

蘭卡斯特大學

**Ethnicity and Cancer: examining psychosocial transitions for older people**  
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民族與癌症：研討長者與其社會及心理的變化

**Final Report to Dimbleby Cancer Care**

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## STRUCTURED ABSTRACT

### Title

*Ethnicity and Cancer: examining psychosocial transitions for older people*

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### Background

Cancer is predominantly a disease of older people with 64% of cases diagnosed in those 65 years of age or older. There is evidence that older people and those from minority cultures may be disadvantaged in access to cancer services. A cancer diagnosis is known to represent a challenge to the coping capacity of many patients and families. This study aimed to address the gaps in knowledge about how older Chinese and ‘white’ British people with cancer understand and adapt to their diagnosis in the context of biographical constructs of loss, transition and resilience.

### Aims

#### *Primary aim*

To investigate the cultural constructs of loss, transition and adaptation in the face of encountering a diagnosis of a life threatening illness.

#### *Secondary aims*

1. To elicit the narratives of older adults about their experiences of a cancer diagnosis.
2. To determine the extent to which narratives provide evidence about coping.
3. To determine which features of narratives display resilience (if any).

### ***Research questions***

1. What are the narratives of transition of older adults encountering a cancer diagnosis?
2. How are cultural constructs of loss and transition articulated within personal narratives?
3. What impact do previous experiences have on resilience and coping?
4. To what extent do perceived family networks affect resilience, coping and adaptation to a cancer diagnosis?

### **Design**

A longitudinal qualitative research study was conducted between July 2006 and June 2008. Older people with cancer were invited to participate in a semi-structured interview to explore their experiences of cancer, previous episodes of loss, transition, migration and adaptation, coping, resilience, reactions to diagnosis, expectations of cancer treatment, views on cancer services and future care preferences. A follow-up interview 3-6 months later was used to identify any changes. Interviews were conducted in English or Cantonese depending upon preference. All interview data were transcribed and where necessary translated into English. The total dataset was submitted to qualitative thematic analysis and a subsample of 30 selected interviews (15 Chinese, 15 'white' British) were examined for narratives that addressed the research aims.

### **Sample**

In total, 71 older people with cancer were recruited from Chinese Community Centres, Cancer Support Centres or Hospice Day Care Units in four areas of England. The sample comprised of 24 older Chinese people (7 male, 17 female) with a median age of 60 (range 50-76 years) and 47 older 'white' British people (17 male, 30 female) with a median age of 74 (range 60-91 years).

## **Key Findings**

Attributes and experiences that are common to both groups of participants are listed, followed by a comparison of the main differences between the two cultural groups.

### **Common experiences**

- Growing older in Britain
- Impact of war on a minority
- Experience of using British cancer care services
- Experience of perceived ageism from health care services for a minority
- Pragmatic and realistic attitudes towards cancer
- Acknowledge cancer as a life threatening disease
- Previous experiences of loss
- Resilience in coping with adverse situations
- Importance of family relationships and for some, friendship networks
- Expectations of family support in illness
- Predominantly secular but religious faith was regarded as a support for some of the participants
- Have some control about their future

### **Experiences of Chinese participants**

- Diversity of socio-economic backgrounds before migration, most had experiences of poverty
- Migration to the UK for largely economic reasons in young adulthood
- Following migration – most worked in catering trade
- Language difficulties on arrival in the UK and for some ongoing
- Majority had limited contact with mainstream British society
- Shared a Chinese ethnic identity but used a variety of self ascribed descriptors
- Cultural identity was highly salient
- Not very well informed about cancer
- Unfamiliar with availability of cancer and other health services
- Most had great respect for doctors and other health professionals who are afforded a ‘high status’ in the traditional Chinese social system and are not to be challenged
- Overall satisfied with NHS but some ‘doctor shopping’ – meaning that a number of second opinions are sought
- Provision of psychological and emotional support was not expected from health professionals
- Some use of traditional Chinese health beliefs and food practices
- Appreciation of interpreting service provided by hospitals but low levels of satisfaction with its quality and availability
- Decision making was shared with family as well as taking advice from medical doctors
- Valuing self-reliance and family support
- Achievement of life goals despite often adverse circumstances.

## **Experiences of ‘white’ British participants**

- Diversity of socio-economic backgrounds
- Some mobility within and beyond UK largely in young adulthood
- Diversity of occupations and variety of economic experiences.
- No language difficulties but some experienced problems with perceived poor communication skills of health professionals
- No evidence of social exclusion
- Largely ‘white’ British identity but with a variety of self ascribed descriptors
- Cultural identity not really salient for most because they formed part of the dominant culture
- Stoicism and valuing of independence
- Fairly well informed about cancer
- Quite familiar with available cancer and other health services
- Doctors and health professionals were respected but they were not seen as ‘someone who should not be challenged’.
- Overall satisfied with NHS but some adverse experiences with poor communication
- Provision of psychological and emotional support was expected from health professionals
- Some use of complementary therapies
- Autonomy was evident although family was also regarded as part of the decision making process
- High levels of satisfaction with hospices reported by those using them.

## **Conclusions**

In conclusion, this sample of older people with cancer from Chinese and ‘white’ British cultures living in the UK tended to cope well with a diagnosis of cancer and draw on previous experiences of overcoming life challenges to contextualise their current situation. Most reported valuing their own self reliance and stoicism in overcoming obstacles and attaining life goals. Both groups regarded family relationships as central to their lives and to current coping with cancer. They were largely satisfied with cancer care services, although both groups reported communication problems. On the basis of the present findings, it can be concluded that cancer services should emphasise the availability of interpreters to non-English speaking patients. Insufficient support for non-English speaking patients was identified. Even when interpreters were available it was evident that greater attention is needed to improve their skills and clarify their remit to patients and professionals. There is a lack of expertise in how best to use interpreters and more research on how to develop and sustain patient-professional relationships via these intermediaries is required. Many of the interviewees reported different expectations of interpreters. Amongst the ‘white’ British participants, there was heterogeneity of experiences, with a few instances of perceive ageism and difficulties with communication with cancer care professionals. Most participants highly valued access to specific services including Cancer Support services, complementary therapies and hospice care. In conclusion, this study has set a diagnosis of cancer in the boarder context of older people’s lives and shown how they draw upon previous life experiences and biographical narratives as a resource in facing cancer.

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## 1. INTRODUCTION

In the last 25 years the experience of cancer has been transformed with many new curative and supportive treatments, greater attention to psychosocial support, increased disclosure of diagnosis and prognosis, improvements in communication and information provision, and changes in societal attitudes to the disease with less stigmatisation (Department of Health 2007). Yet individuals, especially those in later life, generally regard cancer as a feared condition and one that is life-limiting or potentially fatal. Perhaps they are right to do so because cancer is a major cause of morbidity and mortality, accounting for approximately 25% of all deaths in the United Kingdom, with 64% of cases diagnosed and 83.5% of deaths in people aged over 65 years (CancerStats 2005). Evidence suggests that older people are less likely to have access to the health and social services that they and their families require than younger people (Seymour et al 2005). A cancer diagnosis is known to represent a challenge to the coping capacity of many patients and families. In a large survey of the experiences of cancer patients, many reported the emotional impact of cancer as worse than the physical effects (Cardy et al 2006).

This study addresses the concerns, perspectives and resilience of older Chinese and 'white' people who are resident in the UK, as they live with the challenge of a potentially life threatening diagnosis of cancer. We acknowledge the terms 'ethnicity' and 'culture' are problematic and therefore will use a definition based on self ascribed identity for both groups. Arguably, black and minority ethnic (BME) people with cancer are 'doubly disadvantaged' because they are less likely to take up cancer screening (Thomas et al 2005), and have less access to cancer and palliative care services (National Council for Hospices and Specialist Palliative Care Services (NCHSPCS) 2001; Gunaratnam 2001; Ahmed et al 2004). Data from the 2001 Census indicate there were 247,403 people of Chinese origin in the UK, 0.4% of the total population and 5.3% of all BME people. This study focuses on older Chinese people because they are a relatively marginalized and under researched group. It is important to include a group of 'white' older people to help identify those factors which are inherent to ageing in contemporary British society and those factors which can be attributed to cultural identity, migration experiences and possible racial discrimination. In addition, we are interested in the experiences of older 'white' British people with cancer, as the majority of research has focused on younger or middle aged people with cancer.

Psychological theories of loss and transition predict that patterns of experience in coping with loss and change influence subsequent encounters with threatening events and how they are construed (Parkes 1996). In our previous research with older Chinese people (Payne et al 2005b; Seymour et al 2007; Payne et al in press), we found that their attitudes to cancer were strongly shaped by experiences of migration and change. These views were also expressed in the contexts of personal biographical narratives of migration, transition, resilience and adaptation which accords with research on older migrants in Europe (Warnes 2004; Hoeksma 2004) and finds expression in anthologies such as those of older Chinese people who have migrated to live in the South West of England (Wong and Frances 2007). The purpose of the present study is to investigate how cultural constructs, both Chinese and 'white' British, of loss and transition impact upon adaptation to a cancer diagnosis.

## **1.1 Background**

Older people aged 65 years and above accounted for 16% of the British population in 2003-04 and used 43% (£16.47bn) of the total NHS budget, occupying 65% of hospital beds (Department of Health 2007). By 2025 the British population over 85 years old will have increased by 66% (Department of Health 2007). The population in the UK is ageing and this has implications for health and social care services and the extent to which they are prepared to meet the needs of this demographic shift. As people live longer it does not naturally follow that healthy life expectancy also increases. Older people also suffer more chronic health problems and often live with one or more long term conditions. According to the General Household Survey, 59% of those aged 65–74 and 66% of those aged 75 and over reported long-standing illness, disability or infirmity (Bridgwood et al 2000). Current Department of Health initiatives to mediate the effects of long term conditions comes via self care and the Expert Patient programme, Innovations Forum targets and Partnerships with Older People Pilot Projects. They aim to increase self awareness and management, avoid unscheduled hospital admissions, bring care closer to home and improve quality of life and well being in older people. The recent Cancer Reform Strategy (Department of Health 2007) highlights the need to provide appropriate cancer care throughout the trajectory of illness, to improve the quality of information provision and to acknowledge the special needs of cancer survivors for both those who have no evidence of disease and those who live with cancer (Feuerstein 2007). Individual risks of developing cancer are related to lifestyle factors such as smoking and diet, environmental exposure and heredity. The early recognition of cancer is associated with better outcomes, and increased likelihood of cure, helping to reduce hospitalisation and reduce the need for more aggressive treatment.

In the following sections, we offer a brief overview of the literature in three related areas: older people's experiences living with cancer in Britain, Chinese people's view about health, illness and cancer, and psychosocial concepts of loss, transition, adaption and coping in relation to cancer.

### **Older people with cancer in Britain**

Cancer predominantly occurs in older age with 64% of cases diagnosed in people aged over 65 (CancerStats 2005). However, both research and practice are disproportionately skewed in favour of younger people (Bailey and Corner 2003), which may reflect societal expectations that life limiting illness is more 'natural' within the context of later life and less likely to cause individual suffering and distress. Older people are heterogeneous and represent different age cohorts with a large range of life experiences.

There is some evidence that older people may be less aware of symptoms that signify a potential cancer or may attribute physical changes like a cough or changes in bowel habit to 'normal' ageing processes or other co-morbidities (MacFarlane and Kelleher 2002). This is linked to mixed evidence about the uptake of cancer screening by older people where low uptake may be confounded by other factors such as reduced mobility, less access to private transport and attributions that cancer predominantly affects younger people.

The heterogeneity of the older population is rarely acknowledged, even given a growing awareness of the role of individual factors in determining how cancer is understood and experienced. In a review of the literature, there is evidence of both under and over treatment for older people (Seymour et al 2005). While cancer care for older people may be excellent in some hospitals, previous research from the USA has identified that people over 65 diagnosed with cancer are less likely to receive appropriate therapies (Terret et al 2004) and, in particular are more likely to be offered non-curative treatments due to unfounded assumptions that aggressive treatments are both less acceptable and more poorly tolerated. These findings resonate with claims that health professionals may view older people through a 'skewed ageist prism' (Surbone et al 2007: 633) and assume universal frailty, treatment intolerance and cognitive impairment. Bailey and Corner (2003) identify evidence that such universal assumptions about older people carry over into cancer treatment, ultimately leading to a routinisation and depersonalisation of care.

Older age is also associated with lower levels of referral and use of cancer and specialist palliative care services (Burt and Raine 2006, Addington-Hall et al 1998), something which cannot be explained by older people's attitudes towards these services (Catt et al 2005). These findings concur with the conclusions of an extensive review commissioned by Help the Aged where the authors argue that older people, especially those in late old age, who are often women, may experience marked structural and financial discrimination in access to appropriate end of life care (Seymour et al 2005).

Recent policies have recommended improvements in information provision for people with cancer, taking account of issues in access, equity and availability (Department of Health 2007; 2008a). There have been marked changes in disclosure of diagnostic information and to a less extent prognostic information over the last thirty years predominantly in developed countries (Glare and Christakis 2008). These practices may mean that older people are generally better informed about their disease and have more opportunities to participate in medical decisions regarding treatment options and care preferences, than in the past. However, there remain many questions about how, when, and with whom, older people wish to express their care and treatment preferences (Vandrevala 2005).

### **Introduction to Chinese people's view about health, illness and cancer**

Recent research indicates there is a need to elicit the views of minority groups in designing and implementing cancer services to ensure equity in health care. Ethnicity, a problematic term, refers to a collective awareness of shared origins of descent, a sense of identity as a member of a group and difference from others (Field et al 1997; Gunaratnam 2006). Chinese people living in the UK are a heterogeneous group who have come from different countries such as Hong Kong, Singapore, Malaysia, Vietnam and mainland China and their spoken dialects include Cantonese, Hakka, Mandarin and Vietnamese (Chau and Yu 2001). They have widely different life experiences, cultural traditions, educational opportunities and economic positions. Chinese people have experienced different patterns of migration; some having settled in Britain following a period of residence in transitional areas such as Singapore or Hong Kong, while some have moved directly from mainland China. Some Chinese people will have been resident in the UK all their lives but the extent of acculturation

cannot be assumed from either length of residence or place of birth. The most recently available Census data indicate that they are also more likely to be self-employed than those in other ethnic groups with: 19% of Chinese people in paid employment being self-employed, compared with 10% of 'white' people and less than 10% black people (Census 2001). The majority of Chinese people (71%) work in the distribution, hotel, and restaurant sector. Demographic data indicate that most Chinese people are in the 20-35 age group but increasing cohorts are entering into their middle and older years, with approximately 5% (12,370) over 65 years of age in England (Census 2001).

Hence, it can be presumed that there might be an increase in the number of Chinese people who will be diagnosed with cancer since cancer predominantly affects older people (CancerStats 2005). The incidence of cancer amongst minority ethnic groups is thought to be lower than the 'white' English population (Rawaf 1996), but it is expected to rise as migrant's age, adopt western lifestyles and are exposed to environmental risk factors (Winter et al 1999). There is no accurate information about the incidence of cancer in Chinese people living in the UK but as 9% of Chinese women and 18% of Chinese men smoke (Census 2001), they are at a significant risk. Older Chinese people may experience discrimination both because of their ethnicity and their age. Issues of language competence, socio-economic deprivation, institutional ageism and cultural insensitivity may mean that older Chinese people are multiply disadvantaged in accessing acceptable cancer and palliative care services (NCHSPCS 2001). Gunaratnam (1997) warns against simplistic checklists and generalisations as they fail to 'reveal the complexity of the life history of individuals, and their communities and the diversity of their human experience'.

Traditional Chinese perspectives on illness and health are embedded in Chinese philosophies such as Confucianism, Taoism and Buddhism and there is an abundance of literature written on these issues (Chen 2001; Chau and Yu 2001; Owen 1994; Guo 1995). The teachings of Confucius provide principles for social interaction, advocating lack of self-centredness, loyalty to family, having a satisfying social life, happiness and peace, that are all believed to promote health and prevent illness. Taoism promotes harmony with nature (Chen, 1996) and to achieve health an individual has to fit in with the natural rhythms of the universe: death is perceived as natural and an extension of life. In Chinese medicine, health is achieved by having a balance of the forces of 'Yin and Yan' (vital energy) and illness is an imbalance of these forces. Traditionally, Chinese people believe in taking herbal/folk medicines to balance the Yin and Yan in their body. Buddhism believes in 'Fate, Inn (cause) and Ko (effect)' as the factors contributing to health, and being a good person and good to others are of great importance and would promote health (Chen 1996).

Culture fundamentally shapes how individuals and families make meaning out of illnesses such as cancer (Nunez Olarte 2003). However, culture is not static and views of individuals living in different countries are bound to vary over time and through the processes of acculturation in host countries. Chan (2002; 2004) has introduced the notion of 'cultural stagnation' where she argues that migrants retain cultural memories and cultural practices acquired when they left their country of origin, rather than current cultural practices in that place. This is of relevance for older people who may have migrated many years previously and experience cultural disjunctions both in the host country and in their place of origin.

There have been a few studies conducted in recent years examining the views of Chinese people in different countries about illness and cancer. A qualitative study conducted to explore the evolving experience of illness for Chinese women living in Hong Kong with breast cancer (Lam and Fielding 2003) indicated their illness experiences were similar to those living in western countries though the meanings of their illness were embedded in the cultural essences. Many of these Chinese women felt that having cancer would make them different from their social group and disrupt social harmony which is very important in a collective culture. Concerns were also expressed that failure to maintain a healthy body would bring bad luck to the family and society (Koo 1989). The need to avoid being seen as different was very important to them and they hid their cancer from other people. They seemed to value the breast much less as a feminine and sexual feature than in western culture and they felt its loss could be hidden, whereas hair loss and physical changes such as weight loss or gain were more visible features. Many of these Chinese women attributed the cause of their cancer to their own personal acts or previous stressful events and they felt recurrence of their cancer could be avoided by not repeating those acts or experiences. Another qualitative study conducted in the USA (Liang et al 2004) assessed 54 older Chinese women's views on health and illness and the influences of culture and language on cancer screening behaviour. They found their participants adopted a self help model in maintaining health by having outdoor exercise in the morning for fresh air and eating a hot-cold balanced diet which is emphasised in Taoism (the natural rhythm of the Universe). Their fatalistic views about cancer also made them less interested in getting preventive care and cancer screening as they believed whatever happens will happen and it would be beyond their control.

### **Psychosocial concepts of loss, transition, adaptation and coping**

This study is informed by key psychological concepts which will be introduced here. Loss is an inevitable aspect of life and refers to irrevocable changes such as the death of individuals, and also losses such as of function, social status or resources (Payne et al 1999). Theoretical concepts of loss can largely be grouped into three conceptual categories based on their major emphasis: (1) psychological processes, (2) stress and coping, and (3) social and relational aspects of loss (for a more detailed account see Payne et al 2008). Change and transition are conceptualised as having not only physical aspects such as relocation, but also as having psychosocial elements such as challenges to the taken-for-granted life world of the person, as originally described by Parkes (1971). We also draw upon social cognitive accounts of coping, especially the transactional model which proposes that coping is a function of primary and secondary appraisal processes, resulting in adaptive strategies aimed at minimising threat and harm (Lazarus and Folkman 1984).

Understanding lay beliefs about cancer and other aspects of health and their relationship to appraisals of cancer services and other health behaviours is one of the main objectives of our research. While social cognitive models offer some advantages they have been criticised because of assumptions of rationality and failure to incorporate cultural and social contextual factors (Bennett 2000). There has been a growing interest in the use of narrative methods as a way to access the experiences of people with cancer and other life threatening diseases (Bingley et al 2008). Moreover, the elicitation of biographical and autobiographical accounts helps to set current illness experiences in the wider context of individual's social and cultural lives.

According to Crossley (2000) narrative methodologies informed by critical health psychology permit the cultural context of personal biographies to be revealed. Elliott (2005) suggested that the term 'narrative' which is often used interchangeably with 'story' or storytelling is defined as: 'discourses with a clear sequential order that connect events in a meaningful way' (p.26.) For example, Thomas et al (in press) have conducted secondary data analysis on interviews undertaken with cancer patients in the North West of England to explore how narratives are embedded in their constructions of home and other care environments and the influence this has on their preferences for place of care. The authors argue that 'an analytical focus on the naturalistic storytelling of patients and informal carers can throw new light on individuals' perceived illness states and symptoms, their care-related needs, behaviours, and desires.'

Based on both a review of the literature and our previous research experience, and in consultation with members of the Chinese community, we aimed to address the gaps in knowledge about how older Chinese and 'white' British people with cancer understand and adapt to their diagnosis in the context of cultural constructs of loss, transition and resilience. This study therefore aimed to investigate how cultural constructs of loss and transition impacted upon adaptation to a cancer diagnosis.

## **2. AIMS OF THE STUDY**

### **Primary Aim**

To investigate the cultural constructs of loss, transition and adaptation in the face of encountering a diagnosis of a life threatening illness.

### **Secondary Aims**

1. To elicit the narratives of older adults about their experiences of a cancer diagnosis.
2. To determine the extent to which narratives provide evidence about coping.
3. To determine which features of narratives display resilience (if any).

### **Research Questions**

1. What are the narratives of transition of older adults encountering a cancer diagnosis?
2. How are cultural constructs of loss and transition articulated within personal narratives?
3. What impact do previous experiences have on resilience and coping?
4. To what extent do perceived family networks affect resilience, coping and adaptation to a cancer diagnosis?

### 3. DESIGNS AND METHODS

#### 3.1 Research Design

A longitudinal qualitative research study was conducted between July 2006 and June 2008. The research methods and recruitment strategies were informed by negotiation between the research team, the Chinese community, Cancer Support Groups and hospices in four areas of England.

#### 3.2 Ethical Approval

##### **COREC Research Ethical Approval**

Ethical approval for the study was obtained from the Manchester MREC (07/MRE08/7) on 21 February 2007.

##### **NHS Research Governance**

In all sites except in Plymouth, we recruited services or community groups that are not part of the NHS or located on NHS premises. This means that in most sites obtaining NHS research governance was not required. NHS research governance approval was obtained in Plymouth on 2 October 2007.

#### 3.3 Context of the Research

This research was conducted in four areas of England. These areas were selected to reflect the two living patterns of Chinese communities: highly dispersed (Sheffield, Plymouth) and highly concentrated (Manchester, London) (Chau and Yu 2001). In Manchester and London, there are identifiable 'China towns' providing a focus of Chinese speaking resources and cultural supports which may be hypothesised to be more readily accessible than in Sheffield and Plymouth. In the latter cities we were aware of more limited Chinese cultural resources. It should be noted that even in large cities with a 'China town' people of Chinese origin made up only just over 1% of the total population. Data from the Census 2001 indicate the following proportions of people of Chinese origin in each city:

*Sheffield* - 2201 in a population of 513,234 (0.4% of the total)

*Manchester* - 5126 in a population of 392,800 (1.3% of the total)

*Plymouth* - 685 in a population of 241,200 (0.28% of the total)

*Greater London* - 80,201 in a population of 7,188,000 (1.1% of the total).

#### 3.4 Recruitment and Sampling

The sampling strategy was informed by the principles of purposive sampling because we wished to elicit narratives from people in heterogeneous cancer diagnostic and prognostic categories. We were interested in the range of experiences rather than in seeking to make generalizations based on population characteristics. The intention was to identify 50 older Chinese adults with cancer resident in the United Kingdom via community based groups in Sheffield, Manchester, Plymouth and London and 50 'white' British older people with cancer (see Table 1 for study sites). We have used



the term ‘white’ British to signify self ascribed ethnic identity not as a physical marker of skin colour. The ‘white’ British people were recruited from cancer support groups and day care centres associated with hospices in each of the four areas.

**Table 1 - Location of study sites**

Location	Chinese sample	‘White’ British sample
Sheffield	Chinese Community Centre	Cancer Support Centre
Manchester	Chinese Community Centre	Hospice – Day Care
Plymouth	Chinese Community Centre	Cancer Support Centre
London	Chinese Community Centre	Hospice – Day Care

### **Recruitment method**

**Chinese sample:** Building upon existing good links with Chinese Community Centres in Sheffield, Manchester and London, we were able to develop an agreed plan for recruitment with them. Following a meeting in Manchester at a Chinese Restaurant on 16 October 2006, attended by Chinese older people and Chinese community leaders from Manchester, Sheffield and London, we were able to seek advice and collaboration on the recruitment plan for this project. They were keen to assist us with recruitment. Our researcher, Alice Chapman, had established links with the leaders of these centres through her previous work and had discussions with them about recruitment methods. In Plymouth we held a meeting on 12 June 2007 to launch our project attended by 50 Chinese people at a residential home for older Chinese people. There appears to be no formal way to identify older Chinese people with cancer. Local oncologists are unlikely to see many Chinese cancer patients and the incidence of older Chinese people attending hospices is known to be very low. There are very few Chinese cancer patients attending main stream cancer support groups with one of the main reasons being due to language barriers. We therefore decided to recruit through our networks in the Chinese Community for the following reasons:

1. All the community centre leaders are professionally trained and they have assisted us in our previous research.
2. They are likely to have contacts with Chinese people with cancer.
3. The Community centres often act as a support centre for Chinese people.

We also advertised the project via the media. Our researcher was interviewed both in Cantonese and English by BBC radio Manchester in April 2007. A press release article was also published in the local and national Chinese language newspapers in May 2007.

**Recruitment process:** The community leaders from each site identified potential participants and approached them about the project. Our researcher Alice Chapman, who can speak Cantonese and English, contacted only those people who expressed an interest in participating in the study. Written information in Chinese or English was provided to potential participants and they were given time to consider taking part in the study. Interviews were conducted in the participants’ preferred language and at their preferred location which could be their home, at their local community centre, or via the telephone.

***‘White’ British sample:*** ‘White’ British older people were recruited via large day care centres associated with hospices in Manchester and London, and via cancer support groups at Sheffield and Plymouth. This allowed us to recruit different groups of cancer patients, both those with advanced disease and those seeking complementary therapies and psychosocial support.

***Recruitment process:*** Hospice day care leaders distributed project information letters to patients and in cancer support centres project information letters were mailed to patients. Two researchers, Hugh Kidd and Alice Chapman, were involved in data collection. Cancer patients who expressed an interest in the study were provided with written information in English and given time to ask questions and consider if they wished to participate. Interviews were generally conducted in a quiet area of the day care centre or cancer support centre, or where preferred or more convenient at the patient’s home or in a few cases via the telephone.

***Sample inclusion and exclusion criteria:*** Participants were eligible if they were: older adults over 60 years of either gender who had received a diagnosis of any cancer type and at any stage. People were excluded if they were younger than 60 years, did not have a diagnosis of cancer, or declined to participate.

### **3.5 Data Collection**

***Development of semi-structured interviews:***

Building upon our previous research and evidence from the literature, two interview topic guides (see Appendix A) were designed to explore the cancer experiences of older Chinese and ‘white’ British people with cancer. The aim was to collect data relating to: experiences of cancer, previous episodes of loss, transition, migration and adaptation, coping, resilience, reactions to diagnosis, expectations of cancer treatment, views on cancer services and future care preferences. The above topics formed the framework of the contents of the interview but each interview was effectively guided by the interviewee’s own account in order to capture rich data from the interviews. The initial interview was anticipated to take approximately one hour to ensure full coverage of the life story and cancer experiences. The second interview was designed to elicit any changes between 3-6 months later. It aimed to clarify any queries arising from the first interview and was much shorter in duration (10-15 minutes) and was typically conducted via the telephone. The responses from the first two interviews at each time period helped to shape the subsequent interviews. Training was provided to the two interviewers to ensure that they were sensitive to the concerns of cancer patients and that the approach they employed was similar. A demographic questionnaire developed for this study based on Seymour et al (2002) was completed by the participants.

***Place of interview:***

For the Chinese group, interviewees were given a choice of different venues including their own homes, the premises of the Chinese organizations or another venue of their choice. The majority of the interviews were conducted in the participants' home while two interviews were conducted at their local Chinese Community Centre and seven via the telephone. For the 'white' British group, all interviews were either conducted at participants' home, a hospice day care unit or a cancer support centre. Most of the first interviews were conducted face-to-face and most of the second interviews were conducted via the telephone.

***Length of interview:***

It was decided the interview should last no longer than one hour as the interviewees might find it too stressful to discuss such sensitive issues for too long a period. Generally, the interviews lasted between 40–70 minutes. All interviews were audio-recorded. Brief field notes were made following each interview and were attached to the transcripts to provide contextual details.

***Language of interview:***

All the interviews from the Chinese group were conducted in Cantonese or English; and all of the interviews from the 'white' British group were conducted in English.

**3.6 Data Analysis**

All interviews were transcribed verbatim. Where necessary, interview recordings were transcribed into Chinese and subsequently translated into English. The majority of the Chinese transcribing and translation was undertaken by Alice Chapman, and she also checked the quality of all translations done by another translator. Both interviewers checked the quality of the English language transcriptions. NVivo software was used to assist in the handling of the qualitative analysis of interview transcripts.

The analysis aimed to build a description of the cultural constructs of loss, transition and adaptation in the face of encountering a diagnosis of cancer for older Chinese and 'white' British people and to draw out commonalities and differences in their experiences of facing cancer. We undertook two complementary analyses: an initial thematic analysis of the entire dataset and secondly an analysis of narrative threads in a selected sample of 30 interviews, followed by a final phase of integration.

***Thematic analysis:*** This analytic method aims to identify commonalities and differences both within the individual accounts and across the two groups (Chinese and British) (Payne 2007). We used techniques including highlighting elements of text of direct relevance to the study objectives but we were also open to novel constructs. Initial open coding of the first three transcripts was done independently by all members of the research team. An agreed framework of thematic categories was developed and applied to all the interview data. This produced preliminary descriptive codes representing a diversity of experience. These were refined through subsequent research team discussions. Most attention was placed on coding the initial interview which explored experiences in greater depth. Content analysis of the shorter second interview focused upon examining reported changes in personal circumstances, including cancer symptoms and treatments, and accounts of coping with cancer.

### ***Narrative analysis:***

There are many approaches to narrative analysis (Bingley et al 2008). In this study, we decided to focus our analysis on the identification of a number of narrative ‘threads’ which related to our research questions, rather than undertake other types of narrative analysis such as those seeking to identify typologies (Frank 2002) or explore the linguistic or semantic construction. However, there remains a wealth of valuable data which would repay more in-depth secondary data analysis. The aim of our selected type of narrative analysis was to determine the influence of previous life experiences on the way a cancer diagnosis is faced. The narrative analysis was guided by the methods described by Riessman (1993) where a search is made for expressions of continuities and discontinuities in the life narrative *within each individual’s transcripts*. The presence of key threads was identified in the narratives of the selected samples. In this context ‘threads’ are defined as sections of text which are ‘storied’ with the identifiable structure and content, and have relevance to the aims of the study. Key threads were then compared *within* the Chinese and British groups to determine culturally shared narratives and experiences. For example the analysis of a thread about migration experiences was guided by a series of questions including:

- Why did participants move to or within the UK?
- What were the characteristics of participants in relation to their place of origin?
- What were their experiences?
- What were their educational background and language skills?
- What were the effects of their migration?
- What hardships were experienced during and after migration?
- How settled were they? Have they become more settled or have they had difficult lives since migration?
- What made them stay in a certain place in the UK?

Finally higher order threads were compared *across* the Chinese and British groups to determine shared narratives and experiences which may be attributable to ageing, experiences of cancer or receiving care.

### ***Selection of narratives:***

A subgroup of 30 transcripts (15 Chinese, 15 British) was selected using the following procedures:

1. Identification of potentially suitable transcripts using the following criteria:
  - Age group (range of ages)
  - Gender (male and female)
  - Location (4 study sites)
  - Duration of interview (very short interviews were excluded).
2. A list of potentially suitable interviews was made and 30 selected.

3. Brief ‘pen portraits’ of the biographical and illness experiences of the selected participants were prepared. (These have not been included in the Report to maintain participant confidentiality.)
4. Common themes were identified and a matrix showing the presence or absence of the narrative threads for all selected transcripts was constructed.
5. An account of the key threads was prepared for each cultural group.
6. Finally a comparison of the narrative threads across groups was made.

### ***Integration:***

In the final phase we sought to offer an integration of the findings of the thematic analysis and the narrative analysis to answer the research questions. These formed the final reflections on the two methods of data analysis.

## **3.7 Ethical and Methodological Issues**

In the following section we briefly highlight some of the ethical and methodological issues that impacted on this study.

### **NHS Ethical Committee and research governance procedures**

Initially, the NHS Ethics Committee was concerned about the proposed method of identification of the Chinese older people with a diagnosis of cancer through the Chinese community. It was felt that reliance upon the Chinese community group leaders was problematic because it involved acting upon anecdotal evidence from community leaders who might incorrectly identify an individual as having cancer. Also, the NHS Ethics Committee felt the use of a community leader, who by definition would be a highly respected member of the Chinese community, could lead to potential participants feeling coerced into taking part in the research as they might not wish to defy the perceived wishes of the leader. The Committee recommended recruitment from local oncology clinics.

While the issues raised by the NHS Ethics Committee appeared to be reasonable, they also revealed a lack of cultural awareness and highlighted that little is known to the general public about the nature and background of Chinese communities. NHS Ethics Committee approval was subsequently obtained after further discussions as follows:

#### *1. Anecdotal evidence*

Although there might be a remote possibility of Chinese community leaders incorrectly identifying people with a diagnosis of cancer, great care was taken to enable people to clarify their own understanding of their condition.

#### *2. Coercion on potential participants*

Many of the Chinese community leaders are professionally qualified people such as medical doctors, nurses, lawyers and engineers who are bound by strict professional codes of ethics, just as in the ‘white’ community. Many of them are employed by

Chinese organisations and/or donate their time in a voluntary capacity to benefit their community. They had also had previous experiences in assisting with health research. Potential participants were offered repeated opportunities to decline invitations to participate in the interviews without the knowledge of their Chinese community leaders.

### *3. Approach via clinicians at the local oncology centre or Cancer Support Centre*

As people of Chinese origin make up only 0.4% of the total UK population, clinicians working at local oncology centres are not likely to see less many Chinese patients. Evidence from Cancer Support Centres and hospices reveal a very poor record of attendance as older Chinese people tend not to use 'white' English speaking groups due to difficulties with language and a discomfort with some cultural aspects of these organisations.

#### ***NHS research governance:***

We also experienced protracted bureaucratic negotiations and difficulties over five months in completing the NHS research governance procedures in Plymouth. In our view, this wasted precious time and resources during the project.

#### **Ethical issues**

The topic of the investigation was sensitive and the participants could be potentially frail and vulnerable (Muller and Desmond 1992). Therefore the research process was guided by on-going feedback from representatives of the Chinese community and Cancer Support Groups who provided advice and collaborated with the development of the study. Anonymity and confidentiality presented particular challenges when collecting detailed narratives from participants living in a close community who might know each other so it was agreed that minor adjustments to accounts would be made in any publications to maintain confidentiality. The community leaders, who were professional people familiar with assisting in research and aware of the importance of confidentiality made the initial contact with those who had had a cancer diagnosis and discussed the nature of the study with them. Participants were also given a number of opportunities to consider their decision to undertake the research. The researcher contacted potential participants only after they had expressed an initial interest in participation.

#### **Consent procedures**

All consent forms were translated into Chinese for those participants who did not understand English. The standard Participant Information sheet required by the Ethics Committee was translated and simplified as some of the concepts used in the information sheet were not comprehensible to some of the older Chinese participants. Similar to the findings of a previous study (Payne et al 2005b) a high number of the older people in the study (approximately 60%) were functionally illiterate in Chinese and English and therefore all the project information and consent procedures were explained thoroughly by the researcher who also checked participants' understandings. The researcher was aware of the high percentage of illiteracy in these groups of older Chinese people, so she normally asked the participants if they wanted her to help with filling in the forms. However, this raises ethical issues because it was

not possible for participants to independently complete consent and data collection procedures.

In addition, while people from the West might be familiar with signing official documents the research team were aware that older Chinese people might have concerns about signing consent forms because some of them were wary of 'official' documents possibly due to their social or political backgrounds. There was one woman in the study who came from mainland China who was unwilling to sign the consent form although she was keen to participate in the study. She could write in Chinese but did not want to write her name on the form. She eventually agreed to put a 'cross' as her signature on the consent form. During the interview, it was evident that she had encountered political experiences which made her wary of signing any official documents.

We were aware that talking about cancer, cancer services and recalling traumatic life events might be challenging and be distressing. We therefore provided contact numbers of support agencies to all participants as well as informing them that they could contact research team members (in their language of preference) if they had concerns.

### **Sampling**

Recruiting the participants via community centres had its drawback as it was most likely to select those who were socially engaged with, and identified with, a 'Chinese' ethnic identity. They were likely to be those least acculturated into western society but they were probably the most appropriate group for the study. However, the sample also under represented more affluent, more isolated and more westernised Chinese older people.

The process of recruitment of participants was relatively slow and community leaders have revealed that their members do not usually disclose their cancer diagnosis to the Chinese community at large. However, a few of the community centres had a role in offering support to their members who might be ill and it was through that channel they were able to identify potential participants.

### **Community leaders and community centres**

While it was appropriate for this study to recruit via the Chinese community leaders it did present some ethical issues as discussed earlier. Some participants might not wish the community leaders to know that they have been interviewed so the researcher stressed to the participants that their participation in the interviews would not be known to anybody including the community leaders.

The use of community centres presented some methodological and practical issues. One advantage was that participants were familiar with the community centres so they felt quite at ease when interviews were conducted there. However, the environment of community centres did present some minor problems as it could be quite noisy and some participants did not want other centre members to know about their participation in the interview. Hence, interviews were conducted at the community centres only if participants wished to. In the end, only two people chose to be interviewed there and

great care was taken to maintain confidentiality and privacy by having the interview in a quiet room.

### **Cultural appropriateness of data collection**

It was evident that many older Chinese people were unfamiliar with being interviewed. They were used to being given information, for example in health promotion information sessions organised by Chinese organizations, but were not familiar with the role of providing information or talking about their experiences. Therefore, the researcher had to make sure that participants understood that the purpose of the interviews was not to inform them about health matters. In fact, the word 'interview' was avoided as most Chinese people have different understandings of this term. People who came from Mainland China were particularly sensitive to the word 'interview' as a result of the political upheavals they had experienced in the past. Even people from Hong Kong, viewed interviews as something conducted with criminals or with famous people such as film stars or celebrities. Hence, the researcher avoided using the word interview and would invite participants to tell her their experiences in a face to face chat.

### **Perceived role of the researcher**

One of the researchers (Alice Chapman) has been resident in the UK for many years but is originally from Hong Kong and has a self ascribed Chinese identity. She is an experienced cancer nurse and has trained as an interpreter. Prior to working on this study, she was actively involved with the Chinese community in Manchester in health promotion. She was therefore known and perceived by some community members as a health educator. This created some of the difficulties in expectations described above. However, her knowledge and acceptability to community groups was invaluable in gaining access and in ensuring that the project did not inadvertently transgress cultural norms such as the inappropriateness of discussing sensitive topics such as cancer and death and dying in the month following the Chinese New Year and on participants' birthday. Because she was known to some of the community members she had to repeatedly reassure the participants that she would not tell anybody including other community members, about their participation in the study.

### **Translation**

All transcripts were transcribed verbatim into Chinese and then translated into English. While all these were checked for accuracy and consistency by the researcher and proof read by another professional translator, back translation procedures were not performed for reasons of cost. Translation of particular terms and phrases may also be contested. Translation may also distort concepts and understandings which are embedded in Cantonese. However, Alice Chapman and Man Cheung Chung are fluent in Chinese and English and familiar with both cultures so there is a relatively low probability that the interpretations of the data are likely to have been significantly distorted through the processes of translation and analysis.



## **Sensitive topics**

Undertaking this type of sensitive research with the Chinese community has proved to be challenging because there are strong cultural norms which prohibit the discussion of death and dying, especially amongst older people, as there are in many sections of English society. We were aware of the sensitivity of the research topic as cancer is still regarded as a potentially life threatening disease and many Chinese people as well as 'white' British people associate cancer with death. Participants were informed that participation in the study might involve discussing past experiences which might trigger possibly painful memories and they were told that they could end the interview at any point. They were also advised that the researcher would help them seek support or information if necessary. Most of the interviewees did talk freely about their cancer experiences from their own perspectives and did not find the topic too difficult. There was only one woman who avoided the use of the word 'cancer', although it was evident that she knew she had cancer.

For the 'white' British group, we did not encounter any problem with regards to the sensitive nature of the research. The participants from the cancer support group talked frankly about their cancer, although death was not mentioned much by this group. The participants from hospices seemed not to focus so much on their cancer but we had the impression it was not to do with the topic being sensitive. Instead it appeared that they were no longer anxious about their cancer because their focus was on how to cope with everyday life as a lot of them were on their own and had co-morbidities. Thoughts about 'death' were discussed by quite a few of these participants.

## 4. FINDINGS

The findings will be presented in the following main sections:

- 4.1 Description of participants
- 4.2 Thematic content analysis of the complete dataset
- 4.3 Narrative analysis of 30 selected transcripts
- 4.4 Integrative analysis.

### 4.1 Description of Participants

A total of 71 older people with cancer participated. We have provided descriptions of the samples by cultural group.

#### *Chinese Participants:*

**Table 2 – Characteristics of Chinese participants**

	Number of Interviewees	Male	Female	Language Cantonese	Median age
Manchester	14	3	11	14	61.5
Sheffield	6	3	3	6	60.5
London	4	1	3	4	59
Plymouth	0	0	0	0	
<b>Total</b>	24	7	17	24	60

The total number of Chinese participants was 24 with 14 from Manchester, six from Sheffield, four from London (see Table 2). No participants were recruited from Plymouth. No one invited to participate declined, a 100% response rate. Whilst both Manchester and London have a designated China town, not many Chinese people live in inner London and the ‘community centre’ where we recruited our participants acts as an information centre rather than a place to meet socially. In Manchester, the community centres are like ‘drop in centres’ and therefore; a larger sample of participants were recruited from Manchester.

We recruited approximately half of the intended sample of older Chinese participants (24/50), with 7 male and 17 female participants. The age range was between 50-76 years with a median age of 60 years. There is evidence that the health of older Chinese people deteriorates much faster than the same aged group in main-stream society (Owen 1994). In addition, only 5% of the Chinese population is over 65 (Census 2001). Therefore we recruited participants based upon their self-definitions of themselves as an older person.

Fifteen people were married, three were separated or divorced, one was cohabiting and five were widowed. Five identified their ethnicity as British Chinese; 12 as Hong Kong Chinese; 5 as Mainland Chinese and 2 as Malaysian Chinese. Fourteen people were born in Hong Kong, 5 were born in Mainland China, 2 in Vietnam, 2 in Malaysia and 1 in Macau. Three people stated they had lived in England for under 10 years, 1 person between 10-20 years; 6 people between 21-30 years, 9 people

between 31-40 years and 5 between 41- 50 years. Only 1 person described his/her health as excellent, 14 as very good or good; 9 people as fair. None described their health as poor. More than two third (17) of the participants said they did not suffer from any other chronic illness.

Nine people stated they believed in Buddhism, 6 described their religion as Christian or Roman Catholic. Just under half of the participants (9) stated they had no religion. Data from the 2001 Census indicates that over half of the Chinese in Britain stated they had no religion. The majority reported their present/past occupation as working in the food/catering trade and 5 worked as professionals. The main spoken language was Cantonese. Sixteen people described their English as very poor or not good; 5 as average; and 3 said their English was good or very good. No formal assessment of acculturation was undertaken. (For a summary of these details see Appendix B.)

***‘White’ British Participants:***

**Table 3 – Characteristics of ‘white’ British participants**

	Number of Interviewees	Male	Female	Language English	Median age
Manchester	13	5	8	13	77
Sheffield	14	1	13	14	68
London	15	11	4	15	78
Plymouth	5	0	5	5	68
<b>Total</b>	47	17	30	47	74

A total of 47 ‘white’ British people participated in the interviews (see Table 3). There were 30 females and 17 male participants across the four sites. There were 5 men and 8 women amongst the 13 interviewees in Manchester; there were 1 man and 13 women amongst the 14 interviewees in Sheffield; 11 men and 4 women amongst 15 interviewees in London; all 5 interviewees were women in Plymouth. A total of nine people declined to participate (1 from Sheffield, 5 from Manchester, 3 from Plymouth, 0 from London), a response rate of 84%. Twenty seven people were married and 1 single; six people were divorced and 13 were widowed. The age range was between 60-91 years with a median age of 74 years. Of the 47 people: 17 were aged 60-69; 19 were aged 70-79; 9 were aged 80-89. Two were aged 90-91. Twenty eight people identified their ethnicity as ‘white’ British; 5 as British; 7 as English and 5 as ‘white’ English; one as ‘white’ Welsh and one as Irish. The majority (n=41) were born in England, one person was born in Wales and one in Scotland. Only three were born abroad. All the participants apart from one had lived in the UK for most of their life and just a few of them had lived abroad for a few years when they were younger. Just under half of the participants (n=20) described their health as excellent, very good or good; 17 people as fair and 10 as poor. More than half of the participants said they suffered from chronic illness as well as cancer. Participants reported the following religious affiliations: 40 Christian or Roman Catholic and one Jewish. Six people reported no religious affiliations. There was a wide range of occupations amongst the participants. They all spoke fluent English. (For a summary of these details see Appendix C).

While we had intended to recruit older people who had had a cancer diagnosis within two years, difficulties in recruitment meant that we widened our inclusion criteria. Table 4 shows the distribution of participants by organisational type and years since diagnosis. Table 5 shows the cancer diagnosis of the participants. Just over half the sample 38 (53.5%) had been diagnosed within two years. In addition almost a quarter 17 (24%) had either had recurrences of cancer or new cancers diagnosed since their first cancer was diagnosed. There were more hospice participants who were in this category which is partly due to the older age of this group. Cancer tends to affect older age groups and tends not to be as aggressive as in younger people hence there is a longer survival but they are also more risk of recurrences or new cancer with advancing age.

**Table 4 - Cancer diagnosis: years (from diagnosis to time of interview)**

Location of recruitment of participants	2 years or less	2 – 5 years	5 years or more	Not disclosed by participants	Recurrences / new cancer diagnoses
Hospice day care (n=28)	13	5	9	1	12
Cancer Support Centre (n=19)	11	4	4	0	3
Chinese community organisations (n=24)	14	7	3	0	2
Total n=71	38	16	16	1	17

## **Cancer Experiences**

### ***Chinese participants:***

Most of the Chinese participants were relatively young (age range 50–76; median age 60 years) and appeared to be reasonably ‘well’ (mobile and self caring). Two thirds of them were married and lived with their spouses at the time of interview. More than half (14) of them had already completed their treatments and were just having follow ups. The rest of them were still receiving treatments. Most of them appeared to be optimistic and reported that they had been told ‘things were ok.’

### ***‘White’ British participants:***

These participants were relatively older than those from the Chinese group (age range 60-91; median age 74 years). Within this group, the participants recruited from hospices were older (age range 60-91; median age 77.5 years) and just over half of them were widowed/divorced and lived by themselves at the time of interview. Those recruited from Cancer Support centres were relatively younger (age range 63–83; median age 68 years) and the majority of them lived with their spouses. The participants recruited from the hospices were relatively frail (not as mobile and required some assistance) when compared to the participants from the Cancer Support centres. All but a few of them had completed their treatments and were just having hospital follow up or having support from their hospice and Cancer Support Centre.

**Table 5 - Types of cancer in the participants**

<b>Number of Chinese Participants</b>	<b>Number 'white' British Participants</b>	<b>Cancer Type</b>
10	21	Breast
4	4	Bowel/colon
1	3	Lung
2	0	Liver
1	0	Stomach
0	1	Oesophagus
0	2	Ovarian
1	5	Prostate
0	4	Bladder
0	1	Melanoma/Skin
2	1	Lymphoma
1	0	Leukaemia/blood cancer
0	1	Myeloma
1	0	Naso-pharynx
1	0	Kidney
0	2	Pancreas
0	2	Type not declared

## **4.2 Thematic Analysis**

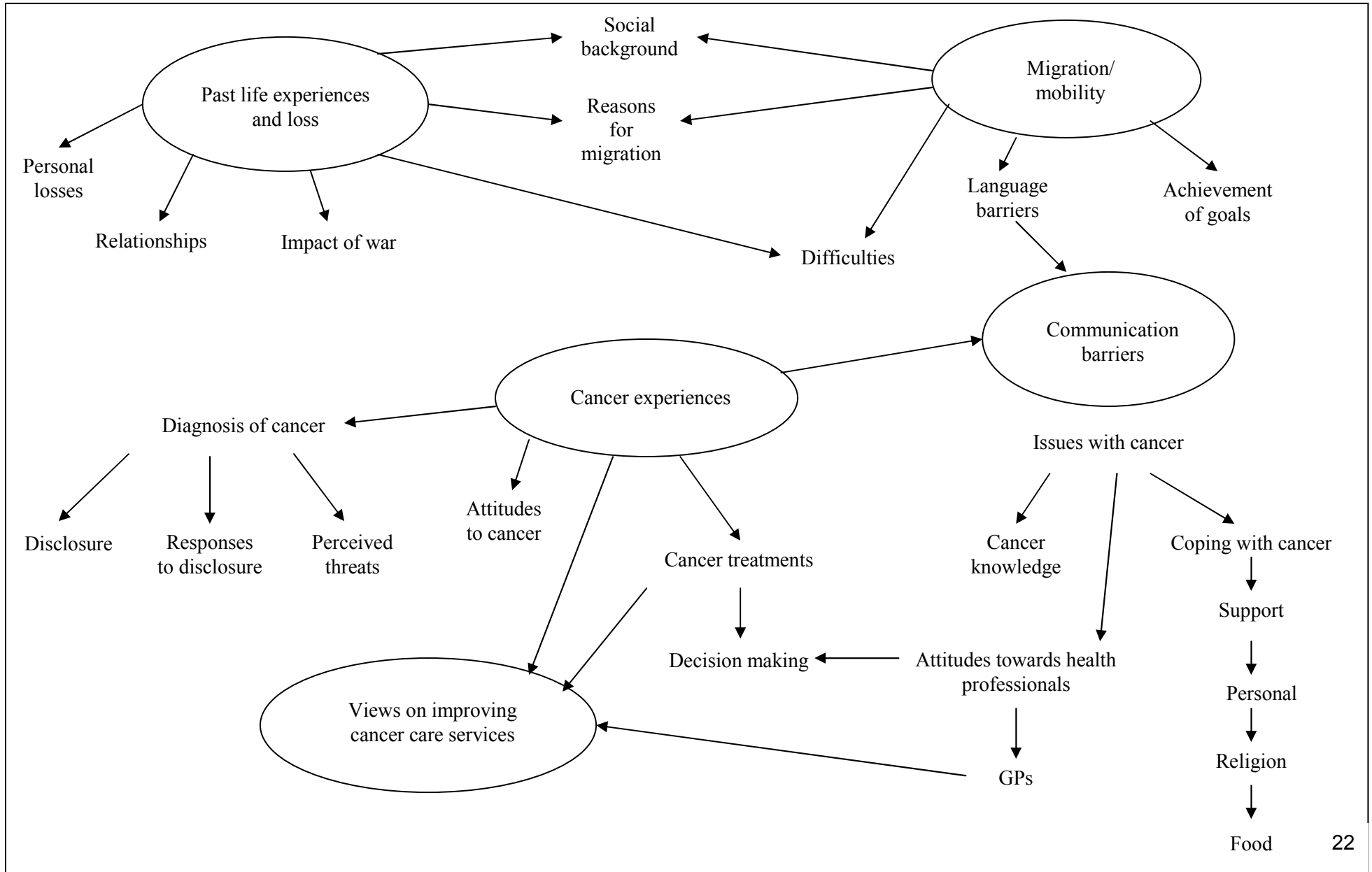
In this section we will present data from the first interviews conducted with all the participants. Using thematic analysis, open coding was used to identify five main thematic categories with their subcategories, displayed diagrammatically in Figure 1. Findings will be presented in relation to each cultural group separately. Verbatim quotes in italics are used to illustrate the range of experiences reported. These findings are presented in the following order:

- 4.2.1 Past life experiences and loss
- 4.2.2 Migration/mobility
- 4.2.3 Cancer experiences
- 4.2.4 Communication barriers
- 4.2.5 Views on improving cancer care services.

### **4.2.1 Past life experiences and losses**

This theme identified the impact of previous life experiences, including losses, on resilience and coping (see Figure 1). The excerpts below illustrate that some of the participants, who despite having had various traumatic life experiences, appeared to remain resilient.

**Figure 1 – Mapping the thematic content of older Chinese and ‘white’ British people’s cancer experiences in the context of life transitions**



#### 4.2.1.1 Personal bereavements

##### ***Chinese Participants:***

The majority of the participants had experienced deaths in the family and one third of the participants had a closed relative died from cancer. They described their reactions to these losses and offered examples of the coping strategies that they had used. For most, there had been intense sadness. In one case, there was withdrawal from the family business.

*“Of course, my wife had cancer and when she ‘went’ it was a saddest time for me when she went....so in the end I just let my chip shop to somebody else because I lost my interests.” (Man, age 64, code BY 36)*

*“Two of my brothers had already passed away and my sixth brother, the one above me, he had ‘gone’ due to cancer and my parents had also ‘gone’ due to cancer as well.” (Woman, age 58, code BY 37)*

One participant reported having lost her young son in a car crash when he was in his late teens; and her daughter had stopped coming to see her:

*“My eldest son was in a car crash; lost him! I have not seen my daughter for 10 years....” (Woman, age 64, code BY 34)*

##### ***‘White’ British Participants:***

Similar to the Chinese participants, the majority of the ‘white’ British participants had experienced deaths in the family and approximately one quarter of the participants had close family who died of cancer. These losses were described as distressing and disruptive, especially if the deceased died young. There were accounts of the impact of different forms of bereavement dependent upon the relationship with the deceased.

*“My daughter in law who never smoked had lung cancer; and it was her funeral last week. She was a lovely person and we were great friends; she was like a daughter to me. It is very sad.” (Woman, age 90, code BX 31)*

Losing one’s parents at a young age was reported as one of the most traumatic times in life:

*“I was eleven when my father died it was quite traumatic. I didn’t understand what was happening and you know, could not believe I wouldn’t see him again.” (Woman, age 63, code CX 55)*

Losing one’s child was described as devastating:

*“.....My youngest son was murdered in his twenties; it is a devastating thing, I think, losing a child is quite bad really.” (Woman, age 75, code DX 68)*

Death of a spouse was also described as stressful and traumatic:

*“Other stressful situations..... I’ve to cope with the sickness of my husband; I had to nurse him for 10 years before he died. He had emphysema and also diagnosed prostate cancer. So I lost him and it took me a long time to get over him.....I used to do 24 hours watch on him.” (Woman, age74, code AX 05)*

#### **4.2.1.2 Problems with relationships**

##### ***Chinese Participants:***

About one third of the participants reported problems with relationships such as with their spouse or children. Three were divorced.

*“Something happened to my family; you know that sort of thing.....my husband.....we are fine now, it was a few years ago that we had separated for two or three years.” (Woman, age 56, code CY 66)*

*“Put it this way, I would say my daughter is not so well behaved and she doesn’t care about me. Now that she has grown up she doesn’t even want to see me as I cannot find her most of the time.” (Woman, age 59, code AY 17)*

Very few Chinese participants talked about their relationship with their parents or guardians which might be due to the traditional belief that ‘parents or guardians are not to be talked about in any disrespectful manner’. However, two participants shared their experiences:

*“Actually I had had an unhappy life, many people close to me loved me but there was one person who didn’t love me; all members of my family loved me except my father because I was just too much like him.....and he favoured my sister.” (Woman, age 61, code BY 41)*

*“I had no parents since I was little. When I was six my aunt asked me to help her looking after her daughter so I went there. I had to get the water from the wells and cooked rice and do the washing at the age of six. If I didn’t do them I would be beaten and it was awful; I would get beaten each day.....” (Woman, age 62, code BY 38)*

##### ***‘White’ British Participants:***

As with the Chinese group, quite a few of the participants reported difficult relationships with their spouse, children and parents. Five of the participants were divorced at the time of interview. A few married participants had also been divorced in the past.

*“Um...the most unhelpful.....probably my husband, ha, ha! Well, life went on just the same for him, you know, I cooked, cleaned and washed, ironed and he never helped at all. (Woman, age 65, CX 52)*

*“Bringing up children had been hazardous. I mean I had my eldest son who has fortunately settled down now but he decided to...you know....travel the world backpacking. Then I had a daughter who was very rebellious and wanted to do her*



*own things but she's turned out to be a wonderful person now.” (Woman, age 85, AX 13)*

Accounts of difficult relationships with parents included this example:

*“My parents’ marriage broke up and it did make quite a lot of impact in my life; it was awful as I was quite young. Yes, it must have affected my life enormously.” (Woman, age 68, code DX 70)*

#### **4.2.1.3 War experiences**

##### ***Chinese Participants:***

In this cohort of older people, many had been touch by experiences of war and civil unrest, either directly in being involved in the armed services, or more commonly, indirectly through the experiences of family members. There was evidence of its impact on family life, restricted resources such as food, limited access to education and perceptions of reduced safety and security. Moreover, the effects of war cast a continuing shadow even following the resolution of armed conflict, with changes in political regimes and continuing shortages of basic food stuff and other necessities. This is most clearly demonstrated in the accounts provided by the three participants from Vietnam who had lived through periods of war in their early years. For these people, their early experiences had created a sense of resilience and in comparison, later challenges were regarded as less demanding.

*“It was much worse after the war was over as the communist came in ....before that we had freedom but after the war it became communist; and because my old man had been in the army and so he was harassed by the communist after the war.” (Woman, age 62 , code BY 38)*

*“I had been through a few wars!! The Japanese.....I was fourteen when the Japanese surrendered....then I went to Vietnam...there was the French war and also the Chinese-Vietnam war.....we have gone through it all and didn't get bombed to death!” (Man, age 76, code CY 62)*

*“Huh, at that time we went to school at the age of 11 and each morning we would just see dead bodies everywhere! I didn't think of anything! We were used to it; we used to see the bombing and open fire.....the Ming army and the cannons....we were not scared and just thought ‘if you die, you die’; that was all.” (Man, age 73, code BY 43)*

##### ***‘White’ British Participants:***

Just over one third of the participants (18) mentioned the effects of war on them. Within this group one third of them recounted experiences of fighting with the armed forces. The rest of the participants mentioned how they lived through the war period without experiencing too much trauma.

*“I was in the army for six years and spent two and half years in Gibraltar.....yes, you might see a bloke ....it is not very nice talking about it.....but you see a bloke running down the road with no head, it's only the nerves. Very bad experiences some of*

*them.....I did volunteer to join the army but I didn't like it." (Man, age 86, code AX 01)*

*"Well, I was in the Forces from '41 to '47. I don't say I liked it or disliked it but that's what life is all about. I saw a lot that went on in the Forces; I saw a lot of death. Probably that's what helped me." (Man, age 83, code BX 30)*

*"I had been married two years and I only saw him for his first vocation leave and then he was sent abroad and he was killed. But I've been on two visits to...Tunisia where he was killed." (Woman, age 85, code AX 13)*

*"I lived right alongside the XX docks so I mean it was constantly bombed every night and....as I say, well, you know, what had to put up with , that's made us a bit more resilient to things." (Woman, age 74, code BX 29)*

#### **4.2.2 Migration/mobility**

##### ***Chinese Participants:***

All the Chinese participants were migrants from Hong Kong, Mainland China, Vietnam and Malaysia. Many of the participants reported having to move around the UK to seek employment which was mainly in the catering trade. The average length of their residence in the UK was just under 30 years but the extent of acculturation cannot be assumed from either length of residence or place of birth.

##### ***'White' British Participants:***

All except three 'white' British participants were born in the UK. Just under three quarters of the participants were born and resided in the same town/area up till the time of interview. Only a minority (n=14) had previously moved house due to work or family requirements.

##### **4.2.2.1 Reasons for migration/mobility**

##### ***Chinese Participants:***

Most of the participants came to the UK between the 1960's and the early 1970's because of socio-economic reasons or for reunion with their families. The majority of them had no knowledge of this 'new country' and they came here through recommendations from friends or families who were already here. Their sole purpose was to seek a better standard of living. There were increased number of Chinese migrants between 1950's and 1960's in the UK and by the 1970's a lot of them had settled in the laundry or catering business and they began to send messages to their family and friends in their home country reporting on their success in the 'new country'. During the 1970's the economic situation in Hong Kong was not optimistic so the encouraging news about the 'new country' contributed to an influx of Chinese people migrating to the UK.

*"Why came to England? Because my father was in England so our family came here to be reunited." (Woman, aged 50, code CY 63)*

*“Because in Hong Kong...well....earning a living was rather difficult and the wages were low.” (Man, age 69, code CY 64)*

*“My brothers in law were already here and said business was good here. So we thought we would bring the children here for their education and we could also have our business and look after them at the same time.” (Woman, age 64, code BY 34)*

Three participants came to England as refugees after having endured hardship in Vietnam.

*“Well, we were scared....it would be like what happened in Cambodia! They were killing Chinese.....they had already killed two hundred Chinese people! (Man, age 76, code CY 62)*

#### ***‘White’ British Participants:***

The reasons for the ‘white’ British participants having moved around in the UK were mainly related to their family’s decision (parents or spouse), the war, changing jobs and retirement. Most of them were mobile when they were children or as a young adult. Most of the participants had settled in the same town since they were adults. Two of those who were born abroad came back to England with their family when they were young children. The other participant who was born abroad was of French origin and came here because she married a British man. In a few cases, people moved home on retirement.

*“I grew up in South London but I decided that I definitely wanted to travel and work abroad and I was drawn to the theatre; so my first venture abroad I went as a dancer. (Woman, age 62, AX 04)*

*“I was born and bred in South Wales and was there till I retired at 60; then I came to live in (South East London).” (Woman, age 82, AX 12)*

#### **4.2.2.2 Language barriers**

##### ***Chinese Participants:***

Overall, language barriers were reported as one of the biggest problems for their adjustment to living in the UK. The majority of the participants reported that they could hardly speak English at the time of their migration to the UK.

*“I didn’t speak English; didn’t even know the names of any streets when I went out, so I asked them to write it on a piece of paper and just asked people how and where to get on a bus.” (Man, age 76, code CY 62)*

Five participants reported they could speak English and most of them were professional people and came from Malaysia or Hong Kong.

*“I grew up in Malaysia so English language was not a problem.” (Woman, age 65, code CY 61)*

### ***'White' British Participants:***

The spoken language for all of the 'white' British participants was English. There was one participant whose native language was French but she had mastered the language since she settled in England.

### **4.2.2.3 Social background**

#### ***Chinese Participants:***

Half of the participants came alone to England but most of them had either a relative or friend living here. While the remaining participants came with either their spouse or family. Most participants worked in the catering trade and formed a small network with their fellow countrymen and supported each other as best they could. They reported having few opportunities to mix with mainstream society and their language difficulty was another factor which prevented them integrating with English speaking people.

*"I had my brother here, I went to work in a Chinese restaurant and a few of the workers were from the same village in Hong Kong....my only wish was to find a firm base and get my wife over here; so after I had worked in the restaurant 2 years and 10 months I bought a chip shop...and brought my wife here." (Man, age 69, code CY 64)*

Due to the unsocial working hours of the catering business, participants reported meeting at casinos after finishing work late at night. Casinos were reported to function as a 'social gathering place' as well as a 'gambling place' for most of the participants. Social isolation and exclusion from mainstream society was a result of their employment and language difficulties.

*"You had very little free time...very little...only when the shop is closed at nights when most people in the mainstream society have gone to sleep, right? Whom can you see? The only people are those in the casino...they would talk about price of potatoes and fish...it is a social setting." (Man, age 64, code BY 36)*

*"Apart from when I was working and serving the customers I had the chance to come in contact with the English; besides that, I had no English friends." (Woman, age 61, code BY 41)*

Participants lived within 'their circle' and if they needed to access essential services, such as health and education or social services, they were often helped by their peers or relatives who spoke limited English.

*"Well, we did have a few Vietnamese who could speak a bit of English." (Man, age 73, code BY 43)*

*"I would not go to see the doctor only if I had something serious I would ask.....my boss's wife who came from Malaysia and her English was good so she could [interpret] ..." (Man, age 69, code CY 64)*

### ***'White' British Participants:***

Most of these participants had different occupational backgrounds when compared to the Chinese participants. They had varied jobs ranging from unskilled to semi skilled or professional employment and included: gas company worker, factory worker, shop manager, sewing machinist, secretary and teacher. They appeared to have good social support networks.

*"I was with the gas company, yeah and then I got made redundant twice there. And I went into another firm where they did sprinklers, fire sprinklers for Marks and Spencer's and all the different shops and factories. I was there till I retired when I was 60."* (Man, age 86, code AX 01)

#### **4.2.2.4 Difficulties**

### ***Chinese Participants:***

Chinese participants listed a number of challenges in adapting to their new life in Britain including: language difficulties, the weather, employment, food availability and discrimination. The following quotes offer some examples. As cited earlier, language barriers were one of the main difficulties encountered by these participants, despite attempts to learn English:

*"The most difficult was because I did not understand the language."* (Woman, age 62, code BY 38)

*"It's definitely the language difficulty! I have tried to learn but without success; I didn't go to school properly so language barrier is the biggest problem."* (Woman, age 56, code BY 45)

Some reported difficulties in adapting to the British climate:

*"At the beginning the most difficult thing to get used to was the climate; the weather was cold. When it was winter it was very cold indeed."* (Man, age 51, code CY 65)

Some reported limited job opportunities and perceived themselves to be restricted to the catering trade:

*"Well, finding a job wasn't very difficult.....however it was narrowed down to working in the restaurants or fish and chip shops."* (Woman, age 56, code BY 35)

The availability of culturally acceptable food was also highlighted as a problem for some:

*"It was the food, at the beginning I could not get used to the English food. As you know the Westerner's food is so different from our Chinese food so I could not get used to it. However, my mother was very good and she used to send me parcels with dried noodles etc."* (Woman, age 65, code CY 61)

A few participants reported episodes of prejudice and discrimination, especially in the period soon after their arrival in the UK:

*“At that time, people did not know much about South East Asia so many of them....I remember one old lady ...she asked me....what she meant was whether we still lived on the trees and if our houses were built on top of the tree!!” (Woman, age65, code CY61)*

**‘White’ British Participants:**

Most of these participants did their travelling while they were younger and settled in one place as a young adult or during middle age. They appeared not to encounter too many difficulties in these transitions. Those few who had moved to another part of the country at an older age or at retirement, reported feeling isolated because their family and friends were far away from them.

*“Because when I came down here from the Midlands, I was still working and I got a job here; I didn’t really want to live down here but it was my husband’s great wish to live down here. It is a mistake in a way, I didn’t want to come as I say because I thought, you know, that time of your life you have got to start afresh and that sort of thing all that family network, and all the rest of it. So I was sorry that we came down really.”(Woman, age 75, code DX 68)*

Another participant who lived abroad for many years found it very hard adjusting life back in England:

*“I would be eight or nine when we came back and it was difficult because when you are with the regiment (my father was in the regiment) your school teachers travel with you; the children of the regiment all went together so your friends were there.” (Woman, age74, code CX 54)*

Another participant who had moved with her family from the Midlands to the North found it difficult to leave her friends:

*“Yes, and initially I did, I mean I didn’t want to come here I cried but after six months it was better.....” (Woman, age 67, code CX 59)*

As with the Chinese participants, one French participant did have some problem with language, climate and people’s attitude when she first came to the UK:

*“Yes, I could understand a little English and you know how you learn when you are there, just sort of guess when you are younger you pick up quicker. But it was a big change for me because of the climate.....but the British people in those days generally they never went abroad much, away from their island; and they really thought any French people were much lower than they were.” (Woman, age 83, code CX 49)*

#### **4.2.2.5. Achieved goals of migration**

##### ***Chinese Participants:***

Most of the participants came to England to seek more financially stable living conditions and they appeared to have achieved their goal. The majority started working in chip shops or restaurants and gradually worked their way to better paid jobs such as chef and shop/restaurant managers. Half of them eventually established their own business.

*“Well, at any place, if you could get to know more people.....make more friends, knowing.....and then I worked at the takeaway till I retired.” (Man, age 76, code CY 62*

*“It was a family business as we wanted to stay together as a family and then we had children.”(Woman, age 54, code BY 39)*

*“I bought a chip shop in XX. In those days, buying a chip shop was cheap and the wages were low.” (Man, age 69, code CY 64)*

Chinese parents are renowned for striving for a good education for their children. Most of the participants came from Hong Kong which is a very competitive society and they viewed education as a key to success so most parents invested their time and money to provide a good education for their children. The Chinese participants invariably talked about their children’s achievements with pride.

*“My eldest is 22 years old and is working as a solicitor after graduated from the university. She got a degree in law...actually she has two degrees... ..my second son is studying in university at XX and when he studied in the secondary school his achievement was brilliant.” (Man, age 51, code CY 65)*

##### ***‘White’ British Participants:***

The ‘white’ British participants who migrated internally within the UK, for reasons of employment, largely achieved their economic and career progression goals and reported a sense of stability and accomplishment.

### **4.2.3 Cancer experiences**

#### **4.2.3.1 Disclosure of cancer diagnosis**

##### ***Chinese Participants:***

All apart from one of the participants in this study were aware of their cancer diagnosis before they had treatment. One participant who did not understand English was not informed about her diagnosis by her daughter who acted as her interpreter. It was after she had had her operation and while she was at a cancer hospital for radiotherapy that she realized she might have cancer.

*“I really didn’t know what was happening..... my daughter said I had a gland which needed to be removed. In the end after I had the operation and they sent me to another hospital for radiotherapy and while I was there, I heard the Westerners mention ‘cancer, cancer’.” (Woman, age 71, code BY 44)*

It was impossible to know if participants would have preferred not to be told about their diagnosis had they been given the choice. As one of the participants said it would be impossible for the doctor to treat her without telling her the diagnosis.

*“Whether I want to know or not....they would just tell you so you would know, right? The doctor cannot hide the facts from you so they would of course want to tell you about your condition and what they would do. How could they carry on with the treatments without telling you?” (Woman, age 72, code BY 33)*

The rest of the participants felt they wanted to know the truth about their diagnosis. The reasons they wanted to know varied from beliefs about having a strong character, wanting to make arrangements for the family and wanting to face up to it.

*“Well, I think it is better knowing because from the point of a patients view I would rather know. I need to consider people around me such as my children and husband. I would want to make arrangements before I ‘go’ (die) with a peace of mind. I have parents and responsibilities and would like to fulfil my responsibilities before I can ‘go’ happily, just like what the elders say ‘can go’ in peace and happily’.” (Woman, age 50, code CY 63)*

The above excerpt came from an interview with a woman who had a strong desire to fulfil her family responsibilities, something prioritised within Chinese culture. In Chinese philosophy, it is believed that one can only die peacefully and happily when one’s family responsibilities are fulfilled. The excerpt also indicates that the participant perceived cancer to be a life threatening disease.

Interestingly, one of the participants felt very strongly that she should be informed of her cancer diagnosis but did not let the consultant tell her husband his cancer diagnosis. She felt he was not strong enough to bear the news so she did not tell him the truth. She managed to ‘control’ the situation because he did not speak English and she was his interpreter.

*“He did not understand English; I did the interpreting for him and the consultant just said it to me. He would not have the will if I had told him, he would just sit there and waited to die...I think it is not up to the consultant to say that I must tell my husband because I knew my husband.” (Woman, age 65, code CY 61)*

Of course, the consultant appeared to have complied with the perceived Chinese culture with regard to the role of family in decision making and the participant believed that she was acting in the best interest for her husband. However, the issue here was that no one really knew the husband’s preferences as he had not been given the choice to express them. Similarly, the consultant could not check his patient’s preferences on the disclosure of his diagnosis. Arguably, if the consultant had mentioned the word ‘cancer’ to his wife in front of him he would possibly have some idea as the English word ‘cancer’ is known to the majority of Chinese people



including those who cannot speak English. Whether this husband had colluded with his wife about his cancer diagnosis is not known.

Another participant talked openly with the researcher about her breast cancer but said she did not tell people apart from a couple of friends because of concerns about the negative impact on her husband's business of revealing her cancer. This example is indicative of the stigmatised nature of both cancer and its perceived potentially fatal outcome in contemporary Chinese society in the UK.

*"My good friends know but others don't know; only a few from the church know. I don't mind but my husband does mind because we don't know what people would think; it might affect our business....you know....they might think 'his wife is going to die.' and so on."* (Woman, age 50, code CY 63)

#### ***'White' British Participants:***

All of the participants were aware of their cancer diagnosis and talked openly about it. The majority of them were told of their diagnosis by the doctors at the hospital and they wanted to be told the truth.

*"Yes, the surgeon....not the consultant, the surgeon told me I got cancer."* (Man, age 85, code AX 11)

*"Yes, the consultant did tell me it was cancer, yes."* (Woman, age 67, code DX 69)

#### **4.2.3.2 Responses to the cancer diagnosis**

##### ***Chinese Participants:***

The participants' responses to their cancer diagnosis varied between being shocked, frightened/ scared, calm, feeling indifferent, accepted it as fate, crying or being oblivious.

*"At that time, I thought the world had come to an end like I was struck by thunder."* (Man, age 51, code CY 65)

*"I think I was a bit calm, I accepted it. I did not cry etc.....I just accepted it...if it is meant to be it is meant to be. If I die, it must be fate."* (Woman, age 65, code CY 61)

*"No feeling! My GP said it was confirmed....In the end, he told me not to be scared but I wasn't, just wasn't!"* (Man, age 69, code CY 64)

##### ***'White' British Participants:***

Over half of these participants, especially those recruited from hospices, reported that they were calm and philosophical in responding to their cancer diagnosis. There was a potential gender difference with men being more likely to report little emotional reaction.

*“I have got a cancer and wound up with one.....but funnily enough, that has never bothered me at all and doesn't bother me.” (Man, age 81, code AX 02)*

*“Well, it's a fact of life, isn't it? You've either got an illness or you've not. So there is nothing I can do about it; it's up to them, isn't it?” (Man, age 79, code BX 26)*

In comparison the female participants, especially those recruited from Cancer Support Centres, reported responding to their diagnosis by being very shocked/frightened, panicked, dismayed, upset or numb.

*“No, it came as a complete surprise to me having had five (benign tumours) before. Yes it was a total shock.” (Woman, age 67, code DX 69)*

*“Well, it was a shock I don't think it sunk in for quite a while.....when I first had the diagnosis at the doctors I had to go and sit in the waiting room; and I was choked, you know, I got tears in my eyes and I couldn't believe I had got a lump.....”(Woman, age 70, code CX 50)*

*“I felt very frightening, very worrying, very upsetting.” (Woman, age 74, code DX 71)*

*“Well, no, I mean I was a bit dismayed I must admit.” (Woman, age 75, code DX 68)*

#### **4.2.3.3 Perceived threats of cancer diagnosis**

##### ***Chinese Participants:***

It was apparent in the interviews that changes in health status, uncertainty about recurrence and death were perceived as some of the threats of a cancer diagnosis.

*“Your health would be affected. I am now weaker and no longer do this and that. I cannot carry heavy things and I am definitely weaker.” (Woman, age 65, code CY 61)*

*“Huh, at the moment everything is ok and you can say we are settled but no one can foresee what will happen in the future. No one knows when the disease recurs, right?” (Woman, age 61, code BY 41)*

*“You asked what my worries are at the moment. I just don't know how long will I live, do I? My GP had said no one could give me any guarantee.....” (Woman, age 56, code CY 66)*

*“Yes, I don't know how long I have got or if it would come back; nobody knows! Now I might be talking to you...who knows...I might not be ok the day after!” (Woman, age 50, code CY 63)*

*“My GP said it was confirmed and it was early stage. I was 64 at the time and thought to myself there is nothing to be scared as everything is already fixed. My grandfather and father both died at the age of 57 so... ” (Man, age 69, code CY 64)*

### ***'White' British Participants:***

Similar to the Chinese participants, death and recurrence of cancer were the two main perceived threats of a cancer diagnosis. It appeared that participants from the hospices talked about the possibility of death more than those from the Cancer Support Centres who seemed to be more concerned with the recurrence of the disease. This was probably related to their different stages in the cancer trajectory, with those in hospice Day Care having more advanced disease.

#### Hospice Day Care:

*"It's on your mind all the time. Whereas if you are not going to get better, you know, well, you're not going to get better." (Man, age 86, code AX 01)*

*"Yes, yes, yes, and as I say we know it's all going to be inevitable. There is nothing they can do you know; and as you say, it is trying to face up to the reality of it.....I must admit I haven't come to terms with it.....Why me?" (Man, age 61, code AX 07)*

*"I just get on with the day as it comes; I mean the future's got nothing to do for me." (Man, age 82, code AX 12)*

*"I presume the tumours gone and hope it doesn't come back." (Woman, age 74, code CX 53)*

*"I was totally out of it for three weeks! I just couldn't cope because I thought you immediately thought you are going to die straightaway....." (Woman, age 67, code CX 59)*

#### Cancer support centres:

*"Yes, I am a bit more nose-y now. And I think I've got a bit more courage, I've finally accepted that maybe I am not going to get better." (Woman, age 60, code BX23)*

*"Well, obviously I thought I was going to die....." (Woman, age 67, code DX 69)*

*"I mean to be honest I go day to day now and I am grateful each time I wake up. Mine may never come back but like they said they can never say; they can't say to you it will never come back." (Woman, age 67, code DX 67)*

### **4.2.3.4 Attitudes towards cancer**

#### ***Chinese Participants:***

The majority of participants had mixed views about their cancer diagnosis. While most of them appeared to be optimistic towards their cancer diagnosis, they were aware of the uncertain outcome of cancer. They were aware some cancer could be cured if discovered early, but that it could also be fatal. Most of the participants took a fatalistic view towards the cause of their cancer. One person attributed her breast cancer to an excessive use of hormone replacement therapy prescribed by her family doctor.

*“Truly, because when you are older you would be affected by illnesses; one kind or another. And one day you will have to die and when you do die it would probably be due to illness, right? My feeling is that first of all, it is discovered early and also I no longer have responsibility, don’t need to look after the children.” (Woman, age 64, code BY34)*

There was a belief expressed that having cancer is ‘paying back the wrongs that the person had done in his/her previous life’ as described by the following participant.

*“There are less than 10 of my friends who know I have this illness.....I don’t want to let them know. Chinese people consider ‘face’ to be very important. Huh, even though you have this illness, you know.....the Chinese always say that.....one reaps what how sows; or that’s to do with your previous life!” (Woman, age 56, code BY 35 )*

### **‘White’ British Participants:**

The majority of participants were aware of the threat of dying from cancer but they also believed there had been significant treatment advances recently.

*“Yes, I mean today there is so much more cure around for cancer; it doesn’t have to be a death sentence.” (Woman, age 75, code DX 68)*

Some still felt cancer was a stigmatised death:

*“I know we have all got to die of something but I think cancer is a filthy death.” (Woman, age 74, code CX 54)*

A number of participants talked about the hereditary aspects of cancer.

*“On my side, as I say my sister’s husband, he’s got colon cancer. And we’ve just found out that my cousin....got Hodgkinson cancer in the family and his partner has got colon cancer. “ (Man, age 61 , code AX 07)*

Quite a few participants had a ‘self blame’ attitude towards their cancer:

*“Oh, it was. But it was my own fault I used to smoke a lot; the trouble is it is too late now....” (Man, age 86, code AX 01)*

*“I smoked when I was a youngster and I didn’t give up until about 35 years ago. I should not have smoked at all.” (Man, age 86, code AX 10)*

#### 4.2.3.5 Cancer treatments

##### 4.2.3.5.1 Choice of treatments

###### *Chinese Participants:*

All participants accepted treatments from the mainstream health care services. They were given choices of cancer treatment offered by the cancer specialists. No mention was made of opting to receive traditional Chinese medicine instead of the Western medical treatments. Apart from four people who did not have surgery, all participants had surgery combined with chemotherapy and/or radiotherapy.

*“They gave you the options; between chemotherapy and surgery. I said I would rather have the operation. He said the best treatment is chemotherapy because it will kill all the cells inside the body, if the chance....there is minute one that has gone out.....you never know.” (Woman, age 65, code CY 61)*

*“They suggested radiating the edges around the area where the lump was removed but it would be painful and I would not need chemotherapy. But the doctor let me choose between radiotherapy and removal of the whole breast.” (Woman, age 50, code CY 03)*

*“Yes, I could leave it. But he said ‘the problem is if it has spread by the time you are over 70 we would not be able to operate on you. You are very healthy at the moment I would suggest it is best to have it done.’ (Man, age 69, code CY 64)*

Two participants mentioned their intention of going back to their homeland to seek further treatment, but there were concerns about medical costs in Mainland China.

*“.....I heard other people say there is a hospital in China which is very good in treating this kind of problem.....I would like to go and have a look and give every possible thing a try. At the moment, I take Chinese herbal medicine.” (Woman, age 56, code CY 66)*

*“It is not free in Mainland China; you have to pay now. Of course I accept it here. Here you could say everything is good.” (Woman, age 72, code BY 33)*

Most participants reported having been told they had a good prognosis and appeared to be relatively well. Traditional Chinese Medicine (TCM) has been used as a supportive role in cancer patients and research indicates that older Chinese people may use TCM to counteract side effects of cancer treatments (Payne et al 2005b). About one third of the participants mentioned taking TCM as a supplementary treatment at some stage of the illness. This suggests that Western medicine was readily accepted by these participants. Also, it appears that participant's preferred surgery to chemotherapy or radiotherapy as confirmed by evidence from an earlier study (Payne et al 2005b).

*“Some friends recommended me to have acupuncture or Chinese herbal medicine. This could help to reduce the side effects from the chemotherapy. Acupuncture would*

*alleviate your symptoms ....I mean it gives your body a comfortable sensation.”*  
(Woman, age 56, code BY 35)

*“My wife had heard how good Ning Ji (Chinese herbal medicine) is and if you started taking them before the chemotherapy treatment...eight tablets daily.....it helps your cells.....boost your immune system. Yes, I took them before my chemotherapy treatment and true enough I did not suffer very badly; and had no hair loss, no vomit, no dry mouth etc.”* (Man, age 51, code CY 65)

### ***‘White’ British Participants:***

Most participants had accepted treatments offered by the mainstream health services. The majority of them had already completed their treatment at the time of interview. Generally, as with the Chinese participants, chemotherapy was viewed as quite a ‘difficult treatment’ which caused a lot of side effects. Most of them had surgery combined with chemotherapy or radiotherapy.

*“After I had the operation the oncologist said I was a borderline case and it was up to me if I had chemotherapy or not. But in two seconds flat I said I wanted it.”* (Woman, age 65, code CX 52)

Where participants were given an option of treatments, quite a few of those with breast cancer chose to have mastectomy rather than having a lumpectomy.

*“As soon as they said ‘you know, we can take the lumps out but it will leave your breast looking a bit funny.’ I said ‘I don’t want a lumpectomy I just want the whole lot off.’ Because .....I know it’s been proved that it’s not the case but in the old days, a lot of people who had lumpectomy it seemed to reoccur.”* (Woman, age 67, code CX 59)

*“I plumped for a mastectomy because had I just had a lumpectomy I wouldn’t have felt safe. I wanted the whole thing gone.”* (Woman, age 63, code CX 55)

A few participants refused to have chemotherapy or radiotherapy treatments:

*“Well, I went on the internet and researched a lot.....the doctor said to me if I don’t want it and can live with the fact that I have turned it down if the cancer came back.....and I said I don’t feel like that; I said if it comes back I will deal with it, so I said no and I won’t regret turning the chemo down.”* (Woman, age 70, code CX 50)

*“I had one bout of radiotherapy on my hip but I said ‘that is it.....I am having no more’.”*(Woman, age 74, code BX 29)

A lot of the participants were interested in, and had taken up, complementary or supplementary treatments. It should be acknowledged that this is biased by our recruitment from Cancer Support Centres where complementary treatments are readily available. It also suggests a greater uptake of these therapies by women.

*“I was very interested in complementary therapies to help me with the chemotherapy. I went to the XX centre where I had a consultation.”* (Woman, age 62, code AX 04)

*“I had reflexology and body massage, yes.” (Woman, age 67, code DX 69)*

*“ Erm, the benefit I had had from acupuncture....it helped with the tingling of my fingers but it was the relaxation that sort of total.....I felt it help me with my well being.....it did not cure my symptoms but it helped my Chi, my spirit.” (Woman, age 72, code CX 60)*

#### **4.2.3.5.2 Decision making**

##### ***Chinese Participants:***

Participants encountered a number of decisions related to their cancer. These decisions involved their clinical care, including treatment of the disease and symptoms, and other decisions related to the rest of their lives. These decisions were often difficult to make and stressful, with much uncertainty about making the ‘right’ choice. Most of them reported making the decisions within the context of opinions and beliefs held by family members. Thus decision making was complicated by individual preferences, competing advice from family members and health professions, and set in the context of the communication skills of health professionals, and participant’s own language skills and understandings of their disease.

*“But after we had a family conference and discussed it....my godmother told me off and said I should have it removed and not have radiotherapy. I discussed with them and they agreed I should have the operation to remove it. Yes, it was best to have all of it removed.” (Woman, age 50, code CY 63)*

*“The doctor said of course it was best to have it done so you would just listen to the doctor, right?” (Woman, age 72, code BY 33)*

##### ***‘White’ British Participants:***

Most of the participants appeared to have made their own treatment decisions after discussion with health professionals, and in some cases, family members. It also appeared that the groups from Cancer Support Centres who were mainly diagnosed with breast cancer were well informed of their treatment options. This could be due to the high profile of breast cancer in the public domain in recent years and the availability of a peer group with breast cancer who could function as a support group.

*“They told me I would need to have chemotherapy after my operation because although they did not find any cells in the lymph nodes they took away they said sometimes a cell can slip past those.....so I had the chemotherapy and that was basically it.” (Woman, age 63, code CX 55)*

Previous knowledge about cancer treatments from family and friends also played a part in decision-making:

*“The doctor told me about the percentage tables ....all the percentage of life expectancy with chemo and without it; there was only two percent difference.....we went away for a fortnight and when we came back all the family said what they*

*thought but they said it was my body...and I decided not to have any chemo because I know several people who had had chemo and it had done all kinds of things to them; they had sore mouths and things like that.” (Woman, age 70, code CX 50)*

#### **4.2.3.6 Issues with cancer experiences**

##### ***Chinese Participants:***

Since language barriers were cited as the biggest problem throughout their cancer experience for all the Chinese participants apart from a few who could speak fluent English, a separate section will be devoted to communication barriers. The following section will report on other issues including a focus on lack of cancer knowledge, attitudes towards health professional, support, food and coping.

##### **4.2.3.6.1 Levels of cancer knowledge**

##### ***Chinese Participants:***

The majority of participants admitted to having little knowledge about cancer before their diagnosis.

*“I had not seen or heard such thing; I had never been to hospital before that. I had never been ill. Bowel cancer, how could I have heard of it?” (Woman, age 72, code BY 33)*

Interestingly, one participant felt despite being a nurse she did not have sufficient cancer knowledge to enable her to detect early symptoms.

*“Though I am a nurse...unless you have studied it you would then know the signs and symptoms of cancer. Like I am in midwifery how would I know? How do we know the symptoms? It is very important...if you are not clear about it you would not know?” (Woman, age 65, code CY 61)*

Another participant said her limited knowledge was gained through reading popular literature.

*“Well, I read it from books, newspapers and magazines.” (Woman, age 50, code CY63)*

Although health promotion sessions are regularly held at the Chinese community centres, very few are focused on cancer; the reasons for this are not clear. One theory is that local Chinese community workers were wary that their members might not welcome discussion of such a sensitive topic.

##### ***‘White’ British Participants:***

When compared to the Chinese group, these participants appeared to be better informed about cancer. Although it was not possible to assess their cancer knowledge directly, all had heard of cancer and talked about cancer openly. Most were well informed of the treatments options available, especially the breast cancer patients.



Those who were less informed were also able to gain information by talking directly with health professionals or read the information leaflets (in English).

*“.....they gave you the leaflets and they go through the actual operation with you. I have had plenty of information.....” (Woman, age 63, code CX 55)*

#### **4.2.3.6.2. Views/attitudes towards health professionals**

##### ***Chinese Participants:***

There were mixed responses with regard to participants' views on their experiences with health professionals. The majority of the participants were satisfied with the ways the medical consultant talked to them when the cancer diagnosis was disclosed. They felt their attitudes were good.

*“The doctor at the hospital was very good; he asked me if I understood English and was worried that I was too upset. He had checked with me a few times if he could tell me the bad news.” (Woman, age 50, code CY 63)*

However, one participant was not happy with the doctor who disclosed her diagnosis:

*“But during the moment when the doctor had a chat with me he told me.....the way he said it as if it was nothing.....I felt I could not accept what the doctor said and why couldn't he comfort me and reassured me?” (Woman, age 58, code BY 37)*

Most of the participants said that the doctors and nurses at the hospital were very good to them.

*“The doctors and nurses at all the hospitals where I had treatments were really good, very nice to me. They really looked after you well and cared about you.” (Woman, age 72, code BY 33)*

*“The staff at the hospital were very good in all aspects; everyone has been good.” (Woman, age 65, code BY 34)*

However, there was one participant who reported an unpleasant experience with a nurse. He perceived the nurse as uncaring and actively doing harm to him. It was not clear if that was due to problems with communication as his English was not very good.

*“I was most unsatisfied with that nurse; the doctor said clearly that I could not eat and take medicine but she mixed the medicine syrup for me to drink....she should not. Another nurse asked her not to give it to me; she said she didn't care. I didn't drink it. She mixed two cups and the Westerner opposite me did take it and he just died in the night.” (Man, age 76, code CY 62)*

***'White' British Participants:***

Most of the participants regarded their doctors and other staff at the hospital highly and were satisfied with the way they were treated at the time of their diagnosis:

*"I saw the consultant, I had two at the time and they were both very gentle with me, yes." (Woman, age 67, code DX 69)*

*"The doctor handled it very well; he said 'I am afraid that I have to tell you, you got lung cancer. We will give you what we can to help you.' Painkillers and all that if it gets any worse." (Man, age 86, code AX 01)*

*"The lady doctor who gave me the news was very good; she did say 'in my opinion, you are more likely to die of old age than from the cancer.'" (Woman, age 69, code CX 58)*

However, one participant reported the experience of having her diagnosis disclosed on the telephone:

*"That is just one of the areas where I have...I have felt something could have been done better because the consultant rang me up and told me it was cancer. I was on my own and nobody about; I mean cancer is such a frightening thing." (Woman, age 75, code DX 68)*

Most participants were satisfied with the way they were treated by hospital staff:

*"The surgeon was excellent...very good to me, everyone, even the ladies who brought your meals, excellent....." (Woman, age 74, code CX 54)*

*"The staff at the hospital were excellent, yes." (Woman, age 65, code CX 52)*

*"The local Macmillan nurses have been very supportive and helpful." (Man, age 76, code AX 03)*

However a few participants did not like the way they were spoken to and ageism was also reported:

*"And it was one of the consultants I saw on this particular occasion. I asked her a couple of questions that were things worrying me and.....she said to me 'have you been on the internet.....all you need to know is such and such a thing.' And she did not answer my questions; I thought what I needed to know was for me to decide." (Man, age 67, code CX 57)*

*"And I think it is an ageist thing; I mean overall I can't fault them up to now.....the last lady doctor I saw I wasn't impressed with her she talked to me as if I was a child.....another patient I met at the hospital said she found it ageist, that fact that you have had your life and you are not as important....." (Woman, age 67, code CX 59)*

#### 4.2.3.6.3 Dissatisfied with family doctor (GP)

##### *Chinese Participants:*

Two participants were dissatisfied with their family doctors. One woman felt her breast cancer was caused by taking hormone replacement therapy longer than the recommended length of time and another reported on medical delays in diagnosis.

*“Going back to my GP, I feel there was negligence on his part. I had to remind him for three times before he sent me to hospital for a check up. He should take some responsibility. If it happened 5 months earlier I would have had it done earlier. But he said I had nothing wrong and I do feel he was wrong. My eldest son asked me to sue him!” (Woman, age 50, code CY 63)*

Another participant felt she had to ask for a private consultation because her family doctor found nothing wrong with her though she felt strongly there was something wrong.

*“I just felt so tired that I had to sleep after lunch till 5pm and then went to bed again in the evening for 10 hours; there must be something wrong with me so I went to see my GP who found nothing wrong. In the end, I told him to write me a letter for me to see a private specialist consultant.” (Woman, age 65, code CY 61)*

##### *‘White’ British Participants:*

Two participants were not satisfied with the service provided by their family doctor because they perceived them to be too distant and not personally engaged in their care:

*“I asked my GP to come out once but he said ‘No, I can’t do that.’ And if we phone him up he just gives me a prescription and he’s never been to see me.” (Man, age 78, code AX 09)*

*“I mean I remember to be honest ten years ago the doctor (GP) I had before he retired was marvellous. I was losing weight I went to see him and he could tell. And he tried to think things over but now they all use computers and haven’t got the time.....they have to follow guidelines” (Woman, age 83, code CX 49)*

#### 4.2.3.6.4 Support

Support was identified in a number of domains – personally, spiritually and socially.

##### 4.2.3.6.4.1 *Personal resources*

##### *Chinese Participants:*

All participants sought emotional support from their close family members or friends. Participants expected health professionals to be responsible for their physical rather than psychological welfare which was similar to the findings of a study conducted in China (Liu et al 2005b).

*“I am lucky as my daughter’s boss said she could take time off to take me to hospital but she did not need to. I was lucky that my friend and her husband had retired and he would drop us to the hospital and picked us up. They were great friends; my friends are great.” (Woman, age 65, code CY 61)*

*“On the day of appointment, I sat in between the interpreter and my daughter who was just listening for me and made sure the interpreter did get everything right. I do say my daughter is a good daughter to me...with filial piety...” (Man, age 69, code CY 64)*

**‘White’ British Participants:**

Most of these participants used their family network as a support but they also had support provided by the health care services:

*“My son lives out but my daughter lives within half an hour’s ride of me; she does my heavy housework but I cook my own meals. And I do have some caring neighbours.” (Woman, age 85, code AX 13)*

**4.2.3.6.4.2 Religion**

While most participants did not report drawing explicitly upon religious or spiritual forms of support, a minority described these types of support as contributing to coping with cancer and other life challenges.

**Chinese Participants:**

*“Because people are not reliable and also there are things you cannot say.....I think it is religion that has been most helpful.” (Woman, age 50, code CY 63)*

*“I do worship Guan Yum (Chinese Goddess); I said to her that my life was in her hands and I hoped I would survive this illness. So she has answered me and maybe... that was what she had answered me.” (Woman, age 65, code CY 61)*

**‘White’ British Participants:**

*“My faith as well.....it is very important. ‘He’ certainly looks after us and I firmly believe; but everybody has their own beliefs don’t they?” (Woman, age 74, code DX 71)*

*“But we all have to....fortunately we’ve all got a great faith. I think my faith has helped me managing this experience.” (Woman, age 73, code CX 59)*

*“I don’t know because you can’t tell other people how to do things; it’s only my faith that gets me through. Definitely my faith, I am very very blessed.” (Woman, age 69, code CX 47)*

#### 4.2.3.6.4.3 **Food**

##### ***Chinese Participants:***

Food was identified as an important issue for most of the Chinese participants and they reported a preference for eating Chinese food. A few participants complained about the lack of Chinese food in English hospitals. The reputation of hospital catering in the United Kingdom is poor and there is little consideration of cultural and religious dietary preferences (Audit Commission 2001). However, participants believed that it was their relatives' responsibilities to bring them suitable Chinese food. This section links to the earlier section where it was revealed that the availability of appropriate food was one of the difficulties encountered in adaptation to life in Britain.

*"I could not eat the hospital food. I could not eat it; they have chips or deep fried food. My family would bring me food." (Woman, age 72, code BY 33)*

*"The biggest problem ...I think the biggest problem was 'eating'! Because I love my food." (Woman, age 65, code CY 61)*

Food is an important part of Chinese culture and the perceived role of food in prevention, cause and cure of cancer and other health conditions is widely recognized (Simpson 2005).

*"They (friends) told me not to eat 'Swallow Saliva' and chicken etc. They also said not to eat duck as it is also poisonous... and beef." (Woman, age 64, code BY 34)*

*"My wife cooked me soup made with fish (special kind) and watercress which is supposed to be good for the healing process." (Man, age 69, code CY 64)*

*"The most important thing for me is food intake during chemotherapy period; because some books tell you how to get rid of the poisons, get rid of it through your excretion; and how to use food remedy to adjust it." (Woman, age 58, code BY 42)*

##### ***'White' British Participants:***

Food did not feature in the accounts and appeared not to be used as a 'support' for these participants.

#### 4.2.3.6.4.4 **Coping**

This section builds upon previous evidence of coping with adverse life circumstances reported by the participants. Some of them attributed personality traits such as being strong or optimistic, and resilience in the face of past life experiences, as two of the main factors which had helped them cope with their cancer experiences.

### ***Chinese Participants:***

For the Chinese participants, their previous self sufficiency meant that most believed that they could cope with cancer. They also highlighted their adaptability to the unknown.

*“I would say that I am very tough; very strong, my will.” (Woman, age 65, code 01)*  
*“It is just that I have grown up from a poor background and that toughens you. My background has some influence.” (Woman, age 50, code CY 63)*

*“Yes, I think some of my past experiences have strengthened me. For example, if you have fallen you have to get up; you would become stronger after you get up; perhaps it is to do with personality as well.” (Woman, age 65, code CY 61)*

*“Well, you got to face it. I was on my own when I left....after the Japanese surrendered....I was all by myself....only a child who had no money to live on. When you had survived from nearly dying you just had to fight...fight for....a human being should be like that.” (Man, age 76, code CY62)*

### ***‘White’ British Participants:***

These participants provided a number of accounts of ‘coping’ including drawing upon the use of humour, optimism and learning from previous life experiences.

*“I have tried to accept it and hope for the best and keep going. Do what I am asked to do and try and cope the best with the best way I can.....” (Man, age 76, code AX 03)*

*“Laughter helped me cope.....I mean you’ve got to laugh because if you don’t, life ain’t worth living.” (Man, age 82, code AX 12)*

*“Yes, I think of things positively. I don’t think of the negative part of things.” (Woman, age 73, code BX 32)*

*“Well, you learn to live with whatever life throws at you because it’s either a case of you go down or you go up. And we have been down that many times.....we will ride through everything that comes in the future.” (Woman, age 63, code CX 56)*

*“But I just think it’s the experience over the years that I have learnt..... travelling and coping on my own had made me stronger, yes.” (Woman, age 85, code AX 11)*

*“I saw a lot that went on in the Forces; I saw a lot of death and probably that’s what helped me cope with this.....I think so.” (Man, age 83, code BX 30)*

#### **4.2.4 Communication barriers**

### ***Chinese Participants:***

The following section illustrates the patterns of communication strategies participants adopted from the earlier years of their arrival in England till the present time.

### ***From ‘no help at all’ to ‘assistance from friends or peers’***

Participants were asked how they managed when they were ill in the early days living in England. Below was a sample of their answers indicating that they drew upon the support of ‘westerners’, friends and colleagues, while others managed alone without any form of interpretation:

*“I was taken there when I was ill and just let them talk; let the doctor have a look at me!” (Man, age 76, code CY 62)*

*“I did dare going to see the doctor by myself. I did not understand English that much but I would use my limited English and topped it up with body language!” (Woman, age 50, code CY 63)*

*“The Westerners went with me when I was ill in those days but I would not know what they said.” (Man, age 69, code CY 64)*

*“I did not know too many people in the community here but I did have a friend who could speak a bit of English and was living with us at the time so I did ask him to help us with going to court etc as I didn’t know anything.” (Woman, age 64, code BY 346)*

*“I was young and strong then; I was rarely ill and seldom went to see the doctors with colds or flu. I could not speak much English especially with complicated things I would need help. If I had something serious I would ask the boss’s wife.” (Man, age 69 code CY 64)*

### ***Assistance from their children and family***

Most of the participants’ children came to England at a young age or were born here so they could speak fluent English. They were often asked to be the interpreters for their parents during any medical encounters. Some concerns were raised about the availability of adult children, accuracy of their interpretation, and protecting the patients’ confidentiality. There were problems with children interpreting for their parents as illustrated by the following excerpts from the interviews.

*“My sons rarely go with me; at the beginning my friends interpreted for me as my sons were not around; they were working.” (Man, age 76, code CY 62)*

*“My children were born over here. They just could not express clearly....they speak mostly English and I speak Chinese; and in fact they are more like a Westerner; it is difficult to communicate with them.” (Man, age 64, code BY 36)*

*“My husband didn’t understand English and I interpreted for him. The consultant told me he had liver cancer but it is not up to the consultant to say I must tell my husband. If I told him he would just sit there and waited to die because he would not have the will. I told him his liver was damaged but he did not know it was cancer.” (Woman, age 65, code BY 34)*

### ***Assistance from professional interpreters***

During the past decade, local Chinese communities began to provide interpreters for their members and initially, they were usually people who were able to speak a bit of English and latterly, some of the interpreters had special training. Due to the increased number of Chinese (and other ethnic groups) patients, hospitals began to realize the importance of the provision of interpreters. Initially, they would seek help from any available staff who were the same ethnicity as the patient. However, health care workers from ethnic minority groups are relatively few in numbers and they might not be available at the time they are needed. Recently, the importance of properly trained interpreters has been recognized which is partly due to the demand from an increased population of ethnic minority groups. The participants in the study raised a few issues about using professional interpreters. There were some concerns expressed about interpreter's language skills and professional standards.

*“They provided interpreters for me when I went to see the doctor; however the interpreter....how should I put it? Some of them are good interpreters, some are bad interpreters.” (Woman, age 56, code CY 66)*

*“The important thing is they should know about medical things and not just get anybody who can speak English to interpret; they might not know these things. You would be afraid that the information they give the patient is wrong.” (Man, age 69, code CY 64)*

*“The interpreter found it even worse than me she was more impatient than me....I thought as an interpreter for the doctors she should know you have to wait and it mustn't be her first time, right? She interpreted afterwards but I didn't quite understand what she interpreted.....” (Woman, age 61, code BY 41)*

*“I hope there is a certain standard with the interpreters; if you just have anybody who can speak English as an interpreter...sometimes able to speak English is not enough, right?” (Woman, age 65, code BY 34)*

Participants regarded the following as key characteristics of interpreters in determining their acceptability.

#### ***Trust:***

*“But for those 5 months, he delayed things....that was a fact. I said there was something wrong with me and he said there wasn't. I did have an interpreter who is still around; but of course the interpreter would always be on the doctor's side!” (Woman, age 50, code CY 63)*

#### ***Confidentiality:***

*“Though it was not such a secret and if they provided me with an interpreter from XX (name of town) I would most likely know him/her. My husband did not want anybody to know I had that condition.” (Woman, age 50, code CY 63)*



### ***Gender of interpreters:***

For a couple of the participants, a choice of the gender of the interpreter was regarded as important due to the type of cancer they had; one with breast cancer and one with prostate cancer.

*“Some people are embarrassed to ask ...well, like the last visit, the hospital did give me an interpreter who was a man and he didn’t really....he did not seem to understand and I think I might as well not have an interpreter!” (Woman, age 64, code BY 34)*

*“Well, another thing about the Chinese being reserved; some men would find it more acceptable if a male interpreter could interpret. The hospital did not ask if I would like to have a male or female interpreter though I am quite relaxed about it. I would suggest it might have been better if I had the choice.” (Man, age 69, code CY 64)*

### ***Perceived role of the interpreters:***

The role of the interpreter was perceived by some of the participants in the study as being an advocate who would provide support as opposed to somebody who would merely convey the conversation between them and the health professionals.

*“When you are ill as a patient you just don’t know what to ask the doctor.....make the initiative to ask the doctor but the interpreters cannot tell the doctor how you feel or ask on behalf of you.....so from the point of communication.....the interpreter would not know what the patient wants to ask and the patient also doesn’t know what to ask in order to be absolutely clear.” (Man, age 64, code BY 36)*

*“Because apart from interpreting for you, I think the interpreter should remind you what to ask and not just say whatever the patient says; how would we know what to ask as we don’t know anything medical? Some would tell me what to ask and also tell me what she has asked extra for me; that would help me more.” (Woman, age 64, code BY 34)*

### ***‘White’ British Participants:***

These participants did not have language barriers as they spoke English but there were a few problems with the communication skills of the health professionals in conveying information to the participants:

*“The surgeon I had was.....very shy and I don’t know what he is; he lacks communication skills and my daughter was horrified when I went back after the surgery. I mean he came in and just sort of stood against the wall and sort of muttering things.....” (Woman, age 72, code CX 60)*

## **4.2.5 Views on improving cancer care services**

### ***Chinese Participants:***

It was evident that all participants were able to access primary health care with the assistance of interpreters. In the UK, cancer care services are primarily accessed through primary health services, namely general practitioners. Some of the difficulties

which the participants' experienced in their consultation with their GP had been mentioned earlier. Participants were asked if they were aware of the cancer services provided in the UK but most of them admitted they had no previous knowledge of cancer and cancer care services. The following section presents the participants' suggestions to improve cancer services for Chinese people. In general, most of the participants were quite satisfied with the cancer services they received.

*"I did not have much problem with the cancer services, from what I can see." (Man, age 76, code CY 62)*

*"Yes, I am very satisfied. During the first week after I had my operation the doctors came to the ward to see me each day." (Woman, age 70, code CY 33)*

However, as one of the participants commented, high levels of reported satisfaction could be due to the low expectations of this group of Chinese participants.

*"I think things are ok because our expectations are not high." (Woman, age 64, code BY 33)*

#### ***Increase in awareness of cancer and access to information***

Participants were aware of their lack of cancer knowledge and had a desire to learn more. Most of the participants could not understand English well enough to access cancer information from the mainstream healthcare sources. They had reported that they had been given some information in Chinese which was downloaded from the computer by the hospital staff but most felt this was not specific enough. There are lots of Chinese leaflets provided by the local Chinese communities but participants strongly favoured the format of 'health talks' rather than written information.

#### ***Health promotion talks about cancer***

*"Actually about cancer, I think the best thing is if we can get more information. For example, they did give me some information which they got from the internet but I don't think the information is adequate. It was just very general and I would have liked to know more. I would like to have more information in Chinese." (Woman, age 64, code BY 34)*

*"Leaflets are no good...if you ask me....because some cannot read and even though I can read I would forget." (Woman, age 50, code CY 63)*

*"Leaflets are not as useful as after you read them....you just put them aside. If you have health talks it would have a direct impact; at the 'health talks' people could ask questions." (Man, age 69, code CY 64)*

*"Yes, having health talks, from the beginning, such as signs and symptoms, characteristics of the illness; talk about treatments and everything. A lot of people take the leaflets home but would not even read them!" (Woman, age 64, code CY 61)*

### ***Provisions of properly trained interpreters***

Participants raised many concerns about the qualifications and training of interpreters. They wanted accessible information about interpreting services which would give them options about which services they could use.

*“I mean in the big city there is interpreting service provided and there is no problem; but in the smaller towns of course it would be better if they can provide interpreters.” (Woman, age 51, code BY 40)*

*“The best thing is to have Chinese people helping with the interpreting....help us communicate...when you can’t communicate...there is just no communication...very much lacking...very difficult.” (Man, age 76, code CY 62)*

*“For our Chinese, it would be best to keep the interpreting service; that would be the main thing.” (Woman, age 70, code BY 33)*

*“Interpreting service would be the most helpful services for us.” (Man, aged 69, code CY 64)*

### ***Availability of Chinese speaking health professionals***

Participants were keen to have more health professionals from their own cultural background mainly because that would help with their language difficulties but also because they could have a shared understanding of health and illness.

*“I would like to have more Chinese staff in the health professions who can explain things thoroughly to me.” (Woman, age 64, code BY 34)*

*“Of course, it would be better if we have Chinese people in the health professions but it is a hard job these days...the pay is not good and who would go for it?” (Woman, age 64, code CY 61)*

### ***Food***

Although food was clearly seen as an important element in helping the healing process by the majority of Chinese participants, most of them did not expect the provision of Chinese food by hospitals. They appeared to expect it to be provided by their family. However, they would welcome the availability of Chinese food in hospitals in future.

*“The aspect of food ...I just would not know what to say. Of course, it would be good if they can provide that; so we do not have to rely on the family all the time, right?” (Woman, age 70, code BY 33)*

*“My wife used to cook me Chinese food though I could eat the hospital food.” (Man, age 69, code CY 64)*

*“Our Chinese say we should not eat deep fried stuffs and not so much diary food. We might just eat a bit of yogurt and seldom eat burgers. I take care of what I eat and drink.” (Woman, age 64, code BY 34)*

### **Referral systems**

Two participants were not satisfied with the referral systems they encountered.

*“If I did not have private insurance and did what my GP said I would have to wait for 6 months! Because the National Health is so slow these days....they say it would take 3-4 weeks just to have a scan. You have to wait for the scan before you can see the consultant and then another few weeks....well, God helps me!” (Woman, age 65, code CY 61)*

*“Well, I am ok now; I did fight to go to hospital. I would like people to take note and not to trust the doctor completely. It doesn't mean there is nothing wrong even when he says there is nothing wrong with you. Just like my case, I had to go 3 times and was delayed 5 months. If I had let it carry on what would have become of me?” (Woman, age 50, code CY 63)*

### **‘White’ British Participants:**

The majority of participants especially those recruited from hospices, were happy with the cancer services they received. Some of the improvements suggested by the participants were:

#### **Car parking facilities**

*“I think another sort of gripe is car parking spaces; and I know for a fact that the car parking spaces that are reserved for renal patents and cancer patients other people use it., and you know I think they just don't care.” (Woman, age 75, code DX 68)*

#### **Health professionals' attitudes and manners**

*“It is really the manner and they way they talk to you and they could probably go on a course, you know, for being empathetic and what have you, you know.” (Woman, age 63, code CX 56)*

*“Well, from my point of view in here there is nothing....shall I say in hospital the staff are too busy and they can't treat you as a person, they don't treat you as an individual.” (Man, age 79, code BX 24)*

*“I think, maybe the doctors should be a little more sympathetic at the time they speak to you; they could be nicer to you.” (Woman, age 74, code CX 53)*

Due to the perceived fast pace of cancer clinics, a few of the participants felt they were not given enough time during the clinical consultation:

*“It's just fast furious bit like....they asked why I hadn't got up but I had just had an anaesthetic and I wouldn't have got up without being told; that was a bit strange. But they said 'You have to get up now.' The bed was very high and I wasn't sure where I would land. That was too fast and furious for my way of thinking.” (Woman, age 68, code DX 70)*

#### **Communication**

*“That is just one of the areas where I have...I have felt something could have been done better because the consultant rang me up and told me it was cancer. I was on my*

*own and nobody about; I mean cancer is such a frightening thing.” (Woman, age 75, code DX 68)*

*“I would like to say, you know, I understand that communicating isn’t easy for everybody. And I think it is something which is becoming part of the training now. If the doctor can be self aware and know that they are not good at communicating but they can delegate.” (Woman, age 72, code CX 60)*

*“They do work hard I mean I cannot complain about that, you know. It’s just the availability to see a doctor or to know about information, to me there is a lot of lack of communication.” (Woman, age 83, code CX 49)*

#### **Information on welfare benefits**

*“One experience.....I mean we’re talking about benefits and people really don’t know what benefits there are out there. You pick up books and then you think oh, well, that won’t apply to me. A lot of people....I mean like me I wouldn’t ask the first time round because I thought ...it is charity kind of thing, you know. But there are benefits available but people are struggling.” (Woman, age 60, code BX 23)*

*“I think I am quite alright with the services what I am getting at the moment; I tell you what, we did have.....when I actually did this leg, people kept saying to us go...you can get disabled benefit or something like that but we never bothered. So, my husband did go to the Citizen’s Advice and .....we did get everything what was going. A lot of people don’t know about this.” (Woman, age 64, code BX 28)*

#### **Information on service availability**

*“Improvement.....I suppose in a way is to make what is available to you. Because if I had known about XX Cancer Centre.....it didn’t make me think I ought to go there until it was brought home to me by the doctor who said I ought to go.” (Woman, age 66, code CX 48)*

They also reported wider issues about difficulties with the ‘system’ of cancer services, as illustrated by this example:

*“You know it is a bit like being on a conveyor belt on a production line; and I felt people did not have time to talk to you as much as I would have liked because I think you do need reassurance. They may have said something to you six months ago but I think you do from time to time you do need someone to talk to.” (Man, age 67, code CX 57)*

### **4.3 Content analysis of second interviews**

Second interviews were conducted with participants 3-6 months after their first interview to identify any changes in their condition or situation and to discuss any unresolved issues. Participant’s permission was sought by the researcher at the end of the first interview to contact them within a few months for a short follow up interview. This was usually conducted via the telephone. All 24 Chinese participants and 27 out of 47 ‘white’ British participants (overall response rate 38%, indicating fairly high attrition in the latter group only) were successfully interviewed for the second time.

## **Summary of the key issues from the second interviews with Chinese participants**

### ***Participants' health***

The majority of the participants remained well although two reported that their health was 'deteriorating' and that they felt poorly and had quite a bit of pain. One participant was very concerned that he could not get enough support and care at home as his children lived elsewhere. He could speak limited English and his partner could not speak English at all so his preference was to receive care in hospital or a hospice. However, because he was no longer having active treatment, the hospital would not readily take him back and he did not fulfil the criteria for admission to the hospice. Fortunately, he was referred to a community Macmillan nurse and it was hoped that a case conference would be held to plan his end of life care. The other participant with poor health reported she was told there were no more treatments offered to her and she planned to go back to Hong Kong for a second opinion and to try traditional Chinese medicine. She could not accept there was no more treatment for her cancer and hoped she could find a good Chinese Herbalist or doctor in Hong Kong.

### ***Cancer treatments***

Five participants were at the end of their treatments and were reasonably well. Two participants were receiving treatments to control their cancer and were unhappy that it could not be cured. These participants planned to go back to Hong Kong for further advice as soon as they could travel. A few participants continued to use traditional Chinese medicine as well as having treatments offered by mainstream health services. Most of the other participants were satisfied with their treatments and their progress and continued to receive follow up care.

### ***Main issues***

Most of this group were relatively 'healthy', in terms of carrying on with their normal activities. A common fear was of cancer recurrence. A number of participants reported focusing on 'eating the right food' to get rid of any residue of 'poisons' as a strategy to prevent recurrence. Some participants also used coping strategies such as not taking things too seriously and trying to become more relaxed. While a few participants wanted to return to Hong Kong for further treatment, the majority wanted to be looked after by the cancer care teams in the UK and appeared to have faith in the cancer treatments they received. Those seeking second opinions appeared to have advanced disease and were not receiving curative treatments. Most of them continued to cope with their illness with support from their family and managed to return to their normal activities (although a few admitted to having a quieter life since their illness.)

## **Summary of the key issues from the second interviews with 'white' British participants**

As already described in Section 4.1, there appeared to be distinct differences between older 'white' people recruited from hospice Day Care units compared from those recruited via Cancer Support Centres. In this section, we have therefore separated the analysis of the follow up interview data into these two groups. The participants recruited from the hospice Day Care units were relatively older and had more advanced disease with other co-morbidities than other participants, so perhaps it was

not surprising that more than half of the sample (14) had died at the time of the second interviews. We were able to interview eight participants (see Table 6).

**Table 6 - Participants recruited from Hospice Day Care**

	Number of second interviews conducted	Number of second interviews not conducted	Reasons for not able to interview the participants
London	<b>1</b>	<b>14</b>	<b>8</b> had died <b>6</b> had been discharged from hospice or unable to be contacted
Manchester	<b>7</b>	<b>6</b>	<b>6</b> had died

Participants recruited from Cancer Support Centres were relatively younger and healthier in terms of their physical conditions and stage of cancer, than others. The majority had breast cancer and attended Cancer Support Centres to receive complementary therapies and psychological support. We were able to interview all of these participants (n=19) (see Table 7).

**Table 7 - Participants recruited from Cancer Support Centres**

	Number of second interviews conducted	Number of second interviews not conducted
Sheffield	<b>14</b>	0
Plymouth	<b>5</b>	0

**Summary of the key issues from the second interviews with ‘white’ British participants recruited from hospice day care units**

***Participants’ health***

Most of the eight participants remained reasonably stable in their condition although two continued to report pain. Because this group also had other co-morbidities a couple of them were actually more concerned with, and affected by, their other illnesses. One participant was more bothered by the immobility caused by her hip trouble than her cancer.

***Treatments/therapies***

Only one participant continued to attend hospice day care. There was also only one participant waiting to have further cancer treatment from the hospital. Most participants valued the care and support they had received from the hospices and missed attending day care.

***Main issues***

Most participants were realistic about their cancer and talked about ‘keeping cancer controlled’ rather than expecting curative treatments. The majority lived alone so realized they might not be able to manage their condition in the unforeseeable future. However, a few participants were aware that they could access hospice care again which seemed to give them hope and comfort. They valued the time and support given

by the hospice staff. Two participants had expressed a wish to continue having complementary therapies but they could not afford to pay for them. (They were able to have these therapies free when they were at the hospice.) Most participants reported trying their best to maintain their normal activities, although a small number disclosed feeling lonely and were experiencing difficulties living alone without external support.

### **Summary of the key issues from the second interviews with ‘white’ British participants recruited from Cancer Support Centres**

#### ***Participants’ health***

The majority of the 19 participants reported remaining well in themselves, although two reported feeling unwell at the time of interview because of other medical conditions and the side effects of their treatments. There were just two participants who reported being unwell because their cancer was still ‘uncontrolled’ and needed further treatments. Most participants were able to continue their normal activities.

#### ***Treatments/therapies***

Most participants (apart from two) had completed their cancer treatments and were just being followed up at clinics. They were satisfied with the treatments they received and the majority expressed the relief they felt after they had been checked at the follow up clinic. Their focus was mainly on the success or failure of their treatments.

#### ***Main issues***

The main issues raised were fears and uncertainty about the course of their cancer. A number of participants were concerned with the threat of recurrence as they had experience of this amongst their friends. Indeed, a few reported feeling anxious that they were no longer having treatment as they felt safe while this was ongoing. For those with breast cancer, there was also concern over the frequency of follow up mammogram’s available from the NHS as some felt it should be done each year. One participant reported she would have it done every year privately for the peace of mind. Most participants coped by trying to get on with their life and resume normal activities. They talked about having holidays with their families. One participant continued to be unhappy with the lack of communication from health professionals at the hospital.

## **4.4 Narrative analysis**

In the following section, we will present the narrative analysis of a subsample of 30 first interview transcripts (15 Chinese, 15 ‘white’ British). Following selection of the transcripts, short ‘case portraits’ were written – one for each of the fifteen participants in each group summarising the main threads provided by each participant. The process of writing these was a first stage in the narrative analysis but, at the same time, the portraits provide a useful handle or memory trigger for each person. The full versions of the transcripts were read again with the aim of locating continuities and discontinuities in the life narratives of each individual. After a period of consolidation, 19 narrative threads emerged (10 for the Chinese group, 9 for the ‘white’ British group). Analysis up to this point was largely done within the cultural



group, followed by an integration stage which sought to determine the presence of common threads and identify those which were culture specific.

#### **4.4.1 Description of the selected Chinese participants' transcripts for narrative analysis**

A description of the key participant variables (gender, age, location) and the length of the interview are provided in Table 8. The following Table 8 illustrates the presence of the ten narrative threads in the Chinese participant's transcripts. In analysing these transcripts we searched for common threads but we made no assumption that these would be present in all the transcripts. We have tried to discriminate where threads occurred in transcripts (indicated by shading the cells in Tables 9 and 12). Particular threads were the focal point of some narratives which the participant kept going back to and they dictated the flow of the story. For example, in one of the Vietnamese participant's narratives, her story was focused on the war period and her relationships with her husband and brother in law rather than her cancer story. While in other transcripts, examples of threads included: 'hard times and good times' which was also a common thread where the participants spent a fair bit of time talking about their hardships (and some good times) throughout their migration experience. Cancer narratives were of course one of the main threads but not necessarily all the stories were dominated by accounts of cancer.

**Table 8 - Summary of the Chinese participants by recruitment site\***

**London**

<b>Identifier Code</b>	<b>Interview length</b>	<b>Gender</b>	<b>Age</b>
AY16M	54 minutes	M	54
AY18F	43 minutes	F	69

**Manchester**

<b>Identifier Code</b>	<b>Interview length</b>	<b>Gender</b>	<b>Age</b>
BY39F	73 minutes	F	54
BY35F	75 minutes	F	56
BY42F	47 minutes	F	58
BY37F	47 minutes	F	58
BY41F	87 minutes	F	61
BY38F	66 minutes	F	62
BY36M	37 minutes	M	64
BY44F	68 minutes	F	71
BY43M	50 minutes	M	73

**Sheffield**

<b>Identifier Code</b>	<b>Interview length</b>	<b>Gender</b>	<b>Age</b>
CY65M	53 minutes	M	51
CY66F	52 minutes	F	56
CY61F	73 minutes	F	65
CY62M	63 minutes	M	76

\*There were no Chinese participants recruited from Plymouth.

**Table 9 – Identification of the presence of narrative threads in the Chinese participants’ transcripts**

Code	CY61	CY62	AY16	BY35	BY36	BY37	BY38	BY39	CY65	BY41	BY42	BY43	BY44	CY66	AY18
<b>Gender</b>	F	M	F	F	M	F	F	F	F	F	F	M	F	F	F
<b>Age</b>	65+	76	54	56	64	58	62	54	51	61	58	73	71	56	69
<b>Site</b>	S	S	L	M	M	M	M	M	S	M	M	M	M	S	L
<b>Migration</b>															
<b>Hard time/good time</b>															
<b>Resilience &amp; loss</b>															
<b>Impact of war</b>															
<b>Communication</b>															
<b>Culture</b>															
<b>Relationships</b>															
<b>Death attitude</b>															
<b>Religion</b>															
<b>Cancer narratives</b>															
<b>Cancer services</b>															

**Key:** Shading indicates where threads are present in the transcript  
 S = Sheffield; L = London; M = Manchester

## 4.4.2 Chinese participant's narrative threads

### 1. Migration

#### *The characteristics of the migrants*

The 15 participants were migrants from: Hong Kong (10), Vietnam (3), Mainland China (1) and Malaysia (2). They described themselves as of Chinese origin. The majority of participants were in their 20's and 30's when they first came to England. Most had not completed secondary education with the exception of two women who had had higher education; both of whom came from Malaysia. Their main spoken language was Cantonese. All participants migrated to the UK during the 1960's and 1970's.

#### *Place of birth and pattern of their migration*

Where participants were born and brought up had some influence on their adaptation to life in England. The majority of participants from Hong Kong chose to come here with the goal of seeking a better life (financially). During the 60's and early 70's the economical situation in Hong Kong was rather unsettled and lots of people were unemployed or had very low income. It was particularly difficult for people in the New Territories whose ancestors were farmers or had agricultural jobs. During the 1960's and 1970's the government began to redevelop the land in the New Territories and agriculture was in a sharp decline. Most of the agricultural foods were imported from Mainland China and nearby Far East countries. The younger people from the New Territories were faced with no prospect of a job in their villages, or in the city as they did not have the necessary educational requirements. In those days, there was also an 'unspoken divide' between people from the New Territories and those from the city. A small number of people therefore started exploring the opportunity of finding work abroad. The USA and UK were two popular options and with Hong Kong at the time being a British colony it was easier to migrate to the UK. Most of our participants fell into this group of people and they had a single minded determination to 'do well' in England before they could return to Hong Kong.

Three people came from Vietnam and the sole reason for their migration was to escape from extreme poverty resulting from war and the communist government takeover. This small group of people were all older, between 60 and 70 years old. They did not speak English and had little education due to the turmoil of war. They appeared to be content with life in England and did not wish to return to live in Vietnam as the shadow of war and poverty still haunted them.

The two participants from Malaysia had relatively greater educational achievements and could speak English when they came to England. They were professionals who came to England to study and subsequently got married and settled here. They reported few problems in adapting to life in England.

There was only one participant who came directly from mainland China, motivated by a desire to be reunited with her daughter. She was relatively younger and could not speak English. She reported finding life quite difficult in England but chose to stay because of her daughter who was her priority.

### ***Mobility and stability***

Mobility and stability were features of many of the narratives. These terms were conceptualised in a number of different domains. For most participants, after coming to England they experienced mobility through employment in different towns (generally in 'chip shops' or Chinese restaurants) in order to achieve financial stability. In fact, the sole purpose of their migration was to have financial stability which they appeared to have achieved. There was little mention about the emotional or family instability caused by their 'mobility'. Most participants mentioned they were homesick and lonely when they first came to England but seemed to accept that was an inevitable consequence of the migration. All participants married and created a family of their own after they came here.

From their narratives, most participants appeared to be socially excluded from mainstream society (due to their circumstances) but they formed their own social circle with other Chinese people. With working unsocial hours, the only time and place they could socialise was at casinos when they finished work. Many participants explained that casinos were more than a gambling place because they were regarded as a social gathering place and more importantly, they also acted as a 'labour exchange' where people seeking work or looking for employees congregated. However, socialising in casinos did encourage some people to become gamblers.

## **2. 'Hard times and good times'**

Many participants described 'hard times' as a precipitating factor for migration, especially experiences of poverty and in a few cases, extreme deprivation. They also recounted 'hard times' in the early years following settlement in England. Those participants who did not have English language skills or much Chinese education came to a strange country with the aim of achieving a better standard of living. Language barriers, the cold weather, unfamiliar food and isolation were some of the difficulties commonly experienced by them. Most of them reported that it was hard to adjust to life in England but they were determined to stay and endured the hardships. There was also another factor which stopped them returning home, that was a fear of loss of 'face' as was evident in the narratives. For two participants who came from Malaysia, they did not admit to finding it difficult to adapt to life here because they could speak English and they had professional jobs and were able to integrate with mainstream society. They also appeared to be more westernized. Their accounts of 'good times' were either drawn from early childhood experiences or were characteristic of later life where business success and some financial security allowed them opportunities for relaxation and enjoyment of leisure activities, albeit modest in scope.

## **3. Resilience and loss**

Most participants migrated to the UK on their own and subsequently got married and had children here, or later brought existing family members over to reside with them. Their narrative accounts suggest that they seemed to go through similar patterns in overcoming adverse circumstances and using their own available resources. It was evident from the narratives that they were self-reliant and adaptable as most of them had had to develop new skills in order to survive. Most did not rely on any help from social security provision. All participants reported experiencing loss – for example

through the initial separation from their families and the loss of social position. But there were gains and achievements as they thrived to fulfil their goals. Most of them were able to work their way up to having a small business and raising a family - achievements of which they were proud.

Personal losses were experienced by most participants, including family deaths, divorce, separation and illnesses. Most participants appeared to cope with their losses with no help or support from mainstream society; instead they reported relying on their personal resources including family support and religion which seemed to be the same coping mechanisms they had always employed.

All participants, apart from two, were virtually unable to communicate in English when they came to England. Later, a few learnt some basic English which they described as sufficient for everyday life. From the narratives, two third of the participants had identified language barriers as one of the difficulties in their cancer experience. Yet, language barriers were not the main 'focus' of the stories for more than half of these participants. Just a few of them found their language difficulty had detrimental effects on their cancer experiences. Most participants coped with their language difficulties by whatever means they could, for example by relying on friends and peers (who might themselves have limited language skills) and using their children as interpreters. The majority of participants expressed concerns about using their children as interpreters because their Chinese was not as good as their English and there were fears about a lack of privacy and accuracy. As their children grew older and lost, or failed to acquire, Chinese language skills and were not readily available because of work or other circumstances, it also became necessary for participants to use professionally trained interpreters. However, problems with using professional interpreters were identified. There appeared to be a lack of uniform standard amongst interpreters and some of the participants were concerned with confidentiality. Interestingly, the role of interpreters was also perceived differently by participants; some expected the interpreters to act as their advocate as well as their translator. The provision of interpreters was also sporadic and they are provided where demand is greatest, disadvantaging those living in more isolated Chinese communities.

Less than half of participants expressed strong religious beliefs from which they sought support and comfort. Interestingly, many of those who did not mention having a religious belief had actually had gone through more traumatic times in their lives.

#### **4. The impact of war**

The three people from Vietnam who had lived through war and were in their late 60's or early 70's, provided descriptive accounts of war time which focused on poverty, the instability of life and experiences of death. Their narratives were marked as rather different from the others in this group because they seemed to have different expectations of life, especially a primary imperative to avoid extreme poverty. They did not want to return to their country of origin because of a fear of living in poverty again. One reported that he had not needed to work since coming to England and was very happy and content with his 'easy life' in England, living on state benefits. Another female participant who had escaped the hardship she endured from her 'male dominant traditional family' in Vietnam was happy to be reunited with her husband,

who had already migrated to England. Participants did not express their emotional trauma in their interviews (although that does not mean they did not experience trauma). Rather they focused their narratives on the ways they had survived through the war periods. They accepted things as they were and reported having to be resourceful and adaptable, which could have affected the way they coped with their cancer experiences. This demonstrates their resilience.

## **5. Communication**

The three people who spoke relatively better English were able to have ‘a relationship’ with the doctors and other health professionals because they were able to talk directly to them and discuss their cancer and able to form some opinions about the doctors’ attitudes. Language skill is obviously an important ‘tool’ in establishing a good relationship with cancer care professionals. Most of the participants could not communicate directly with their health professionals, so it was not surprising that a relationship could not be established.

## **6. Culture**

Cultural heritage is one of the factors which inform an individual’s belief about health and illness and is one of the determinants of choices made about health care. It was evident in the participants’ narratives that they had retained their cultural identity in a number of ways such as through socialising with other Chinese people (eg in casinos), through their beliefs systems about health and medicine, and via food.

Notwithstanding the complexity of cultural beliefs and practices, all of the 15 participants chose to accept the Western cancer treatments offered to them and most of them employed a ‘mix and match’ approach in combining the use of Western treatments and traditional Chinese remedies. Traditionally, Chinese people believe that illnesses are due to having ‘toxins’ in the body and getting rid of the toxins by certain foods or remedies is the required treatment. This belief was evidently shared by most participants. Most had been in England between 20 and 35 years and would therefore have had significant exposure to Western health beliefs and ways of life. Unlike traditional Chinese family practices, most no longer lived with their children but remained quite family orientated. Decisions were shared with their families for example. The cultural narratives shared by participants were beliefs about self preservation of self/body, beliefs in health and illness, the use of Chinese remedies in illnesses, respect and trust in hierarchical structures, fatalistic beliefs about life and death; and the common practice of ‘doctor shopping’.

## **7. Relationships**

Family relationships were an important issue for participants. Half provided narrative accounts indicating good relationships and support from their families while half did not. Those who had problems in their marital relationship (a longstanding issue) seemed to have a relatively pessimistic views of their illness and life in general. From their narratives it appeared that they did not have a close relationship with their children. They tended to rely on their religion and friends for support. Conversely those who had good relationships with and support from their spouse and children appeared to have optimistic views of their illness and were happier in general despite whatever trauma they might have experienced in their past.

## **8. Attitude to death and religion**

Open discussion of death is generally considered to be inauspicious in Chinese culture. However, participants did allude to death in the context of war. For example, one person who spent his early childhood years in Vietnam described the ‘normality’ of walking past dead bodies on his way to school. Moreover, deaths of family members were also recounted. Most of the participants expressed their general views about death and dying. A belief in fate or ‘pre-destiny’ was quite commonly shared by them. A few participants felt religion helped them face death and dying and illness without fear. Only one third of the participants talked about their likelihood of dying from cancer though all of them were aware of the likelihood of cancer recurrence. Preferred place of burial after death was mentioned by a few participants who had a desire to be buried in their country of origin but all of them accepted that it would not be feasible because their children would not be able to join them as they had already settled with jobs in England.

## **9. Cancer narratives**

There were a number of threads that were apparent within the narratives including accounts of resilience, support and encounters with British ‘systems’. The cancer narratives recounted by most participants were concerned with their experiences of diagnosis and treatment. Being shocked, scared and upset were ‘reactions’ commonly shared following the disclosure of a cancer diagnosis but none expressed feeling angry or asked ‘why me?’. Their narratives indicated that some viewed cancer as ‘horrible and scary’. All wanted to be told the truth about their diagnosis, although one participant did not know she had cancer until she was having radiotherapy. After the initial shock of diagnosis, the narratives indicated they all took it in their stride to undergo treatments. There were detailed narratives about the difficulties of having cancer treatment and resultant side effects such as loss of hair. Chemotherapy was one of the treatments most feared by the majority of the participants. Most of them were aware of the risk of cancer recurrence and associated death with cancer as indicated above. The use of Chinese remedies and special foods were regarded as important by most participants.

## **10. Cancer services**

It was evident that most of the participants were not well informed about available cancer services in the UK. Their lack of language skills could have hindered access to cancer information and services. Their narratives were mainly concerned with the length of time in getting a diagnosis, the provision of interpreters and cancer treatments. Their expectation of cancer services was having good medical treatments to get rid of their cancer and they did not seem to expect access to emotional or financial support. They expected to get this type of support from their family and friends. With their language difficulties, most participants did not wish to join cancer support groups but a few did say it might help if a Chinese cancer support group was available. They also felt cancer information should be publicized in Chinese newspapers and disseminated through organizing ‘health talks’ in the Chinese communities. The lack of Chinese speaking health professionals was also a concern.



## **Summary of narratives threads from the Chinese participants**

The narratives followed a pattern in having some core threads which included accounts of their hardships and losses and their experiences in their past life in their country of origin and during their migration to the UK, their coping methods, cultural issues, family relationships and cancer experiences in terms of treatments and services. Communication barriers were known to be a factor affecting their access to cancer services but it was not the core of their stories. Past life experiences and relationships were the core of their narratives which had some influence on their cancer experiences and coping styles. Arguably, language problems might have contributed to some of the hardship experienced by some participants. The narratives of their past life experiences and their ways of coping and managing in the face of adversities seemed to correlate with their ways of dealing with their cancer experiences. It is difficult to say if their personality or their life experiences had helped to shape their coping response. Family relationships also played an important part in their cancer experiences. Participants with good family relationship appeared to be more optimistic and perceived themselves to be better supported.

All participants were migrants from Hong Kong, Mainland China, Vietnam and Malaysia and their migration experiences have shaped their ways of coping. Being adaptable and having a degree of endurance are characteristics found in many migrants and were found in many of our participants. The majority of participants overcame difficulties using their own resources (eg. friends and peers) and managed in the best way they could. They appeared to be pragmatic and realistic in solving their problems. None of them were in the catering trade before they came to England but realized that was the only job they could get and earn a reasonable living in England. They worked long hours and a lot of them managed to start their own catering business eventually.

All participants had grown up children. Although they did not live with their children, it was evident that they remained family orientated. Family support was expected by most of the participants. A few also expressed their wish to go back to their country of birth and be buried there after their death but they all accepted that it was not feasible. They had weighed up the situation and realized their children would not be able to leave England and look after their grave in another country, so it was more important for them to be buried here where their grave could be tended in culturally proscribed ways.

### **4.4.3 Description of the selected ‘white’ British participant’s transcripts for narrative analysis**

#### **Selection**

For the narrative analysis, a selection of 15 transcripts was made out of the 47 ‘white’ interview transcripts available. The process of selection is described in Section 3.6. In short the aim was to identify transcripts that varied by gender, age and location as well as offering enough narrative content with which to work. The selected fifteen are shown in Table 10.

**Table 10 – Fifteen ‘white’ British transcripts selected for narrative analysis**

<b>Count</b>	<b>Pseudonym</b>	<b>Gender</b>	<b>Age</b>	<b>Location</b>	<b>Code</b>
1	Mr Davis	M	81	London	AX02M
2	Mrs Dun	F	74	London	AX05F
3	Mr Norman	M	61	London	AX07M
4	Mrs Hall	F	85	London	AX11F
5	Mr Thorpe	M	75	London	AX15M
6	Mr Holmes	M	79	Manchester	BX22M
7	Mrs Young	F	83	Manchester	BX25F
8	Mr Owen	M	83	Manchester	BX30M
9	Mrs Nun	F	90	Manchester	BX31F
10	Mrs Jeep	F	75	Plymouth	DX68F
11	Mrs Jolly	F	68	Plymouth	DX70F
12	Mrs Heap	F	83	Sheffield	CX49F
13	Mrs Yen	F	70	Sheffield	CX50F
14	Mrs Seed	F	63	Sheffield	CX55F
15	Mr Pit	M	67	Sheffield	CX57M

Within the ‘white’ British sample, ten narrative threads emerged (See Table 11).

**Table 11 – The nine narrative threads that emerged from the 15 transcripts of ‘white’ British participants**

<b>Count</b>	<b>Narrative thread</b>	<b>Explanation</b>
1	Cancer services	Stories of experiences with cancer services
2	Cancer story	The individual’s account of their encounter with cancer and others’ stories of cancer – either people they knew, or knew of, in the media or in books
3	Restriction, loss, illness, death, etc	Stories of restriction, loss, illness and death. This is both restrictions in relation to their cancer and restrictions unrelated to the cancer – either from their past or from other areas of their lives
4	Meaning of life, faith, spirituality, religion	Accounts drawing on spirituality taken in its widest sense.
5	Mobilities & Stabilities	People’s movement across the country or the world or their attachment to a place
6	Ordinary life - hard & good times - work & money	The stories of ordinary living
7	Resilience	Places where participants appear to show resilience to their situation
8	The impact of war	Participants experiences of wartime
9	Significant relationships	Any accounts of personal relationships that are or have been significant – partners, children, parents, siblings, friends, colleagues, neighbours

The nine threads arose across 15 transcripts although not every thread was present in every transcript. Table 12 shows the distribution of the nine threads across the 15 participants.

**Table 12: Distribution of nine threads across the 15 transcripts**

<b>Pseudonym</b>	Mr Davis	Mrs Dun	Mr Norman	Mrs Hall	Mr Thorpe	Mr Holmes	Mrs Young	Mr Owen	Mrs Nun	Mrs Jeep	Mrs Jolly	Mrs Heap	Mrs Yen	Mrs Seed	Mr Pit
<b>Code</b>	AX02	AX05	AX07	AX11	AX15	BX22	BX25	BX30	BX31	DX68	DX70	CX49	CX50	CX55	CX57
<b>Gender</b>	M	F	M	F	M	M	F	M	F	F	F	F	F	F	M
<b>Age</b>	81	74	61	85	75	79	83	83	90	75	68	83	70	63	67
<b>Site</b>	L	L	L	L	L	M	M	M	M	P	P	S	S	S	S
<b>Cancer services</b>															
<b>Cancer story</b>															
<b>Restriction, loss, illness, death, etc</b>															
<b>Meaning of life, faith, spirituality, religion</b>															
<b>Mobilities &amp; Stabilities</b>															
<b>Ordinary life - hard &amp; good times - work &amp; money</b>															
<b>Resilience</b>															
<b>Impact of war</b>															
<b>Significant relationships</b>															

**Key:** Shading indicates evidence of narrative theme in transcript  
L = London; M = Manchester; P = Plymouth; S = Sheffield

#### 4.4.4 'White' British participants' narrative threads

##### 1. Resilience

All 15 participants talked of things that suggested a level of resilience in their lives and in particular in relation to their cancer diagnosis. Sometimes resilience was built up through the support given by a partner, grown up child, sibling, friend or neighbour. Sometimes the participant's resilience (or its opposite) seemed to be built up through the stories the participant told about themselves. In some cases very different accounts are presented by the same person, for example, "I've had to be strong through a number of years" (Mrs Hall) or "I've nothing really to live for" (Mrs Hall). Such stories, whether positive or negative, might create, maintain or undermine their resilience. Connected to this, participants sometimes repeated a phrase such as "where there's life there's hope" (Mr Thorpe), "there's people worse off than I am" (Mrs Dunn) or "tomorrow will look after itself" (Mr Norman) which, in a similar way to stories might act as a means of boosting resilience and function as a social comparison process. Sometimes participants seemed more resilient to their cancer because it played a less dominant role in their narrative accounts because of other powerful and perhaps more salient experiences in their lives – current or in the past. Some drew on past difficult experiences of war or facing change, inferring that this made them stronger now "I saw a lot of death – probably that's what's helped me" (Mr Owen). Sometimes participant's recounted stories that made them appeared resilient in contrast to those around them who were falling apart – maybe because in the lived story they share the expectation that they have to be strong. Finally some of the other themes such as significant relationships; wider cancer stories; and meaning of life, faith, spirituality and religion might contribute to resilience.

##### 2. Narratives of cancer

All 15 participants presented a 'story' about their cancer but it varied in its dominance and intensity. For some, their cancer story was mentioned in passing and it did not dominate their accounts. Sometimes their cancer story was dominated by, or closely entangled with, non-cancer stories that influenced the individual just as powerfully. One participant described how his cancer diagnosis was not a big issue partly because he had suffered for 12 years with another unrelated chronic condition which he regarded as more challenging. For another person, difficult issues from his troubled country of Zimbabwe dominated his account. In contrast to these, there were people's stories that focused strongly on cancer. There were accounts of symptoms, diagnosis or misdiagnosis, tiredness, pain, physical restrictions, fears, surgery, treatments, mistakes, losses and death. For some, cancer was a new threat in their lives, whereas others had lived with it for a number of years.

Four participants drew on others' stories of cancer. The stories they told or alluded to were of people they know personally, sometimes of people once removed from them but who they know through a personal link and sometimes the stories of cancer they used are of people more distant to them – perhaps those they came across in the media or books. The stories drawn on might be frightening or uplifting. There appeared to be connections between the way such stories are drawn on and participant's resilience, for example, cancer 'survival' stories were seen to offer hope.

##### 3. Mobility and stability

Narratives associated with geographical mobility and, alternatively stability in place, were evident in all 15 transcripts. The drivers for mobility were largely economic and securing employment. The narratives focused on the importance and meaning of place. There were stories where a person remained rooted throughout their life in the same locality in England - he or she never lived anywhere else. There were stories of remaining rooted but moving away for periods - either

because of work or because they were in the armed forces during or after the second world war, including moves to Europe, Korea, Delhi, Venezuela, Columbia and Argentina. There were also stories of leaving a location for good and moving within the UK, examples include from: Birmingham to Devon, Essex to Sheffield, North Wales to Cornwall, and Edinburgh to London. Finally there were stories of coming to this country from abroad either as a child or as an adult. They included: a woman from Algiers of French origin who when very young, married a British man and has lived in the UK ever since; a woman from Ireland who came, as a young woman, to England for work in 1952, married an Englishman and stayed; a man who was born, and lived all his life up to recently in Zimbabwe only coming to London a year ago aged 74; or of a woman born in Kenya and brought back to England as a young child.

#### **4. The impact of war**

The lasting resonance of war was apparent of this cohort and their accounts were used for a number of purposes including to demonstrate their resilience in surviving adversity, their experiences of personal loss through death and social disruption and the impact on early childhood experiences. For six of the 15 participants, stories of war are recounted showing how it impacted on their lives. Some experienced difficult conditions directly – fighting, becoming a prisoner of war and facing the aftermath of bombing. The war referred to is predominantly the Second World War but one participant was affected by the current unrest in Zimbabwe. Other stories are of war impacting on them but less directly - for example growing up with the restraints of wartime England with a mother who made it fun or alternatively having a mother who became severely distressed after losing a brother and sister in the war.

#### **5. Meaning of life, faith, spirituality and religion**

Six of the 15 talked about the meaning of life, or of a faith, or some sort of spirituality or religion. The terms faith, spirituality and religion are interpreted here in a broad sense. There were stories of being supported and strengthened by a faith, by the prayers of others or the visit of a clergyman. These seem to add to a person's resources for resilience and can be considered as a coping strategy. On the other hand, there were accounts that linked cancer negatively with punishment and guilt which might have religious origins (perhaps notions of sin) and sometimes might undermine resilience.

#### **6. Ordinary life, hard times and good times, work and money**

There were a wide variety of experiences accounted – working in the printing industry, as a secretary, civil engineering, sorting parcels on Royal Mail trains, working in the police force, the civil service, as a taxi driver, running a market garden, running bookshops, as a retail jewellery store manager, living in expatriate communities abroad, staying with company for 41 years, joys and worries with children, voluntary work, playing golf and travel. What comes across most strongly was how the experiences of cancer were woven in with the contexts of ordinary lives.

#### **7. Significant relationships**

All fifteen participants talked about significant relationships – parents, siblings, marital partners, children, friends, neighbours and colleagues.

There were narratives of:

- Being open about the cancer with significant others
- Finding it difficult to share
- Responses of a partner to one's cancer diagnosis
- Having to be strong for the sake of a partner
- Concern for the partner who is a carer
- Relationships with children and grandchildren
- Support from close family
- Living alone
- Having no immediate family
- Being at a physical distance from those with whom one has significant relationships and missing having them at hand.

## **8. Restriction, loss, illness and death**

Stories of restriction, loss, illness and death were found in fourteen of the fifteen transcripts. These stories focussed on two areas. Firstly, there were those restrictions and losses connected to the cancer. Secondly, there were restrictions and losses unconnected to the cancer - from the person's past or from other areas of their lives. In the first area, participants talked of the emotional pain of coming to terms with restrictions to one's physical ability consequent on the cancer or its treatment – the loss of freedom to come and go and do as one pleases. There were stories of loss – the loss of networks of friends, of independence, of one's energy, of easy travel, of chances to see loved ones, of hobbies such as gardening and walking – all attributed to the cancer. Then there were accounts of restrictions unconnected to a participant's cancer. Sometimes these were current restrictions and challenges such as the person who was unable to return to his home in Zimbabwe. Sometimes they were ongoing losses such as living without a partner, a loved one or a friend who has died or moved away, or living with the impact of another chronic illness. Sometimes the losses were in the past such as the loss of a parent when young, a divorce or the hardships of war.

## **9. Cancer services**

Fourteen of the fifteen interviewees talked of their experiences of cancer services. There were stories of wonderful service and of poor service, of efficiency and of occasions when efficiency seemed to be taken too far. There was talk of places and cultures where one felt accepted and others where as an older or sick person they felt patronised, sometimes quite subtly. There were also pleas for more support for partners who were carers. For those participants using hospice day care, there were accounts of what hospices meant to them and how different they were to hospital cancer services, offering individual attention, a non-clinical atmosphere, friendship and support. Likewise, the Cancer Support Centre users, highlighted the reasons that they found comfort in these environments and the benefits of complementary therapies.

## **4.5 Integrative analysis and discussion**

The purpose of this final section is to briefly return to our research questions and offer an integrated analysis and discussion drawing upon both the content and narrative analyses previously presented. Table 13 presents a comparison of the cancer and biographical experiences across the two cultural groups based on the content and narratives analyses. We have drawn out the common experiences and highlighted distinct experiences for each cultural group. These are explained here and further interpretation is offered in the Discussion section.

**Table 13 – Comparison of cancer and biographical experiences across cultural groups**

Experiences of Chinese participants	Common experiences	Experiences of ‘white’ British participants
<ul style="list-style-type: none"> <li>• Diversity of socio-economic backgrounds before migration, most had experiences of poverty</li> <li>• Migration to the UK for largely economic reasons in young adulthood</li> <li>• Following migration – most worked in catering trade</li> <li>• Language difficulties on arrival in the UK and for some ongoing</li> <li>• Majority had limited contact with mainstream British society</li> <li>• Shared a Chinese ethnic identity but used a variety of self ascribed descriptors</li> <li>• Cultural identity was highly salient</li> <li>• Not very well informed about cancer</li> <li>• Unfamiliar with availability of cancer and other health services</li> <li>• Most had great respect for doctors and other health professionals who are afforded a ‘high status’ in the traditional Chinese social system and are not to be challenged</li> <li>• Overall satisfied with NHS but some ‘doctor shopping’ – meaning that a number of second opinions are sought</li> <li>• Provision of psychological and emotional support was not expected from health professionals</li> <li>• Some use of traditional Chinese health beliefs and food practices</li> <li>• Appreciation of interpreting service provided by hospitals but low levels of satisfaction with its quality and availability</li> </ul>	<ul style="list-style-type: none"> <li>• Growing older in Britain</li> <li>• Impact of war on a minority</li> <li>• Experience of using British cancer care services</li> <li>• Pragmatic and realistic towards cancer</li> <li>• Acknowledge cancer as a life threatening disease</li> <li>• Previous experiences of loss shaping responses</li> <li>• Resilience in coping with adverse situations</li> <li>• Importance of family relationships and for some, friendship networks</li> <li>• Expectations of family support in illness</li> <li>• Predominantly secular but religious faith was regarded as a support for some of the participants</li> <li>• Have some control about their future.</li> </ul>	<ul style="list-style-type: none"> <li>• Diversity of socio-economic backgrounds</li> <li>• Some mobility within and beyond UK largely in young adulthood</li> <li>• Diversity of occupations and variety of economic experiences.</li> <li>• No language difficulties but some experienced problems with perceived poor communication skills of health professionals</li> <li>• No evidence of social exclusion</li> <li>• Largely ‘white’ British identity but with a variety of self ascribed descriptors</li> <li>• Cultural identity not really salient for most</li> <li>• Stoicism and valuing of independence</li> <li>• Fairly well informed about cancer</li> <li>• Quite familiar with available cancer and other health services</li> <li>• Doctors and health professionals were respected but they were not seen as ‘someone who should not be challenged’.</li> <li>• Overall satisfied with NHS but some adverse experiences with poor communication</li> <li>• Provision of psychological and emotional support was expected from health professionals</li> <li>• Some use of complementary therapies</li> <li>• Autonomy was evident although family was also regarded as part of the decision making process</li> <li>• High levels of satisfaction with hospices reported by those using them.</li> </ul>



## **1. What are the narratives of transition of older adults encountering a cancer diagnosis?**

We found evidence of cross-cutting themes about mobility – largely for economic rather than political reasons, affecting the life courses of both Chinese and ‘white’ British participants. The importance of ‘place’ featured in many accounts and was closely tied to identity. The perspectives of older adults of transitions appear to be dominated by their life opportunities and access to social and individual resources. Arguably, the twentieth century was remarkable as a period of rapid social and economic change and of nationalistic and ideological conflicts, often on a global scale. Many of our participants had lived through and been severely impacted upon by these international trends. Overall the accounts suggest that for most participants in both cultural groups their previous experiences of personal losses including family and spousal bereavements, employment losses, relationship problems and experiences of civil unrest and war have influenced their approach to coping with cancer. In our sample of 71 people, all the Chinese participants and three of the ‘white’ British participants were born out of the UK. Geographical transitions were present in the accounts of ‘white’ British participants many of whom had moved to take up employment in their early adulthood or been conscripted into national service. Likewise, Chinese participants provided accounts of migration driven by a desire to seek better standards of living in the UK and for some to escape extreme poverty, especially for those participants from Vietnam. A common theme therefore emerged of young adults seeking better employment opportunities and then for both groups, long periods of relative geographical stability. For example, most of the older Chinese sample had been resident in the UK for 20-30 years and many had settled within specific ‘Chinese’ communities within the UK. We did not get the impression of numerous recent transitions for most of this group or active desires to relocate. However, for a few the diagnosis of cancer had caused them to reconsider their wishes for location of death and burial in their place of origin. Familial burial grounds are important within some Chinese cultural world views but socio-political changes in mainland China such as the Cultural Revolution mean that these places may no longer exist and practices associated with ancestor worship and burial practices have had to be transformed (Chung and Wegars 2005). Within the ‘white’ British sample, there was more evidence of geographical stability especially in their later adult years but perhaps less than we anticipated, once again indicating the impact of economic pressures in the living patterns of British residents.

## **2. How are cultural constructs of loss and transition articulated within personal narratives?**

Within all the interviews, we obtained accounts of loss and change. For most people losses and transitions were attributed to life events other than cancer. For the Chinese group, the experience of migration marked both a loss and a potential gain. The key losses were in relation to language competence, social position and status, ability to use their previous occupational skills, familiar food, families and friends who remained behind, and racial discrimination. Overall, their narratives did not present a negative picture but highlighted life achievements in overcoming adverse early experiences and in celebrating achievement such as acquiring their own business and financial security. In the ‘white’ British group, narratives of loss also focused on wider changes in society such as early experiences resulting from war time restrictions and deaths. The common cross cutting narrative of loss was in relation to cancer with accounts of distress associated with the diagnosis, physical limitations and functional changes resulting from the cancer itself or its treatment. Both groups were aware of their cancer diagnosis (this was a requirement of study participation) and all reported their wish to be told ‘the truth’ and be involved with their families in medical decision making. There was one Chinese participant who was not told of her diagnosis by her family but later realised it. In both groups, we found that while cancer narratives were important, they were set within the larger context of people’s lives.

### **3. What impact do previous experiences have on resilience and coping?**

Resilience in the face of adversity and of adapting to difficulties associated with migration was highlighted in the interviews conducted with the Chinese participants. It is remarkable that they have largely achieved their goals of greater economic prosperity although this may be attributable to our recruitment of those currently living in the UK (the less successful and less resilient may have returned to their country of origin). One common characteristic of both groups, probably attributed to their older age, was that most people had experienced deaths in their family and one third of Chinese and one quarter of 'white' British participants had experienced family deaths from cancer. Thus they drew on real life experiences of loss and many closely associated cancer with death. We noted that cancer appeared to have greater stigma for the Chinese sample. Both groups appeared to draw on media accounts of 'celebrities' with cancer to construct discourses of hope and survival. For the 'white' British participants, their accounts were dominated by valuing their 'ordinary' lives and a wish to maintain 'normality' for as long as possible in their cancer journey.

### **4. To what extent do perceived family networks affect resilience, coping and adaptation to a cancer diagnosis?**

Family relationships were a recurrent theme throughout the narratives of virtually all the participants. Within traditional Chinese culture, great emphasis is placed upon the role of the family in terms of social control and social cohesion; norms of filial piety and respect for elders are embedded in family relationships. Our Chinese participants appeared to value family structures - all had married and had children, most since their arrival in the UK. They reported extensive reliance of family networks, especially in the early period of their residence in the UK, to provide social support, for access to employment opportunities (largely in the catering trade) and to manage negotiations with mainstream culture such as interpreting English in health care contexts. However, at the time of the interview, half reported difficult family relationships with instances of abuse, estrangement from children and other disruptions. There appeared to be an association between those who reported good family relationships and their ability to cope with cancer. They appeared to be more optimistic and resilient about life in general, not just their cancer. The 'white' British group also provided extensive accounts of their family relationships, both the highs and lows, indicating its salience to this group as well. A common cross cutting theme was the importance of family relationships to general feelings of well-being and to supporting participants as older people. These narratives provided rich accounts of reciprocity and mutual dependency and support enacted across the generations. There were more accounts of grand parenting in 'white' British participants probably reflecting their older age. Chinese participants appeared to have greater expectations that their families would provide specific services such as interpreting for them, although as already highlighted this was problematic as the younger generation had less Chinese language skills and for reasons of privacy.

## 5. DISCUSSION

This is the first UK study to examine in detail the experiences of a range of older adults with cancer from Chinese and ‘white’ British backgrounds living in Britain. It was important to include people from both cultural groups to identify the aspects of their experience which are common to those who are growing older in Britain with a diagnosis of cancer, and those that may be attributed to cultural factors and shared life events, and cohort effects including migration. Despite the different cultural backgrounds there were also common experiences shared by both groups. This study is important because it places the current experience of cancer in the context of wider biographical transitions and challenges, rather than assuming that cancer dominates the lived experience as is frequently done. This suggests a number of paradoxes in that for some older people with cancer, their accounts focus on ‘ordinary’ lives and for some simultaneously ‘extraordinary’ circumstances (for example surviving a hazardous ‘boat’ escape from Vietnam or the London blitz). Unlike, other studies, for many of the participants in their narratives of their life, cancer was often not dominant, instead, appearing as a ‘footnote’ in accounts of challenging but largely successful lives. Arguably these are revealed by our use of both thematic content and narrative analyses, and the construction of interviews that encouraged participants to place their ‘cancer story’ in the wider context of their ‘life story’ perhaps allowing a more nuanced version to emerge (Thomas et al in press).

Prior to discussing the findings, a number of limitations must be acknowledged:

- **Sample size**

The findings of this study can provide some insights into the experiences of older Chinese and ‘white’ British people with a cancer diagnosis but they are limited because the sample; in particular the Chinese group is smaller than anticipated. This was due to the difficulty in engaging older Chinese people with cancer in discussions with ‘strangers’ as indicated by evidence from a Hong Kong study (Chan 2000). Cancer remains a stigmatised condition for many Chinese people and they had concerns about discussion of this topic and fears about confidentiality. We were fortunate to have a skilled researcher Alice Chapman who was sensitive to cultural nuances and mores.

- **Sample selection**

A limitation of this study also includes potential biases in the sample arising from the recruitment of a group of older Chinese people who were accessed via Chinese community groups in the north and south of England. In addition, recruitment was facilitated by personal contacts made by Alice Chapman through her wider role in the Chinese community. It is recognized that people who attend community groups are more likely to be less acculturated into British society, and less likely to speak English. The majority of the participants described their English as poor or very poor. Arguably, they are more likely to be a group who would encounter difficulties in accessing cancer care services. Two thirds of the participants in this study were women and this gender skew was probably a consequence of recruiting via community centres as men are less likely to use such places; the proportion of women in the population also tends to increase in older age due to differential life expectancy. In addition, cancer experiences of more isolated older Chinese people who do not participate in community groups were not elicited. ‘White’ British participants were accessed via hospice day care units and cancer support centres which resulted in two distinctive groups; with the older and frailer people in the hospices and the younger and ‘healthier’ people recruited from the cancer support group. Obviously, these two groups did have slightly different perspectives about life and were at different stages of their ‘cancer journey’ and this could be

construed as an advantage. Overall, our samples do not reflect the experiences of those cancer survivors who do not seek services or other forms of community support.

- **Age of sample**

The study focused on older people but there is controversy about when old or older age begins. The arbitrary age of 65 is generally defined by social demographic data as 'old' but this may not reflect biological processes or cultural beliefs. Men reaching 65 and woman reaching 60 of age are currently entitled to receive an old age pension in the UK. However, there is an increased tendency for divergent patterns of employment with some people retiring from the workforce before 60 and for others to continue working beyond 65 years. At the same time, people are living longer and healthier lives so defining old or older age is not easy. The study defined older age as self ascribed by the participants whose age ranged from 50-76 with a median age of 60 in the Chinese group; and from 60-91 with a median age of 74 in the 'white' British group. Therefore, the data are drawn from younger old rather than older old people within the Chinese group. There was a marked difference of 14 years between the medians, and this may account for some of the differences in experiences between our groups. It also highlights that for the Chinese cultural group in Britain, constructions of 'older age' occur at a chronologically younger age than for the mainstream community and research which only recruits people over 65 years may inadvertently exclude this population and discriminate against them. We are mindful that cohort effects must be kept in mind when interpreting these results. Future older people will not have experienced the losses arising from war that has shaped some of these participant's lives.

- **Stage of cancer**

We recruited people who were at different stages of their cancer journey hence there would be different issues within the group. It is recognised that people with cancer have different issues and needs at different stages of cancer. The study focused on people with cancer at any stage and aimed to explore their individual experiences as opposed to concentrate on any particular stage of cancer experience.

- **Methods of data collection**

The use of interview methods is based on cultural assumptions and norms, with interviews being a common form of eliciting information in western cultures (eg. television celebrity interviews, sports personality interviews) but potentially holds other connotations in Chinese culture where interviews may be more commonly associated with disciplinary practices. We were aware of these differing cultural understandings (Payne et al 2005b), and our researcher Alice Chapman sought to introduce the dialogues as a 'conversation' to make it appear less threatening. Perhaps it is not that people from ethnic groups do not want to be involved in research but that research methods are largely designed for people from western cultures. There are difficulties with using telephone interviews for qualitative research because of the lack of non-verbal communication, but previous evidence suggests they are a valid method (Rubin and Rubin 1995). In addition, we predominantly used telephone interviews for the much shorter second interviews where a relationship with the participant already existed.

### **Key Discussion points**

However, despite the above limitations, this is the first in-depth UK study to address the cancer experiences of both older Chinese and 'white' British people and provide an account of their experiences and perspectives of cancer. The data from this study reveals some of the important

issues encountered by these two different ethnic groups throughout their cancer and life experiences.

The findings presented in this report suggest that there are a number of common experiences shared by older people with cancer despite the cultural differences. There was evidence in the accounts that older people with cancer drew on previous life experiences of loss, including spousal loss, and relationship breakdown, and that such losses were regarded as normal life transitions, and provided a cognitive template for coping with subsequent challenges including a cancer diagnosis. Most participants provide vivid examples of how they dealt with personal challenges and portrayed a sense of achievement and resilience. These narratives have a resonance with those elicited from East Londoners by Young and Cullen (1996), in which, the emphasis is placed on accomplishment of life goals, usually defined in terms of successful family relationships and the production of offspring. Family relationships were important as many of the older people were probably the last generation from 'bigger family units'. Most regarded the family as the primary source of practical, emotional and financial support in times of stress and they had strong expectations that families would provide a range of support during times of illness (Hudson and Payne in press). This accords with both national policies within the UK which prioritise the provision of care by family carers (Department of Health 2008b) and evidence from systematic reviews which indicate that the presence of family carers predicts greater choice for cancer patients about place of death (Gomes and Higginson 2006).

Family as well as medical staff played an important role in decision making with regard to undertaking cancer treatments for the participants in this study. After listening to the treatment choice given by the doctor, about one half of the participants had a family conference before they decided on their treatments which seemed to be consistent with findings from previous studies (Huang et al 1999; Waddell and McNamara 1997). The rest made their decision themselves and followed the advice from medical doctors who were regarded as the experts which is compatible with the Chinese tradition in that a benevolent form of medical paternalism is valued and doctors are much respected by patients (Tung 1990). Amongst the Chinese participants, there was uncertainty about the purpose of some services, such as hospices and cancer support groups, due to a lack of knowledge and a failure to understand that psychosocial support may also be available through cancer services. The reliance of Chinese older people upon family support may not be sustainable in the long term, due to increasing numbers of older people and to changing family patterns.

In general, older adults in our study had pragmatic and realistic attitudes towards cancer which were similar to the attitudes they had towards difficulties and challenges they had faced in their past. Clearly with the benefit of hindsight they were recalling the lives but for many participants the outcome of their cancer remained uncertain. They all acknowledged their cancer diagnosis and regarded cancer as a potentially life threatening condition. The Chinese participants seemed to have less general knowledge about cancer than the 'white' British group but both groups made a number of attributions about cancer causation. Likewise, all of them had heard of cancer and most knew of family members or friends, or public figures that had had cancer. The stigma of cancer appears to remain deeply rooted in the beliefs of some older Chinese people. In a previous study of older Chinese people (Payne et al 2005b) some participants felt cancer would bring bad luck to family and friends; also a property where a person has died would be perceived as a 'contaminated' place which would be difficult to sell.

Most of our participants had experienced challenges to their assumptive life worlds and life events that could potentially be construed as positive or negative. In the accounts, we noted the way that events were appraised and the diversity of constructions placed the psychosocial transitions, lending support to the transtheoretical model of stress and coping (Lazarus and Folkman 1984). There were

particular cases where traumatic life events dominated the biographical narratives. For example, one Chinese woman recounted numerous episodes of physical and psychological abuse during childhood and early married life, and her response had been numerous suicide attempts, but latterly she attributed her survival to fate and felt that she was not meant to die. In this example, her cancer was not regarded as a significant life threat as she reported that she had overcome greater challenges. Similar cases were present in the 'white' British sample, where surviving other chronic illnesses placed cancer in a less threatening context. This study is one of the first that provides evidence that older people draw upon previous life experiences in their adaptation to a cancer diagnosis.

All the participants had used the British NHS for cancer treatment and they were largely satisfied with the medical care provided. Overall participants wanted services that recognised differences in people's cultures and individuality, without making assumptions. These findings accord with evidence from cancer patients (Corner et al 2007) and those using social care (Commission for Social Care Inspectorate 2008). None of the Chinese participants were currently using hospice services but for those 'white' British participants who were using hospice day care there were very high levels of satisfaction which is similar to reports from other studies (Thomas et al 2004). There were differences in the expectations of cancer services, in that the Chinese group predominantly expected high quality medical treatment, especially from hospital services, while the 'white' British group also expected psychosocial support and attention to their emotional welfare from health care staff. We noted that some of the 'white' British people talk of 'good' and in some cases 'bad' relationships with their medical consultants and general practitioners. They appeared to expect and appreciate continuity in medical care relationships and liked some recognition of their individuality. In the Chinese group, there were fewer expectations that such relationship would become established, perhaps because of the language difficulties which will be discussed later. In addition, we noted an attitudinal difference, with greater respect for the authority of the medical profession shown by Chinese participants. Overall, the Chinese group had relatively low expectations of NHS cancer services which could possibly be due to their lack of understanding of the available support from the health service and it does not necessarily mean they do not need external support especially as their 'family systems' are also changing with less availability of adult children to provide care and support.

There was greater heterogeneity of employment in the 'white' British group and most of them had reached retirement. In the Chinese group, while there had been occupational diversity prior to migration, most had entered the catering trade in the UK. As they were also a relatively younger sample, many were still engaged in paid work or in contributing to family businesses. The impact of cancer on their working lives and their financial security was not the primary focus of our research, but this would warrant further investigation, as little is known about the economic consequences for self employed workers and for older workers.

One of the major mediating factors for older Chinese people living in Britain is their English language ability. Many of the current cohort of older people, especially those from mainland China, Hong Kong or Vietnam, had relatively little access to education during their formative years because of the Japanese invasion and wars (prior to and during World War II), the communist takeover of China in 1949, and wars in Vietnam in the 1960's. During these turbulent times, there was little opportunity for the current cohort of older people to receive more than basic education and many people experienced periods of severe deprivation and poverty. For example, data from Hong Kong indicates that in 2001 42% of those over 65 years had received no education and a further 39% had received only primary education (Census and Statistics Department 2002).

Perhaps the most marked cultural difference was due to communication difficulties resulting from language difficulties. In ethnic minority groups, problems arising from language barriers have been

a much discussed issue in health care in the UK in recent years (eg. Goddard and Smith 1998). The main spoken language in the UK is English and there are no accurate figures on levels of literacy in spoken and written English amongst Chinese people living in the UK. However, evidence from previous research studies (Gerrish et al 2004; Sproston et al 2001; Chan 2000) indicates that the majority of their participants could not understand English and language barriers have been cited as one of the main difficulties for Chinese people in accessing primary health care services. As cancer services in the UK are often accessed through referrals from primary health care, it is not surprising that evidence (CancerBacup 2004; Randhawa et al 2003) suggested people who do not speak English have particular problems in accessing cancer care services. Two recent UK studies (Payne et al 2005b; Lees et al 2004) exploring the views of older Chinese people about cancer also found that the majority of the participants could not speak English and they would rely on having either their children or professional interpreters to assist them in communicating with health professionals. Our study also highlighted some of the issues associated with the use of interpreters as there was varied standard amongst the interpreters and the service is only available in bigger cities. There is no training provided for health professionals and interpreters who often have different expectations from each other. Interestingly, the service users also had different expectation from the interpreters; some expect them to be an advocate as well being an interpreter. Further research is required to determine the differing expectations placed upon interpreters and to improve the quality of services provided.

Communication in cancer care is challenging especially in relation to disclosure of information about diagnosis and prognosis. Disclosure practices vary around the world and in many Oriental cultures, there remain strong social norms against disclosure to patients directly (Lee and Wu 2002). For example in Taiwan, the normal practice is for a cancer diagnosis to be communicated to family members who make decisions on behalf of the patient, especially when the patient is older (Cheng et al 2008). In Chinese people who are living in western countries, a review of the literature suggests that preferences for open disclosure of the diagnosis to the patient and family simultaneously are now similar to western beliefs and practices (Payne et al 2005a). In our current study, there were no significant differences with regard to preferences about cancer diagnosis or medical decision making between the cultural groups, although perhaps there were some subtle differences of emphasis. We noted that most Chinese participants reported that medical decision making was shared with family members, while in the 'white' British people more emphasis was placed upon personal autonomy but families were generally part of the decision making process. One Chinese participant reported that her family had initially withheld her cancer diagnosis from her, and she interpreted this as a desire to reduce her distress. There were a few complaints about poor communication skills in the 'white' British group, especially related to diagnosis.

While western medical treatment for cancer was held in high regard by both cultural groups, there was some evidence that Chinese older people also used traditional Chinese medicine and consumed special foods that were compatible with their health beliefs (Payne et al in press). Some of the 'white' British participants reported valuing complementary therapies to enhance well-being and relaxation. The key difference was that Chinese people tended to emphasize the physical benefits, while the British older people emphasised the emotional benefits of these supplementary therapies. Both Chinese and 'white' British participants reflect largely secular cultures, with little evidence of religion being used as a means of coping except for a few example such as the use of Buddhist audio-tapes being used for spiritual support.

With the long-awaited End of Life Care Strategy (DoH 2008) now published, research is required on the cultural appropriateness of its recommendations, such as advance care planning, promoting home deaths, public understanding and engagement in debates about end of life choices. It is essential that national policies are scrutinised, and the resultant interventions, are tested within the context of a multicultural society to ensure that new initiatives do not inadvertently discriminate

against or marginalise certain cultural groups. Some of the assumptions underpinning the End of Life Care Strategy (DoH 2008) about the privileging of individual autonomy in medical decision-making, the promotion of 'choice', and the expectation that patients 'plan' for their end of life care and express their wishes formally in written statements or directives, appear to be incongruent with the values of both our samples of older people, but especially some of those with Chinese cultural identities.



## 6. CONCLUSIONS

In conclusion, this sample of older people with cancer from Chinese and 'white' British cultures living in the UK tended to cope well with a diagnosis of cancer and draw on previous experiences of overcoming life challenges to contextualise their current situation. Most reported valuing their own self reliance and stoicism in overcoming obstacles and attaining life goals. Both groups regarded family relationships as central to their lives and to current coping with cancer. They were largely satisfied with cancer care services, although both groups reported communication problems. On the basis of the present findings, it can be concluded that cancer services should emphasise the availability of interpreters to non-English speaking patients. Insufficient support for non-English speaking patients was identified. Even when interpreters were available it was evident that greater attention is needed to improve their skills and clarify their remit to patients and professionals. There is a lack of expertise in how best to use interpreters and more research on how to develop and sustain patient-professional relationships via these intermediaries is required. Many of the interviewees reported different expectations of interpreters. Amongst the 'white' British participants, there was heterogeneity of experiences, with a few instances of perceive ageism and difficulties with communication with cancer care professionals. Most participants highly valued access to specific services including Cancer Support services, complementary therapies and hospice care. All cancer patients wanted support from staff with positive and respectful attitudes to them. In conclusion, this study has set a diagnosis of cancer in the boarder context of older people's lives and shown how they draw upon previous life experiences and biographical narratives as a resource in facing cancer.

## 7. RECOMMENDATIONS

We offer the following recommendations to improve cancer care services. Our recommendations are directed to both NHS and Third Sector cancer services.

### Service development

- Greater accessibility of cancer support services is desirable, especially to patients who are socially isolated. Many derived comfort from complementary therapies but were concerned that they were a restricted, rationed resource. For Chinese cancer patients, educational programmes describing the types of psychosocial support available from mainstream health services and third sector organisations should be available.
- Better signposting of available support services and other sources of Third Sector support. Cancer patients, both ‘white’ British and Chinese often did not know what was available in their locality. These types of services help patients to ‘live with cancer’.
- Interpreting services – national standards and qualifications for interpreters should be implemented. Training should be provided for service providers, patients and families, and interpreters in how to effectively use interpreters. The role of interpreters should be clarified and agreed between all parties prior to the consultation. Interpreters need education and skills in understanding medical English, hospital procedures and practices.
- Translating patient information while important is not sufficient, information needs to be available in an audio format as well as in text.
- Communication skills of health professionals continues to be an issue and further training is needed to educate health professionals how to communicate with, and respect, older people as individuals (ageism was reported by some of the participants).
- Effective communication is the essence of good cancer care and sufficient time must be made available to achieve this in busy follow-up clinics and hospital wards.
- Training for health professionals about cultural issues is necessary to promote their confidence in dealing with patients and their families from diverse ethnic groups, and to prevent stereotyping and discrimination.
- There is a need to increase the number of health professionals from ethnic minority groups who can communicate with patients in their native language.
- A wide range of hospital food should be provided for different ethnic groups.
- Advice on welfare benefits and financial assistance should be more widely provided and not just briefly mentioned at the time of diagnosis (as patients’ main focus at time of diagnosis is their ‘life expectancy’). This needs to take account of any employment that the older person is engaged in, such as a family business.
- Services should enable cancer patients to have contact with families, friends and others who are important to them while they are in hospital, and to be connected to communities that are significant to them.

- Cancer services should ensure that older people feel safe and free from any form of discrimination based on age or race.

### **Community development**

- More education about cancer and health promotion strategies continued to be required amongst older people who may not know much about cancer.
- Increased information about cancer within Chinese communities. Cancer education programmes are needed to disseminate cancer prevention and recognition information and information about cancer treatment and care services for Chinese people and ethnic minority groups more generally. Community leaders are the key people who would be ideal educators so they should be trained to provide cancer information to their local community. Community (ethnic minority) centres are often run by volunteers and their funding is limited so there is a need to provide funding for this kind of training perhaps from mainstream health service. However community groups may be limited in areas with a sparse Chinese population so it is important to use Chinese language media as well.

### **Further research**

- Health professionals often express assumptions that BME patients ‘prefer to be cared for by their own family’ and our research demonstrated that older Chinese participants held similar expectations including provision of food to them by family members while they were in hospital, and in relation to emotional and financial support. However, approximately half our sample lived alone and family structures and living practices are changing. We know little about the changing nature of family support for older Chinese people or the perceptions of younger Chinese people about their obligations and desire to provide care for older family members. A study focusing on this with comparisons with a ‘white’ British sample is urgently required.
- Comparisons of cancer narratives from other BME groups, including one group who have not experienced language difficulties.
- Further detailed secondary data analysis on our existing interviews would be worthwhile, as there are rich accounts available.
- Further research is needed to explore the health needs and views of the ethnic minority populations about cancer.
- Research is required on the cultural appropriateness of research methods and data collection techniques.
- More research is required on the complex decision-making required in cancer, often involving negotiation with the older patient and their family.

## 8. PROJECT PUBLICITY AND DISSEMINATION

### Project Flyer

A project flyer was produced in two versions – a bilingual Chinese/English version and an English only version. We prepared the second version when we received feedback in London and Sheffield that British people did not like the bilingual version.

### Radio Interviews

- BBC Radio Manchester, Eastern Horizon – Broadcasted on 1.4.07  
Our researcher, Alice Chapman, talked in Cantonese to the presenter for 10 minutes about the project and invited listeners to contact her if they were interested in taking part in the study.
- BBC Radio, Manchester Citizen – Broadcasted on 3.4.07  
Our researcher, Alice Chapman, talked in English to the presenter for 10 minutes about the project and invited listeners to contact her if they were interested in taking part in the study.

### Newspapers

An article about the project was published in the *Chinese Gazette* European Edition on 18.05.07 and in the *Sing Tao Daily* European Edition on 21.05.07, to explain the purpose of the study and to invite interested people to contact the research team.

### Conference Presentations

Payne S. 'Ethnicity and Cancer: narrative research'. Talk presented at CECO Narrative Research Workshop, Lancaster University. February 2007

Payne S. 'Older Chinese people's view about cancer and end of life care' Talk presented at 1<sup>st</sup> One Day National Conference, Cultural Diversity in Palliative Care, Douglas Macmillan Hospice, Keele University, 29 April 2008.

Chapman A. 'The use of interpreters: the experiences of older Chinese people in the UK' Talk presented at Palliative Care Congress (PCC), Glasgow, 29 April-1 May 2008.

Payne S, Chung M, Gott M, Seymour J, Chapman A and Froggatt K. The use of interpreters: the experiences of older Chinese people with cancer in the UK. Poster presented at 5<sup>th</sup> Research Forum of the European Association for Palliative Care (EAPC), Trondheim, Norway. May 2008

Payne S. 'Older Chinese people's view about cancer and end of life care in Britain' Talk to be presented at Lancashire and South Cumbria Cancer Research Network Annual Research Conference, Garstang, Lancashire, 15 October, 2008

Payne S. 'Older Chinese people's view about cancer and end of life care' Talk to be presented at Gifts Hospice Conference, Lincoln, 4 November 2008.

### Publications

Payne S, Chung M, Gott M, Seymour J, Chapman A and Froggatt K. The use of interpreters: the experiences of older Chinese people with cancer in the UK. 5<sup>th</sup> Research Forum of the European Association for Palliative Care (EAPC). *Palliative Medicine*, 2008, 22(4): 543.

A number of publications arising from this study are in preparation.

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## **Appendix A - Semi-Structured Interview Schedule**

(Interview was conducted in the participant's preferred language)

### **Introductory Statement:**

Well first of all I would like to thank you for agreeing to take part in this interview and share your cancer experiences with me. My name is (Researcher's name) and I am from Lancaster University. We have been funded by Dimbleby Cancer Care to look at the concerns, perspectives and resilience of older people as they face the diagnosis of cancer. The aim is to develop some guidelines for people providing services so that they will be relevant and helpful to other people in the same situation. It is important that we get the views from people who have used cancer care service and find out if their needs have been met. We will be talking to a number of people like you in Sheffield, Manchester, London and Plymouth. There are no right or wrong answers because we just want to understand your views.

We are using a tape recorder so that we do not miss anything that is said. I would like to say that anything that is said is confidential to me and the Research Team and will not be repeated outside this interview. So, I would like you to feel at ease with the interview. When the results of the research are published I want to assure you that you will not be identified, just the general themes that emerge from the interviews.

Are there any questions you would like to ask before I continue?

Ok, I would just give you a brief account of what we will talk about. I would like to begin by asking you to tell me about your cancer experiences.

Then, I would like you to tell me a little bit about yourself and your background, a bit about your life experiences.

I am also interested to find out how you have coped with the situation; what services were/are available to you; how you were/are helped; what were your concerns and perspectives; what could have been done to help you coping with the situation.

Is there anything you would like to clarify before we start the interview?

If not, I will now turn the recorder on.

### **First Interview – Questions Guide**

#### **Information about the experiences with the cancer diagnosis**

1. We would like you to tell us your story. Can you start by saying how you knew there was something wrong?  
(Probe: When was that? How did you feel about that?)
2. Could you tell me what happened starting from the time you were diagnosed?  
(Probe: How did you find out? Who told you? What were your reactions? Did you understand what they told you? Were you given explanations? Were you asked if you wanted to know everything? How did you find the person(s) who gave you the diagnosis?)

3. Were your family told of your diagnosis  
(Probe: By whom? What were their reactions?)

### **General information about the interviewee**

1. Could you tell me a little bit about yourself?  
(Probe: Married status, job, background.)
2. Where were you born?  
(Probe: How long have you lived in this country? When and why did you come to the UK?)
3. Could you tell me a little bit about your family?  
(Probe: The size of the family; where they are at the moment; how often do you see them?)

### **Information about cancer services**

1. Could you tell me what happened after you were given the diagnosis?  
(Probe: Did you have treatment? Who attended you? What were the services like? How did you find the health care professionals? Did you have adequate information about your treatment and cancer services?)
2. How did you find/have you found the cancer care services?  
(Probe: Were your expectations met? How were they not met?)
3. What kind of services would have been more helpful to you?  
(Probe: If you had that kind of help you would have felt better; they could be information or practical help of other services.)
4. Looking back on your experience, what would you suggest to improve the cancer services?

### **Coping**

1. In your own words, could you tell me how you felt you have coped with the situation?  
(Probe: Did you have to cope with it on your own? If not, what have helped you most? Who have helped you most?)
2. Having cancer can be a difficult experience, thinking back on your previous life experience, you might have had to deal with very stressful situations or traumatic events, how did you cope with the situations at the time?  
(Probe: Had health problems in the past? Family/friends had been seriously ill or died? Lost partners through separation/divorce/death? Migrated from another country?)
3. If you had a friend facing the same issues as you, what advice would you give her/him?
4. What do you think about the future?

Thank you for talking to me. Is there anything else that you want to ask?

## **Second Interview – Questions Guide**

### **Changes**

1. Are there any changes with regards to yourself and your condition since the last time we talked?  
(Probe: How do you feel now compared to when we last talked? What do you think of the cancer services now? How are you coping?)
2. How is your family coping now?

### **Future**

1. How do you see your future?

### **Clarification of the issues raised in the last interview**

1. Ask the interviewee to clarify some of the issues they have raised in the last interview.

## Appendix B - Description of Sample Characteristics – Chinese Participants

<b>Chinese Participants</b>	<b>Interview (n=24)</b>
<b>Gender</b>	
Male	7
Female	17
<b>Age</b>	
< 50 <sup>1</sup>	
50-59	12
60-69	8
70-79	4
80-89	0
<b>Median age</b>	60
<b>Mean age</b>	61.4
<b>Number of people from</b>	
Sheffield	Total = 6 (F = 4 , M= 2 )
Manchester	Total = 14 (F = 12 , M = 2)
London	Total = 4 ( F 3 = , M = 1 )
Plymouth	Total = 0
<b>Marital status</b>	
Married	15
Single	0
Co-habiting	1
Separated	0
Divorced	3
Widowed	5
<b>Perceived ethnic origin</b>	
British Chinese	5
Hong Kong Chinese	12
Mainland Chinese	5
Malaysian Chinese	2
Singapore Chinese	0
Vietnamese Chinese	0
<b>Place of birth</b>	
Hong Kong	14
Mainland China	5
Malaysia	2
Singapore	0
Vietnam	2
Macau	1
<b>Length of stay in UK- years</b>	
< 10	3
10-20	1
21-30	6
31-40	9
41-50	5

(Appendix B cont...)

<b>Chinese Participants</b>	<b>Interview (n=24)</b>
<b>Perceived general health</b>	
Excellent	1
Very good	4
Good	10
Fair	9
Poor	0
<b>Chronic illness</b>	
Diabetes	1
Hypertension	3
Hypertension & diabetes	2
Hypertension & high cholesterol & Hepatitis B (Carrier)	1
None	17
<b>Religion</b>	
Buddhism	9
Christian	3
Catholic	3
None	8
Not declared	1
<b>Present/past occupation</b>	
Professional	5
Food/catering	17
Housewife	1
Not declared	1
<b>Preferred Spoken Language</b>	
Cantonese	19
Mandarin	0
Hakka	0
ToiSan	0
English & Cantonese	4
Cantonese & ToiSan	1
<b>Perceived level of reading in English</b>	
Very good	2
Good	1
Average	5
Not good	7
Very poor	9
<b>Perceived level of speaking in English</b>	
Very good	2
Good	1
Average	7
Not good	4
Very poor	10

## Appendix C - Description of Sample Characteristics – ‘White’ British Participants

<b>‘White’ British Participants</b>	<b>Interview (n=47)</b>
<b>Gender</b>	
Male	17
Female	30
<b>Age</b>	
< 50 <sup>1</sup>	
50-59	
60-69	17
70-79	19
80-89	9
90-99	2
<b>Median age</b>	74
<b>Mean age</b>	73.7
<b>Number of people from</b>	
Sheffield	Total = 14 ( F= 13 , M = 1 )
Manchester	Total = 13 ( F = 7, M = 5 )
London	Total = 15 ( F = 4 , M = 11 )
Plymouth	Total = 5 ( F = 5, M = 0 )
<b>Marital status</b>	
Married	27
Single	1
Co-habiting	0
Separated	0
Divorced	6
Widowed	13
Others	0
<b>Perceived ethnic origin</b>	
‘White’ British	28
British	5
English	7
‘White’ English	5
‘White’ Welsh	1
Irish	1
<b>Place of birth</b>	
Country England	41
Ireland	1
Scotland	1
Wales	1
Abroad	3
<b>Length of stay in UK- years</b>	
< 10	1
10-20	0
21-30	0
31-40	1
41-50	
51-60	3
61-70	18
71-80	14
81-90	9
91-100	1



(Appendix C cont.)

<b>'White' British Participants</b>	<b>Interview (n=47)</b>
<b>Perceived general health</b>	
Excellent	1
Very good	6
Good	13
Fair	17
Poor	10
<b>Chronic illness</b>	
Hypertension	4
Hypertension & diabetes	1
Diabetes & Hypertension & other problems	1
Arthritis & hypertension	2
Diabetes & Arthritis & chronic rhinitis	1
Arthritis & asthma	1
Heart diseases	1
Heart problem & asthma	1
Heart problem, kidney, epilepsy	1
Rheumatism/arthritis & stroke	1
Rheumatism/arthritis	6
Stroke	1
Breathing problems	1
Fibromyalgia	1
Cystic Fibrosis Alvelolitis	1
Sjorgren's disease	1
Nerve pain	1
None	21
<b>Religion</b>	
Christian (Church of England)	32
Church of Scotland	1
Catholic	7
Buddhism	0
Jewish	1
None	6
Not declared	0
<b>Present/past occupation</b>	
Professional	4
Managerial	5
Office work (secretary, admin, finance etc)	8
Skilled worker	7
Semi-skilled worker	8
Own business	3
Manual worker	1
Civil servant	1
Housewife/househusband	6
Volunteer at cancer care centre	2
Not declared	2
<b>Spoken Language</b>	
English	45
English & French	2