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Towards Dignity:
acting on the lessons from black and minority ethnic older people's experiences of hospital care

A Report from PRIAE

for the Help the Aged

Dignity on the Ward Campaign

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December 2000

Organisation of the report

This report is primarily aimed at those who are responsible for bringing about 'patient centred' care as envisaged in the National Plan for the NHS. They are the hospital managers, health authorities, Primary Care Groups and Trusts and practitioners.

The background to this work is explained in the introduction. Section 2 explains the methods used to establish BME elders' responses from the interviews. Section 3 provides the managers' views. Section 4 analyses the responses with reference to related work and the report concludes with a central recommendation. This report was produced by Naina Patel at PRIAE.

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1. Introduction

All people - black and white, women and men, young and old - have one thing in common when going into hospital: personal anxiety and the hope that they will gain a better understanding of their condition and treatment to alleviate it. A simple aim, yet as we know, not a straightforward one for hospitals, staff and managers to achieve.

Older people are the largest group of users of the National Health Service. The NHS Plan announced by the Government in July 2000 seeks to 'give people of Britain a health service fit for the 21st century: a health service designed around the patient' and one which recognises the shortfall in expectations from staff and patients. The focus of the National Plan is thus 'patient centred'.

The purpose of this report is to identify black and minority ethnic (BME) elders' experiences and expectations of hospital care. By doing so we can begin to establish the key elements in improving hospital care and so contribute to the National Plan changes.

Help the Aged, which commissioned this report, has already made considerable strides in identifying examples of good practice in acute hospital care for older people as part of its two-year *Dignity on the Ward* campaign. But it was concerned that the experiences of black and ethnic elders should be more fully explored.

This group - as a segment of older people generally - is growing in numbers. Help the Aged wanted to establish whether the issues they raised reflected those of white elders or whether there were specific concerns.

PRIAE, the organisation that produced this report has a broad aim: to take a systems approach where all the elements in care (users, carers, staff, management, organisations, the political, social, economic and clinical/non-clinical climate in which all the 'agents' operate) are considered. This helps to produce an informed understanding of all the issues and what changes are needed to improve the care and quality of life of BME elders. This in turn helps to inform and improve all elder care.

Constraints of time and resources led us to consider one element - the BME elders' experience of ward care - to establish key issues which hospital managers, commissioning officers and professional carers can use to improve care and experience in the future.

We note that even within this one element there are limitations in interviewing 32 elders from three ethnic groups (with a number of them sharing sub-ethnicity, language, religion and social class). One limitation concerns the issue of subjectivity. Although we have qualitative information of what BME elders' think, experience and aspire to, there may, nonetheless, be several elements of that experience left unexpressed or insufficiently emphasised.

To ensure the effectiveness of this work in generating recommendations and producing a better understanding of the issues, we have drawn on other related work, including the work produced for the Royal Commission on Long Term Care when considering BME elders' perspectives on care. PRIAE's work with nursing staff (Department of Health 1999) and its study on dementia (CNEOPSA 1998) are also relevant. We also refer to the survey commissioned by Help the Aged for the *Dignity on the Ward* campaign. By doing this we hope to place the experiences of BME elders of hospital care in this project within the context of BME elder care and majority elders' issues.

2. Black and Minority Ethnic Elders' Experiences

Method and Characteristics

The aim of the project was to gain a better understanding and identify the changes needed for 'dignity' to be achieved for BME elders in hospital. We limited the focus of BME elder experience to hospital wards rather than the entire system of health care. In devising the questionnaire, we adopted the 'SWOT' method, that is the identification of strengths, weaknesses, opportunities and threats. In this case it was to record the BME elder's experience of hospital ward and hospital managers' issues concerning BME elder care.

The information we gained should help hospital personnel and organisations to build from the strengths identified and improve from the weaknesses cited by BME elders.

The questionnaire went beyond physical aspects of care to consider both medical and non-clinical aspects. PRIAE has commented that service providers and professionals set and interpret their aim of meeting 'culturally appropriate' care as the satisfaction of physical requirements, to the exclusion of other aspects of quality care. The underlying premise to our questionnaire was that BME elders:

- have low expectations regarding hospital care
- are likely to show high satisfaction levels if the ethos of the ward and its staff reflect good hospital care and demonstrate ease with the issues of diversity and racism. This is in addition to age, class, gender and disability related concerns.

The interviews were conducted with 32 black and minority ethnic elders in England and Scotland between October and November 2000. Three hospital managers in London were interviewed. Experienced interpreters helped to conduct of the questionnaire.

The 32 elders came from African-Caribbean, Asian and Chinese backgrounds and were aged between 55 and 80 years and over.[1] Nineteen were women and 12 were men and they came from East Scotland, Leeds and three London boroughs. The majority of interviews were carried out at centres providing day care for BME elders. One group interview and 18 individual interviews were conducted. The group interviews lasted about 2.5 hours and one-to-one interviews from 45 minutes to 1.5 hours.

The questionnaire itself consisted of 14 questions grouped into four broad themes:

- Characteristics of elders interviewed
- Entry and experience in the ward
- Strengths and barriers in hospital care
- Hopes and aspirations on experiencing 'dignity'

The questionnaire for the managers used the same four themes to ascertain the issues they face in providing patient care to BME elders.

The 32 elders admitted to hospitals had a variety of ailments. This included heart condition and bypass, spinal injury and minor operations. The length of stay for the majority of elders was between one week and less than a month. Not all ailments required surgery.

Entry to hospital

'To get well and to get out fast'

All the interviewees understood why they had been admitted to hospital. These were planned admissions in most cases.

Their predominant concern was 'to get better'. Equally important was 'to be well looked after' in the ward. This encompassed the welcome they received when they arrived in the ward as well as the level of care they experienced while in hospital.

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1 1 The age breakdown of the 32 BME elders in the three locations was as follows:

- 5 persons in 55-60 years of age
- 8 persons in 60-65 years of age
- 2 persons in 65-70 years of age
- 12 persons in 70-80 years of age
- 3 persons in 80+ age group
- 2 individuals did not indicate their age.

The managers were not asked this except for their ethnicity - classed as 'white'.

For some, the most important thing was to get prompt and correct treatment accompanied by sensitive and appropriate medical care. Others wanted to be seen and have their worries eased. Learning how long they would be in hospital and the type of treatment they would receive were also important. Ultimately they all wanted to be cured.

'Nurses who make you feel at home'

The majority of elders described their entry into the ward as good. Positives were 'nurses who make you feel homely', the helpfulness and efficiency of the nurses, and in one instance, not having to wait. The attention they were given and being made to feel welcome helped with their entry into the ward, as did the fact that 'it was clean and quiet'. Doctors who were 'ok' and staff who were 'considerate' were indications of a 'good' entry to the ward**.**

'Staff appeared vague about most things'

There were a few elders who described their entry into the ward as poor: being left in a corridor for nine hours after being diagnosed; unwelcoming staff attitudes and very poor timekeeping for planned admission were cited as examples. The time it took to be seen by nursing staff and a poor level of general hygiene were also factors which made elders' entry into the ward poor.

In the ward itself

Although the initial entry may have been good for the majority of elders, most reported a negative experience of their stay in hospital as a whole.

'A willingness to listen and learn from the patient'

A variety of factors contributed to making the stay in the ward a good one. Flexibility and willingness to learn from the patient were cited, as was the standard of personal care received. This included being able to speak in the elder's language; caring and helpful staff; the attentiveness of nurses; having an interpreter to hand; the availability of appropriate food such as halal or vegetarian and visitors being allowed to visit any time. Taking account of the patients wishes -'being listened to' - when preparing a treatment plan was another major consideration in making the elder's stay in the ward satisfactory.

'I am not sure if they are racist'

Communication and food were considered large problems. The ability to understand the doctor and the diagnosis was dependent on one's command of the English language. Elders also said that irrespective of their ability to speak English there remained the issue of being

informed and able to understand the diagnosis, the treatment, issues about side effects and information on choices if certain decisions were to be made.

A few people said racism and a lack of understanding of the needs of ethnic minority older people were why their stay in the ward was poor. Racist comments by a doctor were cited in one case and there was a general feeling of disregard for the person: 'why did they wash their hands off me?'

Appropriate food remained the biggest problem, particularly the inability to provide proper vegetarian food. Difficulty in ordering food (and not getting food even when it was ordered by English speaking relatives) meant having to go without food on occasion. Indeed there was an expectation that food would be a problem and a majority of elders had made alternative arrangements with families.

The unavailability of interpreters was another major concern. There was a feeling by many elders that non-English speaking patients received poor levels of care. Others said crowded wards and low staffing levels at night affected their standard of care and thus 'violated their dignity'. For some their stay was poor because of a lack of attention or having to wait for care. One elder reported being left 'soiled for ages' which made her 'feel embarrassed and angry'.

What is important to BME elder patients?

'Getting the right food'

'A cheerful friendly atmosphere'

Elders were asked what were the most important things to them while they were in the ward. Typical responses were: getting proper treatment; getting the right food; making sure (where there were language barriers) that the doctor understood what their problems were and in turn receiving an explanation At the appropriate time about their condition and their course of treatment.

Being able to maintain dignity in personal hygiene care was particularly important when mobility was restricted or when assistance was needed.

The flexibility or otherwise of hospital regimes made a big impact, determining whether elders could wear their own clothes – in the case of one female elder, wearing a scarf to cover her head – or take a bath when they wanted to.

Were these aspects met?

Only a minority said these factors had been fully met. For this group, good hospital care consisted of:

- a cheerful friendly atmosphere
- multi-racial staff who reflected the elders' backgrounds
- good nursing care
- a clean environment
- having some control over their stay
- being understood as a patient
- care when needed
- doctors who were good at their jobs and took the trouble to explain things
- ward nursing staff who were very good and efficient
- a successful operation followed by good post-operative care.

Barriers to achieving good hospital care

'Not being listened to'

The majority of elders however said these aspects had been only partly met, or not met at all. They said the barriers to good hospital care were:

- lack of interpreters
- poor food both in terms of quality and quantity
- staff insensitivity and attitudes including bad tempered nurses
- racism
- rigid bureaucracy
- staff shortages
- poor communication
- poor standards of care
- staff not trying to understand

- inability to communicate with the doctor

Achieving dignity

'Being treated like I was somebody'

To achieve the level of dignity that elders expect we need to understand what they mean by 'dignity' in relation to the hospital ward.

The elders we interviewed gave a number of definitions. 'Being treated equally and with respect' notwithstanding the language barrier was the most common response. Others were self-respect, honour and appropriate medical care. Having privacy - 'ensuring other people do not overhear your conversations with doctors and nurses' - was also an important factor. Staying in single-sex wards enhances dignity.

The elder from Leeds who defined dignity as 'being treated like I was somebody' probably best sums up what the elders were conveying in this project. To be treated equally and with respect was the most common response.

Since the elders selected in our sample had been admitted to the hospital in the last three years, we asked what levels of dignity they would experience if admitted back to the ward today.

The majority did not think there would be any substantial change and thought they would experience the same level of dignity. Others were more optimistic and said they hoped they would have higher levels of dignity, given the anticipated changes in the NHS. But other elders suggested that increased demands on the Health Service would reduce dignity.

The majority expected the same levels of dignity were they to return to the ward at a later date.

The changes elders would make

The final section of the questionnaire asked elders to name the changes they would make to achieve the level of dignity they expected from today's hospital wards:

- the availability of interpreters on the ward

- to be kept informed about their medical status and to be actively involved in any decisions about their care
- more nursing staff from ethnic minorities
- nursing staff who have a sensitive approach and are aware of racial and cultural needs
- measures to improve rudeness and insensitive attitudes on the part of hospital staff
- radical improvements in the type, quality and quantity of food
- menus could be illustrated as in picture menus to overcome language difficulties
- to have religious needs met
- care tailored to the individual's needs
- better staffing levels
- privacy and confidentiality in the ward
- separate male/female wards
- improved shower/washing facilities.

CONCLUSION

It is to be expected that an individual's response to being in a situation where they are at their most vulnerable will be subjective. Just one experience, good or bad, can determine how they view their stay in hospital and whether their expectations were met.

What is striking is that while the majority of elders described their entry into the ward as good or very good these initial positive responses changed to negative responses when asked about their experiences at various stages of their stay. Their initial high expectations were not met in terms of the dignity they expected. This is reinforced by the fact that the majority of elders said they expected the same, or lower, levels of dignity were they to return to the ward today.

Three issues stand out as common to all the interviewees:

The issue of language, which affected all groups equally. There was a real feeling of differential service depending on one's command of the English language. One interviewee said 'non-English speaking patients

don’t get a fair deal’ and there were examples of having to wait longer for changes of dressings, baths or bedpans at night. This erodes dignity on the ward.

Communication problems (including being given conflicting information), staff insensitivity and attitudes were also mentioned. Elders wanted to be treated equally and with respect despite the language barrier and two of their recommendations reinforce these feelings: the need for interpreters and the need for better trained nurses with a sensitive approach who are aware of racial and cultural needs.

The second issue was that of food. The overwhelming majority of elders were critical of the quality and quantity of the food provided. Some Asian elders were puzzled by the hospital’s inability to provide decent Indian food, given its popularity. But there were concerns too about arrangements for ordering food and about dietary needs not being properly documented. Concerns were expressed about having to go without a meal on occasion.

The third issue relates to the employment of ethnic minority staff. All the interviewees identified the need for more ethnic minority nurses, particularly of the same ethnic group as themselves. For example one elder said being able to speak in Punjabi made her stay in hospital good. A Chinese elder commented that only her first day in hospital was good, when a Chinese nurse was on the ward.

Only a minority of elders gave discrimination and racism as reasons for having a poor stay. Examples ranged from 'I am not sure if they were racist, but they just ignored me. I was afraid to speak out, as I thought they would punish me', to an elder from London who said a doctor asked her why she was in this country.

It is noticeable however that more elders were critical of the attitudes of staff and in this context it is worth asking whether they perceived discrimination but were not prepared to say so.

What is clear is the uniformity of responses regardless of the interviewees’ ethnic origin or their geographical location. Where there were variations, these tended towards emphasis and qualification such as having religious needs met (Scotland) and better staffing levels (Scotland and Leeds). Elders in London identified having more beds available, better washing/showering and toilet facilities and having men/women only wards (Leeds and London). These last two changes were seen to increase privacy and thus enhance dignity.

3. Interviews with managers

Method and Results

Telephone interviews were carried out with three senior professionals from a large London hospital trust whose catchment area included a significant black and minority ethnic population. All three were white.

Interviewees were asked the following questions regarding their work with black and minority ethnic elders:

- What issues do you face in your daily practice on the ward?
- How do you respond to them?
- What improvements do you need to make?
- What elements do you think contribute to 'dignity' on the ward'?

Managing cultural and racial sensitivity

'Getting racial and cultural backgrounds reflected in the ward'

The most important issue for the managers was to ensure that staffing on the wards reflected the racial and cultural backgrounds of elder patients so they did not feel like strangers once in hospital.

This was a central issue and from it flowed other considerations, which need to be taken into account when designing a culturally appropriate service.

One of the problems faced by this group of managers was the small numbers of Asian staff in professions allied to medicine.

In some places, making provision to meet linguistic needs was difficult, given the presence of a young mobile population as well as new arrivals, such as refugee families. The changing nature of the population made it difficult to plan to meet future linguistic needs.

Meeting dietary needs presented difficulties at times. Obtaining the right food involved regular liaison with catering services. Managers stressed that this was a case of 'hit and miss' in contrast to the BME elders' experiences which suggest ad hoc practice.

'Getting equity in service'

A number of initiatives were in place to better meet the needs of BME elders. These were in training (both pre-registration and post-registration); recruitment of ethnic minority staff; outreach work; provision of interpreting services and setting up user representative groups.

In both types of training, the needs of BME communities were a central part of all the components in the courses provided.

Local recruitment drives were used to attract ethnic minority staff. In order to attract bi-lingual staff, an additional increment was offered to those with language skills. Such drives were being run to ensure that staffing reflected local populations.

Outreach work took a variety of forms. Where BME elders were not taking up services offered on-site by hospitals, for reasons to do with language, culture or gender, working relationships were being developed with other agencies that could provide the services required. Two areas where this approach was being adopted were occupational therapy support and health promotion - for example working with women's groups to provide basic training on caring for people with dementia. Further examples were linking in with community organisations which could assist with cultural awareness training or help to meet religious needs.

Setting up user representative groups was seen as a major priority, as a means of involving clients in forward planning or new developments in both policy and practice.

A Changing base

'Expectations have gone up'

The need for support was rooted firmly within the context of meeting rising expectations and implementation of the two NHS framework documents on mental health and on older people. Not surprisingly, training was identified as one of the major areas where support was needed.

This support was identified as:

- more general racial awareness type training
- a multi-faceted approach to training so what was learnt in the lecture room was followed in individual clinical supervision sessions, thus embedding theory into practice

- using action research type projects on cultural appropriateness of care as learning tools
- the recruitment of black and minority ethnic staff, particularly from Asian communities. The over-riding need here was to raise the profile of the nursing profession amongst those communities, devising recruitment strategies targeted at different groups and using role models where possible

Understanding dignity

'Having a full life'

The interviewees' definitions of dignity on the ward were couched in terms of how they expected elders to be treated while they were there. The most common responses were the need to treat elders equally and with respect, to ensure privacy and confidentiality and provide choice. Making elders feel accepted and providing a quality service were other elements ascribed to promoting dignity on the ward.

Conclusion

Managers and black and minority ethnic elders share common views about the meaning of dignity on the ward. These similarities also extend to the issue of employing black and minority ethnic staff and training, which both elders and managers said required urgent attention.

Their views diverge on the issues of providing interpreting services and food, although we note that the BME elders did not attend the hospitals where the managers work.

4. Analysis and Recommendations

Introduction

Today's BME elders are, in the main, yesterday's young 'migrants'. Recently arrived refugees are likely to share similar concerns over communication, appropriate food, religious observance and the need for privacy in physical and personal care. None of these elements are unknowns. Nor are they 'special' needs. Just different.

One recurring theme among others, connected with old age and ethnicity and identified from 1980s and 1990s onwards (Norman 1985; Patel 1990; Askham et al 1993; Pharoah, C. (1995) Lindesay 1997), is the lack of urgency over any action for BME elders. So it is not surprising that the BME elders in PRIAE's report to the Royal Commission (1999), and similarly in Wales (2000) stated unequivocally that *'we have had too much discussion, action is overdue'.*

So how do we arrive at this 'action'?

It is apparent from the black and minority ethnic elders' experiences and expectations and the managers' views in the previous section that:

For BME elders, culture and 'race'-specific issues are part and parcel of their ordinary lives, and in their responses they express the importance of these, as well as the importance of hospital standards and care generally, which is also of concern to elders from the majority community. This was most evident in the Help the Aged survey (1999) and the Health Advisory Service Enquiry report, 'Not because they are old' (2000).

The key issues raised by elders in the Help the Aged survey were:

- " admission delays
- dirty wards
- a lack of working equipment on the wards
- staff who seem rushed and overworked
- some patients didn't get enough to eat
- patients were left poorly clothed
- patients were unhappy on mixed wards

- patients did not like communal toilet and bathroom facilities
- no information was given about what was going on and patients felt isolated and afraid
- there was a poor co-ordination and communication between various staff members - between hospital doctors, with GPs, with social workers and with relatives.
- the discharge was poorly planned with no home care support
- patients with dementia were left 'screaming and crying all night'."

Some 400 elders took part in the Help the Aged survey - through a mix of correspondence and interviews. The issues raised are similar to those in the Health Advisory Service 2000 report. So in spite of the variation in the size of the sample population, there are major similarities in how BME elders describe their treatment, the condition of the wards and the facilities available.

It is clear that there are structural problems in the way hospitals are organised and managed – the facilities on wards, food, supply of staff - and the quality of professional care. It is also clear that BME elders were measured in their comments. They appeared to be geared for change rather than wanting to convey a litany of horror stories. Some expressed their difficult experiences through emotion rather than verbal expression as they relived their hospital experience. And some had amusing tales to recount or were witty in their observations about life on a hospital ward. Yet they all shared one simple aim: to get well and to 'get out fast'.

The underlying premise in our questionnaire - that BME elders have low expectations regarding hospital care - is reflected in the results. A clear expression of low expectations was found in the way they made alternative arrangements for food, for example, and in their comments about the appropriateness, quality and quantity of food.

Some of their comments illustrate how expectations and perceptions may merge where a lower standard of service is then regarded as acceptable. We can also read a feeling of letting people manage for themselves. In the case of BME elders this can also extend from food and language to discharge where it is assumed that 'families will take care of their own'. Elders did not voice this in this study but when asked about 'after care', several were unaware of rehabilitation or intermediate care.

This is supported by our report on rehabilitation in a northern district. During the Royal Commission seminars we found some cases of the extended family stereotype being displayed in the assessment process. For example a Chinese elder in London did not fully understand the diagnosis and the course of treatment offered during his stay in hospital. He was discharged without being assessed until PRIAE brought it to the authority's attention. BME elder organisations are often involved in such cases and provide a crucial element of support, both to the elder and to the authority concerned. Patient centred care will thus need not only to respond to patients' views but also to raise expectations of what a modern 21st health service should routinely provide.

Our second premise was that BME elders are likely to show high satisfaction levels if the ethos of the ward and its staff reflect good hospital care and demonstrate ease with the issues of diversity and racism. This is in addition to age, class, gender and disability related concerns.

This was illustrated in comments about the physical environment (mixed wards; bathing facilities;) and the way staff relate to patients. Even when staff cannot communicate through a shared language, how they relate to elder patients through gestures and contact is a form of communication - and much can be lost or achieved depending on the attempt and behaviour of the professional carer. We know from the experience of Caribbean elders that not being understood or heard in spite of speaking English requires us to look at other processes which interfere with the transmission of messages from care professionals.

We should also note that BME health professionals who come from Asian or Chinese backgrounds will not possess all the languages spoken within their ethnic group (to expect which would be absurd) or even, necessarily, the language of their own sub-ethnicity. Over 40% are born in this country. Elders often comment on the generation gap where the young cannot communicate. By this they mean both an inability to speak the language and a lack of shared values leading to difficulties in understanding. In practice however we know of situations where there are successful interventions in spite of people not sharing the same language. It also follows that even where same language is shared success in communication may not be guaranteed if the interaction is disrespectful - a term frequently used by BME elders when describing poor care.

The results do, though, indicate several positive aspects. For the majority BME elders, entry into the ward was deemed satisfactory. In stark contrast, the stay in hospital was marked by poor experiences. From a manager's perspective, the entry success represents a strength

(in the terms of the 'SWOT' analysis) of the hospital system and a starting point from which the poor experiences of some elders can be corrected. Similarly there were several positive experiences highlighted by a minority of BME elders while in the ward (pg. …….) which represent an opportunity to build on. Generally we learn from deficiencies: for example we know more about mental illness than about mental well being. It is useful to explore further and develop the elements that contribute to a satisfactory experience for some BME elders and aim to widen the effect for all.

The BME elders (and indeed majority elders) say the shortfall in their ward experience concerns physical and personal care. This is a severe comment about the extent of the deficit in care in a 21st century hospital system. So resolving issues, which surround this, would be a mark of significant progress.

But is it sufficient?

For the majority population, several researchers/writers including Kitwood (1997) have argued that to focus purely on supplying essential needs and basic physical care leaves users as 'non-persons'. Unless staff have a personal 'connectedness' and involvement with each patient they care for, that person, as an individual human being, ceases to matter. A health professional's professional training, competence and values will determine his/her judgements and the decisions he/she makes. But this also needs to involve the element of human interaction, an understanding of the carer in relation to the patient and vice versa. And for professionals from a majority background, involved in the care of BME elders, this would require them not only to acquire 'cultural information' but also seriously to examine and understand their own culture, its underlying assumptions, beliefs and heritage of racism in order to appreciate that relationship. As the Institute of Race Relations has argued, *'just to learn about other people's cultures is not to learn about the racism of one's own. To learn about the racism of one's own culture, on the other hand, is to approach other cultures objectively'* (response to the Rampton Committee on multicultural education, 1980). Failure to take this kind of holistic approach to understanding the context in which patient/carer relationships take place can lead, as we pointed out in PRIAE's study on dementia, to the 'checklist' approach to dealing with BME patients. In this regard emphasis is placed on a technical, reified culture-based list of tasks (Patel et al 1998).

By contrast, the more open-ended critique offered here would enable nursing and other health staff to be open about their own values, beliefs and practices and to adjust in response to users' values and

norms in seeking to provide better care. This enables an examination of personal and professional values and an exploration of how racial stereotyping might permeate one's actions without conscious knowledge. Many of the non-overtly racist actions which black and minority care staff complain about, some instances of which are voiced by a few elders in this project, stem from the *taken-for-granted* assumptions made about BME people and the ease with which these then validate an approach that allows racism to filter through *ordinary* actions (Patel 1995).

BME elder patients do not discount the operation of direct racism in the wards or in the health service generally. As one black elder put it at one of PRIAE's Royal Commission seminars, *'we experience these things, if we can respond we do, otherwise we limit our hopes'*. Organisational racism (Patel 1990), as an aspect of institutional racism, reinforces the culture in which such actions can take place. In other words it is seen as *normal*. This is far from suggesting, however, that each and every professional carer is racist: the meaning of 'endemic' racism has been perverted by the media in the recent coverage of the Macpherson Report on the murder of Stephen Lawrence. For example, malaria is endemic in Africa.[2] Racism is endemic in British society. This does not mean that everyone in Africa is infected by malaria. Nor, in Britain, does each and every person 'suffer from the cancer of racism' (Economist, 4 March 1999).

A majority of BME elders (p…..) did not directly state or allude to racism or racial discrimination. This does not indicate its absence. Generally elders do not explicitly use this phrase partly through discomfort and partly because the experience of racism is taken as read. They are also apprehensive about being critical of the hospitals on which they are dependent.

To explain the prevalence of racism we have to look more deeply at their comments about how health staff relate to them and consider the institutional racism evidenced through the recurrence over a long period of a failure to meet appropriate bathing, food and linguistic needs, for example. Some Asian and Chinese elders did enquire why appropriate food still remains a problem for services when it is now part of a British diet.

The Macpherson Report gave a clear direction on the nature of racism in British society in its recognition of institutional racism. It defined it: as *'the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and*

[2] Acknowledgement is made to Dr Suman Fernando for suggesting this analogy.

behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness, and racist stereotyping which disadvantage minority ethnic people (p.321).

One of the National Service Framework standards, 'preserving older people's dignity' will need to address effectively the various aspects of racism (Patel 1990), including institutional racism.

Organisational matters

In the interviews with the managers and our previous survey with nursing staff, they placed emphasis on the need to be personally competent, recognising that the route to achieving this is appropriate training, support in communication and the acquisition of cultural knowledge.

It is clear that the focus remains on 'the need to be equipped' as a professional. This still leaves the issue of how the organisation supports them in this task and how it undertakes the changes necessary to ensure that BME elders - as a group of all elders- gain a higher priority in the hospital system.

Such shifts are essential to establish an *organisational ethos* where good health and nursing care can take place. Practice from other fields informs us that often such changes not only benefit our target group but other groups who (by virtue of class or disability for example) are also excluded.

Recommendations

> ***'What do we see…who do we see…how do we see…why do we see…when do we see' …(Patel et al 1998).***
>
> ***At the end of the day BME elders are people, not peculiar. (carer correspondence to PRIAE during Royal Commission work, 1998)***

The basic tenet of all care is the recognition of one's individual humanity. Yet that humanity appears to cease for many once the stay in the hospital ward begins. We can see from the sections on staff responsiveness and food that in this study BME elders' expectations are not met. Many managers and care professionals recognise the dilemmas and inadequacies while others do not think that ethnicity is a factor in care (PRIAE 1998; 1999; Royal College of Nursing 1998).

BME elders express their fatigue not only in research undertakings but also in the generation of reports and recommendations. We share that frustration. There are limits to producing yet another set of proposals on the same issues expressed by BME elders in this study, though applied specifically to their ward experience.

Are basic things so difficult to achieve?

To be treated equally and with respect were the most common expressions associated with the term 'dignity' by both BME elders and managers. The changes that the BME elders proposed flow from this. They are basic changes. Do their changes represent a threat or an opportunity for organisations and managers? Surely, they should be regarded as an 'opportunity' if hospital care is to fulfil its true function. In particular because of the rapid increase expected in the numbers of BME elders over this and the next decade (Owen 1996).

What is required are organisational, managerial, professional and training changes. We thus limit ourselves to one central recommendation.

A central recommendation: a BME elder sensitive strategy should be produced and implemented.

The strategy should encompass the elements described by BME elders as 'changes' (see p……) and commit resources to acquire specialist support to develop and implement the strategy. Commitment, context, content and conduct would be the key frame references for managing change.

Three key reports contain ready recommendations for improving BME elder care, which should provide the foundation for designing a strategy. They are PRIAE's report to the Royal Commission (1999), Dementia Matters Ethnic Concerns (film and guide, 1999) and Ageing Matters Ethnic Concerns Report to Age Concern as part of the Millennium Debate of the Age (1999).

These are not enumerated to register PRIAE's self-interest as a specialist agency in ageing and ethnicity. Rather to emphasise that we cannot continue to produce endless lists of recommendations without knowing whether they have ever been acted upon. The record on BME elder planning, design of services and training is poor.

We have characterised the general shape of services in the UK for BME elders as, *'some authorities are doing well, others are doing a little and some are doing nothing at all'* (PRIAE 1999). To correct this position requires authorities to seek out and employ people with relevant expertise who can provide the necessary direction and guidance based on the content of this study. In that sense we have provided an important tool. How to manage BME elder care is one of the central questions faced by staff. Just another list of recommendations would simply add to current ad hoc, patchy and piecemeal practice - and a further pile-up of recommendations. Nursing staff interviewed in the PRIAE report to the Department of Health (1999) said that they had not received any specialist training and support in work with BME elders.

In other words, while the major health, social and welfare agencies recognise, at one level, the complex issues involved in 'race' ethnicity and racism, the care professionals are left to their own devices, to adopt a 'hit or miss' attitude, when it comes to the care of BME elders. PRIAE has also publicly registered concern that while Joint Investment Plans (JiPS), Health Improvement Plans (HimPS) and Best Value require planning and action on issues affecting BME communities, on age and race there appears to be a go-slow approach. Commissioning managers need to act urgently, given the expected growth in the BME elder population.

A planned strategy located in an anti-discriminatory framework to develop a BME elder care strategy which reflects the views of the BME elders and managers in this study needs the following. The strategy requires commitment, priority setting, shifts in resource distribution and implementation of the strategy *per se*. For dignity on the ward to be achieved in the modern NHS requires that the one recommendation proposed here take shape *now*. Today's BME elders are not likely to be satisfied with ‘hope’ as an indication of change and commitment by health organisations. Herein lies an opportunity, not a threat

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About the Organisations

Help the Aged

PRIAE

Policy **R**esearch **I**nstitute on **A**geing and **E**thnicity

PRIAE established in 1998 is an independent national and international charity specialising in policy, research, development and practice concerning the care, welfare and quality of life of black and minority ethnic older people. The institute aims to provide an umbrella organisational structure for a range of bodies in ageing and ethnicity, both in the UK and in Europe. Many of PRIAE's programmes in care and quality of life are first of its kind reflecting the historical under investment in the area.

PRIAE is a national and international independent organisation (with charitable status) specialising in policy, research, development and practice concerning the care, welfare and quality of life of black and minority ethnic older people. It is a first such institute in the UK established in 1998 and is associated with the University of Bradford. **PRIAE is** established as an independent body, which harnesses external resources in order to pursue its objectives. Its funding comes from national government; the European Commission and charitable foundations.

PRIAE is managed by Naina Patel, founder with staff and the institute is supported by Sir Herman Ouseley, Chair; Lord Dholakia, Vice Chair and other distinguished board members from health, social care, education, law and housing.

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