

VOLUME ONE

THE DOCTOR, THE OLDER PATIENT AND THE UNMET NEED:

**The Effect of a Patient Centred Approach on
Unmet Needs in Older Adults**

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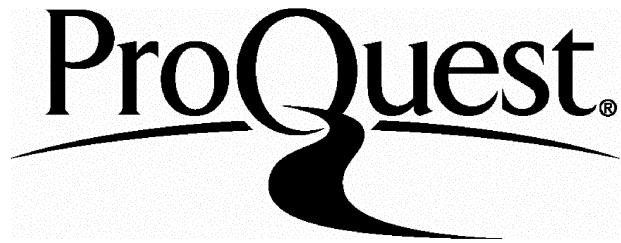
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ABSTRACT

Many older people in the UK have unmet health and social care needs, despite being the most frequent users of primary health care services. Older people may not seek help for reasons of withdrawal, resignation, and low expectations, but no study to date has investigated why many needs remain unmet even after people have seen a doctor. There is some evidence that the communication style and content of the consultations between doctors and older patients is different to that with younger patients, which may impede the identification and treatment of needs. The purpose of this study was to investigate the effect of a general practitioner's "patient centredness" (a widely advocated approach to consultation style) on unmet needs in older adults, and resultant reports of satisfaction.

78 participants over the age of 65 were recruited from two South London general practice surgeries to participate in this study, with 67 completing the follow up interview. The participants were interviewed before and after their meeting with the general practitioner. After the consultation they completed questionnaires of their perception of the doctor's patient centredness and their satisfaction with the consultation. The Camberwell Assessment of Need for the Elderly was administered by semi-structured interview. Patient centredness was significantly associated with satisfaction, but not unmet need. Half of the sample had at least one unmet need after they had seen a doctor, yet almost all of this group said that the consultation had met their needs. The most common unmet needs were for information, sensory difficulties, and help with benefits. These findings have implications for older people's apparent acceptance of unmet need, and the extent to which they can play an active role in their health care if they have an unmet need for information.

CHAPTER ONE

INTRODUCTION

"I've gone to other doctors, and they're very cold and they don't...I like to give suggestions to doctors. Because I know my body and they don't. My doctor will say, 'Well, what do you think it is, Louise? How do you feel? How does it react?' Whereas, I've gone to other doctors and they don't -- well I'm just like a stick there, they just say -- 'well, this is it, I can't do it, I don't know anything about it.' It's just, it's a different thing, it's hard to explain. But my doctor is a person, with feelings, compassion. And because you're old, you still want someone to have feeling and compassion for you."

Louise Di Virgilio, 2003

1.1 OVERVIEW

Older people make substantial use of the National Health Service. Yet, the NHS is facing a crisis with an aging population making increasing demands on limited resources. In order to successfully meet this demand it is imperative that health care provision for older adults is of good quality, accessible, and efficient. General Practitioners are at the frontline of health care provision, seeing more people over the age of 65 than any other age group. As well as the services provided in primary care, GPs are also the gatekeepers for access to other health services so they play a vital role in ensuring that older adults have access to health care from which they might benefit.

The purpose of this study was to examine the efficacy of the General Practitioner - older patient consultation. Specifically, the aim was to investigate how a doctor's "patient centred" communication style with an older patient in a particular consultation might be reflected in the outcomes of that consultation. The outcomes measured were the

patient's subjective beliefs about whether the consultation had met their needs, their satisfaction with the consultation, and whether they had any unmet needs remaining after the consultation, as measured by a standardized assessment tool.

This chapter begins with an overview of the healthcare needs of older people and the challenges facing the NHS to meet those needs, followed by a discussion of the met and unmet needs of older people. The importance of the general practice consultation and doctor-patient communication is considered, and the rationale for a patient centred approach is presented. The concept of patient satisfaction, both generally and for older adults is presented and the hypotheses and aims of the present study are outlined.

1.2 OLDER PEOPLE AND THEIR HEALTHCARE

Aging is one of the most important issues of our time. People are living longer than ever before and the world's population structures are changing. People over 60 currently constitute a fifth of the UK population and this is predicted to grow to a third by 2030 (Tonks, 1999). However, longevity has its drawbacks and with aging comes an increasing number of health problems, many of them chronic. In the General Household Survey (1996; cited in Age Concern, 1998), more than half of all people over the age of 65 reported having a long-standing illness, many of whom said that it limited their lifestyle. This increase in breadth and complexity of physical problems with age leads to a greater need for, and use of health services. Currently, older people account for around 42 per cent of NHS expenditure (Age Concern, 1996) and this figure looks set to rise with an aging population. Yet, despite their high rates of use of health services, older

adults are often excluded from clinical trials and studies examining the use of health services (Avorn, 1997). It is clear therefore that the health of older people and their requirements for health and social care are increasingly important issues throughout the world (Greengross, Murphy, Quam et al., 1997).

If the National Health Service is to adapt to serve an aging population, the issue of age discrimination must be addressed. Historically, older adults have often not received the best possible care in the NHS because of their age, a fact that has been acknowledged by both the Royal College of Physicians and the Medical Research Council. In a recent survey of almost 3000 doctors around half of GP's said that they considered a patient's age when deciding whether a patient should receive treatment (Age Concern, 1999). The charity Age Concern recently published a survey reporting that one in 20 people over the age of 65 had been refused treatment, and one in ten had been treated differently since the age of 50 (Age Concern, 1999). Rationing of NHS services and treatments on this basis of age is widespread, despite both the Patient's Charter and the General Medical Council recommending that health care should be provided on the basis of clinical need rather than any other factor, including age or perceived economic worth.

As the poor treatment of some older adults in the NHS becomes known (Warnes, 1997), the debate has begun on how the NHS can best meet the challenge it faces. The charity Age Concern continues to lobby for legislation to outlaw age discrimination and steps have been taken to redress the imbalance of research about older people (Tonks, 1999). In 2001 the current government introduced the National Service Framework for Older People (Department of Health, 2001), a policy document which set out guidelines and targets for care of older people by the NHS. The aim of the NSFOP was to increase

standards of care and ensure that older people received the most clinically appropriate treatment, regardless of age, across the country. In highlighting older adults, we must take care not to consider this age cohort as a homogenous group as this raises important issues about segregation, stigmatisation and stereotyping. However, this study will discuss people over the age of 65 in general terms for practical purposes with this caveat in mind.

1.3 NEEDS OF OLDER PEOPLE

Studies have shown that comprehensive assessment and treatment of needs in older people can not only improve functioning, but can also prevent admission to hospital and delay admission to residential care (Stuck, Aronow, Steiner et al., 1995). However, there is evidence emerging that even when older people seek help for their problems from their GP, their needs sometimes remain unmet (Walters, Iliffe & Orrell, 2001). With the current drive to address inequalities in healthcare for older members of the population, tackling the problem of unmet needs in this age group should be a priority. In this section, I shall discuss how a need might be defined and assessed, present the research findings on what the most common unmet needs in older adults are, and why they might exist.

1.31 Defining needs

Certain needs have been assumed to be universal in humans (Maslow, 1954) with different subsections of the population having additional specific needs e.g. older people

with dementia have the same needs as everyone else along with additional needs relating to their disability (Murphy, 1992). The concept of an individual need has been defined using various terminology and a consensus on the definition of need is not readily apparent (Phelan et al., 1995). It is possible that the disparity within the literature concerning the definition of need is due to the differing backgrounds and frameworks of the various disciplines that use the term.

There are currently two main ways of defining need (Hamid, Howard & Silverman, 1995). One is to define need as equivalent to any disturbance in health and wellbeing (the 'humanitarian' approach) and the other is to define need in terms of the available resources (the 'realistic' approach) (Hamid et al., 1995). Holland (1983) defines need for healthcare as the requirement for preventative, curative and rehabilitative care which arises from disturbance of health as defined by health professionals. This resource definition gives rise to the concept of problems without a corresponding need. If nothing can be done then there is no need e.g. the absence of literacy skills may not be a need if nothing can be done due to the severity of a learning disability (Brewin et al, 1988). Brewin's (1992) definition which draws the two approaches together refers to lack of health, lack of access to services or lack of action by lay or professional health workers. By defining needs in terms of how an individual's ability compares to a standard population of his or her peers, a need exists when an individual does not have what others of the same age or circumstances have (Brewin, Wing, Mangen, et al., 1987). By defining needs in terms of available resources, we are able to separate needs into those that are presently being met and those that are not being met (Reynolds, Hancock & Orrell, in press). In the present study, need is defined according to whether an intervention exists

to at least partly meet that need (Martin, Pherson and Orrell, 1999). It is important to remember that need is different to illness or disability since a diagnosis of any kind does not automatically imply a need for treatment or intervention, nor is it a good predictor of service use (McCrone & Strathdee, 1994).

An individual's need for health or social care can either be defined by the person themselves, or those involved in their care such as professionals, carers or family members. There are several different ways in which needs can be conceptualised and these vary according to how need is defined, which populations are included, and from whose perspective need is considered. Bradshaw (1972) classified needs into normative need (what professionals define), felt need (what the individual would like), expressed need (what individuals demand and use) and comparative need (differences in service provision between one area and another). Patients may have priorities and views about their needs that differ from professionally defined need (MacCarthy, Benson, Brewin, 1986; McEwan, 1992). Carers may hold a different view and studies have supported the usefulness of both personal and professional viewpoints. Professional assessment of need is important, as people may not recognize they have a mental health problem, particularly those with cognitive problems, psychosis or substance misuse. People may also not realize that they have a physical health problem, such as high blood pressure. These differing perspectives on what an individual may need are required because the definition of what a need is, is somewhat subjective and communication barriers may pose obstacles for assessing the individual themselves.

GPs and Clinical Psychologists are concerned with both normative and felt need in their daily practice. A GP has within their remit a responsibility for treating or

referring on the full range of a patient's health needs, so it can be suggested that although they will consider felt need, they will be more concerned with normative need, as medically defined. A Clinical Psychologist, however, whose remit may be only to address emotional distress and behavioural problems, might be more concerned about felt need, although may keep in mind the impact of other unmet needs on the patient, and inform other services appropriately. In this vein, the clinical psychologist might define a need as being something that the person or carer identifies as being a problem, for which there is some intervention possible.

1.32 Assessment of need

Recent government legislation has emphasised that needs assessment should include both normative assessment of need by professionals and the individual's felt need and a greater emphasis on care services which are person-centred rather than service-centred, has led to a change in the way an individual's needs should be assessed (Department of Health, 2001).

In community surveys it has been found that needs assessment procedures were better than diagnostic procedures in assessing need for psychiatric treatment (Bebbington, 1990). Furthermore, the Medical Research Council recommended the use of needs based approaches in its review on the health of older people in the UK (MRC, 1994). The emphasis on needs based allocation of services has been influenced by the current climate of health care rationing and evidence-based costing of care, as research has shown that individual need is closely related to health outcome (Reynolds, Hancock & Orrell, in press). Government legislation has reflected this change in emphasis for needs based

assessments, with Standard One of The National Service Framework for Older People stating that NHS services will be provided, regardless of age, on the basis of clinical need alone (Department of Health, 2001).

An individual assessment of need should be based on an appropriate assessment tool and should lead to an effective intervention that goes some way to meeting that individual's specific needs (Hughes, Stewart, Challis, et al., 2001). It should also be used to evaluate planned interventions and determine whether they have been successful in meeting the person's needs (Reynolds, Hancock & Orrell, *in press*). This type of assessment should also be used to monitor the intervention provided as individual needs can change over time, and allocation of resources must be monitored. In a research capacity, the tool should be suitable for use as an outcome measure. Properly targeted assessment may reduce demand for services through assessing needs more accurately and by ensuring services remain appropriate to needs (Stuck, Siu, Wieland, et al., 1993). Research on the use of services by older adults has shown a mismatch of needs and provision of services arising from a failure to assess need using the patient's own perceptions (Johnson & Challice, 1983, cited in Iliffe, Haines, Gallivan et al., 1991).

1.33 Needs Assessment Tools

There have been criticisms of some needs assessment measures due to the limited range of needs they cover, imprecise definitions and different methods yielding different results (Baldwin, 1986). Many needs assessment tools were designed with only local one-off use in mind, and often lacked reference to theory (Reverie, Berkowitz, Carter et al., 1996), but the Camberwell Assessment of Needs for the Elderly (CANE: Reynolds,

Thornicroft, Woods, et al., 1998), used in the present study, was specifically designed to comprehensively measure the multiple needs of individuals over 65 years old. It is comprehensive in its coverage of general human needs as well as those specific to mental health and older people. Information about social and practical needs as well as health needs is important because these are often interlinked. The CANE distinguishes between met and unmet need and is intended for use in all settings, from the community to hospital wards. It incorporates staff, patients' and carers' views of needs and has good reliability and validity (Reynolds, Thornicroft, Abas, et al., 2000).

1.34 Common unmet needs in older adults

Studies of unidentified need in older people living in the community have consistently highlighted the under-detection of the needs of this population (Williamson, Stokoe, Gray et al., 1964; Iliffe, Haines, Gallivan et al., 1991; Brown, Stewart, McCracken et al., 1997; Walters, Iliffe, Orrell, et al., 2001). Despite research into service innovation and subsequent government guidelines to encourage identification and treatment of unmet needs in older adults in primary care settings, unmet needs remain. With the increasing number of older people continuing to live longer in the community (Chester & Bender, 1999), it is important to understand what this population's unmet needs are, and how they are best addressed.

Epidemiology studies of unmet need in people over the age of 65 have focused on different sub-groups and used differing methods of assessment, resulting in different findings. One study of older people with a physical disability found that 35% had at least one unmet need, often for help with incontinence (Manton, 1989). Another study of

people over the age of 60 in sheltered accommodation found that 60% of the people interviewed had at least one unmet need, as measured by the CANE (Field, Walker & Orrell, *in press*), the most common being mobility, sight and hearing, company, information regarding treatment and psychological distress.

Brown et al. (1997) reported that almost half of the nearly 2000 patients invited to their GP for an over-75's health check reported a "problem", commonly "physical" (41%), "hearing and vision" (18%), and "mobility" (16%) problems. The authors suggested that a more functionally based assessment would have highlighted more functional and sensory problems. A strength of this particular study was the observation of naturalistic case finding but only a small proportion of assessments were carried out by GPs, although they found that GPs were significantly more likely to detect problems than any other practice health professional. The authors claimed support for case finding in the over-75s, due to the high proportion of problems detected, and the fact that action was taken in 82% of cases.

Another large-scale study randomly identified people over the age of 75 from several GP lists (Iliffe et al., 1991) for detailed home assessment of their needs. Nearly two thirds of participants had initiated contact with their GP during the preceding three months, yet up to 30% of their sample warranted further assessment of depression or cognitive impairment. A smaller qualitative study of older people in the community also found high levels of unmet need as measured by the CANE (Walters, Iliffe, See Tai et al., 2000). 60% of older people had one or more unmet needs, most frequently unresolved problems with 'eyesight/hearing', 'psychological distress', 'incontinence', 'company', and 'information on condition or treatment'. There was varied agreement between older

people and their carers or health professionals involved in their care, with 73% of carers identifying an unmet need, most frequently with ‘mobility’, ‘eyesight/hearing’ and ‘accommodation’. Health professionals had different views to their patients about their unmet needs, most frequently identifying unmet needs with daytime activities, accommodation and mobility. This study also found a high level of unmet need amongst older people who had attended primary care (Walters et al., 2001). The participants in this particular study had sought help from their GP for only 9.6% of the total number of unmet needs identified. Participants and carers were more likely to seek and be offered help for mobility problems than other types of problems such as incontinence, eyesight, psychological distress, memory, accommodation and company.

A recent innovative study involving patients, voluntary organizations for older people, community organizations of older citizens, general practitioners and community nurses, reached a consensus of the most frequently unmet needs of older people living in the community (Iliffe, Lenihan, Orrell et al, in preparation). This study used a mixed methodology of face-to-face interviews using the CANE, postal questionnaires and focus groups, with synthesis and interpretation of results through a consensus conference and a Delphi process involving primary care professionals. They found that five domains of unmet need were identified by the different methods: ‘Senses’, ‘Physical ability’, ‘Incontinence’, ‘Cognition’ and ‘Emotional distress’.

1.35 Identification and Interventions for Unmet Needs

Need for health care means that need for particular interventions can be translated into service equivalents (Donabedian, 1974) so identification of unmet need can lead to the

provision of an appropriate intervention (Slade, Leese, Taylor et al., 1999). Studies of assessment and treatment of older people's unmet needs in primary care can have wide reaching implications, both for quality of life and allocation of resources.

Hendriksen, Lund & Stromgard (1984) found that routine assessment of a group of over 75s in a Copenhagen suburb every three months resulted in a reduction in admission to hospital, a decrease in mortality and an increase in patient confidence. Although the findings were impressive, the level of input required to achieve the same results in routine practice would be unreasonably high. A less intensive approach was investigated by Vetter, Jones & Victor (1984) who conducted a randomized controlled trial examining the effect of health visitors working with patients over the age of 70 in General Practice. They found that annual unsolicited visits to all of their caseload demonstrated a reduction in mortality and an improvement in the patients' own perceived quality of life, as well as an increase in the number of social services made available to, and used by, older people.

Pathy, Bayer, Harding et al. (1992) conducted a three year randomized controlled trial of a case finding and surveillance program based on a self-reporting, functional screening postal questionnaire in the over 65's. In this study, participants who returned their questionnaires highlighting problems were visited by the health visitor and given practical advice, health education, and / or a referral to a GP or community services. It was found that the intervention group participants who were followed up had significantly lower mortality rates than the control group. These were attributed to the clearer identification of health, social, and financial problems and the responses to them and in better social support. They also found a shorter duration of hospital stay among

“younger” older adults (65-74), which they attributed to the resolution of social and domestic problems that prolong hospital admission, as well as fewer home visits by GPs and improved self-rated health status. Interestingly, in their study they found that many differences between the intervention and control groups were present in the ‘young old’ suggesting that arbitrary exclusion of the 65-74 age group from over-75 screening programs was not justified. This study was both methodologically rigorous and employed a functional screening assessment. The use of a two-stage model of screening by postal questionnaire followed by direct contact only with those having unexpected problems which might be amenable to intervention was also more realistic than other studies.

A recent meta-analysis of the literature found that preventative home visitation programs appear to be effective in preventing nursing home admission and functional decline in older adults (Stuck, Egger, & Hammer, 2002). Interventions appear to be most effective when based on multidimensional geriatric assessment and benefits in survival are seen in young-old rather than old-old populations. This lends further support to the notion proposed by Pathy et al. (1992) that the arbitrary exclusion of the 65-75 age group is unjustified from screening programs.

1.36 Factors associated with unmet needs

I have examined what the most common unmet needs are in people over 65 living in the community, and the benefits of identifying and addressing those needs. But there still remains the question of why these needs are not met by routine health and social care as it currently exists.

Walters et al. (2001) explored the perspectives of older people and their carers on perceived barriers to meeting needs. Participants in their study had only sought help for a quarter of the needs identified. The reasons people gave for not seeking help were contained in the themes of 'withdrawal' (isolating oneself from society in preparation for dying), 'resignation' (feeling resigned to one's situation and therefore not seeking help for identified problems), and 'low expectations' (a view of there being little point in seeing the doctor because nothing could be done). They found this last theme was particularly evident for psychological distress, which was also found by a previous study where older people did not perceive psychological problems as having anything to do with the doctor (Farquhar, Bowling, Grundy, et al., 1993). Walters et al. (2001) also found that participants minimized some problems, especially incontinence (the most common unmet need), or they attributed them to age-related changes, especially memory problems. A recurrent barrier to seeking help was lack of information or access to services. This study also explored how older people's perceptions changed when help had been offered or sought. They found that the themes were very similar to those who had not sought help, but there was also a perception that services were rationed and in some cases that help had been denied due to a patient's age. Walters et al also reported that some perceived needs could not have been met by current service provision and that in some instances help had been declined due to the dominant themes of resignation, withdrawal and low expectations.

An individual may not seek help because of beliefs they hold about illness and coping. Willingness to seek and accept help has been shown to be influenced by age itself, as well as ethnicity (Schultz, 1997; Tennstedt and Chang, 1998). There is some

evidence of older adults associating illness with "a lack of moral fibre" (Williams, 1990; Wenger, 1988) and it is possible that some older people minimize their health problems in order not to fulfill the negative stereotype of old age (Wenger, 1988; Sidell, 1995).

Poor agreement between patients and health professionals about their needs has been shown to impact upon intervention (McEwan, 1992; Walters et al., 2001). Older adults in one study needed more help with daily living than professional services allowed for (Farquhar et al., 1993), but what needs are assessed and met can be dependent upon the profession of the assessor (Brown et al., 1997). It has been suggested that in primary health care services it is functional loss that has been traditionally unmet, rather than undiagnosed medical problems (Taylor & Buckley, 1987). As mentioned previously, monitoring of older people's use of health and social services is important, as it has been found to change with age, usually increasing, as health and functional ability decreases (Farquhar et al., 1993).

Research into why older people do not seek help for unmet needs remains equivocal. Walters et al. (2000) did not find any single overarching theme to explain this behaviour which applied to all cases. This finding is supported by anthropological evidence that older adults hold a wide range of attitudes and beliefs that are not homogenous (Wenger, 1988). Another factor that could be associated with unmet needs in older adults is that there has been an inadequate or narrow assessment of their needs by the statutory services involved in their care. This could be either when they have sought help specifically, or when they have had an annual review or check up such as the over-75's health check. It could also be that they have not been assessed at all, and have not sought help themselves for the reasons stated above.

The NSFOP states that whenever older people attend primary care, health professionals should be aware that they might have needs beyond their immediate problem. It says that front line professionals should explore whether these further problems exist through questions that may be asked at first contact. A busy general practitioner is most likely to follow this recommendation if he or she is provided with measures to use that have proven effectiveness in identifying important unmet needs. The CANE is ideal for this purpose and a new short form is being prepared specifically for use in general practice (Iliffe et al., in preparation).

It is important to recognize that factors associated with older adults' unmet needs may change in years to come. The current cohort of people over the age of 65 was all born before the start of the Second World War, when the National Health Service did not exist. These are people who have lived through tremendous social change whose attitudes towards aging and individual needs, as well as their rights to healthcare, may differ significantly from people who will be 65 and over in even just ten years time. We do not yet know what the attitudes of the "baby boomers", all born after world war two, will be towards their own aging and their right to health care, but it can be hypothesized that they will be more demanding of the national health service and may have a clearer understanding of what a doctor can help with. It can also be hypothesized that the next generation of doctors will be better educated about common problems associated with aging and common unmet needs in older adults.

1.37 Summary

Research into effective investigation of needs in older people is vital in modern health

care, with the emphasis of a whole system approach to match services with needs (Department of Health, 2001). The research into unmet needs in older adults to date has consistently identified a range of health and social care unmet needs and has found that identification and intervention of these needs can lead to significant health outcomes. How realistic some of these approaches are though is debatable. This current study aims to examine how the consultation process for older people who attend their GP might be related to needs not being met.

1.4. THE GENERAL PRACTICE CONSULTATION

Many factors may influence the expression of need by the patient and identification of need by the doctor but the most important is the communication process. Hampton, Harrison, Mitchell et al. (1975) posit that information given by the patient is more important than physical examinations in achieving an accurate diagnosis. Therefore, when investigating why some older adults who seek help do not have their needs met in primary care, an examination of the consultation process is crucial.

Addressing older adults' unmet needs is also an issue of quality of care in general practice. As the front line of the health service and the provider of 90% of formal health care, primary care has a key role to play in developing an equitable health service, responsive to the needs of older adults. Reducing inequalities in health care provision and improving the quality of primary care through reducing unacceptable variations in provision have been central and recurring themes of present government health reforms (Campbell, Ramsay, & Green, 2001)

In this section I will present a summary of the current literature on communication between GPs and older patients. By considering the characteristics of these interactions I will explore the possible reasons why older people do not have their needs met by primary health care services. I will also present some of the difficulties involved in asking patients to evaluate their health care.

1.41 Characteristics of the GP-older patient consultation

The history of doctor-patient communication research goes back to Hippocrates and there is a vast amount of literature on this topic. However, only a relatively limited amount has been written about communication between doctors and older patients (Mann, Sripathy, Siegler et al., 2001; Beisecker, 1996), despite a well-documented under-detection of older adults' needs in primary care (Iliffe et al., 1991, Brown et al., 1997), and the fact that older people use primary healthcare services more than any other age group (McNiece & Majeed, 1999).

Older patients often have more sensory difficulties, functional limitations, and complex medical problems than younger patients (Mann et al., 2001). As the health status of a patient has been shown to impact upon the interactional dynamics of the doctor-patient consultation, it may be that an older patient's poorer health status affects the treatment they receive. Balint (1964) believed that the doctor's response to the patient is the major factor in terms of the effectiveness of the doctor. Doctors appear to take a more task-focused approach to sicker patients and appear more attentive to medical and psychosocial concerns, although they are less likely to engage in nonmedical social conversation (Hall et al, 1998). Communication problems between doctors and patients

may arise as a result of doctors focusing on diseases and their management, rather than people, their lives and their health problems (Lewin, Skea, Entwistle, Zwarenstein & Dick, 2001).

It could be argued that as a result of this increased level of need, doctors should spend more time with their older patients, but some studies have found that doctors actually spend less time with their older patients, (Radecki, Kane, Solomon et al., 1988; Keeler, Solomon, Beck et al., 1982) and it has been suggested that this is why older people visit their doctor more. In a large scale study of over 500 consultations, doctors were found to spend the same amount of time with older women as younger women, but more time with older men than younger men (Mann et al., 2001). In another large study, Callahan et al. (2000) found that doctors spent more time with older patients than younger ones. The relatively young age of the doctors in this sample, in comparison to studies that found shorter consultation times, may reflect a different attitude towards older adults. Shorter consultation time and less psychosocial discussion are thought to be subtle expressions of ageism, but this was not found in the data examined by Mann et al.(2001), again, possibly due to the relatively young doctors in the sample (mean age was 34). Supporting the conclusion that doctors do not spend less time with older adults was the finding that doctor satisfaction did not change with age, regardless of gender of the patient.

The content of the consultation is another area where older patients may be treated differently to younger patients. Doctors have been shown to raise significantly more medical topics and fewer psychosocial topics with older patients than with younger patients, and be less responsive to psychosocial topics raised by older patients (Greene,

Hoffman, Charon et al., 1987). The same authors, in a later study, found that doctors provided more information to younger patients (Greene, Adelman, Friedmann et al., 1994). Callahan et al (2000) found that older patients experienced more chatting in their visits, they were given less counseling, asked fewer questions, had less discussion about their families and use of substances, were asked to change their health behaviour habits less often, and were given less health education. More of each visit was spent checking on compliance with earlier treatment than for younger adults. These findings fit with the evidence that it is usually functional or psychosocial needs that are missed in older patients (Stuck, Siu, Wieland et al., 1993).

So why might these differences exist? Older patients may have different expectations of the role of doctors and the role of patients in the medical encounter than younger patients (Haug, 1996) and they may be less likely to challenge the authority of the doctors than younger patients (Haug & Ory, 1979). Older patients may want different things from their GP than younger adults, both in terms of content as well as style. It may be that rules of social interaction with older people mean that doctors are not too personal with them and it has been argued that differences in the consultation process between younger and older adults reflect poorer quality healthcare for older people (Callahan et al., 2000). Yet it is well documented that older people evaluate their medical care more positively than younger adults, in terms of both general evaluations (Campbell et al., 2001) and satisfaction (Breamhaar Vissar, & Kleunen, 1990; Greene et al 1994). However, it must be considered that the older adults' expectations of the roles of the doctor and the patient in the medical encounter will probably change over time as the

next generation of over 65s will have had markedly different experiences and expectations of healthcare to the current cohort.

1.42 Patients' assessments of health care

Patient assessments of primary health care have been reported to be the most direct way of measuring communication and interpersonal care and patient evaluations have been shown to be related to outcomes of primary care such as compliance with medical advice and treatment (Campbell et al., 2001).

One large-scale study of patients' evaluations of primary health care found that older people reported significantly more favourable impressions for all the dimensions examined on the General Practice Assessment Survey (GPAS) (Campbell et al 2001). The authors suggested that higher morbidity and consulting rates among older patients may mean that older people have more contact with primary care services and thus have more opportunity to be favourably influenced by the services provided. This may also reflect cultural differences in willingness to report unfavourable assessments among older patients. But actual differences between the youngest and oldest age groups were substantial. Higher morbidity and consulting rates among older patients may mean that this group may have more contact with their GP and thus have more opportunity to be favourably influenced by the services provided. Alternatively, younger patients may be perceived as somehow having less legitimacy in using primary care services and this may be communicated to, or perceived by, such patients.

It is now widely recognized that there is a need for rigorous methods, other than clinical conversations, to elicit patients' views on such matters as treatment decisions and

quality of care received (Fitzpatrick 1991; Cleary, 1999). Much effort has been devoted to developing and evaluating survey measures that elicit reports about specific care experiences that reflect quality of care, not amenities . This information should not be used to criticize but to educate and inform GPs and consumers and to focus and to facilitate quality improvement efforts (Cleary, 1999).

A systematic review of the literature on patients' priorities for general practice care was conducted as part of a project by the European Task Force on Patient Evaluations of General Practice (EUROPEP) (Wensing 1998). The most highly rated aspect of care was "humaneness" then "competence/accuracy", "patient's involvement in decisions" and "time for care" (Coulter, 2002).

Similar themes have been identified in other studies using different methods. Carroll Sullivan, & Colledge (1998) found that patients in Scotland placed greatest importance on having a "doctor who listens and does not hurry me" and provision of information and opportunities for participation feature highly in most studies of patient satisfaction or dissatisfaction (Coulter, 2000).

Wensing and Elwyn (2002) suggest that collecting the views of service users has been a recent development of society but it has only been over the past decade that the healthcare sector has identified methods for assessing the views of patients. They said there are different dimensions to patients' views – preferences, evaluations and reports, of which evaluation can be conceptualized as a cognitive process in which specific aspects of care are assessed, while satisfaction refers to an emotional response in the whole experience in health care.

In summary, consultations between GPs and older adults have been shown to differ from those with younger people. It appears that the content of the consultation is often different, probably due to several factors including older people's generally poorer health and the impact of social rules and expectations between younger doctors and older patients. This style of interaction may contribute in part to the under detection of older people's needs in primary care.

1.5 PATIENT CENTREDNESS

There is growing evidence that quality of clinical communication is related to positive health outcomes (Stewart, Brown, Donner et al., 2000). Effective doctor-patient communication has been shown to have a positive outcome on emotional health, general functioning, and even biomedical measures such as blood pressure and blood sugar level (Stewart, 1995; Henbest & Stewart, 1990; Henbest & Fehrsen, 1992). Recent research on doctor-patient communication has focused on the concept of a “patient-centred” approach by the doctor.

There are several reasons why patient centredness is an important variable to consider when investigating outcomes of the general practice consultation for older adults. Firstly, patients who are well informed about prognosis and treatment options, including, potential harm and side effects are more likely to adhere to treatments and have better health outcomes (Mullen 1997). Secondly, older people have diverse needs that encompass functional as well as physical domains, and, there is some evidence to suggest that a GP's communication style with older people is not patient centred from the evidence presented (Callahan et al., 2000). Discussing more medical topics and fewer

psychosocial topics does not help the doctor understand the illness experience, or understand the whole person. Giving less information to older people would not encourage the finding of common ground regarding management, nor would it aid prevention or health promotion. The provision of information to and involvement of the patient is at the heart of the patient centred approach to health care (Coulter, 2002). If doctors are ignorant of patients' values and preferences, patients may receive treatment that is inappropriate to their needs.

Evidence supports the shift towards shared decision-making in which patients are encouraged to express their views and participate in making clinical decisions. While doctors are well informed about diagnostic techniques, the causes of disease, prognosis, treatment options and preventative strategies, patients are also experts about their experience of illness and their social circumstances, habits, behaviour, attitudes to risk, values and preferences. Coulter (2002) suggested that both types of knowledge are needed to manage illness successfully and the two parties must be prepared to share information and make joint decisions drawing on a sound base of evidence. There is also evidence that GPs do not discuss health promotion issues with their older patients as much as with their younger ones, one of the central aspects of the patient centred approach.

The patient centred approach with its emphasis on understanding the whole person would seem to be the ideal way to identify and address the complex interaction of health and social problems that often occur with old age. Such an approach would broaden the general practitioner's areas of questioning and interest, increasing the possibility of detecting psychosocial and functional difficulties. It also may be that if a

patient experiences the doctor taking an interest in the effect of the health problem on their life, they might disclose other difficulties they are having, enabling the doctor to question further and take necessary action. Standard two of the National Service Framework for Older People declared that the care of older people by the NHS should be “person-centred”. It is therefore timely to discuss and evaluate the patient-centredness of care received by older people, and whether it is effective in improving consultation outcomes.

1.51 Defining and measuring patient centredness

The patient-centred model is a widely advocated approach to medical care, although there is little agreement about the exact meaning of the term. This has resulted in a variety of definitions and ways of measuring the concept: as a professional attitude (Grol, De Maeseneer, Whitfield et al., 1990; Howie, Heaney, Maxwell et al., 1992), a set of knowledge (Lipkin, Quill & Napodano, 1994) and in terms of consultation behaviours (Stewart, 1984). Edith Balint (1969) describes patient-centred medicine as “understanding the whole human being” and Byrne and Long (1976) describe a style of consulting where the doctor uses the patient’s knowledge and experience to guide the interaction. Brown et al (1995) identify five main components of the approach: exploring both the disease and the illness experience; understanding the whole person; finding common ground regarding management; incorporating prevention and health promotion; and enhancing the doctor-patient relationship.

If the concept of patient centredness is to be used to evaluate primary care services by assessing the quality of individual doctors’ interpersonal care, the tools used

to measure patient centredness must be both reliable and valid (Heaney, 2001). Recent research comparing three different observation-based measures of patient centredness found differences in construct validity between the measures and low concurrent validity. Mead & Bower (2000) compared a measure on which an observer rated five dimensions of patient centredness, a measure on which “utterances” of doctors and patient were coded, and a measure which focused on the doctor’s overall responsiveness to verbal offers made by the patient (Henbest and Stewart, 1989). This study found that observers’ ratings of patient centredness across all three measures were associated with patient-directed eye gaze. Consultation length, perceived acquaintance of the patient, and GP ratings of the importance of psychological factors were significantly associated with patient centredness for the first two measures. The “utterance” method was also significantly associated with patient’s self-reported psychological health before the consultation, and the observer rating method was significantly associated with GP age. Patient age was not found to be significantly correlated with scores of patient centredness, but the relatively small sample size of adults of all ages (N=55) suggests caution when interpreting these findings. A limitation of this study was that the researchers did not measure the patient’s perceptions of the doctor’s patient centredness, which may have increased construct validity, nor did they measure any outcome variables such as patient health status or satisfaction.

It has been argued that the most valid measure of patient centredness is patients’ perceptions of the consultation (Stewart, 2001). Studies of patients’ own assessments of the quality of communication in the encounter have shown that they are more indicative of health outcomes than observers’ ratings (Stewart, Brown, Donner, et al., 2000)

because only the patient can report whether he or she has felt understood or if she has felt adequately involved in developing a treatment plan (Epstein, 2000).

In one study of both observation of the consultation and patients' perceptions, the patients' perception of the patient centredness of the interaction was the stronger predictor of both health outcomes and efficiency of care, as measured by number of diagnostic tests and referrals (Stewart et al., 1995). Stewart et al. (2000) reported that patients' perceptions of having received patient centred care were associated with better recovery from their discomfort and concern, better emotional health two months later, and a reduction of about 50% in diagnostic tests and referrals. The most important association with good outcomes was the patient's perception that the doctor and the patient had found common ground – it was not good enough to simply explore the patient's experience of illness. They also found that observers' ratings of patient centredness correlated only with patients' perceptions, but not directly with any health outcome, suggesting that asking the patient is the most useful way of assessing this construct in practice.

A recent large-scale UK study by Little, Everitt, Williamson et al. (2001) found that patients' perceptions of the components of a patient centred approach could be measured reliably and predict different outcomes. They assessed patients' preferences for this type of approach and found that people wanted patient centred care which (a) explored the patients' main reasons for the visit, (b) sought an integrated understanding of the patients' world; (c) found common ground on what the problem was and mutual agreement on management; (d) enhanced prevention and health promotion; and (e) enhanced the relationship between the patient and the doctor (Little et al 2001). The

patients' preferences strongly supported the conceptual framework of Stewart et al. (1995). They found that patients wanted a patient centred approach from their GP, and their perceptions of having received components of this approach were associated with greater satisfaction, enablement, and reduced symptom burden (Little et al., 2001). Lower referral rates were also found for patients who felt that they had a personal relationship with their doctor. A particular strength of this study was not only its size, but also its method of gathering data on patients' perceptions of the consultation rather than focusing solely on experts' ratings of observed behaviour (Stewart 2001). Patients' perceptions of the patient centredness of an interaction are a stronger predictor not only of health outcomes but also of efficacy of health care (Stewart et al. 1995).

The literature suggests that better communication in consultations, such as patients being able to express their views and doctors giving information (both components of the patient centred model) result in greater patient satisfaction (Stewart, 1995; Savage & Armstrong, 1990)

The crux of the patient-centred approach is shared decision-making (Weston, 2001, Coulter, 2002). But older patients may not want to be equal partners with their GP, and may prefer the doctor to play a more traditional paternalistic role (Haug, 1996). This may reflect a reluctance to play an active role in their healthcare, which could in part explain why their needs are not being met. But critics have argued that ultimately, being patient centred means taking into account the patients' desire for information and shared decision making and responding appropriately (Stewart, 2001). This translates as doctors responding to the patients' preferences for style of interaction and not having a "one size fits all" approach to communication with older patients.

One of the obstacles to being more patient centered, especially in primary care, is lack of time (Pimental, 2001). Also, patient centred care is not cheap, in terms of staffing time and resources, therefore it is important to find out which elements of the patient centred approach are most important to older adults and which have most impact on outcomes. Interest in the patient centred approach is growing among clinicians, particularly those involved in primary care and training is now required to equip doctors with the communication skills needed to help patients play a more active role (Elwyn, Edwards & Kinnersley, 2000).

In summary, the patient centred approach is based on the idea that the process of healing depends on knowing the patient as a person, in addition to accurately diagnosing their disease (Epstein, 2000). Although it has not previously been specifically investigated in this age group, the concept of patient centredness provides us with a model with which to measure and explore the quality of communication between GPs and older adults. This style of interaction has been shown to be associated with both increased satisfaction and positive health outcomes, and may explain why some older people's needs are not met in primary care.

6. PATIENT SATISFACTION

Over the past decade, consumer satisfaction has gained widespread recognition as a measure of quality in many public sector services (Williams 1994) and has become a legitimate health care goal in itself (Andersen, Racowski & Hickey, 1988). Patient *dissatisfaction* is associated with non-compliance of treatment instructions, delay in

seeking further care and poor understanding and retention of medical information (Wilkin et al., 1992). Many studies have investigated patient satisfaction as an outcome of the medical encounter in order to try and improve the effectiveness of doctor-patient consultations, but there have been few that have specifically examined the satisfaction of older patients (Haug & Ory, 1987). Older people consistently report higher levels of satisfaction than younger patients (Greene, Adelman, Friedmann et al., 1989; Breemhaar et al 1990) but research has not systematically examined why this might be, as it has been suggested that older patients' consistent reporting of higher levels of satisfaction than younger adults does not necessarily indicate a better quality of care (Callahan et al., 2000).

There have been several interpretations to attempt to understand why older people report being more satisfied with their health care than younger adults. Firstly, older people may have lower expectations of their health care (Cohen, 1996). Independent of the actual care received, older patients may be generally more accepting and more reluctant to pass judgements (Hall & Dornan, 1990) or they may have different expectations of the role of the doctor and the role of the patient in the consultation than do younger patients. Secondly, it could be that older patients are being treated in a more responsive manner than younger patients are. These two possibilities are not mutually exclusive Cohen (1996), but the positive satisfaction effects across all health care contexts suggest that the first possibility is the most likely, especially when the high levels of unmet need amongst this population are taken into account. There is also evidence to suggest that increased levels of satisfaction are associated with more direct

and recent experience of healthcare (Calnan, Coyle & Williams, 1994) and with old age comes increasing use of health care.

There has been some suggestion that the positive relationship between age and reported satisfaction with health care, reflects a generational effect. Calnan, Almond & Smith (2003) posit that the passivity of older adults towards healthcare reflects the experience of the generation who grew up before the NHS was introduced. They suggest that those brought up solely under the NHS might have different expectations and experiences and might be less passive in that they take for granted the availability of a comprehensive service free at the point of access (Calnan, Almond & Smith, 2003).

Patient satisfaction has also been found to be closely linked with length of visit as well as age (Gross, Zyzanski, Borawski et al., 1998). The length of time spent with the doctor may be perceived by older people as an indication of the doctor's caring. Mann et al. (2001) found that female patients' satisfaction decreased with age, but male patient satisfaction did not change with age, with older men and women being equally satisfied. This finding suggests that doctors may be failing to address issues of importance to older women.

Greene et al (1994) examined interactional correlates of older adults' satisfaction with an initial visit to the GP. They coded audiotapes of the session and both doctor and patient completed post visit satisfaction questionnaires. They found that older patient satisfaction was positively correlated with doctor questioning and supportiveness on patient-raised topics, both elements of a patient-centred approach. The authors suggested that for older patients, doctors' interpersonal affective style may be more important in determining satisfaction than the actual topics which are discussed during their meeting.

There is evidence that consultation styles that allow patients to express their concerns and in which doctors provide adequate information result in patient satisfaction (Hall, Roter & Katz, 1988; Stewart, 1995) and patient satisfaction has also been shown to be positively and significantly associated with patient centred consultations in primary care (Kinnersley, Stott, Peters et al., 1999). Hall & Dornan (1988) conducted a meta-analysis of studies of consumer satisfaction with medical care and found that the aspects of care most related to satisfaction were "overall quality" and "humaneness". In their study "informativeness" and "attention to psychosocial problems" (elements of the patient centred approach) were poorly associated with satisfaction, but this may have been because they looked at all types of medical interaction. Not just primary care which has a unique role in the healthcare system.

Few studies have compared satisfaction with health outcomes as it is usually measured as an outcome itself (Cohen, 1996), and no studies have compared satisfaction with unmet need. Yet, it can be hypothesized that satisfaction would be related to these variables.

Despite numerous studies of patient satisfaction, there has not been a resultant improvement in consultation quality that many expected (Cleary, 1999). This may be because responses to such surveys are subjective and difficult to interpret because they are complex function of expectations that may vary greatly among patients with comparable care and Williams (1994) has suggested that there is a link between expectations and satisfaction.

Measuring patient satisfaction is an important exercise when determining the quality of care received, and this is especially important for a demographic group such as

older adults, for whom the quality of healthcare provided by the NHS has been called into question.

1.7 HYPOTHESES

The National Service Framework for Older People advocates a person centred approach to the care of older people (Department of Health, 2001). In order to support the implementation of this approach by GPs in primary care consultations, there needs to be some evidence that this model of care is effective with this age group. It has been shown that assessing the needs of older people more accurately and ensuring services remain appropriate to needs may reduce demand for services as well as improve functioning and delay admission to residential care. There have been no published studies to date that have investigated unmet need as an outcome of consultation style, nor have there been any studies that have examined the effect of a patient centred approach specifically with older adults. The purpose of this study is to investigate whether a patient centred approach by GPs is effective in meeting the needs of older people attending primary care.

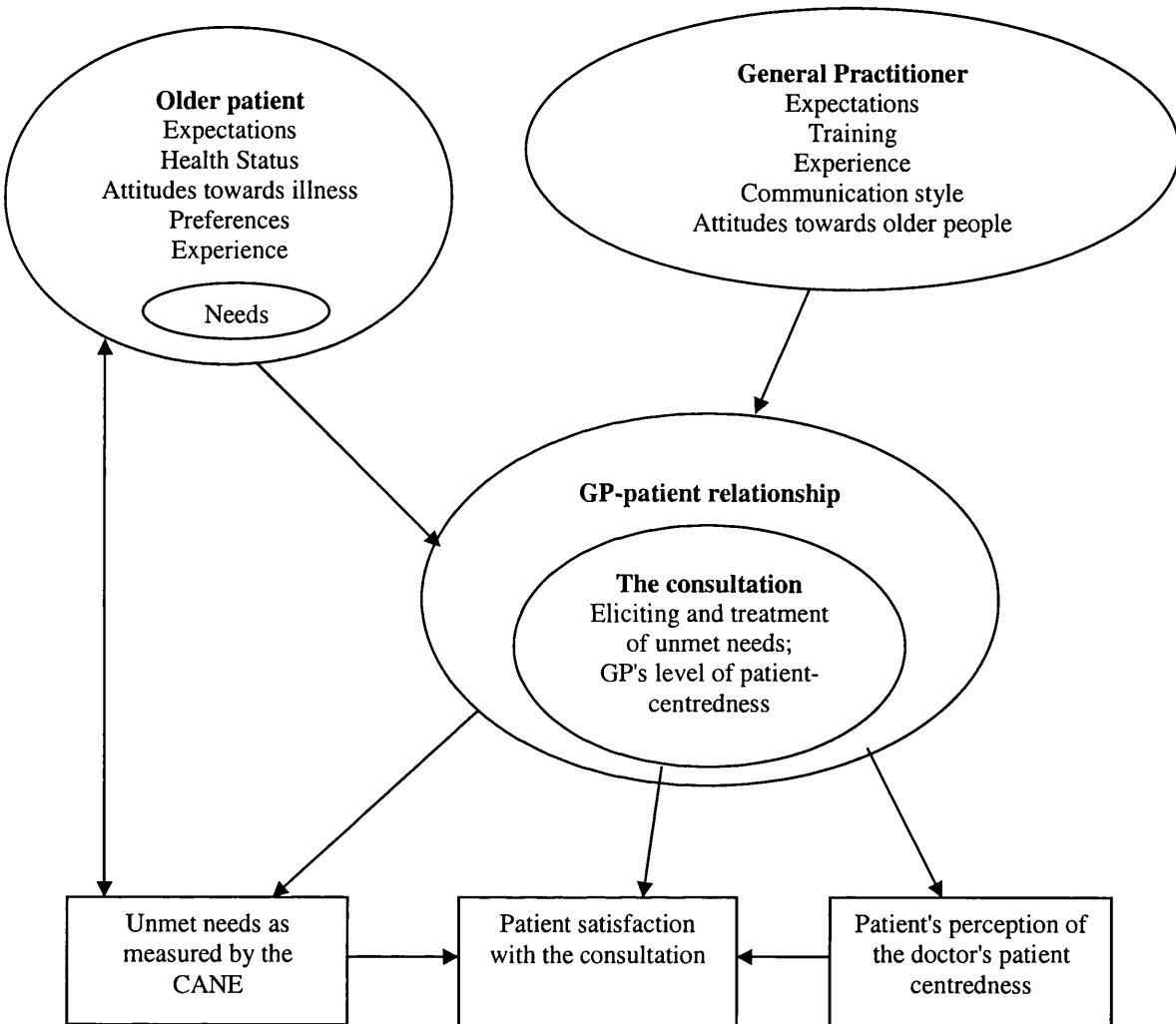
There are three hypotheses in this study:

1. Unmet needs will be associated with lower levels of patient centredness.
2. Unmet needs will be associated with lower levels of satisfaction.
3. Patient centredness will be associated with patient satisfaction.

These hypotheses are presented in the form of a model (Figure 1).

Figure 1.

The effect of a patient centred General Practice consultation on unmet needs and satisfaction in older adults.



1.8 AIMS OF THE PRESENT STUDY

1. To examine whether a patient centred approach by a GP is associated with fewer unmet needs in older adults.
2. To examine whether older patients' satisfaction with the consultation is associated with fewer unmet needs in older adults.
3. To investigate the potential relationship between demographic factors and unmet needs.

CHAPTER TWO

METHOD

2.1 OVERVIEW

The present study was a survey of older adults visiting their General Practitioner in two general practices in South-West London, with reference to their perception of the doctor's consultation style, their health and social needs, and their satisfaction with their visit to the doctor. Ethical approval was granted by and Merton and Sutton Local Research Ethics Committee (Appendix 1) and researcher Fiona Smith (FS) collected the data.

2.2 PARTICIPANTS

The people invited to participate in this study were over the age of 65 and were visiting their doctor for a problem they had not consulted the doctor about in the previous six months. Every effort was made to include potential participants with sensory impairments and those with cognitive difficulties if they had a carer who could assist them with the questionnaire and interview.

Ninety-five people met the inclusion criteria, were available for interview within the study period, and were invited to participate. Of this number, seventy-eight (82%) agreed to participate. The seventeen who declined to participate said that they simply did not want to, and gave no specific reason. Of the seventy-eight people who agreed to participate in the study, eleven cancelled their follow-up appointments due to unforeseen medical or social circumstances.

2.3 SELECTION OF GENERAL PRACTICES

Three general practices in the London Borough of Merton were contacted in the first instance. The selection of the practices was based on the level of social deprivation in their catchment area and their size. As social deprivation indices (Jarman UPA scores) are only available for whole London Boroughs, it was decided that the practices would be selected on the basis of their catchment wards' Standard Mortality Ratios (SMRs), which have been shown to be related to Jarman Scores of Deprivation (Merton, Sutton & Wandsworth Health Authority, 2000). The aim was to select practices whose patients differed in levels of social deprivation in order to obtain a representative sample. The practices were also selected for the number of General Practitioners they had, as it was felt that this would make data collection more efficient.

Practice 1 covered an affluent area of suburban South-West London whose wards had SMRs of 60-79. There were 9 general practitioners registered at this practice. Practice 2 covered a mixed suburban catchment area whose wards had SMR's between 60 and 129. There were 7 general practitioners registered at this practice.

Each practice was sent a letter (Appendix 2) describing the study and asking if FS could meet with them to discuss the study. Meetings were arranged with two of the practices, the third did not get in contact, despite telephone calls and a letter to follow up the request.

FS met with two practices and discussed the study with them. From these discussions, it was decided that an agreement would be made between FS and the practice about what she would do in the following circumstances:

- A patient discloses information about their health that they have not told their doctor.
- A patient is upset about their GP consultation.
- A patient has a complaint about the consultation with their GP.
- Researcher suspects that patient is at risk of harm from themselves or others.
- Researcher suspects that others are at risk of harm from patient.

This agreement was drawn up in the form of a “practice protocol” and was signed by FS and both practices (Appendix 4).

2.4 PROCEDURE

The researcher contacted reception staff, after the managers and doctors of the practices had agreed to participate, to arrange days for her to be present at the surgery.

It was arranged for her to be present at a time when most of the GPs were holding general clinics and there was a room available. The researcher met with the reception staff of both practices. She explained the purpose of the study, asked for their assistance in identifying and informing potential participants about the study, and provided them with written information about the study (Appendix 5). On the days when the researcher was present at a practice, the reception staff provided her with a list of patients who had booked GP appointments that day. The researcher identified from the list patients who were over the age of sixty-five, and gave this list of names to the reception staff. The reception staff then informed the identified patients when they arrived that there was research going on in the practice, gave each of the potential participants an information sheet (Appendix 6), and told them that FS would approach them to invite them to take part. If a patient informed the reception staff that they definitely did not want to be approached, the staff member duly informed the

researcher who did not approach them. In one of the practices, the reception staff notified the researcher when a potential participant arrived and in the other, this information was available on a computer.

The researcher approached identified patients and explained that she was doing a survey to investigate the effectiveness of the GP consultation process for people over the age of sixty-five. She told the patient that the research was only focusing on people coming with problems they have not sought help for in the previous six months and that if they chose to participate she would ask them a few questions before the consultation about why they were seeing the doctor. She explained that she would also like to meet with them at a convenient time within the following two days to ask some questions about their experience of the consultation and any other difficulties they may have. The researcher told the patient that these questions would take about half an hour to administer and that this could take place either in the surgery or in their home. The patient was asked if he or she wanted to participate in this study, and informed that they were under no obligation to do so. If the patient agreed to participate, they were taken to an interview room.

2.41 Pre-consultation interview

In the interview room, the researcher informed the participant that any information they gave would be confidential and used for research purposes only. The patient was warned that some of their problems with consultations may not be able to be solved, but they were assured that any serious problems raised would be fed back to the appropriate doctor. The researcher gave participants an opportunity to ask questions about the study and when the participant felt that these were satisfactorily answered,

the participants was asked to sign a consent form (Appendix 3). The researcher then asked the following questions:

- Why are you seeing your GP today?
- What do you expect to get out of this consultation?

The participants' responses were audio taped and written notes were taken. The researcher gave the participant the patient questionnaire (Appendices 7,8,9) to take away and arranged a time to meet with them for the follow-up appointment.

If a potential participant did not meet the inclusion criteria or if they decided that they were not able or did not want to take part, they were thanked for their time and any audio recording was erased, and written material was destroyed.

2.42 Post-consultation interview

The researcher went to the participant's home at the agreed date and time. She asked for the completed questionnaire and addressed any difficulties the participant had with completing it. She then asked the following questions:

- Did the consultation meet your needs?
- Why do you think this was so?

The participants' responses were audio taped and written notes were taken. The researcher then administered the Camberwell Assessment of Need for the Elderly (Reynolds et al., 2000)(Appendix 10). When this was completed, the participant was given the opportunity to ask questions and discuss the study. They were thanked for their time and told that the researcher would not be contacting them again, but they could contact her if they had any more questions.

2.5 DESIGN

The design of this study was a combination of correlational design and descriptive research. Although a pre-consultation measure of unmet needs was not assessed with the measure employed at post-consultation, the needs assessment section of the study can be considered to be a one-group posttest design. The measure of unmet needs was not employed before the consultation in order not to prime the patient to talk to the doctor about certain topics, and therefore threaten internal validity (Cook and Campbell, 1979). The assumption was made that any unmet needs that were present after the consultation would have also been present before the consultation, and it was possible to assess what needs were met by the consultation during the post consultation interview. The satisfaction section of the study can be considered to be a descriptive, one group posttest design.

2.6 MEASURES

2.6.1 Perception of Patient Centredness Questionnaire (Little et al, 2001)

This is the questionnaire used in the Little et al. (2001) study and is based on the five domains of the patient centred model: exploring the disease and illness experience, understanding the whole person, finding common ground, health promotion, and enhancing the doctor-patient relationship (Brown et al., 1995, Little et al., 2001). Each item is scored on a Likert type seven-point interval scale ranging from strongly agree to strongly disagree, with the items worded both positively and negatively (Appendix 9). Little et al. (2001) developed the questionnaire with the use of factor analysis to establish the distinct components of patient centredness, of which they found five. Scale scores were built by adding the component questionnaire items together (unweighted) and dividing by the number of items. Internal reliability was measured

using Cronbach's α . They found that four components explained 93% of the variance, and the fifth 3%. Cronbach's α for each factor was 0.96 for factor 1 ("communication and partnership"), 0.89 for factor 2 ("personal relationship"), 0.87 for factor 3 ("health promotion"), 0.84 for factor 4 ("positive and clear approach to problem"), and 0.89 for factor 5 ("interest in effect on life") (Little et al., 2001).

2.62 Medical Interview Satisfaction Scale (Wolf, Putnam, James et al., 1978)

The Medical Interview Satisfaction Scale (MISS) is a self-administered questionnaire designed to measure satisfaction with a particular provider or consultation rather than general attitudes towards medical care. It was developed to be responsive to variations in the style and content of the consultation rather than the structural setting where the care is provided. Each item is scored on a Likert type seven point interval scale ranging from strongly agree to strongly disagree (Appendix 8). Scores on positively worded items are recoded so that high scores indicate greater satisfaction. Evidence of construct validity for the MISS has been cited as correlations of MISS scores with patients' reported attitudes and beliefs (Wolf & Stiles, 1981), but there is limited evidence for reliability of the measure because of the problem of recall (Wilkin, Hallam, Doggett et al., 1992). This was the measure of satisfaction used in the aforementioned Little et al. (2001) study.

2.63 Camberwell Assessment of Need for the Elderly (Reynolds et al., 2000)

The Camberwell Assessment of Need for the Elderly (CANE) is a systematic multi-dimensional needs assessment tool that has been validated in a range of settings and populations (Walters et al., 2000; Reynolds et al., 2000) and is a suggested assessment tool for the Single Assessment Process, as introduced in the NSFOP (Department of

Health, 2001). The CANE covers twenty four domains: accommodation, looking after the home, food, self care, caring for someone else, daytime activities, memory, eyesight/hearing, mobility, continence, physical health, drugs, psychotic symptoms, psychological distress, information on condition / treatment, safety to self, behaviour, alcohol, company, intimate relationships, money, benefits (Appendix 10). Each of these potential needs are scored on a three point scale: 0 = no problem, 1 = met need (an identified need with an appropriate intervention in place), and 2 = unmet need (an identified need for which exists a suitable intervention which could potentially alleviate the difficulty in part, but there is no such plan to address the problem in place). The CANE measures the level of help received from friends or relatives as well as statutory services, and it can be used to record staff, carer, and patient views. The CANE has undergone an extensive development process that has included focus groups, a Delphi process and a consensus conference, which have established face and content validity. The number of needs identified by the CANE correlates ($r= 0.66$) with level of dependence as measured by the Clifton Assessment Procedures for the Elderly Behaviour Rating Scale which suggests good concurrent validity. Good test-retest and inter-rater reliability has also been shown (Reynolds et al 1998). The researcher (Fiona Smith) was trained to administer the CANE by an academic experienced in its administration, Dr Martin Orrell.

2.64 Views on the consultation

Responses to the pre-consultation questions of 'Why are you seeing your doctor today?' and 'What do you hope to get out of this meeting?' were coded according to the types of reasons given, e.g. back pain, persistent cough, etc. or medication, referral, reassurance etc. Responses to the post-consultation question of 'Did the consultation

meet your needs?' was coded on a three point scale from 1 = "yes", 2 = "sort of", and 3 = "no". The question 'Why do you think this was so?' was coded according to the types of reasons given e.g. referral obtained, reassurance given etc. Participants were also asked whether they had seen the doctor they usually see when they come to the surgery.

2.65 Demographic and other data

Participants were asked information regarding socioeconomic variables such as age, sex, ethnicity, marital status, who they lived with and type of residence, current or previous job, years in education, and whether they provided full time care for anyone or whether they had full time care provided for them.

2.7 DATA ANALYSIS

As there were no previous studies comparing patient centredness to unmet need, the power analysis for this study was calculated from Cohen's 1992 paper on sample sizes. It was estimated that patient centredness would have a large effect on unmet need in the consultation. To detect a significant difference between mean ratings of patient centredness for those with no unmet needs compared to those with unmet needs for a significance criterion (α) of .01 and power (β) of .08, we needed 38 people in each group, a total of 76 participants (Cohen, 1992).

Parametric tests were used where the data met the requirements of a normal distribution or homogenous variances; otherwise, non-parametric tests were used. An independent samples t-test was used to detect a difference in ratings of patient centredness or satisfaction between those with unmet needs and those without, and to compare patient centredness and satisfaction with categorical demographic variables.

Continuous demographic variables and likelihood of having an unmet need were also compared by independent samples t-test. Pearson's r was employed to compare the association between patient centredness and satisfaction, and between each of these variables and continuous demographic variables. A linear regression was performed to examine which factors of patient centredness were independent predictors of satisfaction, and a logistic regression was performed to examine which factors of patient centredness were independent predictors of unmet need. Chi-square was used to assess the association between likelihood of unmet need and categorical demographic variables, and CANE and consultation unmet needs. A backwards step-wise logistic regression was performed to identify which variables measured in this study accounted for the greatest variance in the likelihood of whether an older person had their needs met by the GP consultation.

CHAPTER THREE

RESULTS

This chapter is divided into seven sections, which aim to follow the chronological procedure of data collection. The first section of this chapter examines the demographic characteristics of the participants. The next section outlines participants' reasons for visiting their doctor and their expectations of the consultation. Participants' ratings of patient centredness are presented in the following section and then ratings of satisfaction are examined. What participants said about the consultation is then presented, as well as whether they felt it met their needs and reasons they gave. The following section describes participants' needs, as measured by the CANE, and compares these to demographic variables. Relationships between the target variables (patient centredness, patient satisfaction and unmet needs) are examined and the study's hypotheses are tested.

3.1 RESPONSE RATE AND DEMOGRAPHIC PROFILE

193 people were approached to take part in this study. 67 people were excluded as they did not meet the inclusion criteria, because they were seeing their GP for a review or follow-up appointment and 16 people were excluded because they had no time for the follow up interview. 110 people met the inclusion criteria. 15 people said that they did not want to take part because they were too ill or they felt too old to participate, and 17 people said that they did not want to take part and did not give a

reason. In total, 78 people (71%) agreed to participate and were included in the study. Eleven participants dropped out before the follow-up assessment by canceling their appointments, all citing unforeseen medical or social circumstances such as emergency hospital appointments, or having to care for a sick relative.

Table 1 illustrates the demographic characteristics of the sample. The mean age of the participants in this study was 73.0 years (*S. D.* 6.3 years, range 65 - 87) with 65% of participants in the 65 -74 age bracket. Tests of skewness and kurtosis showed the data to be normally distributed at $p < 0.05$ (Skewness z-score = 1.72, Kurtosis z-score = 1.44). The average number of years in full time education was 11.3 (*S.D.* = 2.99) with a range of 10-25 years. Table 1 shows that there was a roughly equal split of male and female participants, and an equivalent number from each practice. There was very little ethnic diversity among the participants. Around half the participants were married and just under half the participants lived alone. Very few participants either received or provided full time care.

3.2 REASONS FOR VISITING THE GP AND EXPECTATIONS

In the pre-consultation interview participants were asked why they were seeing their doctor and what they expected to get out of the consultation. Table 2 illustrates the reasons people gave for visiting the doctor, according to Camberwell Assessment of Need for the Elderly classifications (Reynolds et al, 2000, Appendix 10). Needs were coded in this way because this was the measure of unmet need used for outcome of the consultation.

Table 1.**Demographic characteristics of the sample (N = 67)**

| | Frequency | Percent |
|---|------------------|----------------|
| Gender | | |
| Male | 31 | 46.3% |
| Female | 36 | 53.7% |
| Practice | | |
| Practice 1 | 30 | 44.8% |
| Practice 2 | 37 | 55.2% |
| Ethnicity | | |
| White British | 58 | 86.6% |
| White Irish | 3 | 4.5% |
| Indian | 2 | 3.0% |
| Caribbean | 2 | 2.0% |
| Marital status | | |
| Married or living as married | 33 | 49.3% |
| Single | 6 | 9.0% |
| Divorced or separated | 8 | 11.9% |
| Widowed | 20 | 29.9% |
| Living arrangements | | |
| Live with partner | 30 | 44.8% |
| Live alone | 29 | 43.3% |
| Live with relatives | 6 | 9.0% |
| Live with others | 2 | 3.0% |
| Type of residence | | |
| Private house / flat | 66 | 98.5% |
| Sheltered Accommodation | 1 | 1.5% |
| Provides full time care for someone else | 3 | 4.5% |
| Requires full time care | 5 | 7.5% |

Unsurprisingly, the majority of participants said that they were going to see their GP because of a physical health problem. A variety of physical problems were cited, the most common being *joint / muscular pain* (14, 23.3%), *Urine infection / kidneys* (9, 15.0%), and *chest / breathing problems* (8, 13.3%).

Table 2.

Reasons given for visiting the GP (N = 67)

| | Frequency | Percent |
|-------------------------|------------------|----------------|
| Physical Health | 60 | 76.9 |
| Drugs | 7 | 9.0 |
| Mobility / Falls | 4 | 5.1 |
| Psychological Distress | 3 | 3.8 |
| Eyesight/Hearing | 2 | 2.6 |
| Caring for someone else | 1 | 1.3 |
| Information | 1 | 1.3 |
| Total | 78 | 100.0 |

What people wanted to get from the consultation is presented in Table 3. The responses were categorized and reduced by content analysis of the verbatim text. Some participants gave more than one reason for visiting the GP or more than one expectation. Table 3 shows that participants wanted a range of services from their GP, and more than just treatment. The most desired outcome from a consultation was a prescription, closely followed by information, and advice. Most participants (52, 77.6%) had seen their usual doctor for their consultation.

Table 3.**What do you want to get out of this consultation? (N = 67)**

| | Frequency | Percent |
|--------------|------------------|----------------|
| Prescription | 26 | 19.5 |
| Information | 23 | 17.3 |
| Advice | 21 | 15.8 |
| Examination | 18 | 13.5 |
| Diagnosis | 16 | 12.0 |
| Referral | 14 | 10.5 |
| Reassurance | 11 | 8.3 |
| Counselling | 4 | 3.0 |
| Total | 133 | 100.0 |

3.21 Comparison of reasons given for visiting the GP and expectations by participants who did not attend follow-up interview with those who did.

The participants who did not attend the follow-up interview (N=11) gave a total of 13 reasons for visiting the GP. 10 out of 11 people said they were seeing their GP for physical health problems (77% of all reasons given), and three people said they were seeing their GP for mobility problems (23% of all reasons given). The people who did not attend reported similar rates of physical health problems, but a higher proportion of mobility difficulties.

The participants who did not attend the follow-up interview (N=11) expressed a total of 15 expectations. 6 people said they wanted a prescription (40 % of all reasons given), 5 people said they wanted information (33% of all reasons given), one

person wanted reassurance (7%) and one person wanted a referral (7%). A greater proportion of the non-attenders expected a prescription and information than in the group who did attend, but the ranking of the expectations was the same.

3.3 PATIENT CENTREDNESS

Participants' perceptions of how patient centred the GP was in the consultation (the independent variable in this study) was measured using a questionnaire that participants completed themselves after the consultation (Appendix 9). Participants were required to respond to statements about their doctor's approach to them by ticking a box on a seven point Likert scale of "very strongly agree" to "very strongly disagree". The hypothesis was that higher levels of patient centredness would be associated with fewer unmet needs and higher levels of satisfaction. The responses participants gave to the statements are shown in tables 4a and b.

Tables 4a and 4b shows that participants reported high levels of agreement with the positively worded statements, and high levels of disagreement with the negatively worded statements. One fifth of responses for all statements were neutral (mean = 20.8%). Statements relating to noticing disease early had the highest levels of "neutral" responses and high levels of blank answers. The factor with the highest level of both "neutral" and "no answer" responses was factor 5, statements relating to the interest the doctor paid to the effect of the problem on the patient's life. The statement *the doctor understands my emotional needs* had high levels of both "neutral" and blank responses.

Table 4a.

Percentages of participants responding to statements relating to the doctor's level of patient centredness

| | Agree % | Neutral % | Disagree % | Unanswered % |
|--|------------|--------------|---------------|-----------------|
| Factor 1: Communication and Partnership | | | | |
| 1. The doctor was interested when I talked about my symptoms | 94.0 | 1.5 | 0 | 4.5 |
| 2. The doctor was interested in what I thought the problem was | 83.6 | 13.4 | 0 | 3.0 |
| 3. The doctor ignored what I thought the problem was. | 3.0 | 14.9 | 74.6 | 7.5 |
| 5. The doctor was interested in what I wanted to know. | 82.1 | 13.4 | 0 | 4.5 |
| 6. The doctor was interested in what I wanted done. | 74.6 | 16.4 | 0 | 9.0 |
| 7. The doctor ignored what I wanted done. | 1.5 | 14.9 | 73.1 | 10.4 |
| 8. The doctor discussed and reached agreement with me about what the problem really was. | 83.6 | 11.9 | 0 | 4.5 |
| 9. The doctor was interested in my worries about the problem | 89.6 | 9.0 | 0 | 1.5 |
| 15. The doctor was careful to explain clearly the plan of treatment | 70.2 | 25.4 | 0 | 4.5 |
| 16. The doctor discussed and reached agreement with me about the plan of treatment | 79.1 | 19.4 | 0 | 1.5 |
| 18. The doctor was interested in what treatment I wanted. | 62.7 | 31.3 | 0 | 6.0 |
| 26. The doctor was sympathetic | 92.5 | 4.5 | 0 | 3.0 |
| 30. I felt encouraged to ask questions | 89.6 | 9.0 | 0 | 1.5 |
| Factor 2: Personal Relationship | | | | |
| 4. I'm confident that the doctor knows me and my history. | 89.5 | 7.5 | 0 | 3.0 |
| 24. The doctor knows and understands me well. | 82.1 | 11.9 | 0 | 6.0 |
| 25. The doctor understands my emotional needs. | 58.2 | 26.9 | 0 | 14.9 |

Table 4b. Percentages of participants responding to statements relating to the doctor's level of patient centredness

| Factor 3: Health promotion | Agree | Neutral | Disagree | No answer |
|--|--------------|----------------|-----------------|------------------|
| | % | % | % | % |
| 19. The doctor advised me how to prevent future health problems. | 62.6 | 31.3 | 0 | 6.0 |
| 20. Advice about preventing future health problems was omitted. | 28.4 | 23.9 | 40.3 | 7.5 |
| 21. The doctor talked about ways to lower the risks of future illness. | 62.6 | 28.4 | 0 | 9.0 |
| <hr/> | | | | |
| Factor 4: Positive and clear approach to problem | | | | |
| The doctor clearly explained what the problem was | 77.6 | 16.4 | 0 | 6.0 |
| The doctor was definite about what the problem was. | 79.1 | 14.9 | 0 | 6.0 |
| The doctor was positive about when the problem would settle. | 61.1 | 31.3 | 0 | 7.5 |
| <hr/> | | | | |
| Factors 5: Interest in effect on life | | | | |
| 10. The doctor was interested in the effect of the problem on my personal/family life | 64.2 | 28.4 | 0 | 7.5 |
| 11. The doctor ignored the effect of the problem on my personal/family life | 3.0 | 31.3 | 55.2 | 10.4 |
| 13. The doctor was interested about the effect of the problem on everyday activities | 65.6 | 26.9 | 0 | 7.5 |
| 14. The doctor ignored the effect of the problem on everyday activities | 3.0 | 28.4 | 55.2 | 13.4 |
| <hr/> | | | | |
| Statements not loaded onto any factors | | | | |
| 17. The doctor alone decided on the plan of treatment without discussion. | 10.5 | 26.9 | 56.7 | 6.0 |
| 22. The doctor discussed how to notice serious disease early e.g. meningitis, heart disease. | 47.8 | 38.8 | 0 | 13.4 |
| 23. Advice on noticing disease early e.g. meningitis, heart disease was omitted. | 31.4 | 38.8 | 7.5 | 22.4 |
| 27. The doctor encouraged me to be positive | 64.2 | 26.9 | 0 | 9.0 |

3.31 Mean score and distribution

The mean total patient centredness score for this sample was 148.1 (S.D. = 28.2, range = 48-202). The scores were not normally distributed (skewness z-score = 2.925, kurtosis z-score = 3.744; $p < 0.05$) so in an attempt to reduce skewness, a square root transformation was performed, but skewness and kurtosis still remained significant. The data were then checked for outliers, identified as being more than 3 standard deviations from group mean. One was found and when it was removed, the data were normally distributed (skewness z score = -1.342, kurtosis z score = 1.651). With the outlier removed, it was possible to analyze these data with parametric statistics.

Scores of patient centredness were compared to demographic variables in the first instance to examine whether any of these factors (such as age or gender) could independently explain the variance in the ratings. It has been suggested that certain demographic factors such as age can independently predict patient evaluations of primary medical care (Campbell et al., 2001). Tables 5 and 6 show the relationship between ratings of patient centredness and demographic variables.

Table 5.
Correlations between ratings of patient centredness and continuous demographic variables

| | Pearson's r | p |
|------------------------------|--------------------|----------|
| Age | -0.116 | 0.762 |
| Years in full time education | 0.071 | 0.583 |

Table 6.

Associations between total ratings of patient centredness and categorical demographic variables

| | <u>Mean (S.D.)</u> | <u>t-value (df)</u> | <u>p</u> |
|-------------------------|--------------------|---------------------|----------|
| Gender | | 2.380 (64) | .020* |
| Male | 157.32 (20.25) | | |
| Female | 142.89 (27.87) | | |
| Practice | | -1.328 (64) | 0.189 |
| 1 | 145.13 (27.34) | | |
| 2 | 153.44 (23.50) | | |
| Marital status | | 0.895 (64) | 0.374 |
| Married | 152.56 (27.57) | | |
| Single, Widowed or | 146.94 (27.19) | | |
| Divorced / Separated | | | |
| Living situation | | -.0643 (64) | 0.522 |
| Living alone | 147.38 (28.46) | | |
| Living with partner/ | 151.46 (23.08) | | |
| Relatives/others | | | |
| Usual doctor | | 0.723 (64) | 0.473 |
| Yes | 150.85 (28.03) | | |
| No | 145.29 (11.51) | | |

* = p<0.05

Neither age nor level of education was a significant factor in how participants rated patient centredness. The only demographic variable that could independently predict ratings of patient centredness was gender, with men reporting significantly higher ratings than women. There were no differences between the two practices, whether participants were married or lived alone, nor between those who had seen their own doctor and those who had seen a different doctor than usual. However, there was a trend (although not significant) for people seeing their own doctor to give a higher rating of patient centredness.

3.4 SATISFACTION

Participants' satisfaction with the consultation was measured using the Medical Interview Satisfaction Scale (Appendix 8) which participants completed themselves after they had met with the doctor. They were required to rate their satisfaction with different aspects of the consultation by responding to statements about the consultation on a seven point Likert scale from "very strongly agree" to "very strongly disagree". The hypothesis was that participants would be more satisfied with higher levels of patient centredness, and fewer unmet needs. The responses participants gave to the statements are shown in tables 7a and 7b.

Table 7a

Percentages of participants responding to statements relating to their satisfaction with the consultation

| | Agree % | Neutral % | Disagree % | Unanswered % |
|---|------------|--------------|---------------|-----------------|
| 1. The doctor gave a poor explanation of my illness. | 12.0 | 10.4 | 67.2 | 10.4 |
| 2. The doctor told me just what my trouble is. | 79.1 | 16.4 | 0 | 4.5 |
| 3. After talking with the doctor, I know just how serious my illness is. | 70.2 | 16.4 | 0 | 13.4 |
| 4. The doctor told me all I wanted to know about my illness. | 74.6 | 20.9 | 0 | 4.5 |
| 5. I am not really certain about how to follow the doctor's advice. | 16.4 | 14.9 | 59.7 | 9.0 |
| 6. After talking with the doctor, I have a good idea of how long it will be before I am well again. | 55.3 | 32.8 | 0 | 11.9 |
| 7. The doctor seemed interested in me as a person. | 95.5 | 3.0 | 0 | 1.5 |
| 8. The doctor seemed warm and friendly to me. | 100.0 | 0 | 0 | 0 |
| 9. I felt that this doctor did not treat me as an equal. | 3.0 | 4.5 | 85.0 | 7.5 |
| 10. The doctor seemed to take my problems seriously. | 95.5 | 4.5 | 0 | 0 |
| 11. I felt embarrassed while talking with the doctor. | 1.5 | 7.5 | 86.5 | 4.5 |
| 12. I felt free to talk to this doctor about private matters. | 92.5 | 6.0 | 0 | 1.5 |
| 13. The doctor gave me a chance to say what was really on my mind. | 94.0 | 4.5 | 0 | 1.5 |
| 14. I felt really understood by my doctor. | 94.0 | 6.0 | 0 | 0 |
| 15. The doctor did not allow me to say everything I had wanted about my problems. | 6.0 | 3.0 | 85.0 | 6.0 |
| 16. The doctor did not really understand my main reason for coming. | 6.0 | 3.0 | 85.0 | 6.0 |
| 17. This is a doctor I would trust with my life. | 92.5 | 7.5 | 0 | 0 |
| 18. I would hesitate to recommend this doctor to my friends. | 9.0 | 9.0 | 77.5 | 4.5 |

Table 7b

Percentages of participants responding to statements relating to their satisfaction with the consultation

| | Agree % | Neutral % | Disagree % | Unanswered % |
|---|------------|--------------|---------------|-----------------|
| 19. The doctor seemed to know what (s)he was doing. | 98.5 | 0 | 0 | 1.5 |
| 20. After talking with the doctor, I feel much better about my problems. | 82.1 | 17.9 | 0 | 0 |
| 21. The doctor has relieved my worries about my illness. | 71.6 | 25.4 | 0 | 3.0 |
| 22. Talking with the doctor has not at all helped my worries about my illness. | 6.0 | 16.4 | 71.6 | 6.0 |
| 23. The doctor has come up with a good plan for helping me. | 76.1 | 19.4 | 0 | 4.5 |
| 24. The doctor visit has not at all helped me. | 4.5 | 4.5 | 82.0 | 9.0 |
| 25. The doctor seemed to know just what to do for my problem. | 92.5 | 4.5 | 0 | 3.0 |
| 26. I expect that it will be easy for me to follow the doctor's advice. | 86.6 | 10.4 | 0 | 3.0 |
| 27. I intend to follow the doctor's instructions. | 94.0 | 4.5 | 0 | 1.5 |
| 28. It may be difficult for me to follow exactly what the doctor told me to do. | 4.5 | 17.9 | 71.6 | 6.0 |
| 29. I'm not sure the doctor's treatment will be worth the trouble it will take. | 67.1 | 16.4 | 7.5 | 9.0 |

Tables 7a and 7b shows that participants reported high levels of agreement with the positively worded statements, and high levels of disagreement with the negatively worded statements, resulting in a high overall level of satisfaction. Two statements stood out as having high levels of "neutral responses". These were "the doctor has relieved my worries about my illness" (one quarter of the sample) and "after talking with the doctor, I have a good idea of how long it will be before I am well again" (one third of the sample). This latter statement also had the highest proportion of blank responses.

3.41 Mean score and distribution

The mean satisfaction score for this sample was 154.3 (S.D. = 25.6, range = 63-196)

These scores were not normally distributed (skewness z-score = -3.283, kurtosis z-score = 3.460; $p < 0.05$). In an attempt to reduce skewness, a square root transformation was performed, but skewness and kurtosis still remained significant (skewness z score= -4.898, kurtosis z score = 6.519). The data were then checked for outliers, identified as being more than 3 standard deviations from group mean. One was found and when it was removed, the data appeared normally distributed (skewness z-score = -1.820, kurtosis z-score = 1.249). With the outlier removed, it was possible to analyze these data with parametric statistics.

Table 8.

Correlations between ratings of satisfaction and continuous demographic variables

| | Pearson's r | p |
|------------------------------|--------------------|----------|
| Age | -0.116 | 0.357 |
| Years in full time education | -0.008 | 0.357 |

Scores of satisfaction were compared to demographic variables in the first instance to examine whether any of these factors could independently explain the variance in the ratings, as research evidence has suggested that age and gender are independent predictors of satisfaction scores (Callahan et al., 2000). Tables 8 and 9 show the relationship between ratings of satisfaction and demographic variables. Neither age nor gender influenced participants' reported satisfaction with the consultation,

Table 9.

Associations between ratings of satisfaction and categorical demographic variables

| | Mean (S.D.) | t (64) | p |
|-------------------------|----------------|--------|-------|
| Gender | | 1.632 | 0.108 |
| Male | 160.52 (17.13) | | |
| Female | 151.31 (26.92) | | |
| Practice | | -0.171 | 0.865 |
| 1 | 155.10 (22.86) | | |
| 2 | 156.08 (23.70) | | |
| Marital status | | 1.895 | 0.063 |
| Married | 152.56 (27.57) | | |
| Single, Widowed or | 146.94 (27.19) | | |
| Divorced / Separated | | | |
| Living situation | | -1.088 | 0.281 |
| Living alone | 152.14 (27.47) | | |
| Living with partner/ | 158.38 (19.06) | | |
| relatives/others | | | |
| Usual doctor | | 1.266 | 0.210 |
| Yes | 157.50 (24.65) | | |
| No | 148.71 (15.16) | | |

although the average score for male participants was higher than females' average score. None of the other demographic variables impacted upon participants' rating of satisfaction with the consultation. However, marital status appeared close to significance, with a trend for people who were married to give higher ratings of satisfaction than those who were not.

3.5 ASSOCIATION BETWEEN PATIENT CENTREDNESS AND SATISFACTION

Hypothesis – Patient centredness is related to satisfaction

In order to test this hypothesis, a correlation was performed between patient centredness and satisfaction scores (both were normally distributed after one outlier was removed from both data sets). A significant correlation was found between these variables (Pearson's $r = 0.674$, $p < 0.01$).

A linear regression was performed to examine which factors of patient centredness were the strongest predictors of satisfaction levels (Table 10). The patient centredness factor of "communication and partnership" was most significantly related to satisfaction, and the "interest in effect on life" factor was also significantly associated with satisfaction scores. The data show that in this sample, the more patient centred the participants perceived the doctor to be, the higher the ratings of satisfaction they gave. Therefore, the hypothesis that patient centredness is positively associated with satisfaction is supported by the data.

Table 10.**Association of factors of patient centredness and satisfaction**

| | B | S.E. | Beta | T | Sig. | |
|--|--------|-------|-------|-------|------|----|
| Communication and partnership | 11.536 | 3.231 | .449 | 3.570 | .001 | ** |
| Personal relationship | -1.098 | 2.293 | -.063 | -.479 | .634 | |
| Health promotion | .245 | 2.028 | .014 | .121 | .904 | |
| Positive and clear approach to problem | 2.064 | 2.868 | .099 | .719 | .475 | |
| Interest in effect on life | 4.671 | 2.218 | .295 | 2.106 | .039 | * |

*p<.05, **p<.01

3.6 CONSULTATION NEEDS

After the participants had seen their doctor, a post-consultation meeting took place between the researcher (FS) and the participant. At this meeting, the researcher collected the completed patient centredness and satisfaction questionnaires and asked the participant two questions, "Did the consultation meet your needs?" and "Why do you think this was?". The researcher then administered the Camberwell Assessment of Need for the Elderly (CANE) (Appendix 10). This section will present the answers people gave to these two questions, and highlight the themes and patterns that appeared. I will then describe the unmet needs that were identified by the CANE and compare these to demographic variables to check for independent effects.

The majority of the sample (59, 88.1%) said that the consultation met their needs. 5 people (7.5%) said that the consultation met their needs "to some extent", and 3 (4.6%) said that the consultation did not meet their needs. Reasons participants

gave for why they thought that the consultation had met their needs were reduced to seventeen different themes, as shown by Table 11. The reasons were categorized and reduced by content analysis of the verbatim text and were then grouped into three categories - doctor factors, patient factors, and diagnosis / treatment factors. Some participants gave more than one reason.

The most common reason given by participants for why the consultation met their needs was because the doctor answered their questions. The second most frequent reason was because the doctor listened, joint with the fact that they felt that the doctor was very good. Only 8.3% of people who felt the consultation had met their needs attributed this to getting a prescription. The majority of the reasons given for why the consultation met their needs were to do with the doctor's behaviour or attributes. Around a third of the reasons given were to do with the problem itself (32.3%) and only 8.3% of reasons were participant factors.

3.61 Consultation - partially unmet needs

Five participants said that the consultation met their needs "to some extent". In each case, there was evidence that they had not been given treatment, or the treatment had not worked. Two people expressed low expectations, saying, "*I've learned to live with arthritis. I don't see that there is much they can do except give you painkillers*" and "*He couldn't come up with any more than treatment for the symptoms, rather than the cause. I didn't expect much more. I didn't have very high expectations.*" Another participant said that the problem lay in the illness, saying, "*this is a very complicated medical problem, not all problems are susceptible to quick fixes*". Two participants expressed uncertainty about the doctor's behaviour, but appeared reluctant to criticize the doctor. "*She took the trouble to look at me and she examined*

Table 11 : Why do you think the consultation met your needs? (N = 59)

| | Frequency | Percent |
|--|------------|--------------|
| Doctor factors | 79 | 59.4 |
| The doctor answered my questions | 18 | 13.5 |
| The doctor listened | 15 | 11.3 |
| The doctor is very good | 15 | 11.3 |
| The doctor took his time / nothing is too much trouble | 7 | 5.3 |
| The doctor reassured me | 7 | 5.3 |
| The doctor was caring / understanding | 7 | 5.3 |
| The doctor knows me | 6 | 4.5 |
| The doctor was definite / positive | 2 | 1.5 |
| This doctor doesn't talk down to you | 2 | 1.5 |
| Diagnosis / treatment factors | 43 | 32.3 |
| The doctor referred me on | 13 | 9.8 |
| The doctor gave me a prescription | 11 | 8.3 |
| The doctor gave me a diagnosis | 4 | 3.0 |
| The treatment the doctor gave me worked | 1 | 0.8 |
| The doctor examined me | 14 | 10.5 |
| Patient factors | 11 | 8.3 |
| I spoke up in the consultation | 5 | 3.8 |
| There is nothing much they can do for this problem | 1 | 0.8 |
| I have a good relationship with this doctor | 5 | 3.8 |
| Total | 133 | 100.0 |

my chest. She said that antibiotics wouldn't help, as if she assumed I wanted antibiotics or was expecting a prescription. I would have been happier if she had said come back in a fortnight if it hasn't gone. She told me to carry on and said it would go, but I think three weeks is a long time to have something not moving". Another said, "This particular visit was to bring the pain under control, but I am still in pain now. It didn't seem serious to him, but I was in pain. He could have said what was available privately. He did put my mind at rest though. Overall, I want you to put, "I have a lot of confidence in this doctor"".

3.62 Consultation - unmet needs

Three participants said that the consultation definitely did not meet their needs. When asked why this was, they all mentioned that the problem had not resolved and they had not found out what the problem was. One participant said, "*The doctor gave me some antibiotics, but they didn't work. The doctor wasn't able to say what the problem was.*" Another replied, "*He gave me something for my sinuses, but I don't think it's an allergy and it hasn't worked. I don't seem to be able to get any response from him. This problem has been going on for a long time. How can I find out what's wrong?*" The third participant (who visited the doctor after experiencing pains in her leg) said, "*He told me it was arthritis, but other doctors have told me it was something different. I don't think it is arthritis, something is burning. The medication he gave me made it worse. I would have liked another x-ray. I don't like to argue with doctors, they try their best*".

3.63 Association between consultation needs and mean patient centredness / satisfaction ratings

The mean patient centredness score for participants who said their needs were met by the consultation (mean = 151.8, $SD = 26.0$) was higher than for those who said their needs were not met, or were met "to some extent" (mean = 134.0, $SD = 13.6$). An independent samples t-test showed that this difference was significant ($t(15.306) = 3.015$, $p = .009$).

The mean satisfaction score for participants who said their needs were met by the consultation was also higher for participants who said that their needs had been met by the consultation (mean = 158.2, $SD = 22.7$), in comparison to those who said that their needs had not been met or had been met "to some extent" (mean = 136.8, $SD = 17.8$). An independent samples t-test showed that this difference was significant ($t(10.426) = 3.085$, $p = .011$).

Caution must be exercised when interpreting these results due to the small number of participants who said that their needs were not met, or were met "to some extent".

3.7 CANE NEEDS

The main outcome variable for this study was the presence of unmet needs in people over the age of 65 after they had visited the GP. Unmet needs were assessed by the Camberwell Assessment of Need for the Elderly (CANE) during the post-consultation interview (Appendix 10). Each domain was given a rating of "no need", "met need" or "unmet need". In this section, I present the prevalence of met and

unmet needs, as measured by the CANE, after the GP consultation. I will compare how many of the people who reported that their needs were met by the consultation still had unmet needs after seeing the GP and then compare the likelihood of having unmet needs to demographic variables.

3.71 Unmet needs

35 participants (52.2%) had at least one unmet need after they had seen a GP. The mean number of unmet needs was 1.45 (*S.D.* 1.97, *range* 0-7) and they were not normally distributed (skewness z-score = 4.181, kurtosis z-score = 0.490). The skewness was so extreme that it was not possible to normalize the distribution. Table 12 illustrates the frequency and type of met and unmet needs in this sample. The 24 domains of need as measured by the CANE can be grouped into four types: environmental, physical, psychological and social (Martin, 1998). The most common unmet needs in this sample were for *information* (13, 19.4%), *eyesight/hearing* (11, 16.4%) and *benefits* (11, 16.4%). Perhaps surprisingly, *physical health* was the fourth most common unmet need with more than one in five participants having unmet needs in this area (10, 14.9%).

Comparing the needs that participants expressed at the pre-consultation interview (Table 2), and their CANE scores, it was found that 12 participants (18%) did not have the needs met that they themselves identified prior to seeing the GP. 9 of these needs were *physical health* needs, one was *mobility/falls*, one was *psychological distress*, and one was for *information*.

3.72 Met needs

The met needs participants had give us an idea of the general problems experienced by this population. All participants had at least one met need, illustrated in Table 12. The mean number of met needs was 2.88 (*S.D. 1.84, range 0-10*). The most common met needs were *physical health* (55, 82.1%), *eyesight / hearing* (29, 43.3%) and *drugs* (19, 28.4%). The number of met needs a participant had was not related to the number of unmet needs they had (Spearman's rho = .122, p = .326).

3.73 Demographic characteristics and CANE unmet needs

Table 13 shows the association between demographic characteristics and CANE unmet needs. The only demographic variable that significantly predicted likelihood of having an unmet need was marital status, with married participants less likely to have an unmet need than unmarried participants.

Table 12. Met and unmet needs as measured by the CANE (N = 67)

| | Met need | Unmet need |
|----------------------------------|------------|------------|
| Environmental needs | | |
| Accommodation | 1(1.5%) | 9 (13.4%) |
| Looking after the home | 17 (25.4%) | 2 (3.0%) |
| Food | 11(16.4%) | 0 |
| Money / budgeting | 3 (4.5%) | 0 |
| Benefits | 2 (3.0%) | 11 (16.4%) |
| Caring for someone else | 3 (4.5%) | 2 (3.0%) |
| Physical | | |
| Physical health | 55 (82.1%) | 10 (14.9%) |
| Drugs | 19 (28.4%) | 6 (9.0%) |
| Eyesight /hearing/ communication | 29 (43.3%) | 11 (16.4%) |
| Mobility / falls | 16 (23.9%) | 7 (10.4%) |
| Self-care | 5 (7.5%) | 3 (4.5%) |
| Continence | 11(16.4%) | 7 (10.4%) |
| Psychological needs | | |
| Psychological distress | 7 (10.4%) | 9 (13.4%) |
| Memory | 4 (6.0%) | 1 (1.5%) |
| Behaviour | 0 | 0 |
| Alcohol | 0 | 0 |
| Inadvertent self-harm | 0 | 0 |
| Deliberate self-harm | 2 (3.0%) | 0 |
| Psychotic symptoms | 0 | 0 |
| Social needs | | |
| Company | 1 (1.5%) | 5 (7.5%) |
| Intimate relationships | 0 | 1 (1.5%) |
| Daytime activities | 1 (1.5%) | 2 (3.0%) |
| Information | 5 (7.5%) | 13 (19.4%) |
| Abuse / neglect | 2 (3.0%) | 0 |

Table 13. Demographic characteristics and CANE unmet needs

| | Unmet needs (N = 35) | No unmet needs (N = 32) | | | |
|---------------------------|---------------------------------|------------------------------------|----------|----------|-------|
| Mean | | | t | P | |
| Age | 74.2 (SD = 5.7) | 71.7 (SD = 6.7) | -1.654 | .103 | |
| Years in education | 11.27 (SD = 2.4) | 11.30 (SD = 3.5) | -.039 | .969 | |
| Frequency | Row % | Row % | χ^2 | P | |
| Men | 15 | 48.4 | 16 | 51.6 | 0.343 |
| Women | 20 | 55.5 | 16 | 44.5 | |
| Married | 13 | 39.4 | 20 | 60.6 | 4.300 |
| Unmarried | 22 | 64.7 | 12 | 35.3 | |
| Live alone | 18 | 62.1 | 11 | 37.9 | 1.980 |
| Live with others | 17 | 44.7 | 21 | 55.3 | |
| Usual doctor | 26 | 49.1 | 27 | 50.9 | 1.029 |
| Not usual doctor | 9 | 64.3 | 5 | 35.7 | |
| Practice 1 | 18 | 60.0 | 12 | 40.0 | 1.312 |
| Practice 2 | 17 | 63.0 | 20 | 37.0 | |

*p<.05

3.74 Association between CANE unmet needs and patient centredness**Hypothesis – Unmet needs are inversely related to patient centredness**

In order to test the hypothesis that higher levels of patient centredness would result in fewer unmet needs, two statistical analyses were performed. The mean patient centredness scores for participants with at least one unmet need were compared to the mean scores of those with no unmet needs using an independent samples t-test. The mean patient centredness score for participants who had at least one unmet need on the CANE (mean = 150.7, $SD = 26.4$) was actually higher than for those who had no unmet needs (mean = 145.4, $SD = 30.1$). No significant difference was found between these sets of scores ($t(64) = -.334$, $p = .740$). The likelihood of having at

least one unmet need was compared to ratings of the different factors of patient centredness, to see if any of the factors could independently predict this outcome. This was performed using logistic regression to assess the influence of each factor on likelihood of unmet need. Table 14 shows that none of the factors of patient centredness were significantly associated with unmet need, as measured by the CANE.

Table 14.

Association of unmet need and factors of patient centredness

| | B | S.E. | Wald | Df | Sig. | Exp (B) |
|--|-------|------|-------|----|------|---------|
| Communication and partnership | -.821 | .632 | 1.688 | 1 | .194 | .440 |
| Personal relationship | .264 | .453 | .339 | 1 | .560 | 1.302 |
| Health promotion | .407 | .511 | .634 | 1 | .426 | 1.502 |
| Positive and clear approach to problem | -.411 | .527 | .608 | 1 | .436 | .663 |
| Interest in effect on life | .058 | .438 | .018 | 1 | .894 | 1.060 |

3.75 Association between CANE unmet needs and patient satisfaction

Hypothesis – Unmet needs are associated with lower levels of satisfaction

The mean satisfaction ratings for participants who had no unmet needs on the CANE were compared with those who had at least one. Unusually, participants who had no unmet needs had a slightly lower mean satisfaction score (mean = 152.5, $SD = 27.1$) than those who had at least one unmet need (mean = 155.9, $SD = 24.5$).

3.76 Comparison of Consultation unmet need with CANE unmet need

The two types of unmet need were compared to see how many people who said that their needs had been met by the consultation, had actually left with unmet needs, as measured by the CANE. Table 15 shows the number of participants in each of these groups. For the purposes of this analysis, people who said that the consultation had met their needs “to some extent” (N = 5) were included in the group of people who said that the consultation had not met their needs (N = 3), giving a total number of 8 people in this group. Table 15 shows that almost half the sample felt that their needs had been met by the consultation, and had no unmet needs when measured with the CANE. However, a large proportion of the sample reported that the consultation had met their needs, but in fact had needs which remained unmet. A chi-square test showed this to be a significant association at $p < .05$ ($\chi^2 (1) = 4.527$, $p = .033$).

Only a small number of participants said that the consultation did not meet their needs, and all but one of these people had unmet CANE needs. This group of participants had wide ranging types of unmet need, the most common being need for help with mobility, physical health and information. On average, they were likely to have more unmet needs (mean = 4.0), than those who said the consultation had met their needs, but also had at least one CANE unmet need (mean = 2.6).

Table 15 Unmet needs from the consultation and as measured by CANE (N = 67)

| | CANE Unmet needs | CANE column % | CANE No unmet needs | CANE column % |
|-----------------------------|---------------------|---------------------|------------------------|---------------------|
| Consultation unmet needs | 7 | 20% | 1 | 3% |
| Consultation no unmet needs | 28 | 80% | 31 | 97% |
| Total | 35 | | 32 | |

3.8 MULTIVARIATE ANALYSIS

In order to examine which variables most strongly predicted whether or not someone had unmet needs as measured on the CANE after the consultation, a backwards stepwise logistic regression was performed. This enabled the factors that accounted for the least variance in the outcome to be excluded one at a time, until the strongest predictor of unmet need was identified. The factors that were entered into the analysis were chosen because of their association from previous statistical tests and their importance to the hypotheses. These factors were the "communication and partnership" factor of patient centredness, total satisfaction scores, gender, participant stating the consultation had met their needs, marital status and whether they lived alone or not. The results of this analysis are presented in Table 16. These results show that whether or not a person reported that the consultation had met their needs was the only potential predictor of the participant having any unmet needs as measured by the CANE after the consultation ($p = .067$).

Table 16. Backwards step-wise logistic regression of factors that influenced likelihood of CANE unmet needs

| Step | Factors | B | S.E. | Wald | Df | Sig. | Exp (B) |
|------|--------------------------|--------|-------|-------|----|------|---------|
| 1 | Patient centredness | .153 | .379 | .164 | 1 | .686 | 1.166 |
| | Satisfaction | .010 | .015 | .465 | 1 | .495 | 1.101 |
| | Gender | .101 | .578 | .031 | 1 | .861 | 1.106 |
| | Consultation unmet needs | .2082 | 1.171 | 3.163 | 1 | .075 | 8.018 |
| | Marital status | 1.299 | .958 | 1.839 | 1 | .175 | 3.665 |
| | Living arrangements | .603 | .951 | .402 | 1 | .526 | 1.828 |
| | Constant | -7.627 | 4.308 | 3.135 | 1 | .077 | .000 |
| 2 | Patient centredness | .141 | .373 | .143 | 1 | .705 | 1.152 |
| | Satisfaction | .010 | .015 | .464 | 1 | .496 | 1.010 |
| | Consultation unmet needs | 2.077 | 1.169 | 3.153 | 1 | .076 | 7.977 |
| | Marital status | 1.317 | .952 | 1.916 | 1 | .166 | 3.734 |
| | Living arrangements | .583 | .943 | .383 | 1 | .536 | 1.792 |
| | Constant | -7.401 | 4.101 | 3.257 | 1 | .071 | .001 |
| | Satisfaction | .014 | .012 | 1.205 | 1 | .272 | 1.014 |
| 3 | Consultation unmet needs | 2.025 | 1.161 | 3.042 | 1 | .081 | 7.573 |
| | Marital status | 1.355 | .945 | 2.057 | 1 | .151 | 3.877 |
| | Living arrangements | .590 | .942 | .393 | 1 | .531 | 1.804 |
| | Constant | -7.168 | 4.041 | 3.146 | 1 | .076 | .001 |
| | Satisfaction | .013 | .012 | 1.077 | 1 | .299 | 1.013 |
| | Consultation unmet needs | 1.974 | 1.153 | 2.933 | 1 | .087 | 7.200 |
| | Marital status | .879 | .542 | 2.626 | 1 | .105 | 2.408 |
| 4 | Constant | -5.319 | 2.691 | 3.908 | 1 | .048 | .005 |
| | Consultation unmet needs | 1.725 | 1.121 | 2.369 | 1 | .124 | 5.614 |
| | Marital status | .772 | .526 | 2.155 | 1 | .142 | 2.165 |
| | Constant | -2.928 | 1.340 | 4.773 | 1 | .029 | .054 |
| | Consultation unmet needs | 2.014 | 1.100 | 3.349 | 1 | .067 | 7.490 |
| | Constant | -2.083 | 1.191 | 3.059 | 1 | .080 | .125 |

3.8 SUMMARY

The data show that in this sample, neither patient centredness nor patient satisfaction were related to unmet needs. There was some evidence that patients who said that the consultation met their needs had higher ratings of patient centredness than those who said it did not, but the original hypothesis has not been supported. The data show that there was a significant relationship between ratings of patient centredness and satisfaction, supporting this hypothesis. No significant relationship was found between unmet needs as measured by the CANE and participants' ratings of satisfaction. Therefore, we can conclude that the hypothesis that people who had their needs met would be more satisfied was not supported.

CHAPTER FOUR

DISCUSSION

"Thirty-five years ago, when I was a medical student, we were taught to be paternalistic. We were trained to withhold information from patients...we were also instructed to take charge of interviews and to avoid getting "sidetracked" by patients' "irrelevant" concerns. The handbook that my university developed to teach the clinical method referred to the interview as "the interrogation." Patients who did not comply with "doctor's orders" were called defaulters, untrustworthy, unreliable or faithless."

P. Jaret, 2001

The present study was a survey of 67 people over the age of 65 visiting their GP to find out whether the doctor's patient-centred communication style impacted upon the outcome of the consultation, in terms of needs being met, and levels of satisfaction. The data showed that a doctor's patient centredness did not influence whether an older person's needs were met by the consultation, but it did affect how satisfied they were with their meeting with the doctor. This level of satisfaction was unrelated to the person's needs. Thus, one of the three original hypotheses was accepted.

4.1 FINDINGS

Unsurprisingly, most participants said that they were seeing their doctor for a physical health problem. A prescription was the number one expectation, the second and third were information and advice. Although most people said that they thought that the consultation had met their needs, attributing this mainly to the doctor's manner (e.g. "the doctor listened", "the doctor answered my questions"), half the sample actually left the consultation with at least one unmet need, as identified by the CANE assessment. The

most common unmet needs were information, sensory problems, and help with benefits. The few participants who were not satisfied with the consultation, and reported that it did not meet their needs, had a wide range of CANE unmet needs, most commonly for information, physical health, and mobility. Demographically, unmarried people had a greater chance of having unmet needs than married people, and there was a trend for unmarried people to report lower levels of satisfaction. In terms of patient centredness, men reported significantly higher levels than women did.

By comparing the results of this study to the literature I shall examine why no relationship was found between unmet needs and patient centredness and patient satisfaction, taking into account the influence of demographic variables and methodological limitations. I shall also compare the level and type of unmet need found in this study to previous studies and examine participants' perception of need. The implications these findings have for improving the quality of the doctor - older patient consultation will be discussed, along with suggestions for future research.

4.11 Patient centredness and demographic variables

This study's findings can be directly compared to those reported by Little et al. (2001) as the same measures of patient centredness and satisfaction were used. As that large-scale study examined GP consultations with adults of all ages, any differences in findings can be understood as age-related differences.

Most participants in this study rated their consultation as highly patient centred, which could be interpreted as evidence that the GPs in this study provided good quality healthcare to this sample of older people. However, participant age may have impacted

upon positive responding, as it has been shown that older people consistently respond more positively to evaluations of health care than younger people (Campbell et al. 2001). The responses to patient centredness statements were more positively polarized than in the Little et al (2001) study, and this may have also been affected by the method of data collection, as in this study the questionnaires were collected at follow-up interview, whereas Little et al. used an anonymous postal questionnaire.

Participants not answering statements about the doctor's patient centredness, can be interpreted as a desire to disagree, or say something negative or critical about the doctor (and not feel able to tick the appropriate box), or the patient not feeling that the statement had anything to do with their consultation. In the follow-up interview, a few participants said that some of the statements did not seem relevant to their consultation and they therefore left them blank, most frequently "advice on noticing disease early was omitted". Wensing and Elwyn (2002) have suggested that non-responders to health care evaluation may be more ill or less satisfied than those who do respond. It is not possible to compare this sample to Little et al's, as they did not provide such data, but they did provide data on how many of their participants responded "neutral" or "disagree" to particular statements. These responses may indicate that the doctor did not engage in these particular "patient centred" behaviours. The patient centredness statements in this sample that had the highest proportion of "neutral" or "disagree" responses were similar to those in the Little et al study, also suggesting that doctors are as patient centred with older adults as they are with younger adults. These were "the doctor talked about ways to lower the risk of future illness", "the doctor advised me on how to prevent future health problems", and "the doctor understands my emotional needs". Health promotion may not

feature prominently in GP consultations for adults of all ages, and it appears that it is not only older adults who are unsure about whether the doctor understands their emotional needs.

Male participants reported significantly higher levels of patient centredness than did women. This appears to be a characteristic of the older person - GP consultation as Little et al. did not find this in their study and previous evidence suggests that doctors spend less time with older women compared to younger women and that older women are less satisfied with the consultation than younger women (Mann et al., 2001). No difference in levels of satisfaction have been previously found between older women and older men however, and the high patient centredness ratings of the men in this study did not correspond with significantly higher levels of satisfaction. Doctors may be less patient centred with older women because of traditional social power roles resulting in younger male doctors being less intimate with older women about "personal" topics and thereby identifying fewer needs. This theory is supported by the finding that women had a greater likelihood of having unmet needs in comparison to men, although this difference was not significant. Older men may use their (usually male) GP as a resource to talk about problems that are more intimate whereas older females might use traditional female support networks and not expect intimacy from a GP. This difference in expectations could explain why there was no difference in satisfaction scores between men and women, since satisfaction is often related to expectations (Williams, 1994). Investigating the impact of doctor and patient gender on the patient centredness of GPs with older adults would help us understand this phenomenon further.

Participants did not give their own doctor a higher rating of patient centredness than when they were seeing a different doctor which suggests that a doctor does not have to know a patient in order to communicate with them in a patient centred way.

4.12 Patient centredness and CANE unmet need

The main hypothesis of this study was that a patient centred approach would lead to fewer unmet needs in older adults. This hypothesis was not supported as no significant association was found between the likelihood the of someone having at least one CANE unmet need after the consultation and total ratings of patient centredness, or any of the patient centredness factors. Current evidence for a causal link between patient centred communication and health outcomes is equivocal, as health outcomes may not be sensitive to the more interpersonal aspects of medical consultations. Mead & Bower (2002) proposed that a process-referent measure such as patient satisfaction might be a more sensitive indicator of the impact of doctors' communication style, as was shown in this study. There may be another aspect of the consultation that determines more of the variance of whether needs are met or not, than the doctor's communication style. As unmet need has not previously been measured as an outcome of a GP consultation, I can only speculate as to what these variables might be. We know that the information a patient offers the doctor is crucial (Hampton et al., 1975). In this model, it was hypothesized that a patient centred doctor would ask questions about the effect of the problem on the patient's life, thereby eliciting reporting of psychosocial as well as physical unmet needs from the patient. More than their consultation style; doctors' awareness of unmet needs in older adults may also affect whether they identify them.

Ageist attitudes towards treatment of health and social needs in older people and pressure to ration healthcare services based on age will also affect whether the doctor acts to address the unmet needs that are identified. As these factors were not investigated in this study, it is not possible to determine the extent of their influence. A patient's attitude towards their health and social care needs may act as a barrier to them offering personal information to the doctor, regardless of how wide the questioning is. There is evidence that older people do not seek help for unmet needs due to reasons of withdrawal, resignation, and low expectations (Walters et al., 2001), as well as not wanting to conform to the negative stereotypes of old age (Wenger, 1988; Siddell, 1995). These beliefs may also affect the doctor-patient relationship once help has been sought.

An alternative explanation for why patient centredness was not found to be related to unmet need is that the questionnaire may not have been a valid measure of this construct. There is little consensus about what patient centredness actually is (Mead & Bower, 2000b), and it may be that some other elements of this approach are more important than the ones covered by this measure.

4.13 Patient centredness and consultation unmet need

Although half the sample had at least one unmet need, only a small number of participants said that the consultation did not meet their needs, and they gave significantly lower ratings of patient centredness. Doctors may have been less patient centred towards these participants, leading to lower levels of satisfaction and a sense that their needs had not been met. Alternatively, this group of participants may have been exceptions to the norm of older people responding to surveys in a positive manner

(Campbell et al., 2001), answering in a realistic way that reflected their actual experience, as their CANE needs had not been met. Caution must be exercised when drawing conclusions from these findings though because of the small number of participants in this group.

4.14 Patient centredness and satisfaction

The hypothesis that a GP being patient centred would satisfy older people was supported by this study's findings. The factor of patient centredness, which most independently predicted satisfaction in this sample, was "communication and partnership". Little et al (2001) also found this to be significantly related to satisfaction, suggesting that older adults are satisfied with the same aspects of the doctor's communication style as younger adults, i.e. the doctor being interested in the patient's perspective of both the problem and treatment. This study also found that "interest in effect on life" was a significant predictor of satisfaction, but this was not found in Little et al's study, suggesting that older people are more satisfied when the doctor takes an interest in the effect of the problem on family/personal life, or on everyday activities than adults of all ages. In Little et al's study, the factor "positive and clear approach to the problem" was also an independent predictor of satisfaction but this was not found here. Older people may not be particularly influenced by whether or not a doctor is clear, definite about diagnosis, or positive about when a problem might settle. This may be because of the often complex and chronic nature of older people's ill health, which may have lowered older people's expectations for the consultation. There is evidence that older people trust doctors more than younger people so are happy to take whatever

treatment or advice the doctor offers, without a definite diagnosis or prognosis (Haug, 1996). However, older people are not a homogenous group, and older people's attitudes towards healthcare are likely to change over time and this must be considered when interpreting these results.

4.15 Satisfaction

Participants in this study were highly satisfied. This may indicate high quality healthcare from the GPs who participated, or it may reflect the positive association between age and reports of satisfaction. Williams (1994) suggested that the way in which patients assess satisfaction with medical care may be a function of factors other than actual quality of care received. For example, he argued that expectations have been found to have an independent effect on satisfaction, regardless of what a doctor actually does in the consultation. He also proposed that patient satisfaction could be said to reflect the role that patients adopt in relation to health professionals, irrespective of the quality of the care itself.

The relationship between marital status and satisfaction was close to significance and may not have been reached due to a lack of power. This finding may have related to the finding that married people were significantly less likely to have any unmet needs. This study did not find any association between CANE unmet needs (the dependent variable) and satisfaction and previous studies have also only found weak associations between health status and satisfaction (Hall and Dorman, 1990).

The overlap between the content of the patient centredness and patient satisfaction questionnaires must also be considered a limitation as it may have accounted for the high degree of association between these variables.

4.16 CANE unmet needs

Half the sample had unmet needs after they saw the GP. This is a comparable finding to studies of unmet need in the community (Walters et al., 2001; Brown et al., 1997) but it was expected to be lower considering the participants in this sample had just seen a GP.

A need for information about a condition or treatment was the most common unmet need as measured by the CANE in this sample and it was one of the top five unmet needs found by Walters et al (2001). A large-scale methodologically rigorous study of unmet needs in older people in the community however, did not find information to be one of the most common unmet needs (Iliffe et al, in preparation), possibly reflecting differences in the samples. A third of the sample had wanted information from the consultation yet half of these people did not have this need met. There is evidence that doctors do not provide older patients with as much information as they do to younger patients (Greene et al, 1994). It may be that doctors are unaware of this unmet need as older patients may not ask for information directly from the GP, perhaps preferring to accept as much as the doctor tells them (Haug & Ory, 1987). Yet the provision of information to the patient is at the heart of the patient centred approach to healthcare (Coulter, 2002) as it enables patients to participate in medical decisions (Laine & Davidoff, 1996).

Sensory difficulties with eyesight and hearing was also a common unmet need in this sample and is commonly reported as an unmet need in this age group (Brown et al, 1997; Walters et al., 2001; Iliffe et al. (in preparation)). Difficulties with eyesight or hearing may be attributed to the aging process and this may either discourage people from seeking help because they do not think there is much they can do (Walters et al. 2001), or, older people may not want to admit to problems in these areas, precisely because they are common problems in later life and they do not want to conform to this stereotype.

The finding that physical health was the fourth most common unmet need was surprising for a sample of people who had been to see their GP. This may have reflected the longstanding nature of illness for many older people or it may reflect poor communication between the doctor and the patient.

Seven out of eight people who said their needs were not fully met by the consultation had at least one unmet need as measured by the CANE, but half of those who said that the consultation had fully met their needs, also had at least one CANE unmet need. In the multivariate analysis, whether or not a participant perceived the consultation to have met their needs was most associated with likelihood of having CANE unmet needs. This suggests that these measures are related and that participants' perceptions of whether their needs were met are associated with whether they actually were, according to the CANE. The few people who did say that their needs had not been met did not attribute this to the doctor's manner, more that their questions were not answered, usually when they had specifically requested a diagnosis, or that the treatment they had been given had not worked. There was some evidence of the theme of "low

expectations" found by Walters et al (2001) with participants not really expecting that much could be done. There was no evidence of participants attributing their needs not being met to old age or rationing of services on the basis of age and it may be that many older people are simply willing to live with some unmet needs without expressing dissatisfaction. The data showed that people who did not feel that the consultation met their needs were more likely to have unmet mobility needs which accounted for over half the total unmet mobility needs in the whole sample. Walters et al (2001) found that older people were more likely to seek help for unmet mobility needs than any other type of need, suggesting that there is something important about mobility needs. It may be that older adults are more likely to seek help for problems that strongly impact upon functioning, such as mobility (including falls), and report dissatisfaction when these needs are not met. This group also had more unmet needs on average in comparison to those who said the consultation met their needs (even when it did not), suggesting that an accumulation of unmet needs or a disabling impact on function might move the individual to seek help or express dissatisfaction when help was not offered. Although we can speculate, there were so few people in this group it is not possible to make general conclusions about these findings and only further investigation will confirm these hypotheses.

Unmet needs were measured by the CANE in this study, but participants were also asked whether they thought the consultation had met their needs. When participants felt that their needs were met, they most frequently attributed this to the doctor's behavior or manner rather than technical expertise with only 3% of participants saying that the consultation had met their needs because they had been given a diagnosis, suggesting that

this is not what older people want. Although getting a prescription was the number one expectation from the consultation, only 8.3% of participants, who felt their needs had been met, cited this as the reason why the consultation met their needs. Overwhelmingly, participants said that the doctor listening, answering questions, taking his or her time, being reassuring, caring, or understanding was more important than "medical" intervention. This finding supports the notion that the doctor's response to the patient is the main effect of the doctor (Balint, 1964), in terms of whether the patient felt that their needs had been met.

4.2 LIMITATIONS

When making inferences about the statistical findings of this study, three issues of statistical validity must be addressed (Cook & Campbell, 1979). In this sample of 67 participants it was estimated that there was enough power to detect a difference in patient centredness and / or satisfaction scores between those who had at least one CANE unmet need and those who had none. However, levels of patient centredness and satisfaction were generally high whether or not the patients had unmet needs. The little variation in these scores would have reduced the power of the tests used and therefore it is possible that an association between unmet need and patient centredness or satisfaction was missed. The obvious way to increase power would have been to increase the sample size. The second issue is whether or not the right statistical tests were performed. In this study, when a set of scores had a non-normal distribution, attempts were made to address this problem (e.g. for the patient centredness and satisfaction scores, an outlier was removed and the distribution became normal) and when this was not possible, non-

parametric statistics were used. For example, scores of CANE unmet needs were skewed. As this skewness was so great, and because this made sense theoretically, no attempts to change the distribution were made. The third issue is the strength of covariation between variables. The finding that patient centredness was related to satisfaction was significant at the $p = .001$ level which was an expected finding given that previous studies have shown the two to be correlated.

The findings of this study could not be generalized to a broader UK population, rather than a London one, because of the lack of ethnic diversity and suburban setting. This study would be generalizable across other GP settings, but as participants in this study were generally cognitively intact, the findings might not generalize to people with dementia. Over the course of time it might be suggested that the expectations of older people will be higher and that they will demand more from their GP. Similarly, the next cohort of GPs will have undergone different training and will have experienced the emphasis on patient-centred care. So it is likely that in the future, GPs will be more aware of the role of doctor-patient communication and will probably be more patient centred, but older patients will be more demanding of their services. Coe (1986) suggests that future cohorts of elderly individuals may not be inclined to accept the doctor's authority in the way some do now (Haug & Ory, 1987).

A strength of this research design was the use of a self-report method to elicit perceptions of patient centredness and satisfaction, as this has the advantage of giving the respondent's own views directly, and these could be completed privately in their own time, ensuring confidentiality and potentially minimizing social desirability effects.

Conducting the follow up interview meant that it was possible to gain qualitative information from the participant to supplement their answers if they wanted.

The finding that patient centredness was not related to unmet needs but was highly related to satisfaction may have been due to the way in which it was measured. Participants in this sample may have given generally positive ratings of patient centredness that may not have reflected what actually took place in the consultation. Wensing and Elwyn (2002) suggest that when patients evaluate their healthcare, there is a difference between preference and experience. In this study, participants were asked for both these types of evaluations - "preference" through satisfaction, and "experience" through patient centredness. However, participants may have responded to the "experience" evaluation more in terms of how they would like the doctor to be ideally, rather than how he or she actually was, due to socially desirable responses and an unwillingness to "criticize" the doctor. Participants responded very positively to both of these questionnaires, possibly due to positive response sets or acquiescence and social desirability (Crowne & Marlowe, 1964). It is known that individuals sometimes respond to items on questionnaires in ways not specifically related to their content (Bradburn, 1983), due to a tendency to agree rather than disagree. This problem can be addressed by having an equal number of positively and negatively worded items in the questionnaire to cancel out acquiescence.

It may have been possible to increase the validity of the measurement if the constructs had been measured using different methods. Patient centredness could have been measured by semi-structured interview, in a similar way to unmet needs, and it could have been compared to ratings of tape recordings of the consultation. The reason

why I decided to assess patient centredness with the self-report questionnaire used was because it was standardized and had been shown to be a valid measure by previous studies, (Little et al, 2001) and assessment at the follow-up interview would have been prone to the problems of recall and anonymity. Furthermore, the purpose of the study was to examine the effect of the older person's perception of patient centredness on outcomes.

One of the problems with the Little et al questionnaire is that it is easy to see which is the answer that is most favourable to the doctor which puts it at a disadvantage as it is very easy to give socially acceptable answers (Skelton, 2001).

An important limitation of this study is the small sample size, which may have contributed to type II error. The impact of a patient centred approach on meeting needs might be a small one and therefore difficult to detect from a study of this size.

The major limitation of this type of survey is the difficulty in distinguishing between three potential explanations of outcome (Campbell et al, 2001). Firstly, the findings may reflect a high level of patient centredness by the GPs in this study and a high quality of care, resulting in high levels of satisfaction. Secondly, the findings may reflect an unwillingness to report unfavourable assessments in older adults. Lastly, high levels of reported patient centredness and satisfaction may reflect older adults' high expectations of GPs. Evidence for this is that the vast majority of older people said that the consultation fully met their needs, when half of the sample identified an unmet need upon administration of the CANE and there is a well reported association between age and favourable perception of care (Campbell, 2001, Phillips & Brooks, 1998; Baker, 1996).

4.3 IMPLICATIONS FOR FURTHER RESEARCH

This study can be considered a pilot study to examine the gross effect of the doctor's patient centredness on unmet need. Further studies could examine the net effect by using control or comparison groups to rule out the effects of possible confounding variables and examine which components of the intervention are actually responsible for needs being met. The design of this study was felt to be appropriate for the stage of the research and the research question, as the relationship between patient centredness and unmet need had not been explored before.

This study found that only a small group of participants felt that the consultation had not met their needs, despite half the sample having at least one unmet need. Further investigation of this group of people, and others like them, would increase our understanding of which unmet needs older people will live with without seeking help, and which are harder to tolerate. The findings of this study might lead us to hypothesize that an accumulation of unmet needs, and those that impact most upon function (such as mobility) might be more related to seeking help and dissatisfaction than others. It would also be interesting to investigate the mediating variable of health beliefs in this group to see how they differed from people who were satisfied despite their unmet needs.

This has been the first study to specifically investigate the patient centred approach with older adults. In order to evaluate the quality of the general practice consultation for older people, it would be advantageous to be able to compare these findings to a control group of adults under the age of 65 from the same GP surgeries.

4.4 IMPLICATIONS FOR CLINICAL PRACTICE

One of the most striking findings of this study is that many older people live with unmet needs, although why this happens is unclear. By making General Practitioners aware of this fact, and disseminating the growing literature on the most common unmet needs in older adults, GPs can be on the lookout for these problems.

This study did not find any evidence to support the hypothesis that a patient centred approach impacts upon health outcomes such as unmet need. However, a strong association was found between this approach and older people's satisfaction, suggesting that it is an approach that older people value. Specifically, older people want a doctor who listens and takes an interest in the effect of the medical problem on their life.

This study also found that older patients want, and often do not get, information about their condition or treatment. However, this was not found to be an important unmet need in a large scale CANE study (Iliffe et al., in preparation) and it must be remembered that fundamental to patient centred care is determining the appropriate amount of information and participation from the individual patient's perspective. The doctor must not assume that certain types of patients, based on age, ethnicity, or other factors, will favor or disfavor information.

Old age is a fluid concept and this cohort's attitudes and beliefs towards doctors and health may not be the same as the next. The same can be said for doctors' training and attitudes towards older patients as the traditional social roles between doctors and patients evolve. Therefore, the most common unmet needs of this age group should be monitored over time, and every effort made to address them.

4.5 CONCLUSION

This study gave older people a chance to feedback about their healthcare. It asked whether a widely advocated approach to doctor-patient communication resulted in beneficial outcomes for older people specifically. The answer was that a patient centred approach resulted in high levels of satisfaction, but did not appear to influence levels of unmet need. Three important findings arose from this study. Doctors in this study seemed to be patient centred with older people, who were generally very satisfied with their care. However, many older people were satisfied with a consultation and reported that it met their needs, even when it did not, suggesting that a proportion of people over the age of 65 are happy to just "live with" some unmet needs. Information was the second most desired outcome of the consultation and the number one unmet need. This may be a commonly overlooked need, but information is vital if older members of society are to participate in their health care decision making (as advocated by the patient centred approach) and move away from the stereotyped passivity of old age.

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APPENDICES

Appendix 1 - Letter of approval from Merton and Sutton Local Research Ethics Committee.

Appendix 2 - Letter to GP Practices

Appendix 3 - Consent form

Appendix 4 - Practice Protocol

Appendix 5 - Information for reception staff

Appendix 6 - Information sheet

Appendix 7 - Confidential Patient Questionnaire - demographic variables

Appendix 8 - Medical Interview Satisfaction Scale

Appendix 9 - Perception of Patient Centredness Questionnaire

Appendix 10 - Camberwell Assessment of Need for the Elderly

MERTON & SUTTON LOCAL RESEARCH ETHICS COMMITTEE

**Tel: 020 8296 3525
3165**

Fax: 020 8296

15 November 2002

Re: LREC No. 02/61

[Please quote above reference in all correspondence]

Ms. F. Smith

Dear Ms. Smith,

re: Meeting Unmet Needs in Older Adults: the Effect of a Patient Centred Approach on Outcomes of General Practice Consultations

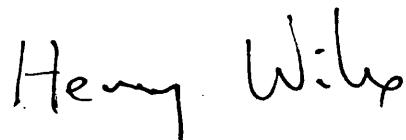
Thank you for your letter and enclosure of 11 November 2002 which deals with the Committee's recommendations very satisfactorily and I am happy to give approval to this study on behalf of the Committee.

LREC approval is given on the understanding that:

- i) the study is commenced within the next 12 months. Should the start of the study be delayed beyond this time, a re-application to the Committee will be required.
- ii) any change or amendment to the protocol will be reported to the Committee.
- iii) the Committee should be sent one copy of any publication arising from your study, or a brief report after completion if there is to be no publication. If the study lasts for more than a year, a brief annual report should be provided.

With best wishes,

Yours sincerely,



Dr Hervey Wilcox
Chairman
Local Research Ethics Committee

All correspondence to:

The Chairman, LREC, R&D Unit, St. Helier Hospital, Carshalton, Surrey SM5 1AA

APPENDIX 2



11th September 2002

Practice Manager [REDACTED]

London
SW [REDACTED]

Dear [REDACTED],

Re: Conducting research at [REDACTED] Medical Centre

Following our telephone conversation earlier on today, I am writing to you with the details of my proposed research project.

I am a Trainee Clinical Psychologist in the third year of my Doctorate in Clinical Psychology (D.Clin.Psy) at University College London. For my doctoral thesis, I am intending to carry out a piece of research investigating the effect of a patient centred approach on outcomes of general practice consultations for adults over the age of 65.

What I would require from the practice is access to patients over the age of 65 attending a GP consultation. I would like to interview them briefly before their consultation, and more extensively afterwards, either at the surgery or in their homes at a time that is convenient for them. I would not require access to patient records, nor would I want to observe any consultations.

I have enclosed a summary of my research proposal with this letter, which explains the purpose and method of the study in more detail. I have also enclosed a copy of the information sheet and consent form that will be given to potential participants, as well as a copy of my CV.

The research proposal has been submitted to Merton & Sutton Local Research Ethics Committee for their meeting on the 18th September.

I would be very grateful if the team would consider permitting me to conduct my research in your practice. I would be happy to come and talk to the General Practitioners about my proposal, and answer any questions they might have.

Many thanks for considering this request.

Yours sincerely,

Fiona Smith

APPENDIX 3**CONSENT FORM****MEETING UNMET NEEDS IN OLDER ADULTS: THE EFFECT OF A PATIENT CENTRED APPROACH ON OUTCOMES OF GENERAL PRACTICE CONSULTATIONS**

The patient or carer should complete the whole of this sheet himself/herself

Please tick appropriate box

Have you read the Patient Information Sheet? YES NO

Have you had an opportunity to ask questions and discuss this study? YES NO

Have you received satisfactory answers to all of your questions? YES NO

Have you received enough information about the study? YES NO

Who have you spoken to? Dr/Mr/Mrs

Do you understand that you are free to withdraw from the study:

- at any time?
- without having to give a reason for withdrawing?
- and without affecting your future medical care?

Do you agree to take part in this study? YES NO

Signed by patient (or carer) Date

Name in Block Letters).....

Signed by Investigator Date

Name in Block Letters)

APPENDIX 4

PRACTICE PROTOCOL FOR

MEETING UNMET NEEDS IN OLDER ADULTS: THE EFFECT OF A PATIENT CENTRED APPROACH ON OUTCOMES OF GENERAL PRACTICE CONSULTATIONS.

This document outlines the action that researcher Fiona Smith is required to take in the following circumstances:

| Circumstance | Action researcher required to take |
|--|---|
| A patient discloses information about their health that they have not told their doctor. | Researcher encourages patient to tell doctor about their problems. |
| A patient is upset about their GP consultation. | With participant's consent, researcher telephones GP to arrange another appointment for participant and GP. |
| A patient has a complaint about the consultation with their GP. | Researcher encourages patient to follow in-house complaint procedure. |
| Researcher suspects that patient is at risk of harm from themselves or others. | Researcher tells GP immediately and consults her supervisor. |
| Researcher suspects that others are at risk of harm from patient. | Researcher tells GP immediately and consults her supervisor. |

Signed on behalf of practice: _____ Date: _____

Signed by researcher: _____ Date: _____

APPENDIX 5

INFORMATION SHEET FOR RECEPTION STAFF AT

MEETING UNMET NEEDS IN OLDER ADULTS: THE EFFECT OF A PATIENT CENTRED APPROACH ON OUTCOMES OF GENERAL PRACTICE CONSULTATIONS.

Who is doing this research?

My name is Fiona Smith and I am a Trainee Clinical Psychologist studying at University College London. I am in the final year of my Doctorate in Clinical Psychology and I am interested in how effective the GP consultation process is for people over the age of 65.

What are you doing at . . . ?

I shall be interviewing people over the age of 65 who are willing to participate in this project **before and after** their consultations with their GP. I shall see people in a private room before their appointment to explain the study and answer any questions they might have. I shall then arrange a time to meet with them at their home after their appointment, to go through some questionnaires.

When will you be at ?

I shall be at **for one morning a week** from January to March 2003. Exactly which day is still to be confirmed, but it will probably be Tuesday. You will be informed in advance which days I shall be present in the surgery.

What help do you want from reception staff?

- It would be very helpful if whoever is on reception could **give an information sheet** about the study to each person over the age of 65 who attends on the afternoons when I am at the surgery.
- Could you please ask them **if it is okay for me to approach them to tell them more about the study** before they decide to take part.
- I will be on hand to answer any questions they may have, and to give them more information before they decide whether to participate.

Who has authorised this study?

This study has been approved by the Merton and Sutton Local Research Ethics Committee and by the Morden Hall GPs.

Many thanks for your help.

APPENDIX 6

INFORMATION SHEET

MEETING UNMET NEEDS IN OLDER ADULTS: THE EFFECT OF A PATIENT CENTRED APPROACH ON OUTCOMES OF GENERAL PRACTICE CONSULTATIONS.

We are conducting research into the effectiveness of the GP consultation process for people over the age of 65. This means that we are interested in the outcome of your doctor's appointment today.

If you choose to take part in this study, we will ask you about your meeting with the doctor today, any problems you have at the moment, and some basic details about yourself.

If you choose to take part in this study we would like to ask you a few questions BEFORE your appointment. This should only take a few minutes. AFTER your appointment we would like to ask you some more questions. This should take 30 to 60 minutes and this can be done here in the surgery or at your home, at a time that is convenient for you.

The information you give us will be held in strictest confidence. This means that it will be used for research purposes only, and all information will remain anonymous. None of your details will be given to anyone else, including your doctor, unless you give your permission.

If you decide to take part in this study, you may withdraw at any time without giving a reason.

The main researcher on this study is **FIONA SMITH**. If you have any questions, please do not hesitate to contact her on

Many thanks. With your help we can improve the care of people over the age of 65.

CONFIDENTIAL PATIENT QUESTIONNAIRE

This questionnaire asks about your visit to your GP and about you. **Please do not take too long over each question: your immediate thoughts are probably more accurate than long thought out answers.**

The answers are strictly confidential and will not be shown to your own GP or nurse, or to any other family member.

Q1. Your age: _____ years

Q2. Are you: Male Female

Q3. How would you describe yourself (please tick):

a. White

British

Irish

b. Mixed

White and Black Caribbean

White and Black African

White and Asian

c. Asian or Asian British

Indian

Pakistani

Bangladeshi

d. Black or Black British

Caribbean

African

e. Other (please specify):

Q4. How would you describe your marital status?

Married or living with a partner as if married?

Divorced or separated

Single

Widowed

Q5. Do you live:

Alone

With your partner

With other relatives

With others

Q6. In what type of residence do you live?

Flat

Sheltered housing

House

Residential home

Nursing home

Other

Q7. If you currently work or have worked, please give **very brief details of your current job** (or if unemployed or retired, your last job)

Q8. If you have or have had a partner who currently works or has worked, please give **very brief details of their current job** (or if unemployed, retired, or deceased, their last job)

Q9. How many years have you had in full time education since age 10? _____ years

Q10. Do you provide full time care for anyone? Yes No

Q11. Does anyone provide full time care for you? Yes No

Q12. Do you normally see this doctor when you come to the surgery?

Yes No

In the following section, please tick the box that applies to you.

Please tick a box for each statement, do not leave any out.

SATISFACTION WITH YOUR VISIT TO THE DOCTOR

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---------------------------|
| I was satisfied | <input type="checkbox"/> |
| The doctor gave a poor explanation of my illness. | <input type="checkbox"/> |
| The doctor told me just what my trouble is. | <input type="checkbox"/> |
| After talking with the doctor I know just how serious my illness is. | <input type="checkbox"/> |
| The doctor told me all I wanted to know about my illness. | <input type="checkbox"/> |
| I am not really certain about how to follow the doctor's advice. | <input type="checkbox"/> |

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|--|------------------------|-------------------|-------|---------|----------|----------------------|---------------------------|
|--|------------------------|-------------------|-------|---------|----------|----------------------|---------------------------|

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---------------------------|
| After talking with the doctor I have a good idea of how long it will be before I am well again. | <input type="checkbox"/> |
| The doctor seemed interested in me as a person. | <input type="checkbox"/> |
| The doctor seemed warm and friendly to me. | <input type="checkbox"/> |
| I felt that this doctor did not treat me as an equal. | <input type="checkbox"/> |
| The doctor seemed to take my problems seriously. | <input type="checkbox"/> |
| I felt embarrassed while talking with the doctor. | <input type="checkbox"/> |
| I felt free to talk to this doctor about private matters. | <input type="checkbox"/> |
| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The doctor gave me a chance to say what was really on my mind. | <input type="checkbox"/> |
| I felt really understood by my doctor. | <input type="checkbox"/> |
| The doctor did not allow me to say everything I had wanted about my problems. | <input type="checkbox"/> |
| The doctor did not really understand my main reason for coming. | <input type="checkbox"/> |
| This is a doctor I would trust with my life. | <input type="checkbox"/> |
| I would hesitate to recommend this doctor to my friends. | <input type="checkbox"/> |

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|--|---------------------|----------------|-------|---------|----------|-------------------|------------------------|
|--|---------------------|----------------|-------|---------|----------|-------------------|------------------------|

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The doctor seemed to know what (s)he was doing. | <input type="checkbox"/> |
| After talking with the doctor I feel much better about my problems. | <input type="checkbox"/> |
| The doctor has relieved my worries about my illness. | <input type="checkbox"/> |
| Talking with the doctor has not at all helped my worries about my illness. | <input type="checkbox"/> |
| The doctor has come up with a good plan for helping me. | <input type="checkbox"/> |
| The doctor visit has not at all helped me. | <input type="checkbox"/> |

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|--|---------------------|----------------|-------|---------|----------|-------------------|------------------------|
|--|---------------------|----------------|-------|---------|----------|-------------------|------------------------|

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The doctor seemed to know just what to do for my problem. | <input type="checkbox"/> |
| I expect that it will be easy for me to follow the doctor's advice. | <input type="checkbox"/> |
| I intend to follow the doctor's instructions. | <input type="checkbox"/> |
| It may be difficult for me to follow exactly what the doctor told me to do. | <input type="checkbox"/> |
| I'm not sure the doctor's treatment will be worth the trouble it will take. | <input type="checkbox"/> |
| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |

THE DOCTOR'S APPROACH TO YOU

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The doctor was interested when I talked about my symptoms. | <input type="checkbox"/> |
| The doctor was interested in what I thought the problem was. | <input type="checkbox"/> |
| The doctor ignored what I thought the problem was. | <input type="checkbox"/> |
| I'm confident that the doctor knows me and my history. | <input type="checkbox"/> |
| The doctor was interested in what I wanted to know. | <input type="checkbox"/> |
| The doctor was interested in what I wanted done. | <input type="checkbox"/> |

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|--|---------------------|----------------|-------|---------|----------|-------------------|------------------------|
|--|---------------------|----------------|-------|---------|----------|-------------------|------------------------|

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The doctor ignored what I wanted done. | <input type="checkbox"/> |
| The doctor discussed and reached agreement with me about what the problem really was. | <input type="checkbox"/> |
| The doctor was interested in my worries about the problem. | <input type="checkbox"/> |
| The doctor was interested in the effect of the problem on my personal/family life. | <input type="checkbox"/> |
| The doctor ignored the effect of the problem on my personal/family life. | <input type="checkbox"/> |
| The doctor clearly explained what the problem was. | <input type="checkbox"/> |
| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The doctor was interested about the effect of the problem on everyday activities. | <input type="checkbox"/> |
| The doctor ignored the effect of the problem on everyday activities. | <input type="checkbox"/> |
| The doctor was careful to explain clearly the plan of treatment. | <input type="checkbox"/> |
| The doctor discussed and reached agreement with me about the plan of treatment. | <input type="checkbox"/> |
| The doctor alone decided on the plan of treatment without discussion. | <input type="checkbox"/> |
| The doctor was interested in what treatment I wanted. | <input type="checkbox"/> |
| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The doctor advised me how to prevent future health problems. | <input type="checkbox"/> |
| Advice about preventing future health problems was omitted. | <input type="checkbox"/> |
| The doctor talked about ways to lower the risks of future illness. | <input type="checkbox"/> |
| The doctor discussed how to notice serious disease early e.g. meningitis, heart disease. | <input type="checkbox"/> |
| Advice on noticing serious disease early e.g. meningitis, heart disease was omitted. | <input type="checkbox"/> |
| The doctor knows and understands me well. | <input type="checkbox"/> |
| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |

| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| The doctor understands my emotional needs. | <input type="checkbox"/> |
| The doctor was sympathetic. | <input type="checkbox"/> |
| The doctor encouraged me to be positive. | <input type="checkbox"/> |
| The doctor was definite about what the problem was. | <input type="checkbox"/> |
| The doctor was positive about when the problem would settle. | <input type="checkbox"/> |
| I felt encouraged to ask questions. | <input type="checkbox"/> |
| | very strongly agree | strongly agree | agree | neutral | disagree | strongly disagree | very strongly disagree |

Any further comments

Thank you for completing this questionnaire

**CAMBERWELL
ASSESSMENT OF NEED
FOR THE ELDERLY**

CANE

Version IV

| | |
|------|--|
| CODE | |
|------|--|

| Interviewee | Date | Interview Time |
|-----------------|------|----------------|
| User | | |
| Carer | | |
| Staff | | |
| Rater/Clinician | | |

Background Details

(please fill in blanks, or circle whichever applies)

CODE NUMBER: _____

Date of Birth: _____ AGE: _____ (years)

SEX: male / female

ETHNICITY: Aslan/ African/ African-American/ Black Caribbean / White/
Other _____

RELIGION: Christian/Muslim/Hindu/Jewish/Other _____

FIRST LANGUAGE : English/Other _____

MARITAL STATUS: single / married / divorced / separated / widowed

LIVING SITUATION: alone / with partner / with other relatives / with others

LIVING ENVIRONMENT: flat / house / sheltered / residential / nursing / other

PREVIOUS OCCUPATION (or partner's): _____

EDUCATION: _____ (years)

CURRENT STATUS: in-patient / day-patient / community patient (Psychiatric / Geriatric/other)

MAIN DIAGNOSES (DSM-IV/ICD 10): _____

CURRENT MEDICATION: _____

DISEASE PREVENTION: (eg blood pressure/smoking/sleep pattern/exercise/health screening/vaccination)

DOES THE PERSON HAVE A CARER? yes / no

IS THE PERSON A CARER? yes / no

Instructions for the CANE

The CANE is a comprehensive, person-centred needs assessment tool that has been designed for use with the elderly. It is suitable for use in a variety of clinical and research settings. The CANE has a person-centred approach which allows views of the professional, user, and carer to be recorded and compared. The instrument uses the principle that identifying a need means identifying a problem plus an appropriate intervention which will help or alleviate the need. Therefore the CANE models clinical practice and relies on professional expertise for ratings to be completed accurately. Professional using the need to have an training and experience working with older people and an adequate knowledge of clinical interviewing and decision making. They should also have good working knowledge of the concepts of need, met need, and unmet need. This knowledge can be gained with experience of full CANE assessments and reference to the manual.

There are 24 topics relating to the user and two (A & B) relating to the carer. There are four columns to document ratings so that one or more of the user (U), staff member (S), carer (C), or rater (clinician/researcher) (R) can each express their view. Note at the top of the column which person has been interviewed.

SECTION 1:

This section aims to assess whether there is currently a need in the specific area. A need is defined as a problem with a potential remedy or intervention. Use the prompts below each area in *italics* on the record form to establish the user's current status with regards to the need area. If there has been a need then assess whether it was met appropriately. Score each interviewee independently, even though their perceptions of need in each area may differ from one another. The administrator should ask additional questions probing into the area until he/she can establish whether the person has a significant need that requires assistance and whether they are getting enough of the right type of help. Once this information has been gathered a rating of need can be made. Judgement of rating in this section should be based on normal clinical practice. The CANE is intended to be a framework for assessment grounded in good professional practise and expertise. Although Section 1 in each problem area is the main section of interest to CANE administrators, it often can not be rated until adequate information has been collected about the area. Indeed, some administrators have found it easier to rate section 1 once information has been collected from the other sections 2 to 5. When adequate information has been gathered the rater should clearly be able to make a clinical judgement as to whether the area is a met need, an unmet need, or is not a need for the person. Confusion with ratings can be avoided by not directly asking a closed question about whether there is a problem in a certain area (e.g., "Do you have any problems with the food here?") because the person can answer "No". This response may then be mistaken as a 'No Need' where in fact it is a 'Met Need' because the person is assisted by someone else.

- ◆ *No Need:* Score 0 there if there is no need in the area then go on to the next page. In this situation the user is coping well independently and does not need any further assistance. For example, the user has reported that they are successfully administering their own medication and do not have any problematic side effects. Or the staff member reports that the user appeared to be comfortable in his/her home environment and that no alterations to the building are needed or planned.
- ◆ *Met Need:* Score 1 if the need is met or if there is a minor need requiring no significant intervention. A need is met when there is a mild, moderate or serious problem which is receiving an intervention which is appropriate and potentially of benefit. This category is also used for problems which would normally not be of clinical significance and would not require a specific intervention. For example, the user is receiving an assessment for poor eyesight or a district nurse is overseeing the administration of medications each day.
- ◆ *Unmet Need:* Score 2 if the need is currently unmet. An unmet need is a serious problem requiring intervention or assessment, which is currently receiving no assistance or the *wrong* type or level of help. For example, if a staff member reported that the user was incontinent of large amounts of urine every night despite toileting twice during the night and the use of pads and further assessment or an intervention was required. Or a carer reported that the user had become very hard of hearing and had not received an assessment or suitable hearing aids.
- ◆ *Unknown:* Score 9 if the person does not know about the nature of the problems or about the assistance the person receives and go on to the next page. Such a score may mean that further information is needed to make a rating

For any topic if Section 1 is rated as 1 or 2 complete sections 2-4.

If Section 1 for the topic is rated as 0 or 9 do not complete sections 2-4 but go to the next topic area.

SECTION 2:

This section asks about assistance from informal sources during the past month. Informal sources include family, friends or neighbours. Use the examples on the assessment form to prompt the interviewee. Score 1 when assistance is given very occasionally or infrequently. Score 2 when assistance is given more frequently or involves more time/effort. Score 3 when assistance is given daily or is intensive (e.g., long periods of respite). Score 4 when assistance is very intensive and/or daily (e.g., family lives with the user and gives them full assistance with most tasks). Score 9 if the interviewee is unsure of the level of assistance provided.

SECTION 3:

- i). This section asks whether the user receives any assistance from local services to help with the problem. These formal supports are defined above to include paid carers, residential care, long-term wards, formal respite, day-care centres, hospitals, community psychiatric nurses or other staff. Use the examples on the assessment form to prompt the interviewee. Score 1 for minimal support, occasional, or light support. Score 2 for more regular assistance, maybe once a week or more significant support occasionally. Score 3 for specialist assistance, currently under assessment or more frequent assistance. Score 9 if the interviewee is unsure of the level of assistance provided. If the person is receiving more help than they require for a particular problem this suggests that there is over-provision for this need.
- ii). The second part to Section 3 asks what formal supports the interviewer feels the user *requires*, using the same scale as in (i) of Section 3. This second part indicates under-met need where the person is getting (part i) less than they require (part ii) or over-provision of need, where the person is getting (part i) a higher level of service than they require (part ii).

SECTION 4:

- i). This section asks whether the person feels that the user is receiving the right type of help with the problem. The answer to this question may have been obvious from the responses to the previous section, especially section 1. However, if in doubt ask more specifically. As well as highlighting unmet needs, this section can point out over-provision of needs, where the person reported that the user was receiving a higher level of assistance than they required.
- ii). The second question in Section 4 asks about the user's satisfaction with the assistance they are receiving. Again this may be obvious from prior responses, but please ask specifically.

SECTION 5:

This section is for noting the individual details of the assessment and the details of the help the user receives and requires (particularly the nature of the unmet needs identified) in order to formulate an action plan. Problems with current interventions or care plans and indicating plans in progress should also be documented in this section. Use codes to document which informant has provided the information (i.e., U = user, S= staff, C = carer, R = rater/professional). User perspectives on their expectations, personal strengths and resources should be noted here. Individual spiritual and cultural information should also be noted in this section. This information is vital for establishing an effective individualised care plan.

SCORING

It is to be noted that scoring is a secondary aspect of the CANE as its primary purpose is to identify and assess individual unmet needs. The total CANE score is based on the rating of section 1 of each of the 24 problem areas. The two areas (A and B) relating to carer's needs are not added into this total score. Count total number of met needs (rated as a 1 in Section 1), out of a maximum 24. Count total number of unmet needs identified (rated as a 2 in Section 1) out of a maximum score 24. Count total number of needs identified (rated as a 1 or 2 in Section 1), out of a maximum 24. The 'Raters' (clinicians or researchers) ratings are made based on all the information gathered through the assessment. Raters ratings of section 1 are used as the basis for total CANE scores.

| 1. ACCOMMODATION | | ASSESSMENTS | | | |
|---|---|---|-------|-------|-------|
| | | user | carer | staff | rater |
| DOES THE PERSON HAVE AN APPROPRIATE PLACE TO LIVE? | | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | | | |
| <i>What kind of home do you live in? Do you have any problems with accommodation?</i> | | | | | |
| 0 = NO NEED | e.g. Has an adequate and appropriate home (even if currently in hospital). No need for assistance with accommodation | | | | |
| 1 = MET NEED | e.g. Home undergoing adaptation/redecoration. Needs and is getting help with accommodation, e.g., in residential care, sheltered housing. | | | | |
| 2 = UNMET NEED | e.g. Homeless, inappropriately housed or home lacks basic facilities such as water, electricity, heating or essential alterations. | | | | |
| 9 = NOT KNOWN | | | | | |
| IF RATED 0 OR 9 GO TO QUESTION 2 | | | | | |
| HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH THEIR ACCOMMODATION | | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | | | |
| 0 = NONE | | | | | |
| 1 = LOW HELP | e.g. Occasionally does odd jobs concerning accommodation e.g., minor redecorations. | | | | |
| 2 = MODERATE HELP | e.g. Substantial help with improving accommodation such as organising redecoration or specific adaptations. | | | | |
| 3 = HIGH HELP | e.g. Living with a relative because own accommodation is unsatisfactory. | | | | |
| 9 = NOT KNOWN | | | | | |
| HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH THEIR ACCOMMODATION? | | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | | | |
| HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH THEIR ACCOMMODATION? | | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | | | |
| 0 = NONE | | | | | |
| 1 = LOW HELP | e.g. Minor redecoration; Referral to housing agency/ assisted housing. | | | | |
| 2 = MODERATE HELP | e.g. Major improvements; actively pursuing change in accommodation. | | | | |
| 3 = HIGH HELP | e.g. Being rehoused; living in supported accommodation residential care, nursing home or continuing care hospital ward. | | | | |
| 9 = NOT KNOWN | | | | | |
| DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH THEIR ACCOMMODATION (0 = NO 1 = YES 9 = NOT KNOWN) | | <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> | | | |
| OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH ACCOMMODATION? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN) | | <input type="checkbox"/> | | | |
| COMMENTS | | | | | |

| | | | | | |
|---------------------------|--|-------------|-------|-------|-------|
| 2. LOOKING AFTER THE HOME | | ASSESSMENTS | | | |
| | | user | carer | staff | rater |

| | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| DOES THE PERSON HAVE DIFFICULTY IN LOOKING AFTER THEIR HOME? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--|--------------------------|--------------------------|--------------------------|--------------------------|

Are you able to look after your home?

Does anyone help you?

| | |
|----------------|---|
| 0 = NO NEED | e.g. Independent in looking after the home, home may be untidy but kept basically clean. |
| 1 = MET NEED | e.g. Limited in looking after home and has appropriate level of domestic help. |
| 2 = UNMET NEED | e.g. Not receiving appropriate level of domestic assistance. Home is a potential health/fire/escape hazard. |
| 9 = NOT KNOWN | |

IF RATED 0 OR 9 GO TO QUESTION 3

| | | | |
|---|--------------------------|--------------------------|--------------------------|
| HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH LOOKING AFER THE HOME? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|---|--------------------------|--------------------------|--------------------------|

| | |
|-------------------|--|
| 0 = NONE | |
| 1 = LOW HELP | e.g. Prompts or helps tidy up or clean occasionally. |
| 2 = MODERATE HELP | e.g. Prompts or helps cleans at least once a week. |
| 3 = HIGH HELP | e.g. Does most or all of the household tasks. |
| 9 = NOT KNOWN | |

| | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH LOOKING AFTER THE HOME? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--|--------------------------|--------------------------|--------------------------|--------------------------|

| | | | | |
|---|--|--------------------------|--------------------------|--------------------------|
| HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH LOOKING AFTER THE HOME? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 0 = NONE | | | | |
| 1 = LOW HELP | e.g. Prompting / supervision by staff. | | | |
| 2 = MODERATE HELP | e.g. Some assistance with household tasks. | | | |
| 3 = HIGH HELP | e.g. Majority of household asks done by staff. | | | |
| 9 = NOT KNOWN | | | | |

| | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH LOOKING AFTER THE HOME? (0 = NO 1 = YES 9 = NOT KNOWN) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|--|--------------------------|--------------------------|--------------------------|--------------------------|

| | |
|--|--------------------------|
| OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH LOOKING AFTER THE HOME? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN) | <input type="checkbox"/> |
|--|--------------------------|

| |
|----------|
| COMMENTS |
|----------|

3. FOOD

ASSESSMENTS

user carer staff rater

| | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| DOES THE PERSON HAVE DIFFICULTY IN GETTING ENOUGH TO EAT? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|---|--------------------------|--------------------------|--------------------------|--------------------------|

*Are you able to prepare your own meals and do your own shopping?
Are you getting the right sort of food?*

| | |
|----------------|--|
| 0 = NO NEED | e.g. Able to buy and/or prepare adequate meals independently. |
| 1 = MET NEED | e.g. Unable to prepare food and has meals provided to met need. |
| 2 = UNMET NEED | e.g. Very restricted diet; culturally inappropriate food; unable to obtain adequate food; difficulty swallowing normal food. |
| 9 = NOT KNOWN | |

IF RATED 0 OR 9 GO TO QUESTION 5

| | | | | |
|---|---|--------------------------|--------------------------|--------------------------|
| HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH GETTING ENOUGH TO EAT? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 0 = NONE | | | | |
| 1 = LOW HELP | e.g. Occasional meal provided and/or occasional help with shopping. | | | |
| 2 = MODERATE HELP | e.g. Help with weekly shopping and/or meals provided more than weekly, but not daily. | | | |
| 3 = HIGH HELP | e.g. Assistance with food provided daily. | | | |
| 9 = NOT KNOWN | | | | |

| | | | | |
|--|--|--------------------------|--------------------------|--------------------------|
| HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH GETTING ENOUGH TO EAT | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH GETTING ENOUGH TO EAT | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 0 = NONE | | | | |
| 1 = LOW HELP | e.g. 1-4 meals a week provided or assisted for one meal a week. | | | |
| 2 = MODERATE HELP | e.g. More than 4 meals a week provided or assisted for all meals. Weekly shopping. | | | |
| 3 = HIGH HELP | e.g. All meals provided | | | |
| 9 = NOT KNOWN | | | | |

| | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH GETTING ENOUGH TO EAT? (0 = NO 1 = YES 9 = NOT KNOWN) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH GETTING ENOUGH TO EAT? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN) | <input type="checkbox"/> | | | |

| | |
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| COMMENTS | |
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5. CARING FOR SOMEONE ELSE

ASSESSMENTS

user carer staff rater

DOES THE PERSON HAVE DIFFICULTY CARING FOR ANOTHER PERSON?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

Is there anyone that you are caring for? Do you have any difficulty in looking after them?

0 = NO NEED e.g. No-one to care for or no problem in caring.

1 = MET NEED e.g. Difficulties with caring and receiving help.

2 = UNMET NEED e.g. Serious difficulty in looking after or caring for another person.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 6

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH LOOKING AFTER SOMEONE ELSE?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE

1 = LOW HELP e.g. Occasional help, less than once a week.

2 = MODERATE HELP e.g. Help most days.

3 = HIGH HELP e.g. Cared for person goes to stay with friends or relatives, assistance required everyday.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH CARING?

| | | |
|--|--|--|
| | | |
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HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH CARING?

| | | |
|--|--|--|
| | | |
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0 = NONE

1 = LOW HELP e.g. Person goes to day care: weekly assistance at home.

2 = MODERATE HELP e.g. Nearly daily assistance at home, on-going carer support/training for user

3 = HIGH HELP e.g. Respite care, 24 hour package or plans for alternative care for the cared for person.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH CARING? (0 = NO 1 = YES 9 = NOT KNOWN)

| | | |
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OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH CARING?

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(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

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6. DAYTIME ACTIVITIES

ASSESSMENTS

user carer staff rater

DOES THE PERSON HAVE DIFFICULTY WITH REGULAR,
APPROPRIATE DAYTIME ACTIVITIES?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

How do you spend your day? Do you have enough to do?

0 = NO NEED e.g. Adequate social, work, leisure or learning activities, can arrange own activities.

1 = MET NEED e.g. Some limitation in occupying self, has appropriate activities organised by others.

2 = UNMET NEED e.g. No adequate social, work or leisure activities.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 7

HOW MUCH HELP DOES THE PERSON RECEIVE FROM
RELATIVES OR FRIENDS IN FINDING OR KEEPING REGULAR
AND APPROPRIATE DAYTIME ACTIVITIES?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE

1 = LOW HELP e.g. Occasional help in arranging activities.

2 = MODERATE HELP e.g. Help at least weekly.

3 = HIGH HELP e.g. Daily help with arranging or providing activities.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL
SERVICES IN FINDING OR KEEPING REGULAR AND
APPROPRIATE ACTIVITIES?

| | | | |
|--|--|--|--|
| | | | |
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HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL
SERVICES IN FINDING OR KEEPING REGULAR AND
APPROPRIATE ACTIVITIES?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE

1 = LOW HELP e.g. Adult Education. Weekly day activity.

2 = MODERATE HELP e.g. Day centre 2-4 days a week. Day Hospital attendance.
Adequate activities 2-4 days week

3 = HIGH HELP e.g. Provision of suitable activity 5 or more days per week e.g., day hospital or day centre

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH
ACTIVITIES? (0 = NO 1 = YES 9 = NOT KNOWN)

| | | | |
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OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF
HELP THEY ARE RECEIVING WITH ACTIVITIES?

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COMMENTS

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7. MEMORY**ASSESSMENTS**

user carer staff rater

DOES THE PERSON HAVE A PROBLEM WITH MEMORY?

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|--|--|--|--|
| | | | |
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*Do you often have a problem remembering things that happened recently?
Do you often forget where you've put things?*

0 = NO NEED e.g. Occasionally forgets, but remembers later. No problem with memory.

1 = MET NEED e.g. Some problems, but having investigations / assistance.

2 = UNMET NEED e.g. Clear deficit in recalling new information: loses things: becomes disorientated in time and/or place, not receiving appropriate assistance.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 8

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR MEMORY LOSS?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE

1 = LOW HELP e.g. Prompting, occasional notes, reminders.

2 = MODERATE HELP e.g. Assistance / supervision most days.

3 = HIGH HELP e.g. Living with relative. Constant supervision.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR MEMORY LOSS?

| | | | |
|--|--|--|--|
| | | | |
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HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR MEMORY LOSS?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE

1 = LOW HELP e.g. Some advice/ assistance with memory, GP clinic reviews.

2 = MODERATE HELP e.g. Undergoing investigations. Regularly sees health care professional, e.g. Memory Clinic, Day Hospital, Specialist day facility. Modified environment.

3 = HIGH HELP e.g. Specially modified care because of memory needs. Intensive assistance.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR MEMORY LOSS? (0 = NO 1 = YES 9 = NOT KNOWN)

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR MEMORY LOSS?

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

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| |
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8. EYESIGHT / HEARING /COMMUNICATION

ASSESSMENTS

user carer staff rater

DOES THE PERSON HAVE A PROBLEM WITH SIGHT OR
HEARING?

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| | | | |
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*Do you have any difficulty hearing what someone says to you in a quiet room?**Do you have difficulty in seeing newsprint or watching television?**Are you able to express yourself clearly?*

0 = NO NEED e.g. No difficulties (wears appropriate corrective lenses or hearing aid, is independent).

1 = MET NEED e.g. Some difficulty, but aids help to some extent, receiving appropriate investigations or assistance to care for aids.

2 = UNMET NEED e.g. A lot of difficulty seeing or hearing, does not receive appropriate assistance.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 9

HOW MUCH HELP DOES THE PERSON RECEIVE FROM
RELATIVES OR FRIENDS WITH EYESIGHT/HEARING?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE

1 = LOW HELP e.g. Help making appointments for sight/ hearing problems. Occasional assistance

2 = MODERATE HELP e.g. Regular help with difficult tasks e.g. reading correspondence.

3 = HIGH HELP e.g. Help with most tasks that are difficult because of hearing/vision problem.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL
SERVICES WITH EYESIGHT/ HEARING

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL
SERVICES WITH EYESIGHT/ HEARING?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE

1 = LOW HELP e.g. Advice about impairment, aids provided or monitored.

2 = MODERATE HELP e.g. Investigations/ treatment. Aids regularly formally reviewed. Regularly assistance with tasks.

3 = HIGH HELP e.g. Assistance several days a week. Hospital appointments / specialist services or specialist day facilities.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH
EYESIGHT / HEARING? (0 = NO 1 = YES 9 = NOT KNOWN)

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF
HELP THEY ARE RECEIVING WITH EYESIGHT/ HEARING?

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

| | | | |
|--|--|--|--|
| | | | |
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9. MOBILITY / FALLS

ASSESSMENTS

user carer staff rater

DOES THE PERSON HAVE RESTRICTED MOBILITY, FALLS OR ANY PROBLEMS USING PUBLIC TRANSPORT?

*Do you have trouble moving about your home? Do you have falls?
Do you have trouble with transport?*

0 = NO NEED e.g. Physically able and mobile.

1 = MET NEED e.g. Some difficulty walking, climbing steps or using public transport, but able with assistance (e.g. walking aids, wheelchair). Occasional fall. Safety plan in place.

2 = UNMET NEED e.g. Very restricted mobility even with walking aid. Frequent falls. Lack of appropriate help.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 10

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR MOBILITY PROBLEMS

0 = NONE

1 = LOW HELP e.g. Occasional help e.g. with transport, support.

2 = MODERATE HELP e.g. Regular help with mobility/ public transport. Help organising home access alterations.

3 = HIGH HELP e.g. Daily help and supervision with mobility/ transport.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR MOBILITY PROBLEMS

HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR MOBILITY PROBLEMS?

0 = NONE

1 = LOW HELP e.g. Advice, one or more aids.

2 = MODERATE HELP e.g. Currently undergoing investigations and/ or O.T./ Physiotherapy assessments, regular transport, e.g. to day centre, light mobility assistance given.

3 = HIGH HELP e.g. Fully appropriate home alterations and aids. Substantial assistance most days. Care home because of mobility needs.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR MOBILITY PROBLEMS? (0 = NO 1 = YES 9 = NOT KNOWN)

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR MOBILITY PROBLEMS
(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

10. CONTINENCE**ASSESSMENTS**

user carer staff rater

DOES THE PERSON HAVE INCONTINENCE?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

*Do you ever have accidents/ find yourself wet if you can't get to the toilet quickly?
(How much of a problem? Ever any soiling? Are you getting any help?)*

0 = NO NEED e.g. No incontinence. Independent in managing incontinence.

1 = MET NEED e.g. Some incontinence. Receiving appropriate help/ investigations.

2 = UNMET NEED e.g. Regularly wet or soiled. Deteriorating incontinence needing assessment.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 11

HOW MUCH HELP DOES THE PERSON RECEIVE FROM
RELATIVES OR FRIENDS FOR INCONTINENCE?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE

1 = LOW HELP e.g. Prompts to maintain continence.

2 = MODERATE HELP e.g. Regularly assists with laundry, hygiene and use of aids.

3 = HIGH HELP e.g. Full assistance with continence (laundry, hygiene, aids).

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL
SERVICES FOR INCONTINENCE?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL
SERVICES FOR INCONTINENCE?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE

1 = LOW HELP e.g. Prompts to maintain continence and provision of aids.

2 = MODERATE HELP e.g. Investigations/ treatment. Regular help with laundry, hygiene and aids.

3 = HIGH HELP e.g. Planned medical intervention (e.g. surgery). Constant care and assistance because
of incontinence (e.g. in care home). Substantial continence programme in place.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR
INCONTINENCE? (0 = NO 1 = YES 9 = NOT KNOWN)

| | | |
|--|--|--|
| | | |
|--|--|--|

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF
HELP THEY ARE RECEIVING FOR INCONTINENCE?

| |
|--|
| |
|--|

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

| |
|--|
| |
|--|

11. PHYSICAL HEALTH**ASSESSMENTS**

user carer staff rater

DOES THE PERSON HAVE ANY PHYSICAL ILLNESS?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

*How well do you feel physically?**Are you getting any treatment from your doctor for physical problems?***0 = NO NEED**

e.g. Physically well. Receiving no medical interventions.

1 = MET NEED

e.g. Physical ailment such as high blood pressure under control, receiving appropriate treatment / investigation. Reviews of physical conditions.

2 = UNMET NEED

e.g. Untreated serious physical ailment. Significant pain. Awaiting major surgery.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 12

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR PHYSICAL HEALTH PROBLEMS?

| | | | |
|--|--|--|--|
| | | | |
|--|--|--|--|

0 = NONE**1 = LOW HELP**

e.g. Arranging appointments to see doctor.

2 = MODERATE HELP

e.g. Accompanied regularly to doctor / clinics.

3 = HIGH HELP

e.g. Daily help with condition arising out of physical health problems, e.g. living with a relative while convalescing or ill.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR PHYSICAL HEALTH PROBLEMS?

| | | | |
|--|--|--|--|
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HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR PHYSICAL HEALTH PROBLEMS?

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0 = NONE**1 = LOW HELP**

e.g. Given dietary or health advice. Occasional visit to GP for medicines.

2 = MODERATE HELP

e.g. Prescribed significant medications. Regularly seen by health care professional (GP, nurse, day hospital staff, out patient clinic).

3 = HIGH HELP

e.g. Inpatient admissions, 24-hour nursing care. Very regular or intensive treatment.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR PHYSICAL HEALTH PROBLEMS? (0 = NO 1 = YES 9 = NOT KNOWN)

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OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR PHYSICAL HEALTH PROBLEMS? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

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COMMENTS

NB: consider oral health, skin care and foot care particularly in those people who are very frail or who have chronic medical conditions

12. DRUGS**ASSESSMENTS**

user carer staff rater

DOES THE PERSON HAVE PROBLEMS WITH MEDICATION OR DRUGS?

Do you have any problems (e.g. side effects) with medication. How many different tablets are you on? Has your medication been recently reviewed by your doctor? Do you take any drugs that are not prescribed?

0 = NO NEED

e.g. No problems with compliance, side effects, drug abuse or dependency.

1 = MET NEED

e.g. Regular reviews, advice, District Nurse/ CPN administers medication, Dosette boxes/ aids

2 = UNMET NEED

e.g. Poor compliance, dependency or abuse of prescribed or non-prescribed drugs, inappropriate medication given.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 13

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH THEIR MEDICATION?

0 = NONE**1 = LOW HELP**

e.g. Occasional prompt. Advice about drug misuse.

2 = MODERATE HELP

e.g. Collection, regular reminding and checking of medication. Advice about agencies.

3 = HIGH HELP

e.g. Administers and holds medication. Support during drug withdrawal programme.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH THEIR MEDICATION?

HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH THEIR MEDICATION?

0 = NONE**1 = LOW HELP**

e.g. Advice from GP. Prompts to take medication.

2 = MODERATE HELP

e.g. Supervision by District Nurse/ CPN/ Day Hospital/ care facility administers drugs.

3 = HIGH HELP

e.g. Intensive program regarding drug administration, compliance, abuse, or dependency (e.g., supervised withdrawal programme for drug dependency).

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH MEDICATION? (0 = NO 1 = YES 9 = NOT KNOWN)

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH THEIR MEDICATION?

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

13. PSYCHOTIC SYMPTOMS

ASSESSMENTS

user carer staff rater

DOES THE PERSON HAVE SYMPTOMS SUCH AS DELUSIONAL BELIEFS, HALLUCINATIONS, FORMAL THOUGHT DISORDER OR PASSIVITY?

*Do you ever hear voices, see strange things or have problems with your thoughts?
Are you on medication for this?*

| | |
|----------------|---|
| 0 = NO NEED | e.g. No definite symptoms. Not at risk or in distress from symptoms and not on medication for psychotic symptoms. |
| 1 = MET NEED | e.g. Symptoms helped by medication or other help e.g., coping strategies, safety plan. |
| 2 = UNMET NEED | e.g. Currently has symptoms or is at risk. |
| 9 = NOT KNOWN | |

IF RATED 0 OR 9 GO TO QUESTION 14

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR THESE PSYCHOTIC SYMPTOMS?

| | |
|-------------------|--|
| 0 = NONE | |
| 1 = LOW HELP | e.g. Some support. |
| 2 = MODERATE HELP | e.g. Carers involved in helping with coping strategies or medication compliance. |
| 3 = HIGH HELP | e.g. Constant supervision of medication and helping with coping strategies. |
| 9 = NOT KNOWN | |

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR THESE PSYCHOTIC SYMPTOMS?

HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR THESE PSYCHOTIC SYMPTOMS?

| | |
|-------------------|---|
| 0 = NONE | |
| 1 = LOW HELP | e.g. Mental state and medication reviewed three monthly or less often, support group. |
| 2 = MODERATE HELP | e.g. Mental state and medication reviewed more frequently than three monthly. Frequent specific therapy e.g. day hospital, high CPN input. |
| 3 = HIGH HELP | e.g. Active treatment/ 24 hour hospital care, daily day care or crisis care at home. |
| 9 = NOT KNOWN | |

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR THESE SYMPTOMS? (0 = NO 1 = YES 9 = NOT KNOWN)

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR THESE SYMPTOMS?

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

14. PSYCHOLOGICAL DISTRESS

ASSESSMENTS

user carer staff rater

DOES THE PERSON SUFFER FROM CURRENT PSYCHOLOGICAL DISTRESS?

Have you recently felt very sad or fed up? Have you felt very anxious, frightened or worried?

0 = NO NEED e.g. Occasional or mild distress. Copes independently

1 = MET NEED e.g. Needs and gets on-going support.

2 = UNMET NEED e.g. Distress affects life significantly, e.g. prevents person going out.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 15

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR THIS DISTRESS?

0 = NONE

1 = LOW HELP e.g. Some sympathy and support.

2 = MODERATE HELP e.g. Has opportunity at least once a week to talk about distress and get help with coping strategies.

3 = HIGH HELP e.g. Constant support and supervision.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR THIS DISTRESS?

HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR THIS DISTRESS?

0 = NONE

1 = LOW HELP e.g. Assessment of mental state or occasional support.

2 = MODERATE HELP e.g. Specific psychological or social intervention for distress. Counselling by staff at least once a week e.g. at Day Hospital.

3 = HIGH HELP e.g. 24 hour hospital care, or crisis care at home, daily assistance for distress.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR THIS DISTRESS? (0 = NO 1 = YES 9 = NOT KNOWN)

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR THIS DISTRESS

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

15. INFORMATION (ON CONDITION & TREATMENT)

ASSESSMENTS

user carer staff rater

HAS THE PERSON HAD CLEAR VERBAL OR WRITTEN INFORMATION ABOUT THEIR CONDITION AND TREATMENT?

Have you been given clear information about your condition, medication or other treatment? Do you want such information? How helpful has the information been?

| | |
|----------------|--|
| 0 = NO NEED | e.g. Has received and understood adequate information. Has not received but does not want information. |
| 1 = MET NEED | e.g. Receives assistance to understand information. Information given that is appropriate for the person's level of communication / understanding. |
| 2 = UNMET NEED | e.g. Has received inadequate or no information. |
| 9 = NOT KNOWN | |

IF RATED 0 OR 9 GO TO QUESTION 16

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS IN OBTAINING SUCH INFORMATION?

| | |
|-------------------|---|
| 0 = NONE | |
| 1 = LOW HELP | e.g. Some advice. |
| 2 = MODERATE HELP | e.g. Given leaflets/ fact-sheets or put in touch with self help groups. |
| 3 = HIGH HELP | e.g. Regular liaison with mental health staff or voluntary groups (e.g. Alzheimer's Society) by friends or relatives. |
| 9 = NOT KNOWN | |

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?

HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?

| | |
|-------------------|---|
| 0 = NONE | |
| 1 = LOW HELP | e.g. Brief verbal or written information on illness/ problem/ treatment. |
| 2 = MODERATE HELP | e.g. Given details of self-help groups. Long verbal information sessions e.g. during Day Hospital attendance. |
| 3 = HIGH HELP | e.g. Has been given specific personal education with or without detailed written information. |
| 9 = NOT KNOWN | |

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN OBTAINING INFORMATION? (0 = NO 1 = YES 9 = NOT KNOWN)

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING IN OBTAINING INFORMATION? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

16. DELIBERATE SELF-HARM

ASSESSMENTS

user carer staff rater

IS THE PERSON A DANGER TO THEMSELVES?

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Do you ever think of harming yourself or actually harm yourself?

0 = NO NEED

e.g. No thoughts of self-harm or suicide.

1 = MET NEED

e.g. Suicide risk monitored by staff, receiving counselling, adequate safety plan in place.

2 = UNMET NEED

e.g. Has expressed suicidal intent, deliberately neglected self or exposed self to serious danger in the last month.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 17

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS TO REDUCE RISK OF DELIBERATE SELF HARM?

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0 = NONE

1 = LOW HELP

e.g. Able to contact friends or relatives if feeling unsafe.

2 = MODERATE HELP

e.g. Friends or relatives are usually in contact and are likely to know if feeling unsafe.

3 = HIGH HELP

e.g. Friends or relatives in regular contact and are very likely to know and provide help if feeling unsafe.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK OF DELIBERATE SELF-HARM?

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HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK OF DELIBERATE SELF-HARM?

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0 = NONE

1 = LOW HELP

e.g. Someone to contact if feeling unsafe.

2 = MODERATE HELP

e.g. Staff check at least once a week: regular supportive counselling.

3 = HIGH HELP

e.g. Daily supervision: inpatient care because of risk.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE RISK OF DELIBERATE SELF-HARM?

(0 = NO 1 = YES 9 = NOT KNOWN)

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OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING TO REDUCE RISK OF DELIBERATE SELF-HARM? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

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COMMENTS

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17. INADVERTENT SELF-HARM

ASSESSMENTS

user carer staff rater

IS THE PERSON AT INADVERTENT RISK TO THEMSELVES?

Do you ever do anything that accidentally puts yourself in danger (e.g. leaving gas taps on, leaving fire unattended or getting lost)?

0 = NO NEED e.g. No accidental self-harm.

1 = MET NEED e.g. Specific supervision or help to prevent harm: e.g. memory notes, prompts, secure environment, observation.

2 = UNMET NEED e.g. Dangerous behaviour, e.g. getting lost, gas/ fire hazard, no appropriate safety plan

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 18

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS TO REDUCE RISK OF INADVERTENT SELF HARM?

0 = NONE

1 = LOW HELP e.g. Periodic supervision: weekly or less.

2 = MODERATE HELP e.g. Supervision on 3-5 days a week.

3 = HIGH HELP e.g. Almost constant supervision/ 24 hour care because of risk.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK OF INADVERTENT SELF-HARM? HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK OF INADVERTENT SELF-HARM?

0 = NONE

1 = LOW HELP e.g. Check on behaviour weekly or less, risk assessment completed.

2 = MODERATE HELP e.g. Daily Supervision, specific plan to prevent harm

3 = HIGH HELP e.g. Constant supervision e.g. residential care because of risk for inadvertent self-harm.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE RISK OF INADVERTENT SELF-HARM?

(0 = NO 1 = YES 9 = NOT KNOWN)

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING TO REDUCE RISK OF HARM?

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

18. ABUSE/ NEGLECT**ASSESSMENTS**

user carer staff rater

IS THE PERSON AT RISK FROM OTHERS?

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Has anyone done anything to frighten or harm you, or taken advantage of you?

0 = NO NEED e.g. No abuse/ neglect issues over past month.

1 = MET NEED e.g. Needs and gets ongoing support or protection. Safety plan in place.

2 = UNMET NEED e.g. Regular shouting, pushing or neglect, financial misappropriation, physical assault.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 19

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS TO REDUCE RISK OF ABUSE?

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0 = NONE

1 = LOW HELP e.g. Occasional advice.

2 = MODERATE HELP e.g. Regular support and protection.

3 = HIGH HELP e.g. Constant support: very regular protection: negotiation.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK OF ABUSE?

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HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK OF ABUSE?

0 = NONE

1 = LOW HELP e.g. Someone to contact when feeling threatened.

2 = MODERATE HELP e.g. Regular support: occasional respite.

3 = HIGH HELP e.g. Constant supervision: legal involvement via services: separation from abuser.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE RISK OF ABUSE? (0 = NO 1 = YES 9 = NOT KNOWN)

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OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING TO REDUCE RISK OF ABUSE? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

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COMMENTS

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19. BEHAVIOUR**ASSESSMENTS**

user carer staff rater

IS THE PERSON'S BEHAVIOUR DANGEROUS, THREATENING,
INTERFERING OR ANNOYING TO OTHERS?

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Do you come into conflict with others e.g. by interfering with their affairs, frequently annoying, threatening or disturbing them? What happens?

0 = NO NEED e.g. No history of disturbance to others.

1 = MET NEED e.g. Under supervision / treatment because of potential risk.

2 = UNMET NEED e.g. Recent violence, threats or seriously interfering behaviour.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 20

HOW MUCH HELP DOES THE PERSON RECEIVE FROM
RELATIVES OR FRIENDS TO REDUCE ANNOYING OR
DISTURBING BEHAVIOUR?

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0 = NONE

1 = LOW HELP e.g. Help/ supervision weekly or less.

2 = MODERATE HELP e.g. Help/ supervision more often than weekly.

3 = HIGH HELP e.g. Almost constant help/ supervision due to persistently disturbing behaviour.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL
SERVICES TO REDUCE ANNOYING OR DISTURBING
BEHAVIOUR?

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HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL
SERVICES TO REDUCE ANNOYING OR DISTURBING
BEHAVIOUR?

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0 = NONE

1 = LOW HELP e.g. Check on behaviour weekly or less.

2 = MODERATE HELP e.g. Daily supervision or night-sitting service, active care plan in place.

3 = HIGH HELP e.g. Constant supervision: intensive behaviour management programme.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO
REDUCE ANNOYING OR DISTURBING BEHAVIOUR?

(0 = NO 1 = YES 9 = NOT KNOWN)

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OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF
HELP THEY ARE RECEIVING TO REDUCE DISTURBING
BEHAVIOUR? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

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COMMENTS

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20. ALCOHOL**ASSESSMENTS**

user carer staff rater

**DOES THE PERSON DRINK EXCESSIVELY OR HAVE A PROBLEM
CONTROLLING THEIR DRINKING?***Do you drink alcohol? How much? Does drinking cause you any problems?**Do you ever feel guilty about it? Do you ever wish you could cut down your drinking?***0 = NO NEED** e.g. Doesn't drink or drinks sensibly.**1 = MET NEED** e.g. At risk from alcohol abuse and receiving assistance.**2 = UNMET NEED** e.g. Current drinking harmful or uncontrollable, not receiving appropriate assistance.**9 = NOT KNOWN**

IF RATED 0 OR 9 GO TO QUESTION 21

**HOW MUCH HELP DOES THE PERSON RECEIVE FROM
RELATIVES OR FRIENDS FOR THEIR DRINKING?****0 = NONE****1 = LOW HELP** e.g. Advised to cut down.**2 = MODERATE HELP** e.g. Advised about helping agencies, e.g. Alcoholics Anonymous.**3 = HIGH HELP** e.g. Constant support and/ or monitoring of alcohol intake.**9 = NOT KNOWN****HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL
SERVICES FOR THEIR DRINKING?****HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL
SERVICES FOR THEIR DRINKING?****0 = NONE****1 = LOW HELP** e.g. Given information and told about risks.**2 = MODERATE HELP** e.g. Given support and details of helping agencies, access to drink is supervised.**3 = HIGH HELP** e.g. Attends alcohol clinic, supervised withdrawal programme.**9 = NOT KNOWN****DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR
THEIR DRINKING? (0 = NO 1 = YES 9 = NOT KNOWN)****OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF
HELP THEY ARE RECEIVING FOR THEIR DRINKING?****(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)****COMMENTS**

21. COMPANY**ASSESSMENTS**

user carer staff rater

DOES THE PERSON NEED HELP WITH SOCIAL CONTACT?

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Are you happy with your social life? Do you wish you had more social contact with others?

0 = NO NEED e.g. Able to organise enough social contact, has enough contact with friends.

1 = MET NEED e.g. Lack of company identified as a problem. Has specific intervention for company needs e.g., lonely at night but attends drop-in or day centre or Lunch Club. Social work involvement.

2 = UNMET NEED e.g. Frequently feels lonely and isolated. Very few social contacts.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 22

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH SOCIAL CONTACT?

| | | | |
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| | | | |
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0 = NONE

1 = LOW HELP e.g. Friends help with social contact or visit less than weekly to provide company.

2 = MODERATE HELP e.g. Friends help with social contact weekly or more often.

3 = HIGH HELP e.g. Friends help with social contact at least four times a week.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN ORGANISING SOCIAL CONTACT?

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HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN ORGANISING SOCIAL CONTACT?

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| | | | |
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0 = NONE

1 = LOW HELP e.g. Occasional visits from befriender or voluntary worker. Referral to centre.

2 = MODERATE HELP e.g. Regular attendance at day centre: regular luncheon club, organised social activity.

3 = HIGH HELP e.g. Day centre or social home visits 3 or more times a week, social skills training, social worker involvement.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH SOCIAL CONTACT? (0 = NO 1 = YES 9 = NOT KNOWN)

| | | | |
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| | | | |
|--|--|--|--|

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH THEIR SOCIAL CONTACT? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

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COMMENTS

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22. INTIMATE RELATIONSHIPS

ASSESSMENTS

user carer staff rater

DOES THE PERSON HAVE A PARTNER, RELATIVE OR FRIEND WITH WHOM THEY HAVE A CLOSE EMOTIONAL/ PHYSICAL RELATIONSHIP?

*Do you have a partner, relative or friend you feel close to? Do you get on well?
Can you talk about your worries or problems? Do you lack physical contact/ intimacy?*

| | |
|----------------|--|
| 0 = NO NEED | e.g. Happy with current relationships or does not want any intimate relationship. |
| 1 = MET NEED | e.g. Has problems concerning intimate relationships, specific plan, counselling/ advice/ support which is helpful. |
| 2 = UNMET NEED | e.g. Desperately lonely. Lack of confidant. |
| 9 = NOT KNOWN | |

IF RATED 0 OR 9 GO TO QUESTION 23

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH INTIMATE RELATIONSHIPS OR LONELINESS?

| | |
|-------------------|--|
| 0 = NONE | |
| 1 = LOW HELP | e.g. Occasional emotional support. |
| 2 = MODERATE HELP | e.g. Regular support. |
| 3 = HIGH HELP | e.g. Help contacting counselling services (e.g. bereavement/ marriage counselling) and possibly accompanying the person there. |
| 9 = NOT KNOWN | |

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH INTIMATE RELATIONSHIPS OR LONELINESS?

HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH INTIMATE RELATIONSHIPS OR LONELINESS?

| | |
|-------------------|--|
| 0 = NONE | |
| 1 = LOW HELP | e.g. Some support/ advice |
| 2 = MODERATE HELP | e.g. Regular support/ advice /contact. |
| 3 = HIGH HELP | e.g. Intensive support. Specific therapy, e.g. marital or bereavement counselling. |
| 9 = NOT KNOWN | |

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH RELATIONSHIPS? (0 = NO 1 = YES 9 = NOT KNOWN)

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH RELATIONSHIPS?

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

23. MONEY / BUDGETING**ASSESSMENTS**

user carer staff rater

DOES THE PERSON HAVE PROBLEMS MANAGING OR BUDGETING THEIR MONEY?

| | | | |
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Do you have any difficulty managing your money? Are you able to pay your bills?

0 = NO NEED e.g. Able to buy essential items and pay bills independently.

1 = MET NEED e.g. Benefits from help with managing affairs or budgeting

2 = UNMET NEED e.g. Often has no money for essential items or bills. Unable to manage finances.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 24

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS IN MANAGING THEIR MONEY?

| | | | |
|--|--|--|--|
| | | | |
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0 = NONE

1 = LOW HELP e.g. Occasional help sorting out household bills.

2 = MODERATE HELP e.g. Frequent assistance, calculating weekly budget, collecting pension.

3 = HIGH HELP e.g. Complete management of finances. Power of Attorney.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN MANAGING THEIR MONEY?

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HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN MANAGING THEIR MONEY?

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0 = NONE

1 = LOW HELP e.g. Occasional help with budgeting

2 = MODERATE HELP e.g. Supervised in paying rent, given weekly spending money

3 = HIGH HELP e.g. Virtual or complete management of finances: Court of protection:
Enduring Power of Attorney

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN MANAGING THEIR MONEY? (0 = NO 1 = YES 9 = NOT KNOWN)

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OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING IN MANAGING THEIR MONEY?

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(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

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24. BENEFITS**ASSESSMENTS**

user carer staff rater

IS THE PERSON DEFINITELY RECEIVING ALL THE BENEFITS
THAT THEY ARE ENTITLED TO?*Are you sure that you are getting all the money that you are entitled to?*

0 = NO NEED e.g. Has no need of benefits or receiving full entitlement of benefits.

1 = MET NEED e.g. Receives appropriate help in claiming benefits, social worker involvement over past month.

2 = UNMET NEED e.g. Not sure/ not receiving full entitlement of benefits.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO CARER'S SECTION OVERLEAF

HOW MUCH HELP DOES THE PERSON RECEIVE FROM
RELATIVES OR FRIENDS IN OBTAINING THEIR FULL BENEFIT
ENTITLEMENT?

0 = NONE

1 = LOW HELP e.g. Occasionally asks whether person is getting any money.

2 = MODERATE HELP e.g. Make enquiries about entitlements and help fill in forms.

3 = HIGH HELP e.g. Has ensured full benefits are being received.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL
SERVICES IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT?HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL
SERVICES IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT?

0 = NONE

1 = LOW HELP e.g. Occasional advice about entitlements.

2 = MODERATE HELP e.g. Help with applying for extra entitlements.

3 = HIGH HELP e.g. Comprehensive evaluation of current entitlement in past month.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN
OBTAINING THEIR FULL BENEFIT ENTITLEMENT?

(0 = NO 1 = YES 9 = NOT KNOWN)

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF
HELP THEY ARE RECEIVING IN OBTAINING THEIR FULL BENEFIT
ENTITLEMENT? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

| A. CARERS NEED FOR INFORMATION | ASSESSMENTS |
|--|---|
| | user carer staff rater |
| HAS THE CARER BEEN GIVEN CLEAR INFORMATION ABOUT THE PERSONS CONDITION AND ALL THE TREATMENT AVAILABLE? | <div style="display: flex; justify-content: space-around; align-items: center;"> Have you been given clear information about X's condition and all the treatment and services available? How helpful has this information been? <div style="display: flex; justify-content: space-around; width: 100px;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div> </div> |
| <p>0 = NO NEED e.g. Received and understood</p> <p>1 = MET NEED e.g. Has not received or understood all information, receives help with information.</p> <p>2 = UNMET NEED e.g. Has received little or no information, has not understood information given.</p> <p>9 = NOT KNOWN</p> | |
| <p>IF RATED 0 OR 9 GO TO QUESTION B</p> | |
| <p>HOW MUCH HELP DOES THE CARER RECEIVE FROM RELATIVES OR FRIENDS IN OBTAINING SUCH INFORMATION?</p> <div style="display: flex; justify-content: space-around; align-items: center;"> 0 = NONE <div style="display: flex; justify-content: space-around; width: 100px;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div> </div> | |
| <p>1 = LOW HELP e.g. Has had some advice.</p> <p>2 = MODERATE HELP e.g. Given leaflets/ fact sheets or put in touch with self-help groups.</p> <p>3 = HIGH HELP e.g. Regular liaison with doctors, other professionals, self help or support groups by friends or relatives.</p> <p>9 = NOT KNOWN</p> | |
| <p>HOW MUCH HELP DOES THE CARER RECEIVE FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?</p> | |
| <p>HOW MUCH HELP DOES THE CARER NEED FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?</p> <div style="display: flex; justify-content: space-around; align-items: center;"> 0 = NONE <div style="display: flex; justify-content: space-around; width: 100px;"> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> </div> </div> | |
| <p>1 = LOW HELP e.g. Brief verbal or written information on condition/ problem/ treatment.</p> <p>2 = MODERATE HELP e.g. Given details of self help groups. Personal explanations of drugs, alternative treatments/ services and likely course of the condition.</p> <p>3 = HIGH HELP e.g. Has been given detailed written information or has had specific personal education: e.g. from key worker.</p> <p>9 = NOT KNOWN</p> | |
| <p>DOES THE CARER RECEIVE THE RIGHT TYPE OF HELP IN OBTAINING SUCH INFORMATION? (0 = NO 1 = YES 9 = NOT KNOWN)</p> | |
| <p>OVERALL, IS THE CARER SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING IN OBTAINING SUCH INFORMATION? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)</p> | |
| <p>COMMENTS</p> | |

B. CARERS PSYCHOLOGICAL DISTRESS**ASSESSMENTS**

user carer staff rater

IS THE CARER CURRENTLY PSYCHOLOGICALLY DISTRESSED?

Do you find it difficult or stressful caring for X? Do you feel you need a break or much more support for yourself?

0 = NO NEED e.g. Coping well.

1 = MET NEED e.g. Some stress: receiving help/ contact/ support that is beneficial.

2 = UNMET NEED e.g. Very stressed or depressed. Wants relief from caring.

9 = NOT KNOWN

IF RATED 0 OR 9 FINISH

HOW MUCH HELP DOES THE CARER RECEIVE FROM RELATIVES OR FRIENDS FOR THIS DISTRESS?

0 = NONE

1 = LOW HELP e.g. Occasional advice/ support.

2 = MODERATE HELP e.g. Weekly practical and/ or emotional support and/ or relief from caring.

3 = HIGH HELP e.g. Regular respite and assistance with tasks (e.g. 3-4 times per week).

9 = NOT KNOWN

HOW MUCH HELP DOES THE CARER RECEIVE FROM LOCAL SERVICES FOR THIS DISTRESS?**HOW MUCH HELP DOES THE CARER NEED FROM LOCAL SERVICES FOR THIS DISTRESS?**

0 = NONE

1 = LOW HELP e.g. Advice e.g. about other options such as residential care.

2 = MODERATE HELP e.g. Weekly day care: occasional respite: CPN visits: carers support groups.

3 = HIGH HELP e.g. Regular respite admissions. Treatment and/ or counselling for stress/depression.

9 = NOT KNOWN

DOES THE CARER RECEIVE THE RIGHT TYPE OF HELP FOR THIS DISTRESS? (0 = NO 1 = YES 9 = NOT KNOWN)**OVERALL, IS THE CARER SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR THIS DISTRESS?**

(0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)

COMMENTS

CANE Summary Sheet

User Name: _____ Date: _____

(Section 2-4b rater's overall ratings)

| Section of the CANE | Section 1 Need | | | | Section 3b Help needed | Section 4a Type of help |
|---|----------------|---|---|---|---------------------------|----------------------------|
| | U | C | S | R | | |
| 1. Accommodation | | | | | | |
| 2. Looking after the home | | | | | | |
| 3. Food | | | | | | |
| 4. Self Care | | | | | | |
| 5. Caring for someone else | | | | | | |
| 6. Daytime activities | | | | | | |
| 7. Memory | | | | | | |
| 8. Eyesight / Hearing | | | | | | |
| 9. Mobility | | | | | | |
| 10. Incontinence | | | | | | |
| 11. Physical Health | | | | | | |
| 12. Drugs | | | | | | |
| 13. Psychotic symptoms | | | | | | |
| 14. Psychological distress | | | | | | |
| 15. Information | | | | | | |
| 16. Safety to self | | | | | | |
| 17. Inadvertant self harm | | | | | | |
| 18. Abuse / Neglect | | | | | | |
| 19. Behaviour | | | | | | |
| 20. Alcohol | | | | | | |
| 21. Company | | | | | | |
| 22. Intimate relationships | | | | | | |
| 23. Money/Budgeting | | | | | | |
| 24. Benefits | | | | | | |
| <i>A. Carers need for information</i> | | | | | | |
| <i>B. Carers psychological distress</i> | | | | | | |
| Met needs: Number of 1s in the column | | | | | | |
| Unmet Needs: Number of 2s in the column | | | | | | |

