription and translation (where necessary) of tapes was performed by an independent translator.

Sample and Recruitment of Participants for Phase Two

To identify an appropriate sample, contact was made with District Nurses, who have considerable involvement with palliative care. The researcher arranged to meet with the district nurses to explain the research and background to the study and to enlist their help. To obtain a variety of perspectives, patients and their carers would be recruited according to age, gender and diagnosis. That is:

- 2 male patients under 60, one with a diagnosis of cancer and one without a diagnosis of cancer
- 2 male patients over 60, one with a diagnosis of cancer and one without a diagnosis of cancer
- 2 female patients under 60, one with a diagnosis of cancer and one without a diagnosis of cancer
- 2 female patients over 60, one with a diagnosis of cancer and one without a diagnosis of cancer

Once agreement was obtained, the researcher arranged to leave the participant information sheets with the District Nurse for distribution. District nurses were asked to confirm whether potential participants were aware that they are terminally ill. Once participants had the information sheets they were asked to read them carefully and discuss with others if necessary. The information sheet gave details of the research, aims, background and information on what the subject's participation would involve. Once they had decided to take part in the study they were asked to contact the researcher within a specified time frame of two weeks. When contact was made, an appointment was arranged for the semi-structured interview.

It was decided that if insufficient numbers were recruited in this way, contact would be made with the Day Care Hospice to try and recruit more people to the study.

Phase Three

It was planned to hold three focus groups with a cross-section of the local South Asian community on their views of services for people who have symptoms related to incurable advanced disease. These groups would also be used to obtain information on the current quality and accessibility of the palliative care services. Where possible the researcher conducted the focus groups which were tape recorded. If there were language difficulties; the interpreter assisted the researcher in conducting the groups. Following this, the researcher discussed and made notes on the main issues arising from the groups. Transcription and translation (where necessary) of tapes was performed by an independent translator.

Sample and Recruitment of Participants for Phase Three

In order to gain access to the local community, contact was made with community based day centres. These centres are not within National Health Service provision and no access to any medical records was required. The researcher worked with staff from the community centres to explain the research and background to the study and to enlist their help. They were given information sheets to distribute containing details of the research, aims and background and information on what the subject's participation would involve. Those who decided to participate in the focus group were asked to contact the researcher who would then arrange an appointment. Initially it was planned to conduct one focus group at a community day centre; following which, the potential for more would be decided.

5. DATA COLLECTION AND ANALYSIS

The questions were designed to cover the research objectives. It is important to note that the interview schedules were used as guides. Other questions were added or amended throughout the individual interview process as a result of the participants' responses.

All generated data were transcribed and analysed by the researcher. Concepts were identified which were then grouped into themes. Thus themes relevant to the phenomena were identified as well as allowing the potential for new themes to emerge.

In order to address quality issues an independent person verified the process of concept and theme identification. It was decided that the final research report would be available for all participants, service providers and other health and social care professionals.

6. LITERATURE REVIEW

ACCESS TO PALLIATIVE CARE SERVICES BY THOSE FROM ETHNIC MINORITY GROUPS

Aim: To review existing literature and present a concise summary of best practice initiatives.

Issues Explored: Definitions of palliative care
The concept of a ‘good death’
Definitions of ethnicity
Demographic data
Cultural Issues
Access & uptake of services by ethnic minority groups

Defining Palliative Care: Clark 1993, Baker 2002, Twycross 2003, WHO 2005

A consensus of opinion is noted pertaining to the definition of palliative care from a range of literature consulted published between the years 1990 – 2005

These definitions identify the following issues as being part of palliative care:

- *Improving the quality of care for the dying*
- *Adopting a multi-professional approach to reflect that dying is a psychological, social, spiritual process as well as physical*
- *Is concerned with active, holistic care when disease is no longer responsive to curative / life prolonging treatments*
- *Promotes effective symptom management*
- *Emphasises patient choice*

A Good Death: Lugden & Kindlen 1999, Twycross 2003, Sandman 2005

From the literature it is apparent that there is an accepted notion of what constitutes a 'good death' which includes the following characteristics:

- *To die with dignity*
- *To have a choice of location, whether that be at home or in hospital. There is evidence that people would choose home but hospital deaths remain high. (NB surveys need scrutinising for sample details as samples may be unrepresentative i.e. it may not be terminally ill people who are asked)*
- *The significance of the effect on relatives / carers – how a person dies lives on in the memory of their family*
- *Debates concerning the value of suffering and the importance of consciousness until the end of life*

Defining Ethnicity: Gerrish et al 1996

- *Ethnicity includes culture, language & shared ancestry but is also determined by a person's self identity*
- *The term 'Ethnic minorities' implies heterogeneity yet each community has wide variations of beliefs and culture*
- *It is preferable to use the term 'cultural pluralism,' 'multiculturalism' or 'diversity'*

Demographic data: ONS Census 2001

According to recent census data, South Asians (Indian, Pakistani and Bangladeshi) are the largest minority ethnic group in Kirklees, representing 11% of the total population

Cultural Issues: Clark D 1993, Gerrish, et al 1996, Mac Lachlan 1997, Clark & Seymour 1999, Somerville 2001, Gatrad et al 2003, Ahmed 2004, Firth 2005, Luff & Oliviere 2005, Szczepura 2005

Culture is generally defined as a set of guidelines for living in the world, which is dynamic and changing, especially when confronted by different world views. It provides a means of communication with those around us and is referred to as the 'lubricant of social relationships.' Cultural identity is often underpinned by physical appearance, dress norms, religious beliefs and customs and influences individual perceptions of health & disease, death & dying

The above authors emphasise the following points in relation to culture:

- *The importance of resisting stereotyping people whose behaviour will conform to an abstracted 'cultural style'*
- *Many minority groups belong to collectivist societies in which the individual is seen in terms of a relational or familial self*
- *Stereotypical conceptions of specific ethnic communities have resulted in naïve & false assumptions about availability of 'traditional' patterns of support*
- *Many elders of such groups can experience the triple jeopardy of poverty / racism & poor health & may have no-one to care for them*
- *Religion is a vital part of culture which often regains significance at times of terminal illness*
- *Religion provides meaning & strategies for coping with suffering & death*
- *There are wide interpretations of Islamic beliefs related to death and dying*
- *Cultural & religious beliefs of patients may act as a barrier to the provision and discussion of end of life care and the ability to make use of services*

- *Some Asians may not access services because the family may fear that the patient will be institutionalised*
- *Variations between Muslim communities in Egypt & Bali illustrate the significance of culture in the response to death (overt expression v complete containment)*

Access to Services:

Department of Health 1999, NCHSPC 1999. Daddy and Clegg , 2001, Select Committee on Health July 2004 , Ledger S.D, 2002 Nyatanga B 2002 and House of Lords July 2005 BBC News 2005

- *Only a small number of referrals to palliative care services are from black and minority ethnic communities*
- *Certain types of cancer less prevalent in these populations*
- *Services are culturally insensitive*
- *There is a need to involve members from minority ethnic groups in the planning and delivery of services*
- *Perception that palliative care services are available only for white middle class patients*
- *Lack of information provided to minority ethnic groups, and a lack of translation facilities*
- *Hospice movement grew out of Christian charitable movement which is not always perceived to be receptive to other faiths and cultures. (Often named after Saints)*
- *Marie Curie hospice in Bradford able to accommodate 250 people who came to grieve for an Asian woman who had died*
- *Current study in Warwickshire to address how inequalities relating to ethnicity in palliative care services can be addressed*
- *Good examples of specialist palliative care found in respect of black and minority ethnic users, such as liaison project workers, and individual access projects. However, the report comments upon the difficulty in mainstreaming best practice. This would appear to be due to the amount of uncoordinated and 'ad hoc' activity*

Hospices and palliative care services need to provide culturally sensitive services and develop policies and systems to meet future requirements. These include the following issues:

- *Recognition of the legal issues (informed consent & negligence) involved when communicating with non-English speaking people*
- *Be aware of the evidence that among South Asians in the UK, the ability to speak English is lower for women than men*
- *Appreciate the problems associated with communication and ensure greater availability of translator and interpreter skills*
- *Utilisation of appropriate interpreters i.e. not young children*
- *Improving signage in palliative care settings to meet European standards of intelligibility*
- *Recognising the limitations of written information and making alternative provision such as liaison workers, audio-visual materials and the use of local radio stations to convey information in the local first language*
- *Addressing the values and health belief systems of different cultures*
- *Providing appropriate and acceptable diet*
- *Ensuring a better dialogue by palliative care providers with user groups from minority ethnic communities*
- *Patient profiling must be mandatory in a environment with a small and diverse cultural and religious population or such groups will be entirely overlooked*
- *Extending the hospice at home service and developing a strategy of recruiting from minority communities*
- *More people to be given the choice to be treated at home*
- *Partnership between voluntary sector and government*
- *Commitment to more research into minority ethnic needs to support service development*

- *The importance of providing appropriate and accessible information to those communities is emphasised*
- *Instigating processes for ethnic monitoring*
- *Ensuring more consistent referral arrangements from General Practitioners and hospitals*
- *Raise cultural awareness through staff training*

Future Research: Supportive and palliative care for people with cancer (NICE& King's College 2004)

This Report comments on the limited amount of research into the preferences of limited amount of research into the preferences of individuals from different cultures with respect to interventions:

- *Research should focus on effective solutions rather than re-assessing need*
- *Service development should be set within rigorous evaluation frameworks*
- *Make available a national core set of accredited information materials in translation*
- *Provision of effective training*
- *Adoption of the spiritual and religious care competencies (Marie Curie Cancer care)*

Examples of 'best practice'

- *Macmillan Ethnic Minorities Liaison Officer – Bradford community palliative care team*
- *Bilingual health-care worker – Bradford*
- *Multi-cultural Link Palliative Care Nurse Rotherham*

Key Reports:

Opening Doors: Improving access to hospice and specialist palliative care services by members of the black and ethnic minority communities (National Council for Hospices and Specialist Palliative Care Services, 1995)

Study of Black, Asian and Ethnic Minority Issues (Department of Health 1999)

No Exclusion Clause Project: Opening doors to better palliative care services for people from culturally diverse communities (DoH 2004)

(A project designed to raise awareness amongst minority ethnic groups of the palliative care services and the potential benefits of accessing them)

**United Kingdom Parliament
Select Committee on Health Report (July 2004)**

7. FINDINGS

PHASE 1 – SERVICE PROVIDERS

7.1 Sample

Recruiting service providers began as planned; however, it soon became apparent that the multi-professional approach to palliative care espoused within the literature was indeed reflected in practice. Following discussion with the steering group the sample was expanded to include representation from religious leaders, bereavement officers, clinical management and general practitioners – all of whom are involved to some degree, in providing palliative care services within North Kirklees and whose views were considered to be of significance in relation to the research.

Twenty interviews with service providers were conducted over a three month period whilst simultaneous interviews were held with service users, carers and focus groups. This proved advantageous in comparison with the more linear approach originally planned, as each phase of the research process could inform the other. The findings also include responses from three General Practitioners who were unavailable for interview but wished to express an opinion via email.

Participants were asked to comment upon their experience in providing palliative care services to people of South Asian origin, to identify any problems with providing the service and to make suggestions regarding future development. The findings are therefore presented in relation to the specific areas explored within the interview.

7.2 Individual experience within the palliative care service

All those interviewed had experience of providing palliative care services to people of South Asian origin although some had more than others. In addition, not everyone regarded themselves as having a direct role although they did get involved with such patients when required.

An example of this was a Muslim chaplain who said:

'I would visit [the day hospice] if asked....if there were any questions regarding Islam which Richard [Church of England chaplain] couldn't answer

He did not visit regularly as there was no identified need; however, later in the conversation it became clear that the notion of 'palliative care' was contestable and he was not clear about what services were covered by the definition.

'Am I right in understanding it's people who have got cancer or people who have got (pause)....very serious....?.'

This is perhaps not as unusual as it first seems, as Professor Aziz Sheikh from Edinburgh University (BBC News 2005) notes that migrant communities in Britain are typically younger and have proportionately higher death rates from diseases not related to cancer. He describes palliative care as a 'relatively recent' phenomenon which focuses on providing services for the elderly dying from cancer and suggests that it is therefore understandable that there is a lack of awareness among the Asian population. It seems somewhat contradictory therefore, to read about expanding palliative care services in India (Asia Pacific Hospice Palliative Care Network, 2005) and Donna Spencer Dugdale who went to Pakistan to work in a palliative care ward in 2003 although she does state that this was in an early stage of development. Nevertheless, amongst service providers in North Kirklees, there did appear to be some confusion concerning what these services actually are and who they are for.

Others involved in the provision of palliative care services, such as those in senior management positions, perceived themselves to have a less direct role, yet acknowledged their influence over strategic development of such services.

'I rely on my ward managers to deal with day to day issues and to let me know if there is anything they can't handle.....they haven't flagged anything up.....I know the information leaflets need updating but I haven't had time to look at them.....As for other problems, I don't know, I've never really taken the time to find out.....'

An interesting contrast in perception of role at this level is seen in the responses by a director of hospice services. Whilst certainly a senior manager, the responses given to

questions regarding personal experience or problems encountered, did not rely on secondary reporting by more junior staff. There seemed to be a shared sense of identity with those who are providing the care, as illustrated in the possessive pronouns which peppered the conversation, for example, ‘a lot of **our** care’ and ‘**we** have of course to be mindful’.

For others who are involved in the provision of these services, the role is both direct and indirect. The district nurses all had experience of caring for those with palliative care needs although involvement with those of South Asian origin was much more limited. The Macmillan nurses saw themselves as having a dual role, of providing specialist advice for general nurses and medical staff yet also acting as the key worker for some individual patients.

7.3 Problems identified in provision of services for those of South Asian origin

7.3.1 Communication

Without exception, all twenty service providers referred to problems of communication with this client group.

‘I suppose the huge thing is communication, particularly in the female population...a lot of the ladies I have seen speak only a minute amount of English,
(Macmillan nurse)

‘Achieving communication with any patient is an essential component of any and every episode of care. This basic component is even more essential when the care relates to that of a dying patient.
(GP North Kirklees)

‘I think one of the reasons that the Asian patients attendance falls down is because of the language difficulty and in amongst that group anybody with language difficulties, any other minority group like Polish, people who are deaf, if there is a reason why people don’t attend day care its often because they miss the general conversation’
(Sister, Day Hospice)

the big problem would be language.....maybe 20 years down the line I don’t envisage the same kind of a problem’
(Muslim chaplain)

This certainly reflects the national situation which has been reported upon by many researchers (for example DoH 1995, Parker 2000).

Gerrish (2001) highlights how ethnic minority patients who are not fluent in English are disadvantaged when there is limited use of professional interpreters and concomitant reliance on family members to translate.

Using others to interpret was similarly identified as an issue

'Language can be a problem, but there is usually a family member who can help'
(District Nurse)

'We have had to have instances where some of the younger members of the families have to translate because a lot of the elderly palliative care ones that I have been to can't speak English properly so they have had to interpret for us.'
(District Nurse, Palliative Care Team Leader)

'I suppose the huge thing is communication, particularly in the female population...a lot of the ladies I have seen speak only a minute amount of English, so a lot of the conversation goes through another family member and if not I ask the Asian translation services which again often can be one to two to three week delay and that's no good really for patients'
(Macmillan nurse)

'That can be difficult at times... umm we have access to interpreter services but quite often the family will say 'oh well we will interpret' and then you are not always sure what is being passed on both ways really. That can be an issue sometimes but we will bring in interpreters if we feel that will be able to help the communication but then you lose some of the immediacy sometimes then I think. There are times when you need to do things or address things with patients like immediately to help them and that can cause problems.'
(Macmillan nurse)

.....interpretation can cause problems becauseeven without communication you can tell when a patient is in pain but the family member is saying 'oh no he hasn't got any pain' so it is very difficult to manage that.
(District nurse)

'it's the biggest problem that we have and if they come and they don't speak English, they don't come with an interpreter you know or they bring a child to interpret. I mean trying to explain things to a child to then explain to the mother. You know you might actually be talking about a diagnosis of cancer or something like that and it's really, really difficult'
(Macmillan nurse)

. We have patients where they have been like dropped off by someone, they are sat in the corridor, they don't speak English, you need to talk to them about treatment, you are talking about chemotherapy, radiotherapy, things like that – its impossible.
(Breast Care Nurse)

However, this was not so for everyone

Well I don't have communication problems. I understand them, what they saying because I am coming from that part of the world myself.
(GP North Kirklees)

This doctor did emphasise that he had made the effort to learn this particular dialect in order to be able to communicate with his patients.

The influence of culture in the communication process was evident in much of what service providers had to say. Gender issues and the position of women were referred to, for example:

'Their husband will come and take over the conversation you know, even though it's about them and they can speak English.... a lot of them can ...and understand English but they will still... you know have the conversation with the doctor about what has been happening to them so there is always that.'
(Breast Care Nurse)

We have had ladies come through GPs where they have not even been examined because its been a male GP and they have said, they have gone to the GP with a lump or a suspected lump, the GP had said you know 'I need to examine you' Oh no, no' the husband says 'oh no, no' so they send them to hospital.
(Breast Care Nurse)

These are certainly challenging situations, and whilst there is some evidence of a shift in cultural values, these examples reflect a traditional Asian perspective on gender roles. (Katbamna et al 1998)

7.3.2 Cultural Issues

The role of women

Cultural issues featured highly amongst the problems encountered by all of the service providers. Without exception, all participants made some reference to the role of women in the home and the challenges that brought. One senior nurse talked about a female patient with cancer:

'...her husband was much older than her. She had a young child. Now up until literally the day this lady died she had excruciating problems with pain, body image with a variety of... you know....huge issues. She was still cooking, cleaning, ironing and there was no sort of way we could get anything like home care, or I don't know any kind of support in for that lady, because it was, I don't whether it was the assumption but she just continued running the household.'
(Macmillan nurse)

This is perhaps unsurprising as Katbamna (1998) reminds us that many women marry, fully expecting what to some may be considered a subservient role. The notion of

Seva, a duty to one's husband, continues to exist despite a woman's own illness. The gender-based division of responsibility for caring similarly persists and is perhaps well illustrated in this example. The woman still regards it as her duty to care for her child up until her own ill health made it absolutely impossible.

Health Beliefs

Culture similarly influences what each of us believes about life and death, which, according to Somerville (2001) will affect the nature of services desired. Given that the majority of service providers in this study were white and English, it could be argued that their perception of need would differ from those of South Asian origin. However, those participants of South Asian origin, identified some interesting issues associated with health beliefs

Beliefs about illness, causation and prognosis can differ widely across cultures. Apparently there is no distinct word for either cancer or palliative care in the languages spoken in South Asian countries. Instead the English words are used. There seems to be a strong fear associated with cancer

'...cancer is such a word that they think: 'hang on they are going to die tomorrow' – they don't even give it a year
(Muslim chaplain)

This fatalistic view was found to be present by Roy et al (2005) who studied the use of denial in an ethnically diverse British cancer population. Using the Mental Adjustment to Cancer scale, he found that Asians had more significant hopeless / helpless scores and were also more depressed than the white Caucasian patients in the study.

Such views could have been shared by the Asian GP, who, when questioned did not seem to understand what palliative care involved. His interpretation of the term equated more with those patients who had long term conditions, such as diabetes and hypertension. In our discussion, the only patient he identified with breast cancer was actually in the first stages of treatment (having just had a mastectomy), rather than requiring palliation.

Alternatively, it could be argued that such apparent ignorance concerning palliative care at the end of life actually reflects an opinion that it is not a medical issue at all. Siriwarvena (2004) discusses the medicalisation of death in western society as a philosophy not shared by Asian cultures who, it is asserted, demonstrate a preference for aggressive care in illness but accept death as inevitable, a gift that enables them to be with God. Siriwarvena describes the belief in this culture, that the process of dying can sometimes be very painful. Various rituals are then discussed, such as the 40 days of mourning and the significance of the 3rd, 7th and 40th day. Interestingly, following this discussion, the author reminds us to avoid a 'cook book' approach to care at the end of life and emphasises the importance of respecting the rights of individuals.

Another GP, well acquainted with palliative care, refers to the difficulties which can arise as a result of differences in health beliefs:

'There are fundamental differences in the Asian health care culture compared to the average Yorkshire Anglo Saxon. In expressing emotional problems somatisation tends to occur e.g. 'total body pain' which is often expressed as the definitive problem has (frequently) nothing to do with pain per se; as a concept to most doctors it is a symptom without meaning and therefore will tend to lead to the patient's global problems being at best minimised or at worst dismissed altogether as it is not in pure physical terms a statement that has any meaning.....I am trying to say that we need help in understanding what exactly such patients are saying and their means of expressing themselves. Without this, we tend towards a vetinary [later clarified to mean 'best guess'] approach to their problem management'
(GP North Kirklees)

This respondent is a GP and also works as a professor of General Practice at a major University Teaching Hospital. It is therefore noteworthy that despite his extensive experience, he openly acknowledges a lack of cultural awareness - a lack which is acknowledged by other health professionals within this study.

Whilst acknowledging this lack of cultural awareness, all participants commented upon death and rituals associated with death amongst the South Asian population they had cared for. For one district nurse, it was dying that was the central issue:

'.....They can cope with death. It's the dying they can't handle'

She felt that there was a large amount of denial associated with dying which could influence access to palliative care services, for to ask for help would mean acknowledging dying. Such attempts at analysis are interesting given that they may be made from a western ideology and therefore not necessarily accurate.

Role of the Family

All twenty of the service providers believed the family had a very significant role in the management of health and illness. All but one of the participants, including those of South Asian origin, believed that services were not accessed because the family preferred to provide the care themselves:

'...because you've got this family network, they would rather stay at home as opposed to coming here (day hospice)
(Senior Islamic religious Leader, North Kirklees)

I think because there is a large extended family that they tend to care for their own and when we have been in they have been very nice and very polite with us but you get the feeling they just want you to come in and do what you have to do and go again and they can deal with everything else.
(District Nurse)

When asked what specific behaviours made the nurse feel like that, she replied:

They stay in the room... umm, which can be a little bit uncomfortable when there is quite a lot of people in the room with you

This was also felt to hinder the assessment process

'...makes it difficult to actually get to the bottom of what the patient sees as priorities for them - usually with family members around which is fine if that gives the patient support but there is always this worry that you are not actually getting to the bottom of what is important for the patient themselves really.'

The belief that Asian people: 'look after their own,' is not unusual and reflects stereotypical views which may not necessarily be true today. It is interesting however, to note the comments in the Department of Health Study in 1999 (p21) that 'today there is greater awareness of the variations in need between individuals within similar communities'

In contrast, a hospital nurse believed that Asians would accept interventions in the home:

'She did want to go to the hospice but her family talked her out of it. It was all arranged for her.... It was all arranged for her and suddenly all the family arrived and said 'no – she coming home....., I think again its 'we look after our own, we don't need this sort of intervention'. They are quite happy for you to have the intervention in their own home, you can go to them but I think they like to look after or be seen to be looking after.....'

There was also the feeling expressed by a South Asian participant that the family may think they are no longer loved if help is sought from elsewhere. This was referred to as:

'Emotional blackmail. So to a certain degree, yes the kids may feel that they are obliged to look after them'
(South Asian hospice care assistant)

The notion of obligation and duty referred to within the literature was certainly apparent within this study

Change is occurring however, within these communities. A degree of westernisation is detected by service providers who note that the extended family no longer necessarily all live together

'...you always feel that most of the Asian people are very close, a family knit group, they are always there for each other but that isn't always the case'

The Community

The Muslim chaplain emphasised the importance attached by South Asians to the opinions of others if they were to receive help from outside the family or Mosque:

'Oh, what will my neighbours think, what will Mr Jones think, what will our community think'

Such feelings are considered by Katbamna (1998) in a study of Asian carers who reported feelings of being bound by expectations, not only from those they

were caring for but from immediate relatives, family and community. They believed they would be 'talked about' if they did not fulfil their duty and when they had accepted help, felt guilty.

The Muslim chaplain also stressed the role of the community in illness:

'the other thing is that if you are very very poorly quite a lot of people would actually come and visit your home and if you are missing from 9.00 to 3.00 they are wondering 'what's happening' – that could be a factor'

The community would therefore seem to have a significant influence on individual behaviour, monitoring both actions and activity.

An interesting perspective was offered by the hospice director who referred to the lack of privacy which illness bestows:

'There is a lot more support available to people from the time of diagnosis now....it can create a lack of privacy sometimes, particularly for a person at home.....so many different health professionals going in, if there is not good coordination between those professionals the patient can feel a bit overwhelmed and confused'

Food

The importance of food within the South Asian culture was remarked upon by the Muslim chaplain as a reason for not seeking day care services.

'Most of the food in our homes is cooked fresh....the Hal-Al food that comes here is reheated so it's not something they're actually used to...especially for the sick and elderly, food is a major part of the day'

Other service providers did not remark upon this as an issue.

Returning Home

Returning to the country of origin was felt to be a significant issue. Some believed that people wanted to return 'home' to die although it was thought that this would not be an issue for very much longer as people would not have relatives living in South Asia in the future.

Personal Hygiene

The Muslim chaplain made explicit reference to matters concerning personal hygiene and praying as potential reasons for not accessing services

'....another problem is of toilet facilities because most Asians tend to use a squatting pan....it is very important to that patient who wants to do his prayers that if the wee comes back onto his clothes will he be able to wash it and that's another problem.....some of the facilities may not be as conducive for the patients'

7.3.3. Health & Safety

A number of participants referred to health and safety issues when caring for South Asian patients which are worthy of note. The first involved having to remove shoes in the home. A district nurse said she did not go barefoot in her own home and therefore would not elsewhere, believing it to be 'Trust Health & Safety policy'

This could potentially cause problems as non-Muslims are advised to 'remove footwear before entering [a Muslim home]...' (Rabetah Al- Ulama – Islamiyyah 2004)

The other concerned a patient who was being nursed on the floor by the family. The district nurse who gave this example stated that she would visit but would be unable to offer any care as there was a health and safety issue for the nursing staff.

7.3.4 Awareness

Many participants felt that a lack of awareness of what services are available could be a reason why services are not accessed very much

'I don't think they are fully aware of the set up in terms of hospices and palliative care at the moment. I am sure as and when this is more exposed they will come more.....'

(Asian hospice care assistant)

'Does it cost or is it free?'

(Senior Islamic religious leader North Kirklees)

Not all participants felt that lack of awareness was a problem, illustrated by a district nurse who stated that:

'well, they seem to know enough about the benefits system don't they'

Another district nurse who drew a comparison with the use of Accident & Emergency services by South Asians

'I don't think so because in casualty the uptakes are very high....there's always been a lot of the Asian families going in there and accessing care and the leaflets and everything that are up are all you know translated as well...but I know of families who have their GP's own number, an Asian GP with his own number and if they needed anything they would ring him so I don't know if they access care directly and sort of cut out the middle man...'

These appear to be rather judgemental statements and perhaps indicate the need for more awareness training.

7.4 Suggestions for Future Service Development

There appeared to be a consensus of opinion in relation to developing the service:

- Improve interpretation / translation facilities
- Educate all staff in cultural awareness which all felt was lacking
- Educate GPs in relation to palliative care services
- Appoint ethnic minority liaison worker
- Link with local Asian communities through community and religious networks

8. FINDINGS

PHASE 2 – SERVICE USERS / CARERS

8.1 Sample

Given the identified problem that people of South Asian origin were not accessing palliative care services, it was not really very surprising that recruiting from that population proved challenging. The planned access route via District Nurses did provide a few people who were willing to participate but not sufficient to meet the identified criteria.

Further potential participants were identified by breast care nurses, GP's and members of the steering group. The final sample was as follows:

Service Users

- 5 female service users aged 33, 52, 55, 57, and 63
- 2 male service users aged 51 and 66
- Of these, only one had a diagnosis of cancer which was the 52 year old female
- The remainder of the sample had long term conditions such as heart failure and renal disease

Carers

- 8 female carers aged from 17 to 65
- 2 male carers aged 19 and 25

Interviews were conducted in people's homes. Most spoke quite good English and an interpreter was not therefore involved. Not everyone was willing to be tape recorded and in a lot of those that were recorded, the background noise made transcription very difficult. In anticipation of this, notes were also made of the conversations held.

Users and carers were asked the same questions concerning the nature of the illness, how they are managing the illness, whether they have been offered any help and if so, the reasons for acceptance or rejection of the offer. Finally, they were asked whether there were any services which could have been helpful but were not currently available. The findings are presented to reflect these specific areas.

8.2 The Nature and Management of the Illness

As mentioned above, most of the users interviewed had long term conditions such as heart failure or renal disease. Of the carers, 7 were actively caring for the users involved in this study whilst 3 were widows whose husbands had died from cancer.

Among the service users, there was a range of experience in managing their illness. All were prescribed some sort of medication which they obtained without problem and for most this included analgesia which provided pain relief.

Issues identified as causing a problem varied. For one young woman, it was the stigma associated with illness:

'...you know its horrible having to admit to having suffering from a medical condition – I don't know it just seems like you know that you don't want to be judged and looked at as not normal and you don't want to be looked at – you know....'

For her the most significant problem was being judged or labelled. The notion of 'admitting' to illness seemed to imply that it was something she had brought upon herself. Indeed, as a single parent, she had referred to herself as 'the black sheep' of the family. It may be that the notion of judgement reflected some feelings of guilt. This, as MacLachlan (1997) suggests, could be an indication of how human suffering is explained by different cultures in different ways.

When asked about the practical aspects of management, such as hoists, stair lifts, help with washing, her reply is interesting:

'oh yes, I was offered all those sort of things...mmm. Some people came to the house andI didn't, don't,....I could manage..'

Services had indeed been offered and refused. This patient wanted to manage on her own – even though she had to crawl upstairs sometimes – it was important to her to maintain her independence.

Services had also been refused by another family, who were caring for their father. He spoke very limited English, his problems were more acute and he was having serious

difficulty in coping. I spoke with his son and two daughters who were caring for him. They described the problems of living in one house sharing one bathroom:

‘..it takes him like two hours to get washed and nobody else can use the bathroom then..’

An occupational therapist had visited the house but was unable to offer any aids or adaptations. The family did not want help with personal hygiene, but rather wanted help to help him maintain some independence.

This same man was in a lot of pain. He wanted me to look at where it was hurting and lifted his night shirt to reveal a severely burned back. On questioning it transpired that he had been using a hot water bottle to try and ease the pain in his back. Despite his GP having apparently visited in the same week, neither the man nor his family were managing the illness well.

In the discussion which followed, when asked if there were any other services they would find helpful, it transpired that they thought their father would be most willing to accept such services as aromatherapy massage or head massage.

Randhawa (2003) asserts that a lot of the research suggests that minority ethnic patients who receive palliative care services in the UK are satisfied with the care they are given. He does, however, recognise that some studies reveal some ethnic minorities’ experiences to be far from perfect. The above example illustrates the latter experience and may influence not just one family’s perception of the service offered, but, given the significance of community networks among South Asians in this locality, the wider community who are involved with them.

Several participants referred to the role of their religion in helping them to manage the illness; ‘it is Allah’s will’ was frequently heard in response to a variety of questions. This is perhaps unsurprising as Katbamna (1998) explains the importance to Muslims of caring for the family, which they believe will result in rewards from Allah. Indeed, if the family do not fulfil their obligation, there is a belief that they will have to pay for this after their own death.

Some of the service users expressed a deepening of their faith following the diagnosis of a life threatening illness:

'I think religion plays a big part in it because, before my illness and during my illness I mean like I am a Muslim and I was religious but not very religious and like after my illness I did become quite religious.....praying...you know that's where we find ultimate peace which works – find peace in it, its good, it helps and that's the answer for everythingGod is making it better and for them that's the big pillar of support that gets them through everything, but what if it doesn't get you through. People generally expect that to be the only thing that they need to get you through and they say it's like waving a magic wand and that's it, no ifs, no buts, nothing else.'

This user then considers the role of the family

'...the relatives, the family and friends are the main people that help in situations like that and they are the ones who understand, they are the ones that we can open up to and talk to and you know come over and have a cup of tea and have a good chat with your daughter or with your son....'

Perhaps this reflects the system of Biraderi which exists in South Asian communities and described by Katbamna (1998). In Biraderi, support is based upon reciprocal relationships of moral, social and financial obligation,

However, this user continued by querying whether family and friends are actually the most appropriate people to help all the time as they may not have answers to all the questions which may arise, perhaps indicating a shift in perspective.

For two of the carers interviewed, it was approaching the first anniversary of the death of their husband. They discussed retrospectively how they had managed the illness but then the conversation changed to how they were managing by themselves now. It was understandably distressing for them to recall certain past events, but one woman was clearly not well herself. Her family were still in Pakistan and her husband's family had shunned her since his death. She had four children aged 12 to 21, 3 of whom were dependent upon her. She was not sleeping, not talking to anyone about her grief and had developed an addiction to mint sweets. She had not received any follow up visits after her husband's death. Interestingly, this woman had been suggested as a participant in the study because she was 'so westernised' and 'coped so well'. It may be that bereavement care is another area requiring attention. However, in response to this information, the support networks established in preparation for the research were contacted with the respondent's permission and hopefully she will now have received some help.

8.3 Meeting unmet needs / solving problems

Those carers whose husbands had died of cancer recalled offers of help when problems were identified. These were mainly problems associated with washing and dressing and toilet facilities.

'oh, yes, yes, yes....my husband was a very proud man....very clean, a perfectionist. He liked everything to beMary (District Nurse) arranged everything He had help to get washed and up every day, then help to get back to bed. He had a bath sometimes too...'
(South Asian Carer)

This man and his wife had lived in England for a long time but still had family in Pakistan. They both worked and he had been very active in the Mosque. Since his death, his wife had received a lot of support from the family, the community and the Mosque.

Similarly, the other carer whose husband had died of cancer had received a lot of help. For her, the main source of support was the social worker:

'...she arranged everything...she was very very good. I had all the help I needed and people came to sit at night with my husband...he just wanted to talk all the time'

All those involved in helping her had been white English. She spoke highly of them all for enabling her to continue with caring for her husband. This respect and reliance on support from health workers is commented upon in the research from the Social Policy Unit at the University of York (Hepworth 2003) who found similar comments made by carers although in contrast in that study, the carers preferred support from Asian workers and support groups.

The 'active' carers did not however; seem to be receiving adequate support for their problems.

'we had a woman round to assess the house, to see if we could have another bathroom. That's what we want....mm but she hasn't been back'
(Young female Asian carer)

When asked if this family would want any additional help in the form of social or personal care assistance they said no, they wanted to do those things for themselves.

This was true of the other carers as well. All of them said they were quite happy to do the actual caring but they would welcome support – either in the form of benefits or adaptations and equipment. Indeed, the confusion concerning benefits was encountered many times during this study.

The offer of hospice services was only identified by one service user

‘..and once I got the telephone call from, I think it was Kirkwood Hospice, that’s in Huddersfield, the problem with that is that I think they said I had to find my own way there and back so that was a bit disappointing because I was upset then thinking that I am not going to do it because it was just difficult for me to get there and then somebody else got back to me, I don’t know who it was, the person in charge of all this and she said that there was a similar thing at Dewsbury, the Rosewood Centre and they do offer a patient and ambulance service and its closer to my house and I was much happier to hear that and they told me that they offered aromatherapy – that’s initially what drew me to try it out.

I didn’t know what to expect when I came here, I just thought I’d get, I don’t know, a massage and that’s it – I didn’t know that it would be such an environment. When I first came I was really depressed and saw all these old people, I know it’s a horrible thing to think but I thought ‘Is this what I am reduced to’ you know not being able to do anything for myself properly because I couldn’t even go upstairs by myself or come down the stairs or anything because I had so much problems, you know with my arms and my legs after my radiotherapy and the memory for me is that there is no difference between me and an older person – there is no difference.

This first impression changed very swiftly and the service user was soon extolling the virtues of the day care hospice. The support required however, is not always physical as this service user identifies:

‘when you have had a serious illness, at the time you are diagnosed, from the time of diagnosis right through to the actual treatment, everybody is on top of you and you know all over you looking after you, asking, treating you with kid gloves and everything then suddenly you know when everything is over, when you have been treated then people just take a step back and they might assume everything is back to normal again or things are getting back to normal but I think the patient needs care and an after care programme I think because I think after you have been diagnosed with everything and after you go home you have more questions.....At the moment whatever questions I have I can come here and I get my answers from the people that I need my answers from but what if you stay at home and you don’t have anybody to answer your questions and that’s where the gap, you know the communication gap stops with Asian people because they don’t take that step forward. They have lots of questions, they probably ask family, they ask friends, relatives, but you know, do they know what they are talking about.’
(Young Asian Service User)

An ongoing need for information is apparent from this. There is also the suggestion that Asian people are reluctant to ask questions of health professionals.

For those who had died, there was some discussion concerning the place of death. Without exception, they were content with the location as long as they were able to be with them at the time of death. Where this had occurred in hospital, there had been no problem and they felt their needs had been met.

9. FINDINGS

PHASE 3 THE FOCUS GROUPS

9.1 The Venue

One of the venues was day centre providing information, recreation and education for the elderly who would otherwise be at home alone. They had accessed the service by word of mouth or read about it in the local Asian magazine. The other was a drop in centre for Asian people.

9.2 The Groups

Three focus groups were held. Community leaders recommended that separate groups were held for men and women as they would be more likely to talk openly in same sex groups. One focus group was comprised of men and the other two of women. One of the women's groups was a group of carers who met regularly for support.

The women did not seem used to sitting and listening or talking for long periods. They did indeed want to talk, but not necessarily about the subject in hand. Initially, one woman just sat and stroked my arm – it transpired she had lived in England for 22 years and had never touched a white skin. At various other points in the group, women would wander in and out, deal with a number of crying children and suddenly talk about something completely different. The propensity for gossip was noted amongst the women – they really enjoyed talking about other people's children – particularly young females who were allegedly misbehaving. This does support the comments made in other phases of this research pertaining to the concern about what other people will think. Gossiping was certainly a central feature within all of the focus groups.

Such digression made data collection and analysis extremely challenging. The participants in the groups represented the South Asian population but could not be considered representative as they were already accessing services themselves by attending the community centres. Notwithstanding this, some useful information was provided and is presented here according to the specific issues addressed within the groups.

9.3 Accessing Palliative Care Services

For all the focus groups, it was necessary initially to clarify exactly what was meant by palliative care services. Nobody actually admitted to having any one within the family who had suffered from cancer). Given the taboo associated with cancer amongst this population, is perhaps not surprising. They preferred to use the terminology previously identified by a GP, of ‘total body pain’. They did not seem to refer to conditions, but rather to specific symptoms. It was explained that palliative care was about symptom management for those with a life threatening illness. It seemed then that most people in two of the focus groups believed that they would actually fit into this category as they were attending a day centre.

When asked about their experience of accessing other services, one woman talked about her husband (now deceased) who had cancer. She spoke of the problems in travelling to Cookridge Hospital every day, where he was receiving radiotherapy. She did not drive and they had a limited amount of support from family and friends. She had never had an ambulance provided for this journey. Transportation problems were one of the issues identified by the Select Committee (2004) and are worthy of greater attention by service providers.

9.4 Problems identified in accessing services

9.4.1 Communication

Interestingly, just as the service providers ranked communication as being the most significant issue, so too did the Asian people in the focus groups:

‘It’s always a problem....there’s never any interpreters at the hospital...even if they have been booked they don’t always turn up.....’

Others similarly referred to the use of family members – for some it was acceptable but it seemed to depend upon the time of day, the illness involved and the age of the child:

‘You can’t keep taking a child out of school to interpret for you.....my daughter, she came....we waited and waited....she missed her science test...’

'children do not always have command of the language....they do not use the correct words'

This implies that misunderstandings can and do still occur when it may be thought that people understand.

In private individual conversations with four of the men it was revealed that they had, or knew someone who had, a sexual problem resulting from their illness and it was therefore wholly inappropriate to have their children acting as interpreters.

Some felt ignored because they were Asian when they visited hospital, and one woman said that everyone else was dealt with before her and that nothing was explained to her. She illustrated this with a description of what happened when she told the doctor that her knees were troubling her and he replied 'they will get better in the grave'

9.4.2 Using Equipment

There was a lot of discussion concerning equipment as many people either had aids and adaptations provided for themselves, or knew of someone in the family who had been provided with them. It was clear from the discussion that people were wary of, and cautious about, using equipment, They emphasised the need for training (not just a demonstration)for the family about how to use devices such as hoists and bath aids.

9.4.3 Food

The focus groups were conducted in the morning and always culminated in lunch. This was prepared with fresh ingredients on site. It was obviously a central focus of the day and the researcher and interpreter were expected to stay and share the meal. This proved useful as it clearly demonstrated the significance that food has in the life of the community Lunch is eaten slowly with much conversation – much of which

was about the food itself. Men and women referred to the poor quality food available in hospital and how they felt it was frowned upon if they took food in for their family to eat.

9.4.4 Benefits

Gaining advice on how to claim benefits was of great importance. People felt they received such information at the day centres and were grateful for it. One question raised during the focus group concerned attendance allowance and whether benefits were reduced if you accessed services. The room went silent when this question was asked – as if everyone really wanted to hear the answer. Perhaps this is another reason why South Asians are not accessing the services if they fear their benefits will be reduced.

9.4.5 Family

There was a general consensus that the family was more involved in caring for Asian people than is the case with English families. People said that family care would be their preference and reflects the Biraderi (Katbamna 1998), considered earlier, but interestingly the group also discussed whether services would be needed by those who live apart from their family as this was indeed becoming more common.

9.4.6 Hygiene Issues

Several of the focus group participants, men and women, made reference to cleanliness in hospital. The toilets particularly were often referred to as being dirty and needing cleaning. Whilst this may not seem unusual given the recent publicity concerning hospital cleanliness in the UK, it is, as has been discussed earlier, of great significance to Muslim patients

10. DISCUSSION

Some views common to both service providers and service users/carers are considered initially, followed by a comparison between the views and perceptions of service providers and service users / carers

10.1 General Issues

10.1.1 The Concept of Palliative Care

Perhaps the issue of primary importance is the contested nature of the term 'palliative care'. Indeed, Koffman & Camps (2004) assert that there is an urgent need to raise public awareness of palliative care services and to provide public education about the care provided, to reduce any misconceptions that may be influencing access. In this study, there seemed to be some confusion among the health professionals, concerning who palliative care is intended for and what services are actually available. The various definitions within the literature all appear relatively straightforward and comprehensible. However, when faced with people from a completely different culture some of whom do not share a westernised conceptual framework in relation to medicine, the limitations of these definitions become all too apparent. Every effort was made to ensure that those who participated in this study understood its nature and focus but, as with any form of communication, it cannot be assumed that a shared meaning was achieved.

10.1.2 Beliefs about Death & Dying

Clark (1993) reminds us of the wide interpretation of Islamic beliefs about death and dying. As with most religions, people of the same faith may not share the same interpretation of that religion. For example, for Egyptian Muslims, the public expression of grief and sadness associated with death and dying is considered good practice, whereas for Muslims in Bali it is considered better to contain the emotions. This should be remembered when considering the findings of this research and the subsequent implications for practice. Those service users and carers who participated

in this research did reflect the differing interpretations and spectrum of beliefs and as such has implications for any cultural awareness education which is planned.

10.1.3 Hope

During the research it became apparent that there may be a relationship between accessing / accepting palliative care services and losing hope. Future research could usefully explore this in much greater depth, but to do so would present problems of a different nature. I had been told by an Islamic religious leader that South Asians possessed a 'different conceptual framework' in relation to illness and adversity and death. Many of the people I interviewed did indeed account for their illness in terms which do not sit easily with the Western medical model and its mind/body separation and diagnostic/prognostic preoccupations. When seeking to explore views of participants related to death and dying the response was often that it was 'Allah's will'. Probing further was unproductive and appeared to be confusing for participants

10.2 Comparing the Views of Service Providers with Service Users / Carers

Communication

Both service providers and users identified communication as a central issue associated with accessing services. The frustration felt by both groups is understandable and not surprising. This problem exists on a national scale and has been noted for many years.

Whilst communication is still a significant problem, the use of interpreters requires further consideration. This was referred to by both groups, with varying views about acceptability. The use of family members and in particular, children in this process has been condemned as unethical within the literature (Gerrish et al 1996) however, the tacit approval by eight of the service providers interviewed in this study of this practice, may indicate the need for further education and debate.

I was informed by several Asians from the service provider groups and community leaders that they do not like to complain. Three of the service providers who were nurses also commented on this uncomplaining attitude which they said they had observed frequently.

This is referred to by Pappas (2004), as piety and stoicism for which acceptance of God's will is paramount. One could argue that there is some similarity in this uncomplaining attitude between those who are older or ill from other cultures. Whatever the reason, this certainly appeared to be true - if a negative comment was made in the individual user / carer interviews it was hastily followed by an apologetic smile and an explanation that it was not meant to be a complaint.

Likewise, when conducting the focus groups, people did not always wish to speak in front of others. In some instance this was because they wished to make a negative observation, and in others it was the desire for privacy to discuss a personal issue. Time was offered the end of the focus groups for people to speak to the researcher individually. At least four people were seen privately in this way at the end of each focus group.

This privacy similarly seems to exist between men and women in an Asian culture. Women spoke differently to me alone than when a man was present. Their conversation seemed more relaxed when in all female company. Those who wore veils would remove them when talking to me but replaced them immediately if a man appeared. This was apparent among those of all ages – even the very young women.

Service providers found such issues to be significant in relation to assessment of individual need, as communication with women was frequently conducted through the husband. The Asians involved in the study however, did not mention this at all, which could be because for them it is considered normal.

The younger men I spoke to said things were indeed changing, and gave the example of speaking openly to me – even shaking my hand which was something culturally unacceptable between all men and women until relatively recently.

Education & Training

Indeed, more education and training about cultural diversity was requested by the majority of the service providers. However, it has become apparent during the course of this research that, whilst cultures may share some similar beliefs and practices, the assumption that cultures are homogenous and that knowledge of the stereotypes associated with a particular culture will deliver unproblematic answers is erroneous. For example, during one of the interviews, I was told by one widow that Asian women do not visit the cemetery after death; however another Asian widow told me she went every day. A one-size-fits-all approach to cultural sensitivity is not appropriate

In contrast, there were no explicit requests for cultural awareness education from the South Asians involved in this study. Part of such cultural awareness arguably involves considering a western perspective of health and illness. Some service providers who participated in this study have tried very hard to disseminate information about available services but their events have been poorly attended. During the course of this research, the local Asian magazine was used to publicise the venture. North Kirklees Primary Health Care Trust now has a regular article in this publication, which may help raise awareness.

Seventeen of the service providers had received additional education in the form of cultural awareness training, and attended Islamic awareness sessions at a local Muslim Welfare Centre. Whilst the majority found the experience beneficial and informative, three of the providers reported what they perceived to be a hidden agenda of conversion to Islam, perhaps associated with the evangelical nature of this particular religion.

The Role of the Family in Palliative Care Provision

Both providers and users referred to the role of the family in providing care. Some authors (for example, Gerrish & Husband 1999) have suggested this is a stereotypical assumption made about the Asian community which is no longer true. Whilst there is evidence that family structures are indeed changing, those participants from the Asian community involved in this study fully supported the notion that the family are and should be the main caregivers.

The other cultural issues identified as being of significance, such as the health and safety issues involved in removing shoes when visiting the home and caring for people on the floor, do not have easy answers. It may be that shared awareness will help to resolve any offence caused.

11. CONCLUSIONS AND RECOMMENDATIONS

11.1 Limitations of the study

The limitations are considered for each phase of the study in turn:

11.1.1 The research

Whilst this may seem somewhat unusual as a limitation, there are some important factors to be considered when reading and interpreting this report, not least of which is the actual concept of research itself. Whilst probably very familiar to the reader of this document, Helman (2004) reminds us that research may be an unfamiliar concept for people of other cultures. Those not used to exploring their own feelings may find it threatening or embarrassing. Being interviewed by a stranger may frighten them - they may be fearful of 'losing face' or 'washing their dirty linen in public'. It certainly felt as though this was the case in some of the interviews, probing for information was difficult and clearly confusing and unacceptable to those with differing explanatory frameworks. It did not seem as though information was deliberately withheld – rather that the subject had never been thought about before. Any conclusions drawn from this research should therefore be made in the light of this.

Additionally, it is well documented that research involving those who are dying / bereaved is a highly sensitive area. By carefully explaining the aims of the research it is hoped that all those who participated, did so with fully informed consent.

11.1.2 The researcher

The researcher did not share the same cultural background as the research population and as such this may influence the interactions which occurred. Indeed it took a long time on occasion to explain exactly what was being researched. In a minority population those in the majority (of which the researcher was one) may be viewed with suspicion and fear – thus affecting the responses given.

11.1.3 The sample

The aim of this research was to explore why people of South Asian origin did not access palliative care services. It was difficult to recruit people to the study – possibly because of the fear identified above, but whatever the reason for this, all those who were willing to be interviewed had previously, or were currently, accessing the services. Those who wish to remain ‘hidden’ will do so and that is their right. The views and suggestions made are therefore from those who have had some experience of the services and are able to comment on that. It is also likely however, that they have some awareness of the reasons why others from the community choose not to access the services.

11.1.4 Communication

Identified by service providers, users and carers as a major issue in the provision/access of palliative care services, communication was undoubtedly challenging in the conduct of this research. The use of interpreters, no matter how well trained, is difficult, and interrupts the flow of conversation. It was impossible to transcribe many of the interviews as it was not clear who was speaking. Similarly there was always a lot of background noise and activity whilst the interviews were being conducted. Notes were therefore made to support the interviews.

11.1.5 7 July 2005

The interviews with service users / carers were in process when there was a major terrorist attack in London. One of the ring leaders for this attack was from the immediate vicinity in which the interviews were being held. The concomitant police activity in the area was difficult to ignore. Every Asian interviewed mentioned the event revealing a sense of horror and also fear of reprisal. The impact of the event on this research should not be underestimated and as such may have influenced both the decision to participate and the subsequent responses given.

11.2 Overall conclusion

Whilst research in this particular subject area is limited, this study does indeed confirm previous findings relating to service access issues. Best practice initiatives have been identified from both within the literature and from direct observation. Indeed, perhaps one of the most important aspects of this particular study is that it has indeed ‘opened doors’ in the form of communication channels with members of minority ethnic groups. It is by establishing such channels that appropriate and relevant service development can occur. There is not going to be a ‘quick fix’ solution to the issues identified within this research - there are, as has been noted, many barriers to be overcome. There is however, a need to confront these barriers if major developments in service delivery are to be made. This research has done just that and recommendations for development in relation to the issues identified from the study are made below.

11.2.1. Recommendations for service development

Palliative Care Steering Group:

- To establish a single multi-professional steering group with representation from voluntary and professional groups, service users and educators.

Communication:

- To clarify the concept of palliative care services
- To publicise palliative care services using:

Leaflets distributed to GP surgeries,
Community Centres. Mosques,
Restaurants, Shops

Development of online information
Service in appropriate languages

Advertisements in the local Asian
magazine

Advertisements on the local radio station
using community languages

Seminar presentations of this research in
conjunction with the University of
Huddersfield

- Consider the possibility of bidding for charity funding for an ethnic minority liaison worker (perhaps from MacMillan)
- Develop protocol for interpretation services in partnership with translation service providers
- Ensure the above protocol addresses the use of family / children as interpreters
- Actively recruit and appoint bi-lingual health workers
- Ensure user involvement in all activities
- Where possible, ensure users are representative of the total population
- Consider the development of assessment aids such as pictorial representations

Education:

- A comprehensive education strategy should be developed for all health service providers which develops cultural awareness
- The development and implementation of such a strategy should involve members of minority ethnic groups and appropriate educationalists

Services:

- Ensure services currently in place and those to be developed demonstrate cultural sensitivity
- Develop processes for ethnic monitoring which include identification of communication needs
- Consider the potential for providing complementary therapies in the community
- Ensure transport needs are included on assessment documentation
- Given the significance of the family in care, consider ways in which the family may be more actively involved

REFERENCES & BIBLIOGRAPHY

Asia Pacific Hospice Palliative Care Network www.aphn.org

Ackroyd R.(2003)‘Audit of referrals to a hospital palliative care team: role of the bi-lingual health-care worker’Int. Jnl. Palliative Nursing Vol.9 Iss.8 pp352-357

Addington-Hall, Altman D, McCarthy M (1998)‘Which terminally ill cancer patients receive hospice in-patient care?’ Social Science and medicine Vol.46Iss.8 pp 1011-1016

Ahmed N.(2004)‘Systematic review of the problems and issues of accessing specialist care by patients, carera and health and social care professionals’ Palliative Medicine Vol.18 No.6 pp:525-542

Baker M R (2002)‘Modernising Cancer Services’ Oxon. Radcliffe Medical Press

BBC News (2005) ‘Minorities Terminal Care Studied’
<http://newsvote.bbc.co.uk/mmmaps>

Bestal J, Ahmed N, Ahmedzai S, Payne S, Noble B, Clark D(2004)‘Access and referral to specialist palliative care: patients’ and professionals’ experiences. Jnl. Palliative Nursing Vol 10 Iss.8 pp381-9

Clark D (1993) ‘The Future for Palliative Care Issues of Policy & Practice’
Buckingham. Open University Press

Clark D, Seymour J (1999) ‘Reflections on Palliative Care’ OU Press Buckingham

Daddy J., Clegg A., (2001) ‘Cultural Sensitivity: a practical approach to improving services’ *Nursing Standard* 15, 33, 39-40

Daniels L (2001) ‘Preparation, information and liaison: conducting successful research in palliative care’ Int. Jnl. Palliative Nursing Vol. 7 Iss.4 pp192-7

Dean R, McClement S (2002) ‘Palliative care research: methodological and ethical challenges’ Int. Jnl. Palliative Nursing Vol. 8 Iss.8 pp376-380

Department of Health (1995) *No Exclusion Clause Project: Opening doors to better palliative care services for people from culturally diverse communities*
www.dh.gov.uk/PolicyAndGuidance/EqualityAndHumanRights

Department of Health (1999) 'Study of Black, Asian and Ethnic Minority Issues
Ziggi Alexander London

Diver F (2003) 'The palliative care needs of ethnic minority patients: Int. Jnl.
Palliative Nursing Vol. 9 Iss.8 pp343-351

Diver F, Molassiotis A (2003) 'The palliative care needs of ethnic minority patients
attending a day care centre: a qualitative study

Firth P (2005) 'Loss, Change & Bereavement in Palliative Care'

Gatrad, A., Sheikh, A., (2002) '*Palliative care for Muslims and issues before
death*' Int. Jnl. Palliative Nursing Vol. 8 Iss.11 pp526-531

Gatrad A, Brown E, Sheikh A, (2003) 'Palliative care needs of minorities'
BMJ Vol 327:177-178

Gerrish K Papadopoulous (1999) 'Transcultural competence: the challenge for nurse
education' British Journal of Nursing, Vol. 8 Iss.21 pp1453-1457

Gerrish K, Husband C, Mackenzie J (1996) 'Nursing for a multi-ethnic society'
Buckingham: Open University Press

Gerrish K (2001) '*The nature and effect of communication difficulties arising from
interactions between district nurses and South Asian patients and their carers*' Jnl
Ad.Nsg.Vol.33 Issue 5 p586

Goddard M, Smith P (2001) 'Equity of access to health care services: Theory and
evidence from the UK' Social Science & Medicine Vol.53 Issue 9 pp 1149-1162

Hardev N (2003) 'Headline' Int. Jnl. Palliative Nursing Vol. 9 Iss.4 p178

Helman C G (2004) 'Cultural Beliefs about Health & Illness & Attitudes to research'
Department of Primary Care and Population Sciences, Royal free & University
College Medical School, Brunel University

Hepworth D., (2003) 'Assessment & Support for South Asian Carers' SPRU Research
Works University of York

House of Lords (2005) The United Kingdom Parliament Hansard Index

Jack CM, Penny L, Wall N (2001) 'Effective palliative care for minority ethnic
groups: the role of a liaison worker' Int. Jnl. Palliative Nursing Vol. 7 Iss.8 pp375-380

Katbamna S. Bhakta P, Parker G, Ahmad N, & Bhler R, (1998) 'Experiences and Needs of Carers from the South Asian Communities' University of Leicester Nuffield Community Care Studies Unit

Koffman J, Camps M, (2004) '*No way in Including the excluded at the end of life*' in Payne S., Seymour J., & Ingleton C, 'Palliative Care Nursing' Open University Press Maidenhead, Berkshire

Ledger S.D, (2002) 'Reflections on communicating with non-English speaking patients' British Jnl Nurs Vol 11 Issue 11 pp773-780

Luff G, Oliviere D (2005) Maidenhead: Open University Press

Lugton J, Kindlen M(1999) 'Palliative Care The Nursing Role' Edinburgh: Churchill Livingstone

MacLachlan M (1997) Culture & Health Chichester: John Wiley

The Milen Day Centre Annual report (2005) Woodwell House Mayman Lane Batley

The Muslim Council (2003) 'Palliative care needs of minorities' www.mcb.org.uk

National Council of Hospice and Specialist Palliative Care Services (2000) *The Palliative Care Survey 1999*. London: NCHSPCS

National Council for Hospices and Specialist Palliative Care Services, (1995) *Opening Doors: Improving access to hospice and specialist palliative care services by members of the black and ethnic minority communities* ()

NICE 'Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer' (2004) NICE London

NICE and Kings College London (2004) *Supportive and Palliative Care* www.nice.org.uk

Nyatanga B, (2002) '*Culture, palliative care and multiculturalism*' Int. Jnl. Pall Care Nsg Vol 8 Issue 5 pp 240-246

ONS Census Data (2001) National Statistics Online www.statistics.gov.uk/census2001

Pappas G, (2004) 'From Concepts to Reality Anthropological Perspectives on Palliative Care' http://hab.hrsa.gov/publications/palliative/anthropological_perspectives.htm

Parker G (2000) 'Practice guidelines for primary health care teams to meet the needs of Asian carers'' <http://www.refer.nhs.uk>

Parliamentary Select Committee on Health www.parliament.the-stationery-office.co.uk/pa/cm/200304/comselect/cmhealth/454/45402htm

Pharaoh C (1995) 'Primary Health Care for Elderly People from Black & Minority Ethnic Communities' Age Concern Department of Gerontological Studies Kings College London HMSO

Policy Research Institute on Ageing & Ethnicity 'Palliative Care. Older People & Ethnicity' 31-32 Park Row Leeds

Rabetah Al- Ulama – Islamiyyah (2004) '*Understanding Muslims Rites and Customs*' Institute of Islamic Scholars P.O. Box 7861 Batley West Yorkshire

Randhawa G, Owens A, Fitches R, Khan Z (2003) 'Communication in the development of culturally competent palliative care services in the UK: a case study' *Int. Jnl. Palliative Nursing* Vol. 9 Iss.1 pp24-30

Regnard C, Kindlen M (2002) 'Supportive and Palliative Care in Cancer' Oxford. Radcliffe Medical Press

Roy R., Symonds R.P., Kumar D., Ibrahim K., Mitchell A., Fallowfield L. (2005) 'The use of denial in an ethnically diverse British cancer population: a cross-sectional study' *NJC advance online publication* 5 April 2005

Sandman L (2005) 'A Good Death' Maidenhead: Open University Press

Sepulveda, C., Marlin, A., Yoshida, T and Ullrich, A. (2002) 'Palliative care: the World Health Organisation's global perspective' *Journal of Pain and Symptom management*, 24 (2): 91-6

Seymour Ingleton C., (1999)

Siriwarvena A.N., Clark D.H. (2004) 'End of Life Care for Ethnic Minority Groups' *Diversity in Medicine* Vol 6 No.1

Somerville J (2001) 'Palliative care: the experience of informal carers within the Bangladeshi community' *Int. Jnl. Palliative Nursing* Vol. 7 Iss.5 pp240-7

Spencer-Dugdale D., (2003) 'Ethnic Minorities & Palliative Care' *Information Exchange National Council of Hospices* October

Spruyt O. (1999) 'Community-based palliative care for Bangladeshi patients in East London. Accounts of bereaved carers. *Palliative Medicine* Vol. 13, No.2 pp: 119-129

Symon C. Cassell G. (Eds) *Qualitative Methods in Organisational Research: A Practical Guide*. London: Sage

Szczepura A (2005) 'Access to health care for ethnic minority populations' Fellowship of Postgraduate Medicine

Tower B.A., (1999) '*Seeking the user perspective in palliative care*' *Int. Jnl Palliative*

Care Vol5. Issue 5 pp240-243

Twycross R (2003) 'Introducing Palliative Care' Oxon. Radcliffe Medical Press Ltd.

Weber, R.P., (1985) *Basic content Analysis* Beverly Hills, C.A.Sage

Weeks L Int. Jnl. Palliative Nursing Vol. 9 Iss.9 pp389-396

World Health Organisation 2005

<http://www.who.int/hiv/topics/palliative/care>