A COMPARISON OF SERVICE AND NON-SERVICE DETERMINANTS OF CARERS' SATISFACTION WITH PALLIATIVE CARE SERVICES

Walid Khaled Hassan Fakhoury, BSc, MPH

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Department of Epidemiology and Public Health
University College London

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ABSTRACT

The association between carers' satisfaction with services delivered by district nurses (DNs), general practitioners (GPs), hospital doctors (HDs), and the health and social services in general (HSS), and various service and non-service variables was examined to assess whether satisfaction is more a reflection of the service characteristics, the non-service related factors, or attributable equally to both.

Analysis was undertaken on a sub-sample of the "Regional Study of Care for the Dying", a retrospective survey assessing the perceptions of 3696 carers of services delivered to deceased in their last year of life. The sub-sample consisted of 1858 carers of deceased who were relatives or close friends/neighbours, whose deceased died from cancer, and whose death was not sudden.

Satisfaction variables were derived from questions recorded in the survey. In bivariate and multivariate analysis, larger odds ratio were found in association with service than non-service variables.

For example, high satisfaction with DNs was strongly associated with visiting the patient very frequently (OR= 10.8, 95% CI= 4.5-25.9); and the GP visiting 20 times or more (OR= 5.5, 95% CI= 3.6-8.5), and informing the carer of the diagnosis (OR= 3.3, 95% CI= 2.3-4.7) were associated with high satisfaction with GPs.

Examples of non-service factor associations included, for example, good post-bereavement psychological state positively associated with high satisfaction with DNs (OR= 2.3, 95% CI= 1.6-3.4) and GPs (OR= 2.0, 95% CI= 1.4-2.8); while perceiving caring as rewarding as opposed to a burden was positively associated with high satisfaction with DNs (OR= 3.7, 95% CI= 1.8-7.5) and negatively associated with high satisfaction with hospital doctors (OR= 0.46, 95% CI= 0.24-0.86).

The findings reflect, in part, the literature on satisfaction in other areas of health care, but there are some differences, for example sociodemographic variables such as age, sex, religious denomination, and housing tenure were found to have no role in predicting satisfaction with DNs, GPs, and HDs.

In post-bereavement surveys evaluating palliative care, carers' satisfaction reflects service characteristics but it is also partly determined by important patient and carer characteristics.

"A major methodological concern about perception of care studies is the extent to which patient opinions accurately reflect care given. Here the issue is external validity. It is unfortunately quite difficult to assess whether patient opinion does reflect the quality of care.."

Lebow (1974)

"In Britain in particular, too little attention has been devoted to developing an understanding of the meaning of patient satisfaction, its potential uses, and its limitations."

Wilkin et al (1992)

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CONTENTS

LIST OF TABLES

ABBREVIATIONS

BFCG - Bereaved Familial Care Giver
CI - Confidence Interval
DN - District Nurses
FCG - Familial Care Giver
FSReg - Forward Stepwise Regression
GP - General Practitioner
HD - Hospital Doctor
HSS - Health and Social Services
MN - Malignant Neoplasm
MV-I - Multivariate Analysis Phase I
MV-II - Multivariate Analysis Phase II
OR - Odds Ratio
PCP - Primary Care Person
PFCG - Primary Familial Care Giver
PVS - Proportion of Variables Selected
RSCD - Regional Study of Care for the Dying
SPSS - Statistical Package for Social Science
UCL - University College London

CHAPTER 1

INTRODUCTION AND LITERATURE REVIEW

1.1. Introduction

Palliative medicine, a specialty within general medicine (Hillier, 1988), is concerned with the relief of physical symptoms and the provision of psychological care (Saunders, 1967). It is mainly directed towards people with cancer who when reaching the end-stage of illness require adequate medical and psychological care; patients with AIDS and others with long-term chronic diseases receiving only symptomatic treatment also benefit from palliative care (Abiven, 1991).

The change of focus to palliative rather than curative care for terminally ill patients is largely due to the influence of Dame Cecily Saunders, the leader of the modern hospice movement. This movement started in 1967 with the foundation of Saint Christopher's Hospice, and provided the model for modern hospice care in both the U.K. and North America.

In the past twenty five years, there has been a rapid increase in the number of specialist services for terminally ill cancer patients (Higginson and McCarthy, 1989). For instance, from 1988 to 1992, the number of independent hospices and NHS units has increased from 120 with over 2300 beds to 178 with almost 2900 beds; the number of support teams or support nurses working in the community or from hospitals has also increased from 250 to 520 (Directory of Hospice Services, 1988; 1992). Hospice care has developed from independent, charitable hospices towards greater reliance on NHS funding, and some hospices are now within the NHS hospitals (Hill and Oliver, 1988). Specialist palliative nurses provide counselling and support for families and advise community nurses and GPs on the management of dying patients. Multi-disciplinary support teams, including a doctor and nurses and sometimes a social worker, and administrator or volunteers, fulfil similar function (Bates et al, 1981). Specialist nurse teams are also developing in hospitals (Hockley et al, 1988). Some hospices have operated outpatient clinics to allow earlier referral, and day centres to relieve carers.

This expansion of palliative care has brought new challenges for accountability, research and evaluation (Dush and Cassileth, 1985). Hillier (1988) mentioned that those working in palliative care must be willing to submit themselves to audit and peer review. Higginson and McCarthy (1989) pointed out that in a climate of increased cost-effectiveness within the health services, hospice growth will not be supported by health authorities unless the care is evaluated.

Hence, there have been several important evaluative studies of palliative care in both Britain and North America (Higginson and McCarthy, 1989). As part of evaluating services delivered to dying patients, researchers have been interested in assessing the consumers' views of the services delivered. This led to an increase in the number of studies using patient and/or carer satisfaction as an outcome measure evaluating palliative care services.

Patient satisfaction with medical care services has been identified by the World Health Organization (1989) as an integral part of any quality assurance programme. In health services research, patient satisfaction is frequently used with the aim to formulate policies that would improve the organization of health services (Berkanovic and Marcus, 1976). Satisfaction with medical care can be viewed as an "ultimate validator of the quality of care" (Donabedian, 1966) which predicts patient behaviours related to the utilization of health services (Hays, 1985), continuity with provider (Baker, 1990), compliance with treatment and advice (Kincey et al, 1975; Ley, 1982), and retention and recall of medical information (Ley, 1982).

In the medical care field in general, a large body of research, both exploratory and explanatory, has been conducted in order to understand the correlates of patient's satisfaction (Lochman, 1983). In palliative care, most studies that used "satisfaction" as a measure have focused on evaluating the different providers involved in the delivery of this type of care (Hannon and O'Donnell, 1984; Kane et al, 1984; McCusker et al, 1984; Parkes and Parkes, 1984; Blanchard et al, 1986; Greer et al, 1986; Kristjanson, 1986; Wilkinson, 1986; Dunlop et al, 1989; Blanchard et al, 1990; Blyth, 1990; Cartwright and Seale, 1990; Herd, 1990; Higginson et al, 1990; Addington-Hall et al, 1991; Dawson, 1991; Addington-Hall et al, 1992; Field et al, 1992; Sykes et al, 1992; Butters et al, 1993). However, little attention has been paid to investigating the service and non-service predictors of satisfaction with the quality of care delivered, and the very few studies that looked at this area of research lacked comprehensiveness and were faced by major limitations (Blanchard et al, 1986; Kristjanson, 1986; Wilkinson, 1986; Blanchard et al, 1990).

It may be inappropriate to adapt what has been reported in the literature on the correlates of patient satisfaction with medical care in general to carers' satisfaction with palliative care, mainly because palliative care, as a specific type of care delivered to dying patients, is different from medical care in general in terms of its components.

The development of the modern hospice movement put emphasis on relieving patients' symptoms, and providing psychological support for both patient and family; it viewed both family members and dying patients as the unit of care (Saunders, 1978). This definition provided the foundation upon which the whole philosophy of palliative care is now based. In palliative care, psychosocial and emotional support are not delivered at the discretion of the medical staff, but rather constitute an indispensable component of care.

There are further differences. The outcome of palliative care is "death of patient" and not cure. The professional team is multidisciplinary, and includes doctors, nurses, social workers, health visitors and counsellors, chaplains, psychologists, physiotherapists, dieticians, pharmacists and volunteers (Portlock, 1984). Also, because of the nature of palliative care, more contacts are expected between the palliative care team members and family members and patients.

In the present analysis, predictors of informal carers' satisfaction with palliative care services will be assessed. The question is not whether carers were satisfied but rather what predisposed them to be so. If health planners and managers are going to act upon the results of studies evaluating palliative care services, they should be aware of the different service and non-service related factors predisposing carers' satisfaction.

1.2. An overview of the thesis

The first chapter in the thesis is divided into three parts. In the first part, the concept and dimensions of patient satisfaction are discussed. In the second part, a review of the correlates of patient's satisfaction with medical care in general is presented. The third part focuses on the main evaluation studies conducted in the palliative care field and in which satisfaction was used as an outcome measure. In this third part, studies that looked at the predictors of patient and/or carer satisfaction with palliative care will be reviewed.

Chapter 2 provides the aim, objectives and the research question of the thesis. Chapter 3 discusses the methodology and the analysis strategy adapted to answer the research question. In chapter 4, the results are presented, and will be discussed in chapter 5. Finally, the main findings of the study, as well as the general recommendations for future research will be presented in chapter 6.

1.3. Patient satisfaction : concept and dimensions

1.3.1. Conceptualization of patient satisfaction

Research into patient satisfaction has often been conducted without a proper theoretical framework, and with a lack of agreement on what satisfaction means, how it is determined, and what dimensions it encompasses (Wilkinson, 1986).

Ware et al (1983) suggest that "satisfaction" is a term that is defined differently by different individuals as a consequence of varying backgrounds and experiences. Pascoe (1983) considers satisfaction as a health care recipient's reaction to salient aspects of his/her experience of a service. To Linder-Pelz (1982), patient satisfaction is "the positive evaluations of distinct dimensions of the health care"; the care under evaluation could be a single clinic visit, treatment throughout an illness episode, a particular health care setting or plan, or the health care system in general. Linder-Pelz based the definition of satisfaction on the work done by Fishbein and Ajzen (1975) and Ware et al (1975).

Fishbein and Ajzen (1975) developed the "Expectancy-Value" theory, which states that "a person's attitude toward an object is related to his beliefs that the object possesses certain attributes and to his evaluations of those attributes". Satisfaction, in this theory, is viewed as an attitude which is affected by expectations (beliefs) and the value or importance of the outcomes related to these beliefs (Linder-Pelz, 1982).

The theory provided by Fishbein and Ajzen was later tested by Ware et al (1975) who constructed scales to measure beliefs and values. Ware et al (1975) developed an attitude measure, which consisted of the sum of the product of the measure of belief strength about attributes and the measure of evaluations of these attributes; they found a significant correlation between the attitude measure and direct measures of satisfaction.

However, when Linder-Pelz (1982) tested hypotheses regarding determinants of patient satisfaction among patients attending the primary care clinics of a university medical centre in Manhattan in the United States, no clear relationship was found between expectations and values on one hand and satisfaction on the other. Instead, Linder-Pelz argued that expectations are the most important antecedents to satisfaction.

The role of expectations in the judgment people make about quality of care has been extensively investigated by a number of researchers. Stimson and Webb (1975) indicated that satisfaction is related to how patients perceive the outcome of care and to the extent this outcome meets their expectations. Oberst (1984) proposed a framework of expectations explaining patient satisfaction with the quality of care; the theory is founded on the assertion that patients enter the health system with a variety of characteristics, attitudes and prior experiences which will be coupled with knowledge and information they got from the hospital and health professionals. This set of factors will allow them to delineate their situation and to define their perceived care needs. Hence, a set of expectations about care outcomes, caregiver behaviours, and system performance is formed. These expectations will be the standard against which the quality of care received will be judged.

Oberst (1984) indicated that people with low expectations tend to express little dissatisfaction compared to those with high expectations of care. However, the author stated that the relationship between expectations and satisfaction is not necessarily a direct one as was indicated by McKay et al (1973) who conducted a study on consumer satisfaction with a social work department. McKay et al showed that 80% of those whose expectations of a service were met were satisfied, but 50% of those whose expectations were not fulfilled were also satisfied.

Locker and Dunt (1978) explained McKay et al findings by drawing on Friedson's theory (1975) of differentiation between practical expectations and ideal expectations. Practical expectations are anticipated outcomes acquired from one's own experiences, reported experiences of others, and knowledge from other sources while ideal expectations are preferred outcomes stemming from one's own evaluation of his/her medical problem, and his/her aims of seeking medical care.

Thus, patients tend to be satisfied because their practical expectations are met, even though the care received does not meet both practical and ideal expectations. This was also suggested by Tagliacozzo et al (1972) who argued that patients form two sets of expectations : ideal expectations which can rarely be met in real-life and more realistic anticipations which take into account the more obvious limitations.

In addition, Locker and Dunt (1978) suggested that patient satisfaction is influenced by patient's knowledge and prior experiences, and that expectations are not static but likely to change with accumulating experience. Gutek (1978) also pointed out that expectations are likely to change with time and exposure. Hence, consumers' assessments of the services provided are expected to change over time with every contact they make because they will be acquiring more experience, information and knowledge about care, affecting future levels of satisfaction. The importance of prior experience and knowledge in affecting judgment of quality is also emphasized by Oberst (1984). Hence, Locker and Dunt (1978) concluded that the expressions of satisfaction are the end product of a comprehensive process of evaluation in which expectations play a very important but not the only role in the perception of the outcome of care.

However, Carr-Hill (1992) noted that expectations are always to be considered within the context of the patient-doctor relationship. Patients who acquire a dominant position in the medical encounter are more likely to pursue their goals (expectations), while those who feel powerless over the encounter are more likely to re-shape their goals to meet the new probable outcome. Thus, any measurement of goals (expectations) is to be done in the realm of the relationship between patients and health care agents.

Another model of individuals' satisfaction with health care was developed by Fox & Storm (1981). This model was based on three assumptions. First, orientations toward care differ from one person to another depending on what an individual wants from the provider and what he/her expects from the health care encounter. Second, providers of care differ in their conditions of care; the authors included under conditions of care the theoretical approaches to care, the situation of care, and outcomes of care. Third, if orientations and conditions are congruent, people are satisfied, if not, they are dissatisfied.

Calnan (1988) suggested another conceptual framework of lay evaluation of health care which is based on the following four elements : the goals of individuals seeking health care in each specific instance; the level and nature of individuals' experiences with health care; the socio-political values or ideologies upon which the particular health care system is based; and the images of health held by the lay population. Calnan proposes that all these elements will interact in the process of evaluation of health care.

Calnan (1988) noted that people's sociodemographic characteristics are excluded from this conceptual framework. He argued that these characteristics could be considered as mediatory elements, having effects on all the four elements. The relationship between age and satisfaction, for example, could be due to different health problems and experiences of health care associated with ageing, or may be related to different norms about health associated with different age groups, or connected to different ideological differences in the approach to care (Calnan, 1988).

This conceptual framework has been criticised by Carr-Hill (1992) who raised the issue of the difficulty of measuring the goals of patients seeking health care in each instance, especially since defining goals depends on people's prior experience and knowledge. Carr-Hill argued that satisfaction is a relative judgment resulting from comparing perceived health status and aspirations. Assessing the level of satisfaction alone is not enough to draw conclusions about the quality of care; both the levels of aspiration and self-perceived status need to be measured. According to Carr-Hill, patients might have unrealistic aspirations which cannot be met given available resources, and may also have a perceived health status which is different from their actual status.

The importance of aspiration and self-perceived health status was also reported by other researchers. Michalos (1985) developed the "Multiple Discrepancy Theory" and argued that the gap between aspiration and self-perceived health status is the principle contributory factor to satisfaction. This was contradicted by Wright (1985) who reported that calculated gaps between levels of aspiration and perceived health status were not correlated to satisfaction and that perceived current health status alone is the most important antecedent to satisfaction.

1.3.2 Dimensions of patient satisfaction

Ware and Snyder (1975) identified four common dimensions underlying patient attitudinal measures regarding doctors and medical care services : (1) physician conduct (humaneness and quality), (2) availability of services, (3) continuity/convenience of care, and (4) access mechanisms (cost, payment mechanism, and ease of emergency care). However, the authors mentioned that the effects of factors such as perceived health status, values, psychological well-being, and general sentiment about life were not taken into account and that other reliable dimensions of patient satisfaction might have been under-represented by the measures studied.

Ware et al (1978) conducted a comprehensive review of 111 articles that tackled consumer satisfaction with care. They looked at the different aspects of care studied in the literature, and suggested eight distinguishable items which were grouped according to the construct they were implicitly intended to measure. These items are : (1) art of care, (2) technical quality of care, (3) accessibility/convenience, (4) efficacy/outcomes of care, (5) finances, (6) physical environment, (7) availability, (8) continuity of care. Later on, Ware (1981) refined the eight-dimension model and suggested a five-dimension one. In the latter model, satisfaction was viewed in terms of (1) accessibility convenience, (2) finances, (3) physical environment, (4) availability, and (5) quality of care.

The multidimensional model of satisfaction developed by Ware et al has been criticised on a number of grounds. For instance, Oberst (1984) wondered whether all possible dimensions of care had been identified and criticized this model on the grounds that it lacks information on whether a hierarchy of satisfaction exists and if so, whether it can be identified. This hierarchy is expected to delineate the aspects of care that are more inherently satisfying and to determine which dimensions are most important. Oberst (1984) noted that even though evidence for such a hierarchy exits (Larsen and Rootman, 1976; Locker and Dunt, 1978; Tagliacozzo et al, 1978), it is unlikely to be stable over time. Cancer patients, for instance, experience a continuous shift of physical and psychological changes. These changes affect both the need for care and concomitant expectations of caregiver response (Oberst, 1984).

In addition, Wilkinson (1986) argued that Ware's concept of multi-dimensionality does not define satisfaction, but rather outlines the different aspects of care that were mostly investigated by researchers. She noted disagreement about this model of satisfaction, especially since researchers (Lebow, 1983; Pascoe, 1983; Oberst, 1984) reported the use of satisfaction as a uni-dimensional construct in some empirical studies. Wilkinson suggested the importance of assessing the dimensions that are more relevant to a particular facility or service, for not all dimensions are of equal importance in all types of services. For example, terminally ill patients treated in a hospital are expected to have more concerns for aspects of care related to physical surroundings, accessibility, availability, and so on than those treated at home (Wilkinson, 1986). Hence, the importance and relevance of dimensions is expected to differ across the different facilities and services. This was also suggested by

Williams and Calnan (1991) who argued that there are aspects of satisfaction which are specific to each area of health care.

1.3.3. Conclusion

No definite conceptual framework for patient satisfaction is provided in the literature. Patient satisfaction was explained by drawing on the "Expectancy-Value" theory formulated by Fishbein and Ajzen (1975). Even though this theory was quantitatively proven by Ware et al (1975), Linder-Pelz (1982) failed to detect a significant relationship between expectations and values on one hand and satisfaction on the other, arguing that expectations are the most important antecedents to satisfaction.

Research has also focused on the dimensionality of satisfaction. A multi-dimensionality concept of satisfaction has been proposed (Ware et al, 1978; Ware, 1981). However, this concept did not define satisfaction in any way, but rather outlined the different aspects of care that were most frequently investigated in the field (Wilkinson, 1986). Despite the fact that researchers have accepted the factorial composition of satisfaction, little agreement is found on its dimensions (Pascoe, 1983; Wilkinson, 1986; Williams and Calnan, 1991).

1.4. Patient satisfaction : overview of the field

Patient satisfaction, a reflection of the impact of the service on individuals and communities (Donabedian, 1966), is frequently used in the field of public health as an important outcome of the quality of care (Donabedian, 1966; Zastowny et al, 1983; Leger et al, 1992).

Patient satisfaction is believed to be determined, at least in part, by the structural and the process components of the quality of medical care (Donabedian, 1966; Tarlov et al, 1989). As defined by Donabedian (1966), the **structure** of a service describes "the setting in which the intervention takes place and the instrumentalities of which it is the product", while the **process** is "those activities triggered by any patient who enters the health care system".

To have a better understanding of what is actually happening in the patient satisfaction field, Hall et al (1988a; 1988b) conducted two meta-analysis on research assessing patient satisfaction. In the first meta-analysis, Hall et al (1988a) focused on 221 studies that assessed satisfaction. Studies were included in the meta-analysis if (1) they were stated by their authors to measure patients' satisfaction with medical care or used measures that were indistinguishable from satisfaction measures used in other studies, (2) satisfaction was measured quantitatively, (3) at least one correlate of satisfaction was reported, (4) sample size exceeded 10, and (5) they appeared in an English language book or journal.

Findings indicated that (1) only in 14% of the studies, satisfaction was related to experimentally manipulated variables, the others were observational, (2) in 43% of studies patients were directly asked about their satisfaction with a particular aspect of care, (3) 52% of all the studies focused on particular events or episodes of care (such as hospital stay or visit), (4) 42% investigated satisfaction with ambulatory care compared to other types of care, (5) 65% of the studies were interested in assessing satisfaction with humaneness, 50% with informativeness, and 45% with the overall quality of care, (6) 45% of all studies covered two to four aspects of care compared to 6% that covered eight to eleven aspects, and (7) 71% of all studies used "self-designed" instruments compared to 26% that used instruments provided in the literature. Patients were more dissatisfied with services provided by interns or residents compared to physicians with post-graduate training; greater satisfaction was linearly associated with the specificity of the event being judged (satisfaction with a specific type of medical care), which explains the lowest satisfaction scores when assessing satisfaction with medical care in general. Patients were more satisfied if they were sampled from a health care system rather than the community at large; the number of items in the satisfaction measure was negatively related to satisfaction, indicating that the more the aspects covered by the instrument, the less the level of satisfaction; and finally, highest satisfaction was detected by "self-designed" instruments than by instruments adapted from the literature.

The major recommendations of this meta-analysis, as stated by Hall et al, were the need to have : (1) more complete reporting of sample characteristics and of satisfaction results (both satisfaction mean data and correlations with other variables), (2) more studies of infrequently studied groups (e.g. elderly patients, non-medical providers, etc), (3) more studies that measure infrequently measured aspects of satisfaction (e.g. satisfaction with handling psychological problems, outcomes of care), and (4) more frequent incorporation of satisfaction measures into randomized studies, so that causal determinants of satisfaction can be uncovered rather than simple correlations of satisfaction with other variables.

In the second meta-analysis, Hall et al (1988b) assessed what patients like about medical care and how often they are asked about it. The research team analyzed the various aspects that were investigated in 221 studies on patient satisfaction. Ranking the items according to the number of times they were investigated in the literature indicated that humaneness, technical and overall quality of care were ranked at the top whereas aspects of non-physical needs occupied lower ranks. Hall et al gave a two-fold explanation for the ranking results : (1) because satisfaction is considered as a powerful predictor of system performance, more attention is being paid to the technical part for evaluation purposes to the relative neglect of patients' needs, and that (2) people tend to value highly technical care either out of total ignorance of the content of technical care or out of total conviction that they have chosen the best service in terms of quality. As far as the frequencies of the studies in which the different aspects of satisfaction were mentioned, it was indicated that the most frequently studied aspects tend to be at the process level, followed by the structural aspects and that only 3% of all studies assessed satisfaction with psychological support, emphasizing the need for more studies in this area if we are to have a better understanding of overall satisfaction with medical services.

1.5. Factors affecting patient satisfaction with medical care

As indicated earlier (section 1.4.), satisfaction is affected by both the structural and process elements of the quality of care. However, studies have also focused on patient characteristics, both sociodemographic and psychosocial, as important variables affecting satisfaction. In the next section, the effect of the structural and process elements of the quality of care on patient satisfaction will be reviewed, followed by that of the patient characteristics.

1.5.1. Structural elements

Some studies on satisfaction with medical care have addressed the issue of the effects of the structural components of care on patient satisfaction. Variation in both the process and outcomes of care can be highly affected by these variables (Tarlov et al, 1989). However, these components have been perceived by researchers to be of less importance when compared to the process elements of care, which are expected to reflect the aspects of care that are related directly to the patient-provider interaction (Segall and Burnett, 1980; Hall et al, 1988b).

Factors such as the organization of the setting in terms of specialty mix, financial incentives, efficiency of service, workload, and so on (Greenly & Shoenherr, 1981; Linn et al, 1985), access and convenience (Kaim-Caudle, 1975; Gray, 1980; Fox & Storm, 1981; Patrick et al, 1983; McCarthy et al, 1988), and mode of payment

(Gray, 1980; Ross et al, 1981; Dutton et al, 1990) have been found to be associated with patient satisfaction. The effects of the structural characteristics on patient satisfaction have been reviewed by Lochman (1983).

1.5.2. Process elements

Tarlov et al (1989), in the Medical Outcomes Study, identified two main components of the process of care : (1) technical and (2) interpersonal style. The technical style refers to doctor competence, and includes characteristics such as medications prescribed, referrals made, test ordering, hospitalization rates, and coordination of care. The interpersonal style refers to the doctor-patient relationship, and includes characteristics such as interpersonal manner, patient participation, counselling and communication.

Even though there is a general agreement that the process elements consist of technical competence and interpersonal relationship as two distinct categories, Ware and Snyder (1975) indicated the presence of an overlap between the "humaneness" aspect and the "quality/competence" aspect reflecting a general attitude toward the way doctors conduct themselves with patients.

The literature showed that patient satisfaction is related to both physician competence and the doctor-patient relationship (Gray, 1980; Wartman et al, 1983; McCarthy et al, 1988; Brody et al, 1989; Rashid et al, 1989; Baker, 1990; Wiggers et al, 1990). As an important aspect of the doctor-patient relationship, communication has been shown to be closely related to satisfaction (Ley et al, 1973; Kincey et al, 1975; Ley et al, 1976). The literature on patient-doctor verbal interaction indicated the importance of two aspects in affecting patient satisfaction: (1) physician's understanding of the patient's concern (Liptack et al, 1977; Stewart et al, 1979), and (2) doctor giving the patient all information the latter wanted on illness and treatment (Stiles et al, 1979). The importance of the clarity of patients' communication to physicians is still a controversial issue, especially since some studies did show a significant correlation between physician's awareness of patients' concerns and patient satisfaction (Romm et al, 1976; Liptack et al, 1977), while others failed to demonstrate this correlation (Romm et al, 1979; Stewart et al, 1979). DiMatteo et al (1980) showed that the ability of doctors to decipher various affective states through non-verbal cues was significantly related to patients' satisfaction with the socio-emotional aspects of the physician role. Carter et al (1982) stressed the importance of behaviours revealing tension on patient satisfaction, and indicated that tense behaviours of both patients and doctors were negatively associated with satisfaction, and that the timing of certain behaviours was also found to be associated with satisfaction. For example, if patient requests for medication occur early in the encounter, this behaviour is positively related to subsequent patient satisfaction; however, if they occur in the concluding segment, a negative relationship results.

Stiles et al (1979) indicated that affective satisfaction, measured by items assessing physician's warmth and the patients' feelings of trust, confidence and freedom to express themselves, was associated with the transmission of information from patient to physician in "exposition" exchanges during the medical history, in which the patients told their story in their own words. Cognitive satisfaction, measured by items assessing the physician's function of giving information and the patient's understanding of diagnosis, etiology, prognosis, and treatment, was associated with transmission of information from physician to patient in "feedback" exchanges during the conclusion segment of the interview, in which physicians gave patients information about illness and treatment. Stiles et al (1979) noted that their findings is in agreement with Szasz and Hollender's (1956) model of "mutual cooperation" where the success of the medical interaction depends on both patient and provider, as well as in agreement with Lazare et al (1975) model of the "customer approach" of patient care where the physician has the role of eliciting and understanding patient needs if the patient is to be satisfied.

The results of these studies demonstrating the importance of the process elements in determining satisfaction have been supported by the results of the meta-analysis conducted by Hall et al (1988c) on the correlates of patient-provider interaction in medical encounters. The authors studied the results of forty-one studies containing correlates of objectively measured provider behaviours in medical encounters. The research team identified six process categories which are : (1) information giving, (2) questions, (3) competence, (4) partnership building (both technical and interpersonal), (5) socio-emotional behaviour, and (6) amount of communication. For each process category, several variables were identified. The relation between providers' behaviours in medical encounters and six variables external to the encounters were studied. These variables were (1) patient satisfaction, (2) compliance, (3) recall, (4) patient attributes of social class, (5) gender and (6) age. The research team calculated average correlations and combined significance levels for each combination of process category and external variable. Even though there were significant relations ranging from small to moderate average magnitude between these external variables and almost all of the provider behaviour categories, the study showed that satisfaction had the most consistent relation to provider behaviour. Satisfaction was related to the amount of information given by providers, to greater technical and interpersonal competence, more partnership building, more immediate and positive non-verbal behaviour, more social conversation, more positive talk, less negative talk, and more communication overall, emphasizing that satisfaction with care is a reflection of both task and socio-emotional behaviours of providers.

1.5.3. Patient characteristics

In this section, patient characteristics will be grouped into two categories: (1) patient sociodemographic characteristics and (2) patient predispositional characteristics.

1.5.3.1. Patient sociodemographic characteristics

Research into the effects of patients' sociodemographic characteristics on their satisfaction with medical care has been inconclusive (table A.1.). While many studies performed in the last decade have found no relationship between patient satisfaction and age (Romm & Hulka, 1979; Like & Zyzanski, 1987; Weiss, 1988; Hall et al, 1990), sex (Gray, 1980; Treadway, 1983; Weiss, 1988; Hall et al, 1990; Hall et al, 1990a, Williams & Calnan, 1991; Stein et al, 1993), race (Breslau et al, 1981; Fox & Storm, 1981; Like & Zyzanski, 1987; Weiss, 1988, Hall et al, 1990a; Stein et al, 1993), education (Breslau et al, 1981; Treadway, 1983; Like & Zyzanski, 1987; Weiss, 1988; Hall et al, 1990; Williams & Calnan, 1991), and social class (Romm et al, 1979; Breslau et al, 1981; Treadway, 1983; Like & Zyzanski, 1987; Weiss, 1988; Williams & Calnan, 1991), other studies have.

Studies have reported that older patients (Fox & Storm, 1981; Linn and Greenfield, 1982; Linn et al, 1982a; Greenly et al, 1983; Hall et al, 1990a), women (Fox & Storm, 1981; Patrick et al, 1983; Zastowny et al, 1983; Like & Zyzanski, 1987), those whose race is "white" (Hulka et al, 1975; Gray, 1980), and sometimes those of "black" race (Linn et al, 1982; Zastowny et al, 1983) have expressed more satisfaction with received medical care. There is no consensus to the effect of education, with some studies finding that high levels of education are related to high satisfaction (Hulka et al, 1970; Zastowny et al, 1983) while others showing similar relationships with lower levels of education (Fox & Storm, 1981; Linn et al, 1982; Greenly et al, 1983; Wartman et al, 1983; Stein et al, 1993). Similarly, both low social class (Hulka et al, 1975; Fox & Storm, 1981), and middle to upper social class (Wartman et al, 1983; Hall et al, 1990a) have been shown in different studies to be associated with high satisfaction.

For a wider perspective of the effects of the sociodemographic variables on satisfaction, Hall et al (1990a) conducted a meta-analysis study of correlations between patients' satisfaction with medical care and selected patient sociodemographic variables. The sample used in the meta-analysis consisted of 110 studies, and only sociodemographic variables that were mentioned in ten or more studies were investigated in the meta-analysis. The criteria for inclusion of studies in the meta-analysis was discussed earlier (section 1.4.). The sociodemographic variables investigated in this meta-analysis were patient's age, ethnicity, sex, social status (measured by occupation), income, education, marital status, and family size. Community type, religion and unemployment were measured infrequently and hence were excluded from the meta-analysis. Furthermore, correlations with medical care were extracted from each study and only a single correlation was assessed for a given study for a sociodemographic variable.

Results indicated that patient's age and education were significantly related to satisfaction with patient's social and marital status having nearly significant relations. Greater satisfaction was found to be correlated with being older, having less education, having higher social status, and being married.

Hall et al (1990) did comment on the fact that two indices of social class (education and occupational status) go in opposite directions; the explanations provided were that: (1) apparent differences might not be real and would disappear if more studies were to be located or conducted and included in the meta-analysis, (2) there is no statistical necessity for having congruent signs for correlations between sociodemographic indices and satisfaction, for different indices of sociodemographic status are not perfectly correlated with each other and (3) it might be that the group that reported the lowest satisfaction is the one experiencing status inconsistencies, e.g. highest education and lowest occupational prestige, and that the feeling of being deprived and resentful towards other privileged groups (including physicians) is being translated into a dissatisfaction with medical care (attitude towards physicians) as well as with other facets of life (attitude to other privileged members in the society). The authors acknowledged that none of these interpretations can be considered confident explanations for this unexpected trend. The research team suggested that more research is needed on how variation in medical care is responsible for the correlation between sociodemographic variables and satisfaction.

1.5.3.2. Patient predispositional characteristics

The review of the literature (table A.2.) indicates that characteristics of patients, other than their sociodemographic characteristics, also have effects on patients' satisfaction. For instance, having confidence in the medical care system in one's own community (Weiss, 1988), having a regular source of care (DiMatteo & Hays, 1980; Fox & Storm, 1981; Weiss, 1988), and being satisfied with life in general (Linn, 1975; Roberts et al, 1983; Carmel, 1985; Weiss, 1988) were found to be associated with high patient satisfaction.

Although it might be expected that improved health would be associated with increased satisfaction, the association between patient's health status and his/her satisfaction with medical care was not consistent across the literature. Fox & Storm (1981), in their survey on patient satisfaction with medical care, indicated that while respondents having a chronic condition tended to be more satisfied with care, no significant association was found between satisfaction and disability days. This was contradicted by Linn et al (1982) who reported that chronically ill patients who spent more days in beds in the month preceding the interview were significantly less satisfied with efficacy, technical quality and art of care. Linn et al also reported that patients with more physical limitation were more likely to be dissatisfied with the technical quality and efficacy of care, but not with the art of care. Patrick et al (1983) assessed disabled patients' satisfaction with medical care and found no statistically significant association between patients' satisfaction with doctors in general and their need for practical assistance in routine daily living tasks, their physical and psychosocial disability. However, patients' need for practical assistance was positively and patient's psychosocial disability negatively associated with their satisfaction with the medical care delivered by their own doctors. Romm et al (1976) indicated that patients with congestive heart failure who had greater functional activity at the end of the treatment period were more likely than others to report high satisfaction with medical care. Hall et al (1990), in their study on older patients' satisfaction with an Health Maintenance Organization, indicated that the relation between satisfaction and health status differed across the dimensions of health so that satisfaction was strongly related to better physical function and more social activity. However, Greenly et al (1982) reported that social health (social interaction, involvement in social activities) had no significant association with chronically ill patient's satisfaction with medical care.

Seriousness of illness had a moderate negative correlation with cancer patients' perceptions of the quality of medical care in general, the quality of nursing care, their satisfaction with diagnostic information, and their satisfaction with self-care information (Oberst, 1984). Persons having greater numbers and/or frequency of HIV-related symptoms were also found to have lower satisfaction scores with medical care (Stein et al, 1993). Additionally, the less the symptoms at the end of treatment, the higher the reported satisfaction with medical care of patients with congestive heart failure (Romm et al, 1976).

Patients' anxiety and emotional distress were also found to be related to patient satisfaction. Oberst (1984) indicated that anxiety was found to have a weak negative correlation with the extent to which cancer patients' expectations were met, their satisfaction with diagnostic information, and their satisfaction with self-care information. Greenly et al (1982) reported that psychologically distressed patients who admit and discuss problems were more likely to be satisfied with medical care than those who do not admit having problems. Greenly et al also reported that higher dissatisfaction was associated with an increase in the number of reported psychological symptoms by these patients. The literature also indicated the presence of a negative association between emotional distress and older patient satisfaction (Hall et al, 1990), and between self-rated depression and satisfaction of chronically ill patients with medical care (Linn et al, 1982).

Finally, self-rated current overall health was found to be statistically significantly associated with patient satisfaction, with those perceiving their health as fair or poor being dissatisfied with care provided than those who have more positive perceptions of their current health status (Linn et al, 1982; Patrick et al, 1983; Hall et al, 1990).

1.5.3.3. Conclusion

Although there is quite a lot of agreement on the effects of the patient health status on his/her satisfaction with medical care, little agreement has been found on the effects of other patient characteristics. The discrepancy in the literature may be attributed to that sampling methodology, sample size, study subjects, study design, statistical measures and tests, and so on, differ from one study to another and may influence the possibility of having a significant correlation or association between a sociodemographic or a predispositional characteristic and patient satisfaction. Given this discrepancy, the main conclusion to be drawn from the literature is that the role and effects of patients characteristics on a particular outcome in any study should be checked carefully and not taken a priori.

1.6. Satisfaction with palliative care

Very little research has been conducted on the determinants of satisfaction with palliative care services. Instead, satisfaction is used an important outcome variable (Mor and Masterton-Allen, 1987) in studies evaluating services providing care to terminally ill patients. The focus was on assessing the views about a service rather than on understanding the determinants of satisfaction with that service. Table 1.1. presents the main studies that have empirically addressed the issue of patient and/or carer satisfaction with palliative care. These studies assessed either overall satisfaction with care and/or satisfaction with services delivered by a specific provider.

Overall, high satisfaction with services was reported by carers of dying patients (Cartwright et al, 1973; Hinton, 1979; Parkes, 1980; Barzelai, 1981; Creek, 1982; Wilkinson, 1986; Blyth, 1990; Cartwright, 1990; Herd, 1990; Field et al, 1992; Butters et al, 1993). Carers were also reported to be significantly more satisfied with hospice care than conventional care (Kane et al, 1984; Seale, 1991). However, the National Hospice Study (Greer et al, 1986) found no statistically significant difference in terms of carers' satisfaction with services delivered to hospice or hospital patients. As far as home care is concerned, McCusker (1984) reported that carers were satisfied with a Hospice Home Care Team's care delivered at the patients' home, while Greer et al (1986) indicated that although home care patient family members were satisfied, they were not significantly more satisfied than were non-hospice patients' families.

Table 1.1. Research on satisfaction with palliative care services

Reference	Subjects	Design	Results
Cartwright et al, (1973) (U.K.)	Carers of 785 deceased who died in twelve areas in England and Wales in 1967	Retrospective survey	-69% of carers said that GP had time to discuss things -87% of carers said that GP was an easy person to talk to
Hinton, (1979) (U.K.)	80 married people expected to die within 3 months from neoplasms, and who received care in a hospital (20 patients), foundation home (20), hospice inpatient unit (20), and hospice outpatient unit (20)	Multi-site study	When praise was rated as 1 and censure as 9, the mean scores were 3.4 ±1.5 for physical treatment, 1.8 ±1.8 for opinion of staff, 4.1 ±1.3 for discussion with staff, and 2.5 ±1.3 for place of care
Parkes, (1980) (U.K.)	31 surviving spouses of patients who received home care from a team at St. Christopher's Hospice	Retrospective survey	-97% indicated that patients' comfort and peace of mind had been improved -86% indicated that patients' peace of mind improved -100% caregivers reported that their own peace of mind had been improved
Barzelai, (1981) (U.S.A.)	20 surviving relatives of patients who were admitted to Fairview hospice, in Minneapolis	Retrospective survey	-82% of relatives reported that hospice staff managed to control pain most or all of the time -88% reported some success in the relief of physical symptoms -64% reported relief from anxiety -100% would recommend the hospice for a relative/friend

continue, table 1.1.

Reference	Subjects	Design	Results
Creek, (1982) (U.S.A.)	70 caregivers of patients dying in Columbus Hospice	Caregiver report	-92% of caregivers were satisfied with hospice care
Jones, (1984) (U.S.A.)	126 family members of 75 dying cancer patients at Boston area oncology units	Prospective interview	-76% of family members were satisfied with medical management of illness
Hannon & O'Donnell, (1984) (U.S.A.)	148 community-based hospice patients caretakers 43 non-autonomous hospital-based hospice patient caretakers 159 autonomous hospital-based hospice patient caretakers	Multi-site comparison study	-PCPs' satisfaction with hospital care for community-based programs was significantly lower than PCPs' satisfaction with the hospital-based programs
Kane et al, (1984) (U.S.A.)	137 hospice patients and 110 control in a Veterans Hospital Administration	Randomized controlled trial	-Hospice patients were significantly more satisfied with care than controls -Hospice patients' FCGs were significantly more satisfied

continue, table 1.1.

Reference	Subjects	Design	Results
McCusker, (1984) (U.S.A.)	Home Care Team study : 102 terminally ill patients randomly assigned to Home Care Team or community health agencies 111 patients caretakers 39 bereaved carers Terminal Care study : 96 surviving relatives of patients who died from cancer	Randomized controlled trial	-In the Home Care Team study, patients reported higher levels of satisfaction with care received than the caretakers -Home Care Team caretakers were more satisfied with the different aspects of care than were the caretakers of patients receiving services from the community health agencies -Surviving relatives had similar preferences for both home care and physician decisions to control group caretakers
Wilkes, (1984) (U.K.)	A random sample of relatives of 262 patients (2 hospital/1 home deaths) who died in England and Wales between 1978-1979	Retrospective survey	-24% of relatives reported especial gratitude for the skill and support of the GP -14% of relatives praised the services by district nurses -27% of relatives criticized the "uncaring attitude" of the hospitals, 29% expressed "especial gratitude" to hospital doctors, compared to 34% who praised the hospital nurses
Greer et al, (1986) (U.S.A.)	833 home care hospice patients and their primary caretaker persons (PCPs) 624 hospital-based hospice patients and their PCPs 297 non-hospice patients and their PCPs	Multi-site non-randomized trial	-No statistically significant difference among patients in terms of satisfaction -PCPs of patients in Hospital-Based hospices were more satisfied than others with care

continue, table 1.1.

Reference	Subjects	Design	Results
Wilkinson, (1986) (U.S.A.)	114 surviving relatives of patients who died in Shenectady Hospice between 1981 and 1985	Retrospective survey	-On a scale of 1-5, the mean score of carers' satisfaction with overall care was 4.80 ±0.61, and that of carers' perceptions of patients' satisfaction with his/her quality of life was 3.59 ±1.31
Blyth, (1990) (U.K.)	34 relatives of patients with terminal illnesses who died in 1987 5 general practitioners from one practice	Retrospective survey	-In 8 cases, relatives were dissatisfied with GPs' care -In 6 cases, doctors were dissatisfied with the care they delivered
Cartwright et al (1990) (U.K.)	Carers of 639 patients who died in ten areas in England and Wales between October and November 1987	Retrospective survey	-74% described the care the person who died got from his/her GP as excellent (41%) or good (33%) -87% thought that the doctor was an easy person to talk to -82% felt that he/she had time to discuss things -83% felt the way the doctor looked after the person who died was very (63%) or fairly (20%) understanding
Herd, (1990) (U.K.)	102 doctors, 119 nurses, and 93 bereaved carers of patients who died in West Cumbria	Retrospective survey	-92% of carers rated the services delivered by GPs and district nurses as "good" or "excellent" -76% rated the services of the hospital doctors as "good" or excellent -86% rated the services of the hospital nurses as "good" or excellent

continue, table 1.1.

Reference	Subjects	Design	Results
Higginson et al, (1990) (U.K.)	65 terminally ill patients with their family members	Prospective interview	-58(89%) patients and 59(91%) of family members rated the services delivered by the support team as excellent or good -46(71%) patients and 46(71%) family members rated the services delivered by GPs and district nurses as excellent or good -22(34%) patients and 35(54%) family members rated services delivered by hospital doctors and nurses as excellent or good
Addington-Hall et al, (1991) (U.K.)	80 bereaved carers of cancer patients who died between 1987 and 1989	Retrospective descriptive study	-50% of carers were dissatisfied with hospital care -27% of 64 carers who had had contact with the GP during the final illness were dissatisfied with the care provided -20% of 56 carers who had had contact with district nurses were dissatisfied with the services provided by these nurses
Dawson, (1991) (U.S.A.)	25 bereaved familial care givers (BFCGs) whose deceased received care at home supported by a community-based hospice program 25 BFCGs whose deceased received care in a hospital affiliated with a community based hospice program 25 BFCGs whose deceased had care in a hospital with its own hospice 25 BFCGs whose deceased received care in a conventional hospital	Comparison study	-Conventional care group had the lowest levels of basic needs satisfaction, satisfaction with the psychosocial support of the nurse, and overall program satisfaction -Overall satisfaction was consistent across hospice groups -home hospice care provided the highest quality of basic needs satisfaction, and the highest level of satisfaction with the nurse

continue, table 1.1.

Reference	Subjects	Design	Results
Seale, (1991) (U.K.)	Carers of 811 deceased in ten areas in England and Wales	Retrospective survey	-Carers of patients who died in hospices were more satisfied than those whose deceased died in hospitals with both doctors and nurses care
Addington-Hall et al, (1992) (U.K.)	554 cancer patients expected to survive less than a year entered the trial and were randomly allocated to a coordination or a control group	Randomized controlled trial	-Bereaved carers in the two groups were equally likely to be satisfied with the place of death, both from their own and from the patient's perspective -No significant differences between groups in satisfaction with care and information received from hospitals, general practitioners, and district nurses
Field et al, (1992) (U.K.)	Phase I : 59 relatives or carers interviewed one week after the patient admission to the hospice Phase II : 37 bereaved carers interviewed around three months after the patient's death	Caregivers and bereaved caregivers report	Phase I : -9(18%) carers rated GPs' services as excellent, 5(10%) rated the services as good, and 11(22%) gave a fair or poor rating -12(29%) rated the services of the district nurses as excellent, 9(22%) rated the services as good, and 3(7%) gave a fair or poor rating -19(32%) rated the hospice doctors' services as excellent, 13(22%) rated the services as good, and 1(2%) gave a fair or poor rating -34(58%) rated the hospice nurses' services as excellent, 10(17%) rated the services as good, and 2(3%) rated the services as fair or poor

continue, table 1.1.

Reference	Subjects	Design	Results
Field et al (1992) (U.K.)	Phase II : 37 bereaved carers interviewed around three months after the patient's death	Caregivers and bereaved caregivers report	Phase II : -23(62%) of bereaved carers rated the services provided to them by the hospice staff as excellent or good -36(97%) of bereaved carers rated the services provided to their dying patients by the hospice staff as excellent or good
Sykes et al, (1992) (U.K.)	106 bereaved carers of terminally ill cancer patients, interviewed six months after bereavement	Retrospective survey	-45 carers were satisfied with GPs' and district nurses' care
Butters et al, (1993) (U.K.)	19 HIV/Aids patients referred to a Community Care Team (CCT), and 8 carers	Prospective interview	-100% of patients and 88% of carers rated the care given by the Community Care Team as excellent or good

1.6.1. Overview of the field of satisfaction with palliative care

Even though some prospective studies assessing patients' perceptions of the quality of palliative care has been conducted (Hinton, 1979; Kane et al, 1984; Greer et al, 1986; Higginson et al, 1991; Butters et al, 1993), most of the investigations done in the field are retrospective (Barzelai, 1981; Hannan and O'Donnell, 1984; Wilkes, 1984; Cartwright and Seale, 1990; Blyth, 1990; Dawson, 1990; Addington-Hall et al, 1991; Field et al, 1992; Sykes et al, 1992), and subjects are carers of deceased rather than dying patients, in contrast to medical care field in general where patients are the subjects of the studies. This is mainly because of the difficulties in identifying patients with terminal illness (Higginson et al, 1994), and also because terminally ill patients are expected to be too ill or confused to be interviewed (Seale, 1991).

Evidence suggests that proxies report less satisfaction with medical care in general than original subjects (Epstein et al, 1989), and that family members rate patients' health more negatively than patients do (Rubenstein et al, 1984). In contrast, when both patients and carers views were prospectively assessed about the quality of palliative care, family members were significantly more satisfied with the hospital and community services than were patients (Higginson et al, 1990). Several studies have also found that patients and informal carers have different perceptions (Ahmedzai et al, 1988; Cartwright and Seale, 1990). Furthermore, bereaved people are susceptible to various psychological and emotional disturbances (Parkes, 1964; Parkes, 1965; Madison and Viola, 1968; Seale, 1991a). Therefore, their satisfaction with the palliative care services may have been determined, at least in part, by their mental state and their opinions about care that were formulated during the bereavement period rather than by the care itself. Therefore, it is dangerous to presume that the predictors of carers' satisfaction with care will be the same as those reviewed in section 1.5. The literature on predictors of satisfaction with palliative care will be reviewed in the next section.

1.6.2. Predictors of satisfaction with palliative care

Few studies have looked at the service and non-service predictors of satisfaction with palliative care. These studies will be reviewed in this section.

The satisfaction with care provided to hospitalized cancer patients was the main focus of two major prospective studies conducted by Blanchard et al in the state of New York, in the U.S.A. The first study assessed the impact of oncologists' behaviours on patient satisfaction with morning rounds. The second study examined the potential predictors of cancer patient satisfaction with physicians behaviours.

In the first study, Blanchard et al (1986) selected an Haematology-Oncology unit in an inpatient setting in N.Y. where patients are admitted for diagnostic evaluation, treatment or terminal care. The aim of the study was to assess patient's perception of physician behaviours during the daily morning rounds . The morning round period was chosen as the only time where there was real medical interaction between the patient and his attending oncologist. The authors focused on 401 patient-oncologist interactions. Data was collected on 157 different patients. Patient demographic data were obtained from the patient's chart, and the disease status data were obtained from doctors making the round that day. To collect the data on physician behaviours and patient satisfaction, one or two observer joined the daily rounds. Their role was to assess the different physician behaviours during the interaction with the patient. The observer used the Physician Behaviour Check List (PBCL) as an instrument to assess these behaviours. This check list was used by the authors in previous studies, and was tested for reliability. The PBCL assessed thirty-four behaviours in terms of their occurrence and non-occurrence. The behaviours assessed were those related to the technical competence and the affective performance (or bedside manner) of physicians. After the medical rounds, the observer returned to the patient and asked him/her to complete three visual analogue scales. The first scale assessed the patient's perception of the extent of which the physician addressed his/her needs; the second the extent of patient's involvement in the medical interaction; and the third the patient's overall satisfaction with the oncologist visit.

The authors divided the sample into two groups for an analysis of the predictors of satisfaction : (1) high satisfaction group (mean satisfaction score of 9.82) and (2) low satisfaction group (mean satisfaction score of 7.36). The authors conducted for both groups regression analyses of patient satisfaction by physician behaviours, time spent by physician in patient's room, and patient's characteristics. The results showed that older age, poorer prognosis, and positive quality of the day's news from doctor were potential predictors of higher satisfaction with the oncologist morning round for the high satisfaction group. Four physician behaviours proved to be important predictors for satisfaction in the high satisfaction group; discussing the role of the family and examining non-truncal areas were negatively associated with satisfaction, whereas the use of patient's first name by the oncologist during the medical interaction and attempts to establish privacy during a medical examination had a very positive impact.

For the low satisfaction group, the social skills behaviours of physicians played important roles as predictors of satisfaction. Items such as sitting down while talking to the patients, not interrupting patients, and engaging in small talk were each related to increased satisfaction. In addition, identifying future tests or treatments, and discussing the possibility of leaving the hospital were also associated with an increase in satisfaction in the low satisfaction group.

In the second study, Blanchard et al (1990) were interested in detecting the predictors of hospitalized cancer patients satisfaction with oncologists morning rounds. The authors focused on 1423 interactions between 366 cancer patients and their attending oncologists admitted to the same Haematology-Oncology unit where the first study was conducted. The study design was the same as that used in the first study but with few changes in both design and measurements. First, and in order to compare observer's perceptions and patient's perceptions, the observer rated on visual analogue scales their perceptions of the extent the physician addressed the patient's needs that day, and of the degree of patient's involvement in the medical interactions. Second, in assessing patient satisfaction, the authors used two different instruments : (1) The Patient Satisfaction Questionnaire (PSQ), and (2) three visual analogue scales. The PSQ was designed in the first study and consisted of 17 physician behaviours that were selected from the PBCL, and were assessed in terms of their occurrence/non-occurrence that day. The patient was asked to complete the same two visual analogue scales that were completed by the observer earlier. In addition, patients were asked to rate on a visual scale their overall satisfaction with the day's visit.

Results showed that cancer patient satisfaction was high. The mean patient satisfaction score on the 100-mm scale was 87.8. Patients also provided higher ratings than the observer for both "extent of needs addressed" and "degree of involvement". Path analysis also showed that four variables explained 62% of total variance in patient satisfaction. The strongest predictor was patient's perception of needs addressed that day; the other predictors were patient's perception of emotional support, patient's age (older), and physician discussing treatment. In addition, several physician behaviours were found to predict satisfaction through one or two patient perception items that were related to satisfaction. These behaviours were discusses discharges, establishes privacy for physical examination, inquires about signs and symptoms of illness, and identifies future tests and treatments. Furthermore, behaviours involving information such as diagnosis and future tests and treatment were found to predict patient perceptions of such behaviours. Finally, being male was found to be related to the perception that "signs and symptoms were discussed", while poor prognosis related to "inquires about signs and symptoms" and better diagnosis related to "identifying future tests and treatment" . Blanchard et al concluded that patient perceptions of physician behaviours were powerful predictors of satisfaction than the actual occurrence or non-occurrence of those behaviours.

Blanchard et al ignored the fact that the samples used in both studies consisted of patients who were admitted to the Haematology-Oncology unit for a variety of reasons. Hence, one would expect patients admitted for diagnostic evaluation to have different needs and expectations than patients admitted for treatment, who in turn are expected to have different perceptions than those admitted for terminal care. The authors did not acknowledge the effect of patient's perceived severity of the disease on patient satisfaction, especially since the higher the perception of the disease as life-threatening, the greater the satisfaction with care (McCusker, 1984).

Wilkinson (1986) conducted a retrospective study to evaluate the services provided by a small, community-based, home-care program that started to provide services to patients in 1981. The sample consisted of 266 hospice patients who were discharged due to death, between 1981 and 1985. Surviving family members were sent a mailed-questionnaire approximately three months after the death of their loved ones. Of the 266 questionnaires mailed out, 118 were returned. Of the 118 returned questionnaires, 114 were usable and provided almost complete information.

The instrument used by the author consisted of eight items, four of which were related to patient's concerns, and four others related to family concerns. A likert scale from 1 to 5 was used, with 1 pertaining to the most negative answer, and 5 referring to the most positive one. The instrument was tested for reliability, and a coefficient alpha of 0.79 was reported, indicating that the scale used in the study has a fairly strong internal consistency for basic research and for comparisons of groups.

Results indicated a high level of satisfaction with the hospice services. Highest scores were reported for the family satisfaction item, patient satisfaction item, and expectations of hospice care item compared to other items in the instrument. No significant relationships were detected between age, sex, length of stay of patients and any of the eight questions in the questionnaire. In addition, no significant relationships were found between age and sex on one hand and average satisfaction on the other. Factor analysis indicated that family satisfaction was correlated with whether family members' expectations of care delivered by the hospice were met. Furthermore, family members satisfaction was also correlated to their perception of patient satisfaction, as well as to the degree of pain control. Family members tended to be satisfied if they perceived that patient was satisfied, that pain was controllable, and that their expectations of hospice care were met.

The author concluded that pain control is an important determinant of carers satisfaction, and acknowledged the fact that her survey did not inquire about other discomfort such as vomiting and nausea which have serious effects on the quality of life of patients, and may be essential factors in the judgments people make about the care received. Wilkinson's study, even though important because it demonstrates that expectations of carers are important determinants of satisfaction, suffered from a low response rate (44%).

Kristjanson (1986), in a study on the identification of health care provider behaviours that affect families of cancer patients with advanced disease, selected 210 family members from 120 families of terminally ill cancer patients from three different tertiary care settings in Canada. The selected family members were defined by the patients as the individuals the most involved in, or affected by their illness. The aim of the research was to identify salient indicators of the quality of terminal care and to test a tool to measure family satisfaction with terminal care. Kristjanson used Q-sort methodology, a norm-referenced technique designed to measure the degree of similarity between different subjects or different groups of subjects (Waltz et al,1984), for the identification of the salient indicators by the family members.

Findings indicated that carers ranked as most important the items related to the need for prompt, attentive, thorough medical care, and expressed the need for information that could help them in caring for their dying patients. It is worthy to note that the ranking of patient care items was highly influenced by two demographic variables: (1) Religion and (2) Age. Carers with religious affiliation were more interested with spiritual care than in medical care per se out of confidence in the physician, in contrast to families with no religious affiliation who valued the item referring to the physician paying attention to the patient's description of his/her symptom. Nevertheless, older family members revealed greater needs for home care, access to health services and caregivers, and assistance with care decisions where as family of younger patients wanted information regarding treatment choices.

Even though Kristjanson's study is one of the very few studies that considered the effects of the sociodemographic variables in the terminal care field, the author noted that the results of this study cannot be generalized because they are based on a non-random selected sample of patients. Nevertheless, This study is of prime importance because it indicates that different groups of carers valued different aspects of care. This difference could be due to differences in needs and expectations of carers about the care that should be delivered to the patient which, given the relationship between expectations and satisfaction (reviewed in sections 1.3., 1.3.1., and 1.3.3.) , could affect satisfaction rates.

1.6.3. Conclusion

Researchers in the field of palliative care have looked at satisfaction as an indicator of service performance describing the patient's and/or carer's perceptions of the quality of care. The delivered service might be at the community, hospital, or hospice care level. However, and unlike the field of medical care in general, little attention has been paid to assessing the determinants of satisfaction. A comprehensive understanding of the possible role of different service and non-service related factors in predicting carers' satisfaction with services delivered to their dying patients is needed. It is this need that will be addressed in this thesis.

CHAPTER 2

PURPOSE OF THE STUDY AND OBJECTIVES

2.1. Aim and objectives

The aim of the analysis reported in this thesis is to determine the predictors of bereaved carers' satisfaction with palliative care services delivered by district nurses, general practitioners, hospital doctors, and health and social services in general.

The objectives of the research are :

1. to review in the field of health services research in general, and palliative care specifically, evidence on the different factors predisposing carers to have positive or negative perceptions of the quality of care delivered.

2. to compare the importance of service and non-service related factors in predicting the satisfaction of bereaved informal carers, and thus, assess the appropriateness of using " carers' satisfaction " as an outcome measure in post-bereavement studies on palliative care.

3. to detect which of these factors best predict bereaved informal carers' satisfaction.

2.2. Research question

The main research question is :

1. Is bereaved informal carers' satisfaction more a reflection of the service characteristics, the non-service related factors or attributable equally to both ?

2.3. Importance of the research

This research will :

1. help health planners improve the delivery of services to terminally ill cancer patients by understanding the factors predisposing high or low satisfaction with medical and nursing care.

2. outline the possible limitation of using post-bereavement carers' satisfaction as an outcome measure assessing perceptions of service characteristics.

3. open the field of palliative care to more research into informal carers' satisfaction.

CHAPTER 3

METHODS

3.1. Introduction

The analysis conducted for the thesis was based on data collected for the " *Regional Study of Care for the Dying* (RSCD)". The RSCD is the largest British study to collect information retrospectively on the care and services delivered to dying patients in their last year of life, as well as on the bereavement experience of carers. The RSCD was initiated in April 1990, and the research team is based at UCL.

This chapter is divided into two major sections. In the first section, the methodology of the RSCD is briefly described, while in the second section, the emphasis is on the methodology used in the analysis conducted for the thesis.

3.2. RSCD aim and methodology

Background

The RSCD was initiated as a response to the need to evaluate the broad range of services received by dying people and their families, especially since evidence from population based surveys suggested that there is still room for improvement in care for the dying, not just for cancer patients but also for those with other chronic diseases, unexpected acute deaths, and deaths in the elderly (Wilkes, 1984; Hockley et al, 1988; Houts et al, 1988; Addington-Hall et al, 1991).

In addition, there was a need to detect whether the growth of the hospice movement over the past twenty years as well as the increase in the number of specialist nursing services for terminally ill cancer patients have had a positive impact on the care delivered to dying patients in general, not only the minority who receive hospice care (Addington-Hall & McCarthy, 1992).

Aims of RSCD

The aims of the study were :

-to describe patients' experiences and use of services in the last year of life, the satisfaction of informal carers with these services, and carers' views about bereavement care;

-to provide health districts that participated and funded the study with data that enable them to compare their provision for the dying with that provided in other districts;

-and to identify outcome measures for dying and bereavement care that could be used for quality assurance and targets.

Methods

The methodology used in the RSCD study was kept, for comparison purposes, as similar as possible to two other nationally representative retrospective surveys of the last year of life of dying people conducted by the Institute of Social Studies in Medical Care in 1969 (Cartwright et al, 1973), and 1987 (Cartwright and Seale, 1990). These two studies aimed at showing the ways in which a multiplicity of services delivered to terminally ill patients functioned, or failed to function.

Ethical committees

The RSCD was approved by the Ethics Committee of the Faculty of Clinical Sciences, UCL. It was also given approval by the Ethical Committees in each of the 20 participating districts. In total, the U.C.L. research team had 112 contacts by telephone or letter with the Ethical Committees, or with a local contact responsible for getting ethical permission for the study. Delays of up to 8 months were experienced before permission was granted by the 20 Committees.

Sample

All districts health authorities in England were invited to participate in the study subject to payment of a participation fee. Twenty districts took part. They were:

- Bloomsbury and Islington
- Bexley
- Bristol and Weston
- Bromley
- Canterbury
- City and Hackney
- Cornwall
- Dartford
- Dudley
- West Berkshire
- Great Yarmouth
- Hillingdon
- Mid Essex
- Newcastle
- Newham
- North Manchester
- Redbridge
- Norwich
- Tunbridge Wells
- Frenchay

Sample size

Within each district, 270 deaths of district residents from all causes occurring in the last quarter of 1990 were randomly sampled from death certificates. This district sample size was sufficient to allow comparisons between participating districts with regional and national results, taken into account the fact that the national study of life before death conducted in 1987 achieved a response rate of 80%.

A sampling fraction of three people certified as dying from cancer to one other death was used. This is because cancer patients are the focus of most specialist palliative care services . In total, 5375 deaths were sampled, 2913 of whom died from cancer.

Response rate

3696 interviews were successfully completed. This resulted in a response rate of 68.8%. Interviews were obtained for 2074 cancer and 1622 non-cancer deaths. The response rate for cancer deaths was significantly higher than that for non-cancer deaths (71.2% versus 65.9%, $X^2 = 16.8$, df=1, $P < 0.001$).

Representativeness of sample

The 1989/1990 Department of Health Performance Indicator package was used in the analysis on the representativeness of the districts. A series of barcharts is presented in Appendix B. The barcharts show data for the country as a whole, with the position of the 20 districts considered in the analysis in black, with numbers to indicate which of them belongs where.

Figure 1. to Figure 9. (Appendix B) show that the districts have a good spread on measures of social deprivation (Department of Health Social Index), population density, standardized death rates, deaths in NHS hospitals, and service provision (total number of district nurses, available bed days, total number of senior medical and dental staff, and the total number of geriatricians (consultants in geriatric medicine) per 100,000 district catchment population).

Table 3.1. compares the interviewed cancer sample in the RSCD with national mortality statistics of England and Wales (1990) for sex, age and type and site of

neoplasm for deceased who were not less than 15 years of age. No significant difference was found between the RSCD and the national statistics in terms of death from cancer and sex of the deceased.

Even though significant difference (P< 0.01) was found between age of deceased and death from cancer between the RSCD and the national statistics, analyses have indicated no statistical difference in terms of specific age category, with the exception of the 65-74 age group (P= 0.02). The national statistics show that 23.5% of people who died from cancer in England and Wales in 1990 belonged to the 65-74 age group, while 21.6% of deceased, who were included in the RSCD, belonged to that age group. In other words, compared to the national statistics, the RSCD has less cancer deaths of people who were 65-74 years of age.

As far as the site and type of neoplasm is concerned, a marginally significant difference (P= 0.05) was found between the number of people sampled in the RSCD and who died from a malignant neoplasm of the respiratory and intrathoracic organs (18.4%, n= 468) and the national statistics on deaths from that type of cancer (19.9%, n= 35919). Significant differences were found between the number of people who died from a malignant neoplasm of unspecified parts (11.5%, n= 269), and those who died from neoplasms of uncertain behaviour (0.6%, n= 12) and the national statistics (9.4%, n= 15015 for the former, and 1.2%, n= 1728 for the latter).

Table 3.1. Comparison of interviewed cancer sample with national mortality statistics of England & Wales (1990) for sex, age and neoplasm for deceased who were not less than 15 years of age

	RSCD		England and Wales 1990		Significance
	n	(%)	n	(%)	
Sex					
male	1048	(50.5)	75364	(52.3)	X^2= 2.47, df=1, P= 0.12
female	1026	(49.5)	68829	(47.1)	
Age					X^2= 15.80, df=4, P< 0.01
15-44	70	(3.3)	4835	(3.2)	X^2= 0.003, df=1, P= 0.95
45-64	463	(18.2)	32877	(18.6)	X^2= 0.17, df=1, P= 0.68
65-74	573	(21.6)	44317	(23.5)	X^2= 5.04, df=1, P= 0.02
75-84	688	(24.9)	45703	(24.1)	X^2= 1.05, df=1, P= 0.30
85 or more	280	(11.9)	16461	(10.2)	X^2= 6.84, df=1, P= 0.09
Neoplasm					X^2= 27.83, df=7, P<0.001
MN of lip, oral cavity, and pharynx	22	(1.0)	1655	(1.1)	X^2= 0.13, df=1, P= 0.71
MN of digestive organs and peritoneum	568	(21.5)	40952	(22.1)	X^2= 0.58, df=1, P= 0.44
MN of respiratory and intrathoracic organs	468	(18.4)	35919	(19.9)	X^2= 3.69, df=1, P= 0.05
MN of bone, breast, and connective tissue	252	(10.8)	16105	(10.0)	X^2= 1.57, df=1, P= 0.21
MN of genito-urinary organs	335	(13.9)	23444	(14.0)	X^2= 0.01, df=1, P= 0.91
MN of lymphatic and haematopoietic tissue	148	(6.7)	9375	(6.1)	X^2= 1.18, df=1, P= 0.28
MN of other and unspecified parts	269	(11.5)	15015	(9.4)	X^2= 11.33, df=1, P< 0.01
Benign neoplasms and neoplasms of uncertain behaviour	12	(0.6)	1728	(1.2)	X^2= 6.56, df=1, P=0.01
number of deaths	2074		144,193		

Local contact

A local contact was appointed in each health district. The local contact was responsible for communicating between the district health authority and the research team at UCL, solving problems at the local level, ensuring access for the research team to the death certificates from which the sample was taken.

Interviewers

75 interviewers participated in collecting the information by conducting either face-to-face interviews or telephone-interviews. They were selected on basis of sensitivity and maturity, along with accuracy and some experience in interviewing. All interviewers were invited for training sessions for a period of three days at UCL.

Interviews

A letter was sent to the address of the deceased as appeared on the death certificate (Appendix C). The letter was addressed to " Relative/Friends " of deceased. It was sent out by UCL on behalf of the health districts and printed on the district notepaper. The letter was signed by the local organizer. Telephone numbers of the local contact as well as the research team at UCL were given in the letter. The content of the letter gave the respondent the choice of participating in the study, and informed them that any information given will be treated with utmost confidentiality. The letter also indicated that the interviewer will be contacting them to ask whether they are willing to take part in the study, and to arrange for interviewing. Some of the respondents who did not wish to take part in the study phoned either the local contact in their health district or the research team at UCL. Others just informed the interviewers of their decision when the latter contacted them.

Interviewers were given " Contact Sheets " on which they recorded their success or failure, as well as the number of attempts to contact a particular respondent (Appendix C). Reasons for aborting a particular search or for failing to conduct an interview were also recorded. This was of prime importance to monitor the work of the interviewers on whom data collection depended.

Interviews with respondents who agreed to participate in the study started about ten months after the death event. The time between death and interview had a median of 43.85 weeks (almost 11 months), with a 25th centile of 39.57 and a 75th centile of 49.71. In the 1969 study, Cartwright et al (1973) indicated that nine months after the death event it was more difficult to find a suitable respondent; however, in the RSCD, in 87.7% (n=3240, N=3696) of the interviews conducted, the interviewers felt that the informant was the most appropriate person to tell them about the last year of life of the deceased, while in 7.4% (n=275) they were uncertain and only in 4.1% (n=152) they perceived that another person would have been a better source of information.

The timing of the interviews varied and this might have depended on factors related to both interviewers and interviewees. For example, while 39.7% (n=1467, N=3696) of the interviews were completed within two hours, it took some of the interviewers more than three hours to complete the questionnaire (6.2%, n=230).

Questionnaire

The questionnaire used in the RSCD was an adapted version of the interview schedule developed by Cartwright and Seale (1990). It is a complex questionnaire with many skips purposely made to cover the different range of circumstances associated with death. It has 32 pages with 238 questions, many of which have sub-questions in them, and additional sheets to record information on admissions to more than one hospital or hospice, and to services received at home from the different types of nurses. The RSCD questionnaire is structured (Appendix C), with most of the questions being pre-coded. A few questions were open-ended, with the aim to use the answers for qualitative analysis.

The questionnaire itself covers the last year of life of deceased, and contains questions about sources of formal and informal care, and respondents' experience of caring for the person who died; symptoms and symptom control; restrictions experienced by the patients and the help received with these; experience of, and respondents' satisfaction with, community nursing services, inpatient care in hospital and hospice, other services such as social services; information and communication with health professionals about illness (largely diagnosis and prognosis); and carers' experience of bereavement and bereavement care.

Data processing

Coding of data was done by the RSCD research team at UCL, including myself. Weekly meetings were conducted to ensure consistency and accuracy in the coding work undertaken by the different coders. A coding manual was designed and updated as the coding work was progressing. After being coded, data were double-entered by a professional data entry organization. Programs to clean the data were written to check for all possible inconsistencies in following the different skips in the questionnaire and to detect invalid codes. Outputs of these programs were checked, and corrections were made on the corresponding computer file.

3.3. Methodology used in the thesis

3.3.1. Sample A

The analyses for the thesis were conducted on a sub-sample, Sample A, of the original RSCD interviewed sample. Sample A consisted of 1858 informal carers who were relatives or close friends/neighbours of deceased, whose deceased died from a malignant neoplasm, and whose deceased's death was classified as not-sudden. Table 3.2. presents the demographic characteristics of cases in Sample A.

Cases included in sample A received a wide range of services. In the thesis, the focus is on services delivered by district nurses, general practitioners, and hospital doctors. Table 3.3. shows the percentage of people in sample A who, in their last year of life, received services from district nurses, GPs, and hospital doctors.

Table 3.2. Demographic characteristics of cases in sample A (N=1858)

Variable	N	Per Cent
Age of deceased		
under 55	198	10.7
55-64	307	16.5
65-74	523	28.1
75-84	609	32.8
85 or more	221	11.9
Sex of deceased		
Male	961	51.7
Female	897	48.3
Ethnic origin of deceased		
White	1835	98.8
Non-white	22	1.2
Missing	1	0.1
Site of Malignant Neoplasm		
Digestive organs/Peritoneum	508	27.3
Respiratory/Intrathoracic	420	22.6
Bone/Breast/Skin/Connective tissue	228	12.3
Genito-urinary organs	297	16.0
Lymphatic/haematopoietic tissue	138	7.4
Neoplasms of other/unspecified site	258	13.9
Neoplasms of unidentified nature	9	0.5
Place of death		
Home	571	30.7
Hospital	937	50.4
Hospice	257	13.8
Old people/Nursing home	88	4.7
other	5	0.3
Relationship of respondent to deceased		
Spouse/Partner	868	46.7
Child/Grandchild/Child-in-law	590	31.8
Relative	292	15.7
Close friends/Neighbours	108	5.8
Age of carer		
Under 55	752	40.5
55-64	447	24.1
65-74	402	21.6
75 or more	233	12.5
Missing	24	1.3
Sex of carer		
Male	626	33.7
Female	1232	66.3

Table 3.3. Percentage of deceased who, in their last year of life, received services from district nurses, GPs, and hospital doctors (N=1858)

Variable	N	Per Cent
Deceased had services delivered from :		
-district nurses		
yes	1100	59.2
no	758	40.8
-general practitioners		
yes	1854	99.8
no	4	0.2
-hospital doctors (longest length of stay)		
yes	1648	88.7
no	210	11.3

3.3.1.1. Selection of hospitals

Information on hospital care was recorded on the interview schedule firstly for the hospital the deceased died in or was in the longest, and secondly, for the one they were in next longest. This led to similar multiple observations for the same case, which could not be treated as independent (Altman, 1991). Therefore, there were two alternatives for the analysis. The first was to use dataset about services delivered in the hospital where the deceased died. The second was to restrict the analysis to the hospital where the deceased had the longest stay, regardless of the deceased's place of death.

The first alternative decreases markedly the number of cases to be considered in the analysis, and has a selection bias towards those who died in hospitals. However, and by restricting the analysis to the hospital where the deceased had the longest stay, information on the services delivered by the hospital where the deceased had died will be lost if he/her had died in a different hospital. However, the second alternative has less effect on the number of cases, and allows analysis to be conducted on hospital care for both those who died in a hospital and those who did not.

Additionally, the choice of having the hospital where the deceased had the longest stay as the unit of analysis is based on the effect prior experience with care has on patients' expectations (Gutek, 1978; Oberst, 1984; Carr-Hill, 1992). Because time and exposure are important factors affecting patients' expectations of care (Gutek, 1978), it is most likely that patients' and carers' expectations of care and consequently their perceptions of the quality of care delivered by hospital doctors are shaped by the experience of care they had in the hospital where they had most contact with.

3.3.2. Model specification

The analysis is mainly directed towards exploring the predictors of satisfaction of bereaved carers with services delivered to deceased in the last year of life. Factors such as bereavement experience, caring characteristics, deceased's clinical conditions, which are of prime importance in the palliative care field, have never been looked at as possible predictors of carers' satisfaction. The inclusion of such variables in the model aims at providing an insight on the complex formulation of carers' satisfaction. Similarly to satisfaction with medical care in general, the usual background variables, i.e. sociodemographic characteristics, were considered for model building for both statistical control and theoretical contribution. Because the aim is to assess whether carers' satisfaction is a reflection of service characteristics, a set of service-related variables was also used in modelling.

3.3.3. Variables

3.3.3.1. Dependent variables

There are four dependent variables. Informal carers were asked to provide a rating of excellent, good, fair or poor to services delivered by (1) the health and social services in general, (2) district nurses, (3) general practitioners and (4) hospital doctors in specific. For example, the question assessing carers' perceptions of the quality of care delivered by the district nurse was :

> *" Do you feel the help and care deceased got from the district nurse was excellent, good, fair or poor ? "*

Table 3.4. shows the frequency distribution of carers' rating of the health and social services in general, as well as of services delivered by district nurses, general practitioners, and hospital doctors.

Table 3.4. Frequency distribution of informal carers' rating of the health and social services in general, as well as services delivered by district nurses, general practitioners and hospital doctors to dying cancer patients in their last year of life

Rating of services	N	Per Cent
Rating of services delivered by district nurses	1100	
excellent	558	50.7
good	381	34.6
fair	95	8.6
poor	37	3.4
other	5	0.4
don't know	16	1.5
missing information	8	0.7
Rating of services delivered by GPs	1854	
excellent	691	37.3
good	579	31.2
fair	280	15.1
poor	220	11.9
quality of care varied / other	12	0.6
no care delivered	24	1.3
don't know	40	2.2
missing information	8	0.4
Rating of services delivered by hospital doctors	1648	
excellent	535	32.5
good	651	39.5
fair	235	14.2
poor	113	6.9
quality of care varied / other	5	0.3
no care delivered	3	0.2
don't know	93	5.6
missing information	13	0.8
Rating of health and social services in general	1858	
excellent	504	27.1
good	741	39.9
fair	296	15.9
poor	145	7.8
quality of services varied other	150	8.0
don't know	4	0.2
missing information	18	1.0

For the purpose of the analysis, the dependent variables were dichotomized into high and low satisfaction. In order to use multiple logistic regression, the choice was either to recode the variables into satisfied (excellent, good) and dissatisfied (fair, poor, quality of care varied/other), or highly satisfied (excellent) and less satisfied (good, fair, poor, quality of care varied/other). The second alternative was chosen because it led to a better distribution of cases, for the proportion of carers who were highly satisfied (rating of excellent) being larger than that of dissatisfied carers (rating of fair, poor, quality of care varied/other). Table 3.5. presents the frequency distribution of the dichotomized satisfaction variables, excluding don't knows and missing data.

Table 3.5. Frequency distribution of informal carers' satisfaction with health and social services in general, as well as services delivered by district nurses, general practitioners and hospital doctors to dying cancer patients in their last year of life

Satisfaction with services	N	Per Cent
Services delivered by district nurses	1076	
high	558	51.9
low	518	48.1
Services delivered by GPs	1782	
high	691	38.8
low	1091	61.2
Services delivered by hospital doctors	1539	
high	535	34.8
low	1004	65.2
Health and social services in general	1836	
high	504	27.4
low	1332	72.6

3.3.3.2. Independent variables

The independent variables are broadly divided into (1) non-service and (2) the service related factors.

3.3.3.2.1. Non-service related factors

They are themselves divided into two main categories : (1) the patient and (2) the informal carer's characteristics.

Patient characteristics

The patient characteristics encompass nine sociodemographic and four clinical variables. The sociodemographic variables are : age, sex, marital status, housing tenure, occupation, having living children, having living siblings, religious denomination and place of death. Table D.1. shows the frequency distribution of these variables.

The clinical variables are : site of malignant neoplasm, intensity of functional limitation, duration of functional limitation, and duration of symptoms.

The intensity and duration of functional limitation, as well as the duration of symptoms are composite measures obtained by factor analysis. Factor analysis is an appropriate method for scale development for interval-level, non-dichotomous variables. It is a mathematically complex method of reducing a large set of variables to a smaller set of underlying variables referred to as factors (De Vaus, 1991).

The intensity of functional limitation measure was obtained by subjecting all the seven activities related to daily living in terms of their presence to a factor analysis (Table 3.6.). The result was a one-factor solution that explained 68% of the variance in the factor (Table 3.7.), and which had a reliability alpha scale of 0.92.

Table 3.6. **Variables used in factor analysis of the intensity of functional limitation**

Variable name	Variable formulation
Bath	Did deceased need help in getting in/out of bath or shower
Dress	Did deceased need help in dressing/undressing
Toilet	Did deceased need help in going to toilet /coping on his own there
Wash	Did deceased need help in washing/shaving
Toe	Did deceased need help in cutting own toe nails
Drink	Did deceased need help in making a hot drink
Night	Did deceased need help at night

Table 3.7. **Factor matrix, communalities, eigenvalues, and per cent of explained variance in the factor solution of the intensity of functional limitation**

Variable	Factor matrix	Communalities	Eigenvalue	% variance
Bath	0.80	0.65	4.77	68.1
Dress	0.87	0.76		
Toilet	0.85	0.72		
Wash	0.84	0.70		
Toe	0.77	0.60		
Drink	0.85	0.73		
Night	0.77	0.61		

a. Unrotated one-factor solution
b. Listwise deletion of cases

The eigenvalue is a measure that attaches to factors and indicates the amount of variance in the pool of original variables that the factors explain. The higher this value, the more variance it explains. To be retained, factors must have an eigenvalue greater than 1 (De Vaus, 1991).

To transform the scale into a dichotomous variable, the median was used as a cut-off point. This led to having two categories : low functional limitation corresponding to a value equal to the median or less, and high functional limitation referring to a value greater than the median (table D.15.). The same procedure was used in the development of the dichotomous duration of functional limitation measure (table D.2a., table D.2b., table D.2c., and table D.15.).

As far as symptoms experience is concerned, factor analysis was done on the duration for which a symptom was experienced. Pain was considered separately. The other 15 symptoms (Table D.3a.) were grouped into the following four factors (table D.3b., table D.3c., and table D.3d.) :

> **Sym1** : gastro-intestinal symptoms : dry mouth, loss of appetite, difficulty swallowing, vomiting, constipation
>
> **Sym2** : incontinence related symptoms : loss of bladder control, loss of bowel control, bedsores, unpleasant smell
>
> **Sym3** : psychological and cognitive functioning : sleeplessness, mental confusion, feeling low or miserable, anxiety
>
> **Sym4** : respiratory symptoms : breathing problems, cough

For each factor a score was obtained. The median was also chosen as the cut-off point in transforming each of the factor into dichotomous variables (table D.15.). This led to having two categories, long-term and short-term experience, for each group of symptoms. Table D.4. shows the frequency distribution of the deceased's clinical characteristics.

Informal carers' characteristics

The informal carers' characteristics refer to the sociodemographic characteristics, the characteristics of caring for the patient at home and those related to bereavement experience.

Nine sociodemographic characteristics are included : age, sex, relationship to deceased, living alone/with others, carer lived with the deceased, marital status, housing tenure, strength of religious faith, and religious denomination. Table D.5. shows the frequency distribution of the informal carers' sociodemographic characteristics.

The experience of caring at home was assessed by four variables : the perception of caring as rewarding, the restriction of the carer's activities as a result of caring, the perception of the patient's residence as a suitable place for caring, and the perception of unmet needs for more help in caring for the deceased at home. The latter is a composite variable and refers to a perception of need for more help with domestic services and/or self-care activities, and/or the perception that relatives/friends should have visited and helped (table D.6a., table D.6b., and table D.6c.). Table D.7. presents the frequency distribution of the informal carers' caring characteristics .

Bereavement experience was assessed by five variables. These are : adjustment to bereavement, psychological functioning, having at least one practical worry/anxiety caused or made worse by the death event, having at least one bereavement-related psychological problem caused or made worse by the death event, and self-assessment of current health.

Psychological functioning was measured by the General Health Questionnaire (GHQ) (Goldberg and Hillier, 1979); scores on the GHQ were calculated, and the variable was dichotomized into high and low GHQ scores by splitting at the median (table D.15). Adjustment to bereavement, having at least one bereavement-related psychological problem, and having at least one practical worry/anxiety are composite measures obtained by factor analysis (table D.8a., table D.8b., table D.8c., table D.9a., table D.9b., table D.9c., table D.10a., table D.10b., and table D.10c.). Adjustment to bereavement was dichotomized by splitting at the median (table D.15.). Table D.11. shows the frequency distribution of the informal carers' bereavement experience variables.

Other non-service related variables

Two other non-service related variables are considered. These are (1) whether the patient had financial problems resulting from illness and (2) whether the carer had the same GP as the one the deceased had. The first variable is used in the analysis on the predictors of carers' satisfaction with health and social services in general for it may reflect the patient/carer ability to purchase services if not satisfied with what has been delivered from the NHS and the social services. The second variable assesses the carer's objectivity in evaluating the GPs' services delivered to deceased for if they do have the same GP as the one the deceased had, they might be less willing to formulate any criticism since they might depend on him/her for the delivery of care (Table D.1. and table D.5. present the frequency distribution of these variables).

3.3.3.2.2. Service-related factors

These are the characteristics of services delivered by district nurses, general practitioners, and hospital doctors.

Seven characteristics were used to reflect the services delivered by the district nurse. These are : (1) the number of visits made by the nurse to the deceased home in the last year of life, (2) the frequency of these visits, (3) the type of services provided, whether the district nurse (4) coordinated with other professionals, (5) provided advice, (6) visited at night, and (7) made a post-bereavement visit to carer.

Table D.12. presents the frequency distribution of the district nurses' service characteristics.

Eight service-related characteristics were considered when GPs' care was assessed. These are : (1) the number of home visits made by GP the deceased home in the last year of life, (2) the number of night visits made, and whether the GP (3) made a post-bereavement visit to carer, (4) provided information regarding diagnosis to carer, and whether he/her provided treatment for (5) pain, (6) breathlessness, (7) vomiting, and (8) constipation. Table D.13. presents the frequency distribution of the GPs' service characteristics.

Finally, the service characteristics related to hospital care encompass twelve variables. These are (1) whether the deceased had enough privacy when in hospital, (2) had a room on his/her own, (3) had an operation, (4) had chemotherapy, (5) had radiotherapy, (6) had choice about treatment, whether the hospital doctor (7) told carer about the diagnosis, (8) provided treatment for pain, (9) breathlessness, (10) vomiting, (11) constipation, and finally, (12) whether the carer perceived the journey to visit the deceased in hospital as tiring. Table D.14. presents the frequency distribution of the hospital doctors' services characteristics.

All variables except (3), (4), and (5) are specific to the care delivered by the hospital doctors at the hospital in question. Questions on whether the deceased had operation(s), hormonal/chemical or radiotherapy in the last year of life were asked without a reference to a particular hospital. The decision to include them in the analysis was made because of the likelihood of such experiences affecting the way carers perceived the quality of care delivered, bearing in mind the timing effect. It is possible that deceased had any of the operation(s) and/or treatment(s) in the hospital not selected for the analysis. However, this possibility is quite remote for it is expected to experience the wide range of services in the hospital where the patient had the longest length of stay.

3.3.4. Data analysis

The analysis of data is divided into two main phases : (1) Bivariate phase and (2) Multivariate phase. The statistical package used is SPSS/PC+ (Norusis, 1990).

3.3.4.1. Bivariate phase

In this phase, we look at whether each independent variable in each set is associated with the dependent one. Since all the variables are categorical, the statistical test used is the Pearson's Chi-Square. The significance level used at this stage was $P < 0.1$, which is enough to indicate departure from the null hypothesis (Altman, 1991). This bivariate stage is a first selection stage for variables that will be subjected to further multivariate analysis. Selection was based on a lax criteria, in this case $P < 0.1$, because variables may contribute to a multiple logistic model in unforseen ways due to complex interrelationships among the variables (Altman, 1991).

3.3.4.2. Multivariate phase

3.3.4.2.1. Statistical procedure

The statistical procedure used in this phase is the multiple linear logistic regression (Norusis, 1990). Logistic Regression has as the dependent variable the logarithm of the odds that a particular binary response occurs. Regression-like coefficients derived from maximum likelihood estimation are explained as the change in the logarithm of the odds of the dependent variable associated with a unit change in the predictor variable, controlling for all other predictors in the equation. For a clearer explanation of the results, the regression-like coefficients were transformed into odds ratios by exponentiation.

The chi-square goodness-of-fit statistic was used to assess how well the regression model fitted the data. This test is analogous to the F-test in ordinary least squares (McHorney and Mor, 1988). Like ordinary least squares regression, logistic regression considers that there is no near or exact linear dependence among the predictors variables. Therefore, inspection of bivariate interrelationships, which is referred to as a multicollinearity check, was done before model building. Zero-order correlations between each of the independent variables were calculated. Because the sample is large, a correlation coefficient of 0.70 or more was considered an indicator of multicollinearity (De Vaus, 1991). Decision must then be made to choose which of any highly inter-correlated variables will enter model building.

3.3.4.2.2. Analytic approach

The multivariate phase is itself divided into two sub-phases : (1) Multivariate Phase-I (MV-I), and (2) Multivariate Phase-II (MV-II).

MV-I

A first selection of the variables is done. Non-service related variables are forcibly entered as a first block in the model. Afterwards, the service-related factors are forcibly entered as a second block in the model already containing the non-service related ones. This will detect which of the service and non-service factors independently predict informal carers' satisfaction.

MV-II

Factors that were found to predict satisfaction at MV-I with a significance level of $P < 0.1$ were subjected to forward stepwise logistic regression. This procedure determines which of the service and non-service related factors best predict satisfaction. In MV-II, selection procedure was stopped if the residual chi-square of variables not in the equation has a P value greater than 0.05, otherwise there is a risk of building models which can not be generalized to other samples taken from the same population (Norusis, 1990).

Outliers

In MV-I and MV-II, outliers were detected. Outliers can affect many types of statistical analysis, often by inflating the variance of a set of observations and so obscuring the effect of interest (Altman, 1990). In logistic regression, outliers are the misclassified cases with the highest predicted probability of being in the other category and which had the highest effect in reducing the fit of a model. The literature on outliers indicated that it is not easy to decide what to do with them (Cox & Snell, 1989).

In the current analysis, a case was considered an outlier if its studentized residual (SRESID) was greater than 2.00 (Norusis, 1990). Models with and without outliers are compared, and reported in the results section. However, if omitting these observations changes the numerical values of the estimated regression coefficients in the fitted multiple logistic regression model but does not affect their qualitative interpretation, and has no drastic effect on the main components of the designed model, the models without outliers will be retained as final results.

3.3.4.2.3. Steps in analysis

The following are the different steps followed in model building when outliers are removed :

- Step 1 : Variables significant at $P< 0.1$ at the bivariate level were subjected to logistic regression, forced entry (MV-I)

- Step 2 : Detect outliers, SRESID= 2.00

- Step 3 : Repeat Step 1 without outliers

- Step 4 : Variables in the model obtained after Step 3 that are significant at $P< 0.1$ were subjected to forward stepwise logistic regression

- Step 5 : Detect outliers, SRESID= 2.00

- Step 6 : Repeat Step 4 without outliers

CHAPTER 4

RESULTS

4.1. Introduction

This chapter is divided into three main sections following the plan of analysis discussed in section 3.3.4. The first section presents results at the bivariate level of the data analysis, while the second section focuses on the presentation of the results obtained at the multivariate phase. The third section summarizes results at both the bivariate and multivariate level.

4.2. Bivariate phase

In this section, associations between each set of independent variables and the four dependent ones (satisfaction with DNs, GPs, HDs, and health and social services in general) will be presented. Missing information, don't know, and other not valid answers for each variable were excluded from the analysis.

4.2.1. Non-service characteristics

4.2.1.1. Deceased sociodemographic characteristics

Table 4.1., 4.2., 4.3., and 4.4. show the associations between the deceased sociodemographic characteristics and satisfaction with district nurses, general practitioners, hospital doctors, and health and social services in general.

Table 4.1. **Informal carers' satisfaction with district nurses' services by deceased's sociodemographic characteristics**

Sociodemographic characteristics	Satisfaction with service high n	 (%)	 low n	 (%)	 Total N
Sex					
male	294	(53.9)	251	(46.1)	545
female	264	(49.7)	267	(50.3)	531
X^2= 1.92, Df=1, P= 0.165					
Age					
under 65	159	(55.2)	129	(44.8)	288
65 or more	399	(50.6)	389	(49.4)	788
X^2= 1.77, Df-1, P= 0.184					
Ethnic origin					
white	551	(51.7)	514	(48.3)	1065
non-white	7	(63.6)	4	(36.4)	11
X^2= 0.62, Df=1, P= 0.432					
Marital status					
married	348	(54.7)	288	(45.3)	636
not married	209	(48.5)	222	(51.5)	431
X^2= 3.99, Df=1, P= 0.046					
Housing tenure					
owner-occupier	375	(55.1)	305	(44.9)	680
not an owner-occupier	167	(46.0)	196	(54.0)	363
X^2= 7.92, Df=1, P= 0.005					
Had living children					
yes	481	(53.8)	413	(46.2)	894
no	76	(43.2)	100	(56.8)	176
X^2= 6.65, Df=1, P=0.010					
Had living siblings					
yes	420	(54.1)	356	(45.9)	776
no	134	(46.5)	154	(53.5)	288
X^2= 4.86, Df-1, P= 0.027					
Religious denomination					
Roman Catholic	52	(54.2)	44	(45.8)	96
Church of England	319	(51.8)	297	(48.2)	616
other Protestant	75	(60.0)	50	(40.0)	125
non-christian	16	(48.5)	17	(51.5)	33
X^2= 3.14, Df-1, P= 0.588					
Place of death					
home	301	(64.2)	168	(35.8)	469
institution	256	(42.4)	348	(57.6)	604
X^2= 50.23, Df=1, P< 0.001					

Table 4.2. Informal carers' satisfaction with general practitioners' services by deceased's sociodemographic characteristics

Sociodemographic characteristics	Satisfaction with service high n	(%)	low n	(%)	Total N
Sex					
male	360	(39.0)	563	(61.0)	923
female	331	(38.5)	528	(61.5)	859
X^2= 0.04, Df-1, P= 0.838					
Age					
under 65	201	(41.0)	289	(59.0)	490
65 or more	489	(37.9)	802	(62.1)	1291
X^2= 1.48, Df=1, P= 0.224					
Ethnic origin					
white	689	(39.1)	1072	(60.9)	1761
non-white	2	(9.5)	19	(90.5)	21
X^2= 7.66, Df=1, P= 0.006					
Marital status					
married	423	(42.3)	577	(57.7)	1000
not married	261	(34.2)	503	(65.8)	764
X^2= 12.08, Df=1, P< 0.001					
Housing tenure					
owner-occupier	451	(41.0)	648	(59.0)	1099
not an owner-occupier	216	(34.6)	409	(65.4)	625
X^2= 7.05, Df=1, P= 0.008					
Had living children					
yes	581	(39.9)	874	(60.1)	1455
no	109	(34.4)	208	(65.6)	317
X^2= 3.37, Df=1, P=0.066					
Had living siblings					
yes	521	(40.3)	771	(59.7)	1292
no	166	(35.5)	301	(64.5)	467
X^2= 3.29, Df=1, P= 0.069					
Religious denomination					
Roman Catholic	60	(34.3)	115	(65.7)	175
Church of England	402	(39.6)	613	(60.4)	1015
other Protestant	78	(45.9)	92	(54.1)	170
non-christian	27	(39.7)	41	(60.3)	68
X^2= 4.86, Df=3, P= 0.182					
Place of death					
home	272	(49.1)	282	(50.9)	554
institution	418	(34.2)	805	(65.8)	1223
X^2= 35.73, Df=1, P< 0.001					

Table 4.3. Informal carers' satisfaction with hospital doctors' services by deceased's sociodemographic characteristics

Sociodemographic characteristics	Satisfaction with service high n	(%)	low n	(%)	Total N
Sex					
male	280	(35.1)	517	(64.9)	797
female	255	(34.4)	487	(65.6)	742
X^2= 0.10, Df=1, P= 0.753					
Age					
under 65	160	(36.9)	274	(63.1)	434
65 or more	375	(33.9)	730	(66.1)	1105
X^2= 1.18, Df=1, P= 0.277					
Ethnic origin					
white	530	(34.9)	989	(65.1)	1519
non-white	5	(25.0)	15	(75.0)	20
X^2= 0.85, Df=1, P= 0.356					
Marital status					
married	312	(36.5)	543	(63.5)	855
not married	219	(32.7)	451	(67.3)	670
X^2= 2.39, Df=1, P= 0.122					
Housing tenure					
owner-occupier	330	(35.6)	596	(64.4)	926
not an owner-occupier	186	(33.0)	377	(67.0)	563
X^2= 1.04, Df=1, P= 0.307					
Had living children					
yes	441	(35.0)	818	(65.0)	1259
no	94	(34.2)	181	(65.8)	275
X^2= 0.07, Df=1, P=0.790					
Had living siblings					
yes	379	(33.5)	752	(66.5)	1131
no	151	(38.7)	239	(61.3)	390
X^2= 3.46, Df=1, P= 0.063					
Religious denomination					
Roman Catholic	54	(36.0)	96	(64.0)	150
Church of England	309	(35.5)	561	(64.5)	870
other Protestant	45	(32.4)	94	(67.6)	139
non-christian	24	(37.5)	40	(62.5)	64
X^2= 0.706, Df=3, P= 0.872					
Place of death					
hospital	396	(35.2)	728	(64.8)	1124
home/other institution	137	(33.3)	275	(66.7)	412
X^2= 0.521, Df=1, P= 0.470					

Table 4.4. Informal carers' satisfaction with health and social services in general by deceased's sociodemographic characteristics

Sociodemographic characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Sex					
male	265	(28.0)	682	(72.0)	947
female	239	(26.9)	650	(73.1)	889
X^2= 0.28, Df=1, P= 0.598					
Age					
under 65	142	(28.5)	356	(71.5)	498
65 or more	361	(27.0)	976	(73.0)	1337
X^2= 0.42, Df=1, P= 0.518					
Ethnic origin					
white	499	(27.5)	1315	(72.5)	1814
non-white	5	(22.7)	17	(77.3)	22
X^2= 0.25, Df=1, P= 0.617					
Marital status					
married	308	(30.5)	703	(69.5)	1011
not married	191	(24.5)	590	(75.5)	781
X^2= 10.85, Df=1, P< 0.001					
Housing tenure					
owner-occupier	335	(29.9)	786	(70.1)	1121
not an owner-occupier	149	(22.7)	506	(77.3)	655
X^2= 10.62, Df=1, P= 0.001					
Had living children					
yes	426	(28.5)	1069	(71.5)	1495
no	78	(23.0)	261	(77.0)	339
X^2= 4.17, Df=1, P=0.041					
Had living siblings					
yes	366	(27.4)	972	(72.6)	1338
no	135	(28.0)	347	(72.0)	482
X^2= 0.08, Df=1, P= 0.783					
Religious denomination					
Roman Catholic	51	(28.5)	128	(71.5)	179
Church of England	300	(28.8)	740	(71.2)	1040
other Protestant	52	(29.5)	124	(70.5)	176
non-christian	16	(22.9)	54	(77.1)	70
X^2= 1.24, Df=3, P= 0.743					
Place of death					
home	194	(34.2)	373	(65.8)	567
institution	308	(24.4)	956	(75.6)	1264
X^2= 19.08, Df=1, P< 0.001					
Had financial problems as a result of illness					
yes	37	(19.4)	154	(80.6)	191
no	446	(28.3)	1132	(71.7)	1578
X^2= 6.79, Df=1, P=0.009					

4.2.1.1.1. Summary

Sex, age, and religious denomination of the deceased were not significantly associated with carers' satisfaction across the four dependent variables. The associations of the other variables with carers' satisfaction varied across providers; for instance, housing tenure of deceased was significantly associated with carers' satisfaction with DNs, GPs, and health and social services in general, but failed to reach statistical significance with satisfaction with HDs' services.

Attention should be also drawn to two other important variables : ethnicity and place of death. Carers of "white" deceased were more likely than others to report high satisfaction with GPs' services. Even though the number of non-white cases considered in the analysis is small (21 cases), the chi-square test was found to be valid following Cochran's criterion that 80% of the cells in the table should have an expected frequency greater than 1 (Altman, 1991).

In addition, dying at home compared to dying in other places was found to be positively statistically significantly associated with carers' satisfaction with DNs, GPs, and health and social services in general. In order to test whether place of death is a possible determinant of carers' satisfaction with providers in that place, the variable was recoded to reflect deaths in hospitals versus deaths in other places; it was not found to be significantly associated with carers' satisfaction with hospital doctors' services.

4.2.1.2. Deceased clinical characteristics

Tables 4.5., 4.6., 4.7., and 4.8. present the associations between the deceased clinical characteristics and carers' satisfaction with DNs, GPs, HDs, and HSS.

Table 4.5. Informal carers' satisfaction with district nurses' services by deceased's clinical characteristics

Clinical characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Site of malignant neoplasm					
digestive organs and peritoneum	172	(53.6)	149	(46.4)	321
respiratory and intrathoracic organs	114	(50.7)	111	(49.3)	225
bone, breast and connective tissue	71	(49.3)	73	(50.7)	144
genito-urinary organs	95	(50.3)	94	(49.7)	189
lymphatic and haematopoietic tissue	33	(53.2)	29	(46.8)	62
other and unspecified parts	71	(53.8)	61	(46.2)	132
X^2= 1.32, Df=5, P= 0.933					
Intensity of functional limitation					
low	171	(45.1)	208	(54.9)	379
high	341	(56.6)	262	(43.4)	603
X^2= 12.19, Df=1, P< 0.001					
Duration of functional limitation					
short	190	(50.4)	187	(49.6)	377
long	296	(53.7)	255	(46.3)	551
X^2= 0.99, Df=1, P- 0.319					
Duration of pain					
short	352	(53.2)	310	(46.8)	662
long	182	(46.8)	190	(51.1)	372
X^2= 1.72, Df=1, P= 0.189					
Duration of gastro-intestinal symptoms					
short	254	(55.5)	204	(44.5)	458
long	226	(50.7)	220	(49.3)	446
X^2= 2.08, Df=1, P= 0.149					
Duration of incontinence					
short	241	(53.7)	208	(46.3)	449
long	288	(52.7)	259	(47.3)	547
X^2= 0.104, Df-1, P= 0.747					
Duration of psychological and cognitive functioning symptoms					
short	279	(59.1)	193	(40.9)	472
long	222	(46.7)	253	(53.3)	475
X^2= 14.55, Df=1, P< 0.001					
Duration of respiratory symptoms					
short	316	(56.0)	248	(44.0)	564
long	230	(47.1)	258	(52.9)	488
X^2= 8.30, Df=1, P= 0.004					

Table 4.6. Informal carers' satisfaction with general practitioners' services by deceased's clinical characteristics

Clinical characterstics	Satisfaction with service high n	(%)	low n	(%)	Total N
Site of malignant neoplasm					
digestive organs and peritoneum	191	(39.3)	295	(60.7)	486
respiratory and intrathoracic organs	153	(38.2)	248	(61.8)	401
bone, breast and connective tissue	101	(46.5)	116	(53.5)	217
genito-urinary organs	106	(36.7)	183	(63.3)	289
lymphatic and haematopoietic tissue	53	(40.5)	78	(59.5)	131
other and unspecified parts	84	(33.7)	165	(66.3)	249
X^2= 8.99, Df=5, P= 0.110					
Intensity of functional limitation					
low	295	(34.9)	550	(65.1)	845
high	338	(43.6)	438	(56.4)	776
X^2= 12.70, Df=1, P< 0.001					
Duration of functional limitation					
short	280	(33.6)	554	(66.4)	834
long	318	(45.4)	383	(54.6)	701
X^2= 22.26, Df-1, P< 0.001					
Duration of pain					
short	437	(39.0)	683	(61.0)	1120
long	222	(38.0)	362	(62.0)	584
X^2= 0.16, Df=1, P= 0.686					
Duration of gastro-intestinal symptoms					
short	330	(40.6)	482	(59.4)	812
long	265	(40.5)	390	(59.5)	872
X^2= 0.005, Df=1, P= 0.944					
Duration of incontinence					
short	356	(41.8)	496	(58.2)	852
long	294	(37.1)	498	(62.9)	792
X^2= 3.73, Df=1, P= 0.053					
Duration of psychological and cognitive functioning symptoms					
short	347	(42.8)	464	(57.2)	811
long	275	(35.8)	494	(64.2)	769
X^2= 8.16, Df=1, P- 0.004					
Duration of respiratory symptoms					
short	373	(41.2)	533	(58.8)	906
long	307	(36.6)	531	(63.4)	838
X^2= 3.76, Df=1, P= 0.052					

Table 4.7. Informal carers' satisfaction with hospital doctors' services by deceased's clinical characteristics

Clinical characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Site of malignant neoplasm					
digestive organs and peritoneum	149	(35.0)	277	(65.0)	426
respiratory and intrathoracic organs	98	(29.9)	230	(70.1)	328
bone, breast and connective tissue	69	(40.8)	100	(59.2)	169
genito-urinary organs	76	(29.8)	179	(70.2)	255
lymphatic and haematopoietic tissue	58	(46.8)	66	(53.2)	124
other and unspecified parts	83	(36.2)	146	(63.8)	229
X^2= 10.06, Df=5, P= 0.004					
Intensity of functional limitation					
low	299	(38.8)	471	(61.2)	770
high	193	(30.5)	439	(69.5)	632
X^2= 10.48, Df=1, P= 0.001					
Duration of functional limitation					
short	286	(38.0)	467	(62.0)	753
long	178	(31.2)	393	(68.8)	571
X^2= 6.61, Df=1, P= 0.010					
Duration of pain					
short	342	(35.1)	632	(64.9)	974
long	166	(33.3)	332	(66.7)	498
X^2= 0.46, Df=1, P= 0.497					
Duration of gastro-intestinal symptoms					
short	255	(36.4)	445	(63.6)	700
long	181	(31.9)	386	(68.1)	567
X^2= 2.82, Df=1, P= 0.093					
Duration of incontinence					
short	275	(37.2)	457	(62.4)	732
long	216	(31.6)	468	(68.4)	684
X^2= 5.60, Df=1, P= 0.018					
Duration of psychological and cognitive functioning symptoms					
short	259	(36.9)	443	(63.1)	702
long	211	(31.6)	457	(68.4)	668
X^2= 4.28, Df-1, P= 0.038					
Duration of respiratory symptoms					
short	285	(36.4)	498	(63.6)	783
long	237	(32.9)	483	(67.1)	720
X^2= 2.00, Df-1, P= 0.157					

Table 4.8. Informal carers' satisfaction with health and social services in general by deceased's clinical characteristics

Clinical characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Site of malignant neoplasm					
digestive organs and peritoneum	146	(29.0)	358	(71.0)	504
respiratory and intrathoracic organs	102	(24.6)	312	(75.4)	414
bone, breast and connective tissue	69	(30.8)	155	(69.2)	224
genito-urinary organs	85	(29.1)	207	(70.9)	292
lymphatic and haematopoietic tissue	38	(27.5)	100	(72.5)	138
other and unspecified parts	62	(24.3)	193	(75.7)	255
X^2= 5.15, Df=5, P= 0.397					
Intensity of functional limitation					
low	210	(23.9)	667	(76.1)	877
high	247	(31.4)	539	(68.6)	786
X^2= 11.64, Df=1, P< 0.001					
Duration of functional limitation					
short	202	(23.5)	657	(76.5)	859
long	227	(31.8)	487	(68.2)	714
X^2= 13.47, Df=1, P< 0.001					
Duration of pain					
short	323	(28.9)	793	(71.1)	1116
long	155	(27.0)	420	(73.0)	575
X^2= 0.74, Df=1, P= 0.390					
Duration of gastro-intestinal symptoms					
short	244	(30.5)	555	(69.5)	799
long	172	(26.7)	471	(73.3)	643
X^2= 2.49, Df=1, P= 0.114					
Duration of incontinence					
short	251	(28.7)	623	(71.3)	874
long	224	(27.7)	585	(72.3)	809
X^2= 0.220, Df=1, P= 0.639					
Duration of psychological and cognitive functioning symptoms					
short	261	(32.5)	543	(67.5)	804
long	184	(24.1)	578	(75.9)	762
X^2= 13.30, Df=1, P< 0.001					
Duration of respiratory symptoms					
short	276	(30.6)	625	(69.4)	901
long	217	(26.1)	613	(73.9)	830
X^2= 4.27, Df=1, P= 0.039					

4.2.1.2.1. Summary

Duration of pain was not statistically significantly associated with carers' satisfaction across the four dependent variables, in contrast to the duration of psychological and cognitive functioning symptoms which had a negative association. Site of malignant neoplasm was only significantly associated with carers' satisfaction with HDs, with high satisfaction being more reported by carers whose deceased died from lymphatic and/or haematopoietic tissue cancers than those whose deceased died from any other type of cancer.

While intensity and duration of functional limitation were found to be significantly associated with carers' satisfaction with GPs, HDs, and health and social services in general, the duration, but not the intensity of such limitation, failed to be associated at $P< 0.1$ with carers' satisfaction with DNs' services. It is also worthy to note that the largest number of significant associations was found between the deceased clinical characteristics and carers' satisfaction with HDs (six of eight associations), followed by carers' satisfaction with GPs (5 associations). Only three significant associations were found with carers' satisfaction with DNs' services.

4.2.1.3. Carers' sociodemographic characteristics

Table 4.9., 4.10., 4.11., and 4.12. present the associations between carers' sociodemographic characteristics and their satisfaction with services delivered by DNs, GPs, HDs, and health and social services in general.

Table 4.9. Informal carers' satisfaction with district nurses' services by carers' sociodemographic characteristics

Sociodemographic characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Sex					
male	183	(52.4)	166	(47.6)	349
female	375	(51.6)	352	(48.4)	727
X^2= 0.06, Df=1, P= 0.793					
Age					
under 65	349	(51.6)	328	(48.4)	677
65 years or more	207	(53.4)	181	(46.6)	388
X^2= 0.32, Df=1, P= 0.571					
Relationship to deceased					
spouse	308	(56.3)	239	(43.7)	547
not spouse	250	(47.3)	279	(52.7)	529
X^2= 8.82, Df=1, P= 0.003					
Lived with deceased					
yes	412	(57.2)	308	(42.8)	720
no	144	(41.3)	205	(58.7)	349
X^2= 23.99, Df=1, P< 0.001					
Living alone after deceased's death					
yes	297	(58.3)	212	(41.7)	509
no	256	(46.0)	300	(54.0)	556
X^2= 16.12, Df=1, P< 0.001					
Marital status at time of interview					
married	159	(44.9)	195	(55.1)	354
not married	394	(55.6)	315	(44.4)	709
X^2= 10.74, Df=1, P= 0.001					
Housing tenure					
owner-occupier	396	(52.9)	352	(47.1)	748
not an owner-occupier	155	(49.8)	156	(50.2)	311
X^2= 0.85, Df=1, P= 0.357					
Religious denomination					
Roman Catholic	55	(57.3)	41	(42.7)	96
Church of England	329	(51.7)	307	(48.3)	636
other Protestant	52	(52.0)	48	(48.0)	100
non-christian	25	(55.6)	20	(44.4)	45
X^2= 1.21, Df=3, P= 0.750					
Strength of religious faith					
strong	164	(55.2)	133	(44.8)	297
not strong	387	(50.7)	376	(49.3)	763
X^2= 1.73, Df=1, P= 0.19					

Table 4.10. Informal carers' satisfaction with general practitioners' services by carers' sociodemographic characteristics

Sociodemographic characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Sex					
male	247	(41.0)	356	(59.0)	603
female	444	(37.7)	735	(62.3)	1179
X^2= 1.83, Df=1, P= 0.176					
Age					
under 65	415	(35.9)	741	(64.1)	1156
65 years or more	270	(44.7)	334	(55.3)	604
X^2= 12.93, Df=1, P< 0.001					
Relationship to deceased					
spouse	385	(45.3)	464	(54.7)	849
not spouse	306	(32.8)	627	(67.2)	933
X^2= 29.49, Df-1, P< 0.001					
Lived with deceased					
yes	498	(44.7)	617	(55.3)	1115
no	188	(28.7)	466	(71.3)	654
X^2= 43.99, Df-1, P< 0.001					
Living alone after deceased's death					
yes	355	(44.4)	445	(55.6)	800
no	330	(34.2)	634	(65.8)	964
X^2= 18.93, Df=1, P< 0.001					
Marital status					
married	195	(30.8)	438	(69.2)	633
not married	490	(43.4)	639	(56.6)	1129
X^2= 27.08, Df=1, P< 0.001					
Housing tenure					
owner-occupier	493	(39.6)	751	(60.4)	1244
not an owner-occupier	192	(37.2)	319	(62.4)	511
X^2= 0.64, Df=1, P= 0.422					
Religious denomination					
Roman Catholic	58	(34.9)	108	(65.1)	166
Church of England	402	(39.5)	617	(60.5)	1019
other Protestant	71	(43.0)	94	(57.0)	165
non-christian	32	(44.0)	48	(60.0)	80
X^2= 2.31, Df-3, P= 0.511					
Strength of religious faith					
strong	204	(43.4)	266	(56.6)	470
not strong	480	(37.4)	805	(62.6)	1285
X^2= 5.29, Df=1, P= 0.021					
Have the same GP as deceased					
yes	458	(48.6)	485	(51.4)	943
no	228	(27.7)	594	(72.3)	812
X^2= 80.21, Df-1, P< 0.001					

Table 4.11. Informal carers' satisfaction with hospital doctors' services by carers' sociodemographic characteristics

Sociodemographic characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Sex					
male	188	(35.6)	340	(64.4)	528
female	347	(34.3)	664	(65.7)	1011
X^2= 0.25, Df=1, P= 0.616					
Age					
under 65	339	(33.0)	687	(67.0)	1026
65 years or more	194	(39.0)	304	(61.0)	498
X^2= 5.16, Df=1, P= 0.023					
Relationship to deceased					
spouse	286	(59.8)	432	(60.2)	718
not spouse	249	(30.3)	572	(69.7)	821
X^2= 15.26, Df=1, P< 0.001					
Lived with deceased					
yes	359	(37.9)	589	(62.1)	948
no	174	(29.8)	409	(70.2)	583
X^2= 10.24, Df=1, P= 0.001					
Living alone after deceased's death					
yes	267	(39.7)	406	(60.3)	673
no	267	(31.2)	589	(68.8)	856
X^2= 11.92, Df=1, P< 0.001					
Marital status					
married	162	(29.5)	388	(70.5)	550
not married	370	(37.5)	607	(62.1)	977
X^2= 10.98, Df=1, P< 0.001					
Housing tenure					
owner-occupier	364	(34.4)	695	(65.6)	1059
not an owner-occupier	167	(36.2)	294	(63.8)	461
X^2= 0.48, Df=1, P= 0.486					
Religious denomination					
Roman Catholic	48	(34.5)	91	(65.5)	139
Church of England	319	(36.8)	548	(63.2)	867
other Protestant	45	(31.9)	96	(68.1)	141
non-christian	26	(34.2)	50	(65.8)	76
X^2= 1.48, Df=3, P= 0.687					
Strength of religious faith					
strong	148	(37.4)	248	(62.6)	396
not strong	380	(33.8)	745	(66.2)	1125
X^2= 1.67, Df=1, P= 0.196					

Table 4.12. Informal carers' satisfaction with health and social services in general by carers' sociodemographic characteristics

Sociodemographic characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Sex					
male	168	(27.3)	448	(72.7)	616
female	336	(27.5)	884	(72.5)	1220
X^2= 0.01, Df-1, P= 0.903					
Age					
under 65	301	(25.2)	892	(74.8)	1193
65 years or more	202	(32.2)	425	(67.8)	627
X^2= 10.03, Df=1, P= 0.001					
Relationship to deceased					
spouse	288	(33.6)	568	(66.4)	856
not spouse	216	(22.0)	764	(78.0)	980
X^2= 30.89, Df=1, P< 0.001					
Lived with deceased					
yes	372	(32.7)	765	(67.3)	1137
no	131	(19.0)	560	(81.0)	691
X^2= 40.80, Df=1, P< 0.001					
Living alone after deceased's death					
yes	276	(33.5)	548	(66.5)	824
no	225	(22.5)	776	(77.5)	1001
X^2= 27.55, Df=1, P< 0.001					
Marital status					
married	143	(21.7)	515	(78.3)	658
not married	359	(31.9)	768	(68.0)	1127
X^2= 17.22, Df-1, P< 0.001					
Housing tenure					
owner-occupier	360	(28.1)	919	(71.9)	1279
not an owner-occupier	140	(26.1)	397	(73.9)	537
X^2= 0.82, Df=1, P= 0.366					
Religious denomination					
Roman Catholic	48	(28.2)	122	(71.8)	170
Church of England	312	(29.7)	738	(70.3)	1050
other Protestant	43	(24.6)	132	(75.4)	175
non-christian	23	(27.7)	60	(72.3)	83
X^2= 2.03, Df=3, P= 0.567					
Strength of religious faith					
strong	157	(32.7)	323	(67.3)	480
not strong	341	(25.5)	997	(74.5)	1338
X^2= 9.26, Df=1, P- 0.002					

4.2.1.3.1. Summary

Sex, housing tenure and religious denomination of carer were not statistically significantly associated with satisfaction across all four dependent variables. When asked about the strength of their religious faith, carers with strong religious faith were more likely to report high satisfaction with the community staff and the health and social services in general than those with some or no religious faith. Carers who were 65 years of age or older were more likely to report high satisfaction with GPs', HDs' and the health and social services in general than carers who were less than 65 years of age.

Some of the associations were significant across all four dependent variables : Spouses were more likely to report high satisfaction with delivered services than non-spouses. Carers who were not married were also more likely to report high satisfaction than married ones. Additionally, those who lived with the deceased and those who are living alone after deceased's death were more likely to be highly satisfied with services delivered than those who did not live with the deceased and those who, after deceased's death, are living with other people. Finally, carers who have the same GP as the one deceased had were found to report higher satisfaction with the GP services than those having a different GP.

4.2.1.4. Carers' bereavement experience

In this section, the focus is on assessing associations between carers' bereavement experience/characteristics and how they perceived the care delivered to their loved ones in the last year of life (Table 4.13., 4.14., 4.15., and 4.16.).

Table 4.13. **Informal carers' satisfaction with district nurses' services by carers' bereavement characteristics**

Bereavement variables	**Satisfaction with service**				
	high n	(%)	low n	(%)	Total N
Self-assessment of post-bereavement health					
excellent	143	(60.3)	94	(39.7)	237
good	271	(49.6)	275	(50.4)	546
fair/poor	141	(50.2)	140	(49.8)	281
X^2= 8.19, Df=2, P= 0.017					
Psychological functioning					
low GHQ score	282	(57.2)	211	(42.8)	493
high GHQ score	231	(48.1)	249	(51.9)	480
X^2= 8.04, Df=1, P= 0.004					
Adjustment to bereavement					
good	273	(50.5)	268	(49.5)	541
poor	260	(52.7)	233	(47.3)	501
X^2= 0.53, Df=1, P= 0.464					
Had bereavement-related psychological problems					
at least one problem	368	(49.6)	374	(50.4)	742
no problems	185	(57.8)	135	(42.2)	320
X^2= 6.04, Df-1, P= 0.014					
Had practical worries resulting from deceased's death					
at least problem	176	(47.7)	193	(52.3)	369
no problems	369	(54.4)	309	(45.6)	678
X^2= 4.33, Df=1, P= 0.037					

Table 4.14. **Informal carers' satisfaction with general practitioners' services by carers' bereavement characteristics**

Bereavement variables	Satisfaction with service				
	high n	(%)	low n	(%)	Total N
Self-assessment of post-bereavement health					
excellent	196	(46.9)	222	(53.1)	418
good	334	(37.4)	558	(62.6)	892
fair/poor	155	(34.4)	295	(65.6)	450
X^2= 15.78, Df-2, P< 0.001					
Psychological functioning					
low GHQ score	353	(42.3)	481	(57.7)	834
high GHQ score	272	(35.2)	501	(64.8)	773
X^2= 8.60, Df=1, P= 0.003					
Adjustment to bereavement					
good	344	(36.6)	596	(63.4)	940
poor	319	(41.2)	455	(58.8)	774
X^2= 3.82, Df=1, P= 0.051					
Had bereavement-related psychological problems					
at least one problem	446	(37.4)	748	(62.6)	1194
no problems	237	(41.9)	328	(58.1)	565
X^2= 3.41, Df=1, P= 0.065					
Had practical worries resulting from deceased's death					
at least one problem	232	(38.2)	375	(61.8)	607
no problems	442	(39.0)	691	(61.0)	1133
X^2= 0.1041, Df=1, P= 0.747					

Table 4.15. **Informal carers' satisfaction with hospital doctors' services by carers' bereavement characteristics**

Bereavement variables	Satisfaction with service				
	high n	(%)	low n	(%)	Total N
Self-assessment of post-bereavement health					
excellent	152	(43.3)	199	(56.7)	351
good	265	(34.6)	502	(65.4)	767
fair/poor	115	(28.3)	291	(71.7)	406
X^2= 18.68, Df-2, P< 0.001					
Psychological functioning					
low GHQ score	269	(38.2)	435	(61.8)	704
high GHQ score	215	(31.4)	470	(68.6)	685
X^2= 7.12, Df=1, P= 0.008					
Adjustment to bereavement					
good	291	(36.3)	511	(63.7)	802
poor	229	(33.3)	458	(66.7)	687
X^2= 1.42, Df=1, P= 0.234					
Had bereavement-related psychological problems					
at least one problem	351	(34.0)	681	(66.0)	1032
no problems	179	(36.5)	312	(63.5)	491
X^2= 0.87, Df=1, P= 0.349					
Had practical worries resulting from deceased's death					
at least one problem	182	(34.3)	349	(65.7)	531
no problems	345	(35.4)	630	(64.6)	975
X^2= 0.19, Df-1, P= 0.667					

Table 4.16. Informal carers' satisfaction with health and social services in general by carers' bereavement characteristics

Bereavement variables	Satisfaction with service high n	(%)	low n	(%)	Total N
Self-assessment of post-bereavement health					
excellent	165	(38.6)	262	(61.4)	427
good	246	(26.5)	683	(73.5)	929
fair/poor	92	(19.7)	375	(80.3)	467
X^2= 41.23, Df=2, P< 0.001					
Psychological functioning					
low GHQ score	277	(31.9)	590	(68.1)	867
high GHQ score	180	(22.7)	614	(77.3)	794
X^2= 17.89, Df-1, P< 0.001					
Adjustment to bereavement					
good	273	(27.8)	708	(72.2)	981
poor	213	(26.9)	579	(73.1)	792
X^2= 0.19, Df=1, P= 0.661					
Had bereavement-related psychological problems					
at least one problem	317	(25.9)	907	(74.1)	1224
no problems	182	(30.5)	415	(69.5)	597
X^2= 4.24, Df=1, P= 0.039					
Had practical worries resulting from deceased's death					
at least one problem	151	(24.3)	470	(75.7)	621
no problems	344	(29.1)	837	(70.9)	1181
X^2= 4.73, Df=1, P= 0.029					

4.2.1.4.1. Summary

Carers' self-assessment of post-bereavement health and carers' psychological functioning as measured by the GHQ were significantly associated with their satisfaction with DNs, GPs, HDs, and the health and social services in general, with high satisfaction being associated with perceiving post-bereavement health as excellent, and having a low GHQ score.

Carers who reported having at least one bereavement-related psychological problem were more likely to report low satisfaction with the community staff and the health and social services in general. The relationship was not significant with satisfaction with hospital doctors. Carers who had adjusted well to bereavement were more likely than others to report low satisfaction with GPs' services, while those who indicated having no practical worries which were caused or made worse by deceased's death were more likely to be highly satisfied with DNs and the health and social services in general.

4.2.1.5. Carers' experience of caring

In this section, those respondents who did not provide practical help to deceased were considered as a separate category in some of the variables in order to prevent a decrease in the number of cases subjected to multivariate analysis.

Table 4.17., 4.18., 4.19., and 4.20. indicate the associations between carers' caring characteristics and their satisfaction with services delivered by DNs, GPs, HDs, and health and social services in general.

Table 4.17. Informal carers' satisfaction with district nurses' services by carers' experience of caring

Experience of caring	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Perception of caring					
rewarding	311	(61.0)	199	(39.0)	510
burden	20	(32.3)	42	(67.7)	62
other but not burden	155	(44.2)	196	(55.8)	351
carer did not provide practical help	65	(45.5)	78	(54.5)	143
X^2= 37.20, Df-3, P< 0.001					
Level of restriction in carer's activities as a result of caring					
severely fairly restricted	329	(52.4)	299	(47.6)	628
little/not at all restricted	156	(53.1)	138	(46.9)	294
carer did not provide practical help	66	(45.8)	78	(54.2)	144
X^2= 2.32, Df=2, P= 0.313					
Carer perceived the need for more help in caring for deceased at home					
yes	247	(44.8)	304	(55.2)	551
no	280	(59.8)	188	(40.2)	468
X^2= 22.81, Df=1, P< 0.001					
Carer perceived deceased's home as an easy place for care					
yes	391	(53.7)	337	(46.3)	728
no	154	(47.8)	168	(52.2)	322
X^2= 3.09, Df=1, P= 0.078					

Table 4.18. Informal carers' satisfaction with general practitioners' services by carers' experience of caring

Experience of caring	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Perception of caring					
rewarding	334	(48.8)	350	(51.2)	684
burden	25	(28.4)	63	(71.6)	88
other perceptions but not burden	181	(35.4)	330	(64.6)	511
carer did not provide practical help	144	(29.9)	338	(70.1)	482
X^2= 51.63, Df-3, P< 0.001					
Level of restriction in carer's activities as a result of caring					
severely fairly restricted	368	(43.3)	482	(56.7)	850
little/not at all restricted	171	(39.7)	260	(60.3)	431
carer did not provide practical help	144	(29 8)	339	(70.2)	483
X^2= 23.81, Df-2, P< 0.001					
Carer perceived the need for more help in caring for deceased at home					
yes	297	(34.3)	570	(65.7)	867
no	348	(43.4)	454	(56.6)	802
X^2= 14.66, Df=1, P< 0.001					
Carer perceived deceased's home as an easy place for care					
yes	498	(40.4)	736	(59.6)	1234
no	174	(35.7)	313	(64.3)	487
X^2= 3.14, Df-1, P= 0.076					

Table 4.19. Informal carers' satisfaction with hospital doctors' services by carers' experience of caring

Experience of caring	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Perception of caring					
rewarding	211	(36.8)	362	(63.2)	573
burden	29	(38.2)	47	(61.8)	76
other perceptions but not burden	119	(27.7)	311	(72.3)	430
carer did not provide practical help	168	(37.7)	278	(62.3)	446
X^2= 12.65, Df=3, P= 0.005					
Level of restriction in carer's activities as a result of caring					
severely fairly restricted	239	(33.6)	472	(66.4)	711
little/not at all restricted	123	(33.3)	246	(66.7)	369
carer did not provide practical help	168	(37.6)	279	(62.4)	447
X^2= 2.31, Df=2, P= 0.314					
Carer perceived the need for more help in caring for deceased at home					
yes	229	(30.3)	526	(69.7)	755
no	274	(39.4)	421	(60.6)	695
X^2= 13.21, Df=1, P< 0.001					
Carer perceived deceased's home as an easy place for care					
yes	377	(35.2)	695	(64.8)	1072
no	144	(34.5)	273	(65.5)	417
X^2= 0.05, Df=1, P= 0.817					

Table 4.20. Informal carers' satisfaction with health and social services in general by carers' experience of caring

Experience of caring	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Perception of caring					
rewarding	249	(35.8)	447	(64.2)	696
burden	18	(19.8)	73	(80.2)	91
other perceptions but not burden	118	(22.8)	400	(77.2)	518
carer did not provide practical help	114	(22.2)	400	(77.8)	514
X^2= 39.77, Df=3, P< 0.01					
Level of restriction in carer's activities as a result of caring					
severely fairly restricted	256	(29.9)	599	(70.1)	824
little/not at all restricted	129	(28.8)	319	(71.2)	436
carer did not provide practical help	114	(22.1)	401	(77.9)	498
X^2= 10.37, Df=2, P< 0.006					
Carer perceived the need for more help in caring for deceased at home					
yes	182	(20.2)	718	(79.8)	900
no	287	(34.7)	540	(65.3)	827
X^2= 45.69, Df=1, P< 0.001					
Carer perceived deceased's home as an easy place for care					
yes	367	(28.8)	909	(71.2)	1276
no	119	(24.1)	375	(75.9)	494
X^2= 3.90, Df=1, P= 0.048					

4.2.1.5.1. Summary

Carers' perception of caring at home was significantly associated with carers' satisfaction with DNs, GPs, HDs, and health and social services in general. Carers who perceived caring as rewarding were more likely than others to express high satisfaction with district nurses, general practitioners and the health and social services in general, while high satisfaction with hospital doctors was reported by carers who perceived caring as a burden.

Additionally, the need for more help at home in caring for the deceased was also found to be significantly associated with carers' satisfaction; carers who had no perceptions of such need were more highly satisfied than others with care delivered.

Finally, the perception of home as an easy place for caring for deceased was significantly related to carers' satisfaction with community staff, and the HSS.

4.2.2. Service-related characteristics

4.2.2.1. District nurses' services

In this section, the associations between the characteristics of services provided at the deceased home by the district nurses and carers' satisfaction with these services will be presented (Table 4.21.).

Table 4.21. Informal carers' satisfaction with district nurses' services by service characteristics

Service characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Number of times DN visited deceased at home in last 12 months					
less than 20 times	178	(36.5)	310	(63.5)	488
20-49 times	176	(62.2)	107	(37.8)	283
50 times or more	199	(67.7)	95	(32.3)	294
X^2= 87.87, Df=2, P< 0.001					
Frequency of visits					
DN visited very frequently	356	(65.9)	184	(34.1)	540
DN visited fairly frequently	179	(42.6)	241	(57.4)	420
DN visited infrequently	21	(19.8)	85	(80.2)	106
X^2= 100.78, Df=2, P< 0.001					
Type of care					
practical	433	(53.9)	371	(46.1)	804
talking	75	(39.3)	116	(60.7)	191
both equally	45	(73.8)	16	(26.2)	61
X^2= 25.06, Df=2, P< 0.001					
Nurse contacted other services					
yes	294	(62.8)	174	(37.2)	468
no	241	(43.4)	314	(56.6)	555
X^2= 38.29, Df=1, P< 0.001					
Nurse gave advice					
yes	362	(60.2)	239	(39.8)	601
no	161	(42.3)	220	(57.7)	381
X^2= 30.27, Df=1, P< 0.001					
Nurse visited at night					
yes	154	(68.1)	72	(31.9)	226
no	398	(47.4)	442	(52.6)	840
X^2= 30.74, Df=1, P< 0.001					
Nurse visited carer after deceased's death					
yes	209	(71.3)	84	(28.7)	293
no	345	(44.6)	428	(55.4)	773
X^2= 60.68, Df=1, P< 0.001					

4.2.2.1.1. Summary

Results indicated significant associations with all the service characteristics under investigation and carers' satisfaction with the DNs services. High satisfaction was reported by carers who indicated that DN visited the deceased at home very frequently, made 50 visits or more, provided both practical and psycho-social care (talking), gave advice, contacted other services, made night visits and visited carer at home after deceased's death.

4.2.2.2. General practitioners' services

The service characteristics under investigation are divided into three major categories. First, characteristics of the home visit in terms of number, frequency, and whether GP visited carer after the deceased's death. Second, provision of treatment for major symptoms experienced by dying patients. Finally, provision of information regarding diagnosis to carer.

In order not to loose many cases when assessing provision of treatment by the GPs, and because the number of deceased who had experienced a particular symptom and had not been given treatment for it is small compared to those who either had not had the symptom or had the symptom but were not given a treatment for it, and given that the number of cases considered at MV-I and MV-II is going to be reduced, which will eventually leave very few cases who were not provided with a treatment for that symptom, those who did not experience that symptom were included in the same category as those who experienced it but were not given a treatment for it.

Table 4.22. shows associations between the characteristics of the services delivered by GPs, and carers' satisfaction with these services.

Table 4.22. Informal carers' satisfaction with general practitioners' services by service characteristics

Service characteristics	Satisfaction with service high n	 (%)	 low n	 (%)	 Total N
Number of times GP visited deceased at home in last 12 months					
less than 20 times	482	(33.4)	960	(66 6)	1442
20 times or more	188	(68.6)	86	(31.4)	274
X^2– 119.78, Df–1, P< 0.001					
GP visited at night					
yes	19	(59.4)	13	(40.6)	32
no	667	(38.5)	1065	(61.5)	1732
X^2= 5.75, Df=1, P= 0.016					
Carer knew the diagnosis from GP					
yes	187	(56.0)	147	(44.0)	334
no	489	(34.5)	927	(65.5)	1416
X^2= 52.47, Df=1, P< 0.001					
GP provided treatment for pain					
yes	516	(41.2)	735	(58.8)	1251
no/ deceased had no pain	151	(33.0)	306	(67.0)	457
X^2= 9.47, Df=1, P= 0.002					
GP provided treatment for breathlessness					
yes	182	(41.7)	254	(58.3)	436
no /deceased had no breathing problems	483	(37.4)	808	(62.6)	1291
X^2= 2.58, Df=1, P= 0.108					
GP provided treatment for vomiting					
yes	268	(46.0)	315	(54.0)	583
no /deceased had no vomiting	390	(35.2)	719	(64.8)	1109
X^2= 18.76, Df–1, P= 0.001					
GP provided treatment for constipation					
yes	335	(45.0)	409	(55.0)	744
no /deceased had no constipation	323	(35.1)	596	(64.9)	919
X^2= 16.78, Df=1, P< 0.001					
GP visited carer after deceased's death					
yes	19	(59.4)	13	(40.6)	32
no	667	(38.5)	1065	(61.5)	1732
X^2= 5.76, Df–1, P= 0.016					

4.2.2.2.1. Summary

With the exception of provision of treatment for breathlessness, all the characteristics of services delivered by GPs reached a significance level of $P< 0.1$.

Highly satisfied carers were those who indicated that GP visited deceased at home 20 times or more, made night visits, visited them after deceased's death, provided them with information regarding diagnosis, and had provided the deceased with treatment for pain, vomiting and constipation when he/her experienced these symptoms.

4.2.2.3. Hospital doctors' services

Table 4.23. presents the associations between the different variables assessing the characteristics of services delivered by hospital doctors and the carers' satisfaction with these services.

Table 4.23. Informal carers' satisfaction with hospital doctors' services by service characteristics

Service characteristics	Satisfaction with service				
	high		low		Total
	n	(%)	n	(%)	N
Deceased had enough privacy while in hospital					
yes, all the time	381	(46.4)	441	(53.6)	822
sometimes/never	139	(21.0)	523	(79.0)	662
X^2= 103.55, Df=1, P< 0.001					
Deceased had a room on his/her own					
yes, all the time	93	(46.5)	107	(53.50)	200
sometimes/never	439	(33.1)	886	(66.9)	1325
X^2= 13.67, Df=1, P< 0.001					
Carer's perception of the journey to visit deceased in hospital					
tiring	129	(31.5)	280	(68.5)	409
not tiring	377	(36.6)	652	(63.4)	1029
X^2= 3.33, Df=1, P= 0.068					
Doctor provided treatment for pain					
yes	364	(34.9)	679	(65.1)	1043
no/deceased had no pain	106	(35.9)	189	(64.1)	295
X^2= 0.108, Df=1, P= 0.743					
Doctor provided treatment for breathlessness					
yes	172	(38.4)	276	(61.6)	448
no/deceased had no breathlessness	322	(33.7)	634	(66.3)	956
X^2= 2.97, Df=1, P= 0.085					
Doctor provided treatment for vomiting					
yes	132	(33.9)	257	(66.1)	389
no/deceased had no vomiting	310	(35.7)	559	(64.3)	869
X^2= 0.36, Df=1, P= 0.550					
Doctor provided treatment for constipation					
yes	140	(36.7)	241	(63.3)	381
no/deceased had no constipation	237	(33.9)	463	(66.1)	700
X^2= 0.906, Df=1, P= 0.341					
Deceased had a choice about treatment					
yes	356	(44.5)	444	(55.5)	800
no/ other non-affirmative answers	90	(21.7)	325	(78.3)	415
X^2= 61.21, Df=1, P< 0.001					
Deceased had an operation(s) in a hospital in the last year of life					
yes	241	(37.7)	398	(62.3)	639
no	290	(32.6)	600	(67.4)	890
X^2= 4.32, Df-1, P= 0.038					
Deceased had chemotherapy/hormone treatment in a hospital in the last year of life					
yes	151	(42.3)	206	(57.7)	357
no	368	(32.7)	759	(67.3)	1127
X^2= 11.09, Df-1, P< 0.001					
Deceased had radiotherapy treatment in a hospital in the last year of life					
yes	151	(34.6)	286	(65.4)	437
no	372	(34.9)	695	(65.1)	1067
X^2= 0.01, Df-1, P= 0.909					
Carer knew the diagnosis from a hospital doctor					
yes	267	(39.1)	415	(60.9)	682
no	262	(31.4)	573	(68.6)	835
X^2= 103.55, Df=1, P= 0.002					

4.2.2.3.1. Summary

Results show that carers who reported that deceased had enough privacy while in hospital all the time, who indicated that deceased had a room on his/her own all the time, and who did not perceive the journey to visit the deceased in the hospital as tiring were more likely than others to report high satisfaction with the hospital doctors services.

As far as treatment provision is concerned, no significant associations were found between provision of treatment for pain, vomiting and constipation, and carers' satisfaction with the hospital doctors' services. However, those who indicated that doctors provided treatment for breathlessness were more likely than others to be highly satisfied with the service delivered. Additionally, high satisfaction with hospital doctors services was expressed by carers whose deceased had hormone/chemotherapy treatment, and those whose deceased had an operation (s) sometime in their last year of life. Whether the deceased had had a choice about the treatment was also significantly associated with high carers' satisfaction.

Finally, carers who received information from hospital doctors about the diagnosis were more likely to express high satisfaction with their services.

4.3. Multivariate phase

Analysis at this phase follows the plan outlined in sections 3.3.4.2. Four models of independent variables are designed for each dependent variable. These models will be obtained following the steps outlined in section 3.3.4.2.3.

This section will be broadly divided into 5 sub-sections. The first sub-section will deal with the problem of multicollinearity of the independent variables, while each of the four others will focus on presenting models predicting carers' satisfaction.

4.3.1. Multicollinearity

The main problem of two highly correlated variables is that they provide very similar information and it is very difficult to separate out the effects of the individual variables (Norusis, 1990). Therefore, a check for multicollinearity is necessary before building any model.

For this purpose, categories of the same variable were transformed into variables by themselves. For instance, religious denomination of carer was divided into 3 variables :

Variable 1 : Roman Catholics, code 1 if yes, 0 if no.
Variable 2 : Church of England, code 1 if yes, 0 if no
Variable 3 : other Protestant, code 1 if yes, 0 if no

In this case, "non-christian" cases were accounted for by the 0 code.

As explained earlier (section 3.3.4.3.), a zero-order correlation coefficient of 0.70 or more was used to indicate multicollinearity of independent variables. This criterion is usually used in large samples (De Vaus, 1991). The multicollinearity check was conducted on all the variables subjected to multiple logistic regression. Table 4.24. shows the correlation coefficients of the variables that were found to be highly inter-correlated.

Table 4.24. Correlation coefficients of the variables which were highly inter-correlated in the sample as a whole

Variable I	Variable II	Correlation coefficient
Relationship of carer to deceased (being a spouse)	Marital status of deceased (being married)	+0.68
Relationship of carer to deceased (being a spouse)	Marital status of carer (not married)	+0.90
Relationship of carer to deceased (being a spouse)	Carer lived with deceased (yes)	+0.86
Marital status of deceased (married)	Carer lived with deceased (yes)	+0.81

It is important to note that the variables presented in table 4.24. pertain to the deceased and carers' sociodemographic characteristics. These high correlations were in fact expected since 46.7% (n=868, N=1858) of carers included in sample A are spouses of deceased who are most likely to have lived with the deceased and who have been widowed by the deceased's death.

Because in one of the planned steps of the multivariate analysis variables will forcibly be entered into the model, including highly inter-correlated variables will lead to a masking of the effects of these variables, rendering them not significant contributors in predicting satisfaction. All four variables presented in table 4.24. are highly inter-correlated and consequently only one of them was included in multivariate analysis. The decision was made to keep "relationship of carer to deceased (spouse/non-spouse)".

This decision was based on evidence which showed that spouses are more likely to have bereavement problems (Parkes, 1964; Madison & Viola, 1968; Seale, 1990; Seale, 1991), and since carers' bereavement characteristics is one of the sets of independent variables, it was viewed that including this variable in the model could control for possible associations between carers' bereavement characteristics and their satisfaction with the palliative care services.

4.3.2. Satisfaction with district nurses

Table 4.25. shows the multivariate associations of the service and non-service related factors with carers' satisfaction with DNs services at the MV-I stage, with no outliers removed.

Table 4.25. Multivariate associations at MV-I of the service and non-service related factors in predicting informal carers' satisfaction with DNs' services, with no outliers removed

Selection criteria : Enter
Number of cases : 683

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-4.92	0.001	
Non-service characteristics:			
Deceased had living children			
yes vs no	+0.79	0.007	2.21 (1.25 to 3.93)
Relationship to deceased			
spouse vs not spouse	-0.54	0.036	0.58 (0.35 to 0.96)
Carer lives alone			
yes vs no	+0.62	0.011	1.85 (1.15 to 3.00)
Carer had bereavement-related psychological problems			
no vs yes	+0.54	0.040	1.72 (1.02 to 2.89)
Carer's perception of caring		0.003	
rewarding vs burden	+1.42	0.002	4.13 (1.68 to 10.12)
other but not burden vs burden	+0.86	0.062	2.36 (0.96 to 5.84)
no practical help vs caring is a burden	+1.53	0.007	4.60 (1.51 to 14.03)
Carer had perceptions of need for more help in caring for the deceased at home			
no vs yes	+0.48	0.021	1.55 (1.07 to 2.46)
Service characteristics :			
Number of visits		0.001	
50 or more vs less than 20 visits	+0.79	0.003	2.20 (1.29 to 3.74)
20-49 vs less than 20 visits	+0.76	0.001	2.14 (1.34 to 3.41)
Frequency of visits		0.001	
very frequently vs infrequently	+1.56	0.001	4.78 (2.01 to 11.36)
fairly frequently vs infrequently	+1.14	0.007	3.14 (1.37 to 7.19)
Nurses contacted other services			
yes vs no	+0.69	0.001	2.00 (1.33 to 2.99)
Nurses provided help at night			
yes vs no	+0.59	0.023	1.81 (1.08 to 3.01)
Nurse visited bereaved carer			
yes vs no	+0.54	0.023	1.72 (1.08 to 2.74)

a.Cases correctly classified : 72.80%
b.Model chi-square= 96.52, Df=10, P< 0.001
c.Goodness-of-fit chi-square=583.46, Df=573, P=0.372
d.Number of outliers with SRESID of 2.00 or more : 9

Ten variables were entered in the model but had a significance level greater than 0.1. These are: deceased had siblings; deceased's housing tenure; intensity of functional limitation; duration of psychological/cognitive functional symptoms; duration of respiratory symptoms; carer's practical worries which were caused/made worse by the death event; carer's self-assessment of post-bereavement health status; carer's perception of deceased home as an easy place for care; nurse gave advice; type of care provided by nurse.

Table 4.26. presents the multivariate associations of the service and non-service related factors with carers' satisfaction with DNs' services at the MV-II stage. At this stage, variables presented in table 4.25. were subjected to forward stepwise logistic regression. Even though they were detected, outliers were kept in this analysis.

Table 4.26. Multivariate associations at MV-II of the service and non-service related factors independently predicting satisfaction at MV-I with informal carers' satisfaction with district nurses' services, with no outliers removed

Selection criteria : Forward stepwise
Number of cases : 933

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-3.43	0.001	
Non-service characteristics :			
Deceased had living children			
yes vs no	+0.50	0.016	1.66 (1.10 to 2.49)
Carer lives alone			
yes vs no	+0.46	0.004	1.58 (1.16 to 2.15)
Carer had bereavement-related psychological problems			
no vs yes	+0.59	0.001	1.81 (1.29 to 2.54)
Carer's perception of caring		0.001	
rewarding vs burden	+1.05	0.002	2.86 (1.47 to 5.56)
other but no burden vs burden	+0.49	0.152	1.64 (0.83 to 3.21)
no practical help vs caring is a burden	+0.93	0.019	2.53 (1.17 to 5.50)
Carer perceived the need for more help in caring for deceased at home			
no vs yes	+0.40	0.009	1.50 (1.10 to 2.02)
Service-related characteristics :			
Number of visits		0.001	
50 or more vs less than 20	+0.79	0.001	2.44 (1.66 to 3.59)
20-49 vs less than 20	+0.89	0.001	2.20 (1.53 to 3.16)
Frequency of visits		0.001	
very frequently vs infrequently	+1.63	0.001	5.12 (2.75 to 9.54)
fairly frequently vs infrequently	+0.90	0.004	2.45 (1.32 to 4.54)
Nurses contacted other services			
yes vs no	+0.62	0.001	1.85 (1.37 to 2.50)
Nurse visited bereaved carer			
yes vs no	+0.73	0.001	2.07 (1.46 to 2.93)

a.Cases correctly classified : 71.49%
b.Model chi-square= 238.55, Df=13, P< 0.001
c.Goodness-of-fit chi-square=939.50, Df=919, P=0.312
d.Residual chi-square for variables not in the equation= 5.55, Df=2, P=0.06
e.Number of outliers with SRESID of 2.00 or more : 14

Two variables were not selected in the equation. These are : relationship of respondent to deceased; nurse provided help at night.

Table 4.27. shows the multivariate associations of the service and non-service related factors with carers' satisfaction with DNs' services when the outliers detected in the model presented in table 4.25. were removed.

Table 4.27. Multivariate associations at MV-I of the service and non-service related factors in predicting informal carers' satisfaction with district nurses' services, with outliers removed

Selection criteria : Enter
Number of cases : 594

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-6.18	0.001	
Non-service characteristics :			
Place of death			
home vs institution	+0.37	0.099	1.45 (0.93 to 2.25)
Deceased had living children			
yes vs no	+0.92	0.003	2.51 (1.37 to 4.59)
Deceased had living siblings			
yes vs no	+0.39	0.088	1.48 (0.94 to 2.34)
Relationship to deceased			
spouse vs not spouse	-0.56	0.037	0.57 (0.34 to 0.97)
Carer lives alone			
yes vs no	+0.62	0.015	1.86 (1.13 to 3.06)
Carer had bereavement-related psychological problems			
no vs yes	+0.74	0.008	2.10 (1.21 to 3.64)
Carer's perception of caring		0.001	
rewarding vs burden	+1.77	0.001	5.87 (2.28 to 15.08)
other but not burden vs burden	+1.04	0.031	2.84 (1.10 to 7.33)
no practical help vs caring is a burden	+1.87	0.001	6.46 (1.99 to 20.98)
Carer had perceptions of need for more help in caring for the deceased at home			
no vs yes	+0.51	0.019	1.67 (1.09 to 2.58)
Service-related characteristics :			
Number of visits		0.001	
50 or more vs less than 20 visits	+0.83	0.003	2.30 (1.32 to 3.98)
20-49 vs less than 20 visits	+0.86	0.001	2.36 (1.45 to 3.84)
Frequency of visits		0.001	
very frequently vs infrequently	+2.28	0.001	9.76 (3.36 to 28.37)
fairly frequently vs infrequently	+1.88	0.001	6.55 (2.32 to 18.47)
Nurses contacted other services			
yes vs no	+0.82	0.001	2.27 (1.49 to 3.46)
Nurses provided help at night			
yes vs no	+0.68	0.011	1.98 (1.16 to 3.37)
Nurse visited bereaved carer			
yes vs no	+0.71	0.005	2.03 (1.24 to 3.31)

a.Cases correctly classified : 73.40%
b.Model chi-square= 119.78, Df=10, P< 0.001
c.Goodness-of-fit chi-square=531.96, Df=564, P=0.830
d.Number of outliers with SRESID of 2.00 removed to obtain this model : 9

The following variables were in the model but had a P value greater than 0.1 : deceased's housing tenure; duration of psychological/cognitive functional symptoms; intensity of functional limitation; duration of respiratory symptoms; carer's perception of deceased home as an easy place for care; carer's psychological functioning; carer's self-assessment of post-bereavement health status; and carer's practical worries; nurse gave advice; and type of care provided by nurse.

Then, the variables presented in table 4.27. were subjected to forward stepwise logistic regression. Outliers were detected and removed from the analysis, and forward stepwise regression analysis run again. The results are presented in table 4.28.

Table 4.28. Multivariate associations at MV-II of the service and non-service related factors independently predicting satisfaction at MV-I with informal carers' satisfaction with DNs' services, with outliers removed

Selection criteria : Forward stepwise
Number of cases : 904

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-5.09		0.001
Non-service characteristics :			
Place of death			
home vs institution	+0.46	0.008	1.59 (1.13 to 2.23)
Deceased had living children			
yes vs no	+0.65	0.004	1.91 (1.23 to 2.98)
Carer lives alone			
yes vs no	+0.53	0.002	1.69 (1.21 to 2.37)
Carer had bereavement-related psychological problems			
no vs yes	+0.86	0.001	2.36 (1.62 to 3.43)
Carer's perception of caring		0.001	
rewarding vs burden	+1.30	0.001	3.66 (1.78 to 7.50)
other but no burden vs burden	+0.46	0.214	1.55 (0.77 to 3.62)
no practical help vs caring is a burden	+1.05	0.014	2.85 (1.24 to 6.54)
Carer had perceptions of need for more help in caring for the deceased at home			
no vs yes	+0.45	0.007	1.56 (1.13 to 2.17)
Service-related characteristics :			
Number of visits		0.001	
50 or more vs less than 20	+1.03	0.001	2.79 (1.85 to 4.23)
20-49 vs less than 20	+0.95	0.001	2.58 (1.75 to 3.80)
Frequency of visits		0.001	
very frequently vs infrequently	+2.38	0.001	10.86 (4.55 to 25.92)
fairly frequently vs infrequently	+1.82	0.004	6.16 (2.62 to 14.48)
Nurses contacted other services			
yes vs no	+0.80	0.001	2.37 (1.61 to 3.09)
Nurse gave help at night			
yes vs no	+0.51	0.015	1.67 (1.10 to 2.54)
Nurse visited bereaved carer			
yes vs no	+0.84	0.001	2.32 (1.59 to 3.39)

a.Cases correctly classified : 73.56%
b.Model chi-square= 325.04, Df=15, P< 0.001
c.Goodness-of-fit chi-square=826.50, Df=888, P=0.930
d.Residual chi-square for variables not in the equation= 2.67, Df=2, P=0.263
e.Number of cumulative outliers (MV Phase I and II) removed to obtain this model : 23

Two variables were not selected in the equation. These are : relationship of carer to deceased; and deceased had siblings.

Further analysis

Table 4.28. has indicated that carers whose deceased had been very frequently visited by the district nurse were eleven times (odds ratio= 10.86) more likely to be highly satisfied with the district nurse's services than those who had been infrequently visited by the DN. It might be that the patients who had very frequent visits from the DN had had help from such a nurse over a long period of time compared to those who were infrequently visited by the DN and who might have had contacts with the DN for a shorter period of time.

To test whether the period for which the deceased had had help from a DN acted as a confounder to the association between carers' satisfaction and the frequency of the DNs' visits, this variable was forcibly entered to the final logistic model presented in table 4.28. Results are presented in table 4.29.

Table 4.29. Multivariate associations at MV-II of the service and non-service related factors independently predicting satisfaction at MV-I with informal carers' satisfaction with DNs' services, controlling for the period for which deceased had help from a DN

Selection criteria : Enter
Number of cases : 903

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-5.15	0.001	
Non-service characteristics :			
Place of death			
home vs institution	+0.45	0.010	1.57 (1.11 to 2.22)
Deceased had living children			
yes vs no	+0.64	0.005	1.90 (1.22 to 2.97)
Carer lives alone			
yes vs no	+0.52	0.002	1.68 (1.20 to 2.35)
Carer had bereavement-related psychological problems			
no vs yes	+0.88	0.001	2.39 (1.64 to 3.50)
Carer's perception of caring		0.001	
rewarding vs burden	+1.30	0.001	3.65 (1.78 to 7.51)
other but no burden vs burden	+0.44	0.233	1.56 (0.75 to 3.22)
no practical help vs caring is a burden	+1.06	0.013	2.89 (1.25 to 4.01)
Carer had perceptions of need for more help in caring for the deceased at home			
no vs yes	+0.44	0.008	1.56 (1.12 to 2.17)
Service-related characteristics :			
Number of visits		0.001	
50 or more vs less than 20	+0.96	0.001	2.61 (1.49 to 4.53)
20-49 vs less than 20	+0.86	0.001	2.37 (1.53 to 3.67)
Frequency of visits		0.001	
very frequently vs infrequently	+2.41	0.001	11.07 (4.46 to 27.45)
fairly frequently vs infrequently	+1.79	0.000	6.00 (2.53 to 14.20)
Period for which deceased had help from a district nurse		0.643	
1-3 months vs less than a month	+0.26	0.255	1.30 (0.83 to 2.04)
3-6 months vs less than a month	+0.20	0.504	1.22 (0.68 to 2.20)
6-12 months vs less than a month	+0.06	0.833	1.07 (0.59 to 1.94)
Nurses contacted other services			
yes vs no	+0.79	0.001	2.20 (1.59 to 3.06)
Nurse gave help at night			
yes vs no	+0.52	0.015	1.67 (1.10 to 2.54)
Nurse visited bereaved carer			
yes vs no	+0.85	0.001	2.34 (1.60 to 3.42)

a.Cases correctly classified : 73.20%
b.Model chi-square= 326.70, Df=18, P< 0.001
c.Goodness-of-fit chi-square=828.57, Df=884, P=0.908

4.3.2.1. Summary

Comparing results presented in table 4.26. and table 4.28. indicates that all the variables that were selected by the forward stepwise logistic regression with no outliers removed (table 4.26.) were also selected, together with other variables, when a total of 23 outliers were excluded from the analysis (table 4.28.). Therefore, the model presented in table 4.28. is more comprehensive than the one presented in table 4.26. and is retained as the main result on the predictors of carers' satisfaction with district nurses services. This model correctly classifies 73.56% of the cases and has a chi-square goodness-of-fit statistic of 826.50 with a P value of 0.93, suggesting that the model fits the data well.

The model indicates that carers who are highly satisfied with district nursing services are those who are living alone after the deceased's death, who have no bereavement-related psychological problems, who perceived caring as rewarding or who did not provide practical help to deceased, who perceived no need for more help while caring for the deceased at home, whose deceased died at home and whose deceased had living children. These predictors were independent from one another and also independent from the characteristics of the services delivered by the district nurse.

Further analysis (table 4.29.) has shown that the association between the frequency and number of visits and carers' satisfaction is independent from the length of time for which the district nurse had provided services for the deceased which had no significant contribution in predicting satisfaction. Almost no change in the odds ratio of the service-related characteristics of variables already in the model (table 4.28.) occurred when the period for which services had been provided by district nurses was forcibly entered into the model already containing the main predictors (table 4.29.).

4.3.3. Satisfaction with general practitioners

Results at MV-I and MV-II when no outliers were removed are presented in Appendix E. Table E.1. presents the multivariate associations at MV-I of the service and non-service related factors in predicting carers' satisfaction with the general practitioners. Table E.2. shows the multivariate associations at MV-II of the service and non-service related factors which significantly and independently predicted satisfaction at MV-I with carers' satisfaction with the GP services.

Table 4.30. presents the results at MV-I level when the outliers were removed, while table 4.31. shows results obtained at MV-II level when outliers were excluded.

In these analyses, the ethnicity of the deceased was not included because of the very small number of cases of "non-white" deceased left, when cases with complete and valid data for all variables considered at the multivariate level were selected.

Table 4.30. Multivariate associations at MV-I of the service and non-service related factors in predicting carers' satisfaction with the general practitioners' services, with outliers removed

Selection criteria : Enter
Number of cases : 888

Variable	Regression coefficient	P value	Odds(95% C.I.) ratio
Constant	-3.93	0.001	
Non-service characteristics :			
Place of death			
home vs institution	+0.51	0.005	1.66 (1.16 to 2.38)
Intensity of functional limitation			
low vs high	+0.50	0.039	1.64 (1.02 to 2.63)
Duration of functional limitation			
short vs long	-0.95	0.001	0.38 (0.24 to 0.63)
Duration of incontinence			
short vs long	+0.29	0.001	1.34 (1.12 to 1.59)
Duration of respiratory symptoms			
short vs long	+0.39	0.021	1.39 (1.06 to 2.06)
Carer's age			
65 years or more vs less than 65	+0.43	0.038	1.53 (1.02 to 2.29)
Carer's strength of religious faith			
strong vs some or no faith	+0.42	0.021	1.52 (1.06 to 2.16)
Carer's self-assessment of post-bereavement health		0.015	
excellent vs fair poor	+0.54	0.031	1.71 (1.05 to 2.78)
good vs fair/poor	-0.03	0.888	0.97 (0.64 to 1.48)
Carer had bereavement-related psychological problems			
no vs yes	+0.70	0.001	2.01 (1.32 to 3.06)
Carer's adjustment to bereavement			
high vs low	+0.61	0.003	1.84 (1.23 to 2.73)
Carer's psychological functioning			
low vs high GHQ score	+0.32	0.099	1.38 (0.94 to 2.03)
Carer has the same GP as deceased			
yes vs no	+0.96	0.001	2.62 (1.85 to 3.72)
Carer had perceptions of unmet needs for more help in caring at home			
no vs yes	+0.43	0.016	1.53 (1.08 to 2.16)
Carer's perception of caring		0.029	
rewarding vs a burden	+0.68	0.111	1.98 (0.85 to 4.58)
other but not burden vs a burden	+0.12	0.778	1.13 (0.48 to 2.65)
no practical help vs caring is a burden	+0.33	0.504	1.38 (0.53 to 3.61)
Service-related characteristics :			
Number of home visits made by GP			
20 or more vs less than 20 visits	+1.78	0.001	5.95 (3.59 to 9.85)
GP told carer about diagnosis			
yes vs no	+1.25	0.001	3.48 (2.29 to 5.28)

a.Cases correctly classified : 72.30%
b.Model chi-square= 103.99, Df=7, P< 0.001
c.Goodness-of-fit chi-square=818.67, Df=855, P=0.809
d.Number of outliers removed to obtain this model : 21.

The following variables were in the model but had a significance level of P greater than 0.1 : deceased housing tenure; deceased had living children; deceased had living siblings; duration of psychological and cognitive functioning symptoms; deceased's functional limitation; relationship of carer to deceased; carer lives alone; the level of restriction in the carer's activities as a result of caring; GP visited carer after deceased's death; GP visited deceased at night; and GP provided treatment for pain; GP provided treatment for constipation; GP provided treatment for vomiting; GP provided treatment for breathing problems; carer's perception of deceased home as an easy place for care.

Table 4.31. Multivariate associations at MV-II of the service and non-service related factors independently predicting satisfaction at MV-I with informal carers' satisfaction with the general practitioners' services, with outliers removed

Selection criteria : Forward Stepwise
Number of cases : 1096

Variable	Regression coefficient	P value	Odds(95% C.I.) ratio
Constant	-3.68	0.001	
Non-service characteristics :			
Place of death			
home vs institution	+0.42	0.008	1.52 (1.11 to 2.07)
Duration of functional limitation			
short vs long	-0.71	0.001	0.49 (0.34 to 0.70)
Duration of incontinence			
short vs long	+0.73	0.001	2.08 (1.52 to 2.84)
Duration of respiratory symptoms			
short vs long	+0.44	0.003	1.56 (1.16 to 2.09)
Carer's strength of religious faith			
strong vs some or no faith	+0.45	0.005	1.56 (1.14 to 2.14)
Carer's self-assessment of post-bereavement health		0.001	
excellent vs fair/poor	+0.80	0.001	2.22 (1.46 to 3.38)
good vs fair poor	-0.03	0.867	0.97 (0.67 to 1.40)
Carer had bereavement related psychological problems			
no vs yes	+0.68	0.001	1.97 (1.38 to 2.80)
Carer's adjustment to bereavement			
high vs low	-0.43	0.009	0.64 (0.47 to 0.90)
Carer has the same GP as deceased			
yes vs no	+0.99	0.001	2.70 (1.99 to 3.67)
Carer had perceptions of unmet needs for more help in caring at home			
no vs yes	+0.57	0.001	1.78 (1.31 to 2.40)
Carer's perception of caring		0.026	
rewarding vs a burden	+0.62	0.088	1.87 (0.91 to 3.83)
other but not burden vs a burden	+0.13	0.730	1.14 (0.55 to 2.36)
no practical help vs caring is a burden	+0.31	0.425	1.37 (0.63 to 3.98)
Service-related characteristics :			
Number of home visits made by GP			
20 or more vs less than 20 visits	+1.72	0.001	5.57 (3.62 to 8.57)
GP told carer about diagnosis			
yes vs no	+1.19	0.001	3.29 (2.30 to 4.70)

a.Cases correctly classified : 73.08%
b.Model chi-square= 327.20, Df=16, P< 0.001
c.Goodness-of-fit chi-square=1008.38, Df=1079, P=0.938
d.Residual chi-square for variables not in the equation= 19.31, Df=5, P= 0.002
e.Number of cumulative outliers (MV Phase I & II) removed to obtain this model : 35.

Three variables were not selected in the equation. These are : intensity of functional limitation; carer's age; and carer's psychological functioning.

4.3.3.1. Summary

Similarly to the results obtained with carers' satisfaction with district nurses services, and when the forward stepwise models with and without outliers were compared, all variables, with exception of carers' adjustment to bereavement which had a minor role in predicting satisfaction (odds ratio= 0.64), selected in the equation with no outliers removed were also selected when a total of 35 outliers were excluded from the analysis. The forward stepwise model without outliers also included additional variables. The model without outliers has a more comprehensive variable profile in predicting satisfaction, and therefore was retained as the final result on predictors of carers' satisfaction with GPs. This model correctly classifies 73.08% of cases, and has a goodness-of-fit chi-square statistic of 1008.38 with P value of 0.94, indicating that the data fits the model well.

The model shows that carers who are highly satisfied with GPs' services are those who have strong religious faith, who perceive their post-bereavement health as excellent, who have no bereavement-related psychological problems, who have low adjustment to bereavement, who have the same GP as the one deceased had, who perceive caring at home as rewarding, who perceive no need for more help in caring for the deceased at home, and who were reporting for deceased who died at home and those who experienced long duration of functional limitation, short duration of incontinence, and short duration of respiratory symptoms. These predictors were independent from one another and from the number of home visits made by the GP as well as from the provision of information about diagnosis to carers.

4.3.4. Satisfaction with hospital doctors

Table E.3. shows the multivariate associations of the service and non-service related factors with carers' satisfaction with hospital doctors' services at the MV-I stage, while in table E.4., the multivariate associations of service and non-service related factors with carers' satisfaction at the MV-II stage with no outliers removed will be presented.

Table 4.32. presents the associations of service and non-service characteristics with carers' satisfaction with hospital doctors' services at MV-I stage, with outliers removed. Table 4.33. presents the associations of service and non-service characteristics with carers' satisfaction with hospital doctors' services at MV-II stage, with outliers removed.

Table 4.32. Multivariate associations at MV-I of the service and non-service related factors in predicting informal carers' satisfaction with the hospital doctors' services, with outliers removed

Selection criteria : Enter
Number of cases : 659

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-2.66	0.001	
Non-service characteristics :			
Deceased had living siblings			
yes vs no	+0.47	0.04	1.60 (1.03 to 2.48)
Carer's self-assessment of post-bereavement health		0.003	
excellent vs fair/poor	+0.87	0.003	2.38 (1.35 to 4.19)
good vs fair/poor	+0.18	0.464	1.20 (0.73 to 1.96)
Carer's psychological functioning			
low vs high GHQ score	+0.60	0.015	1.64 (1.10 to 2.44)
Carer's perception of caring		0.031	
rewarding vs a burden	-0.90	0.036	0.41 (0.18 to 0.94)
other but not burden vs a burden	-1.28	0.004	0.28 (0.12 to 0.66)
no practical help vs caring is a burden	-0.95	0.042	0.39 (0.24 to 0.97)
Carer had perceptions of unmet needs for more help in caring for deceased			
no vs yes	+0.36	0.073	1.44 (0.97 to 2.13)
Service-related characteristics :			
Carer perceived that deceased had a choice about the treatment given			
yes vs no	+1.09	0.001	2.98 (1.97 to 4.50)
Carer perceived that deceased had enough privacy in hospital			
all the time vs sometimes/never	+1.49	0.001	4.46 (2.89 to 6.86)
Carer perceived that doctor provided treatment for respiratory symptoms			
treatment was provided vs treatment not provided/did not have such symptoms	+0.72	0.001	2.06 (1.35 to 3.13)

a.Cases correctly classified : 71.78%
b.Model chi-square= 91.28, Df=7, P< 0.001
c.Goodness-of-fit chi-square= 598.74, Df= 629, P=0.802
d.Number of outliers with SRESID of 2.00 or more removed to obtain this model : 10.

The variables that were in the model but had a significance level greater than 0.1 are : site of malignant neoplasm; relationship of respondent to deceased; intensity of functional limitation; duration of functional limitation; duration of bodily functioning symptoms; duration of psychological and cognitive functioning symptoms; duration of gastro-intestinal symptoms; carer's age; carer lives alone; carer knew the diagnosis from a hospital doctor; deceased had a room on his/her own; deceased had chemotherapy; deceased had operation(s); and carer's perception of the journey to the hospital to visit the deceased as tiring.

Table 4.33. Multivariate associations at MV-II of the service and non-service related factors independently predicting satisfaction at MV-I with informal carers' satisfaction with the hospital doctors' services, with outliers removed

Selection criteria : Forward Stepwise
Number of cases : 1043

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-1.99	0.001	
Non-service characteristics :			
Carer's self-assessment of post-bereavement health		0.001	
excellent vs fair/poor	+0.93	0.001	2.54 (1.69 to 3.82)
good vs fair/poor	+0.32	0.082	1.37 (0.96 to 1.97)
Carer's perception of caring		0.021	
rewarding vs a burden	-0.78	0.016	0.46 (0.24 to 0.86)
other but not burden vs a burden	-1.03	0.002	0.36 (0.18 to 0.69)
no practical help vs caring is a burden	-0.79	0.012	0.45 (0.24 to 0.87)
Service-related characteristics :			
Carer perceived that deceased had a choice about the treatment given			
yes vs no	+1.13	0.001	3.10 (2.30 to 4.19)
Carer perceived that deceased had enough privacy in hospital			
all the time vs sometimes/never	+1.51	0.001	4.52 (3.32 to 6.15)
Carer perceived that doctor provided treatment for respiratory symptoms			
treatment was provided vs treatment not provided or did not have such symptoms	+0.39	0.012	1.47 (1.09 to 1.99)

a.Cases correctly classified : 70.18%
b.Model chi-square= 206.71, Df=8, P< 0.001
c.Goodness-of-fit chi-square= 974.72, Df=1034, P=0.906
d.Residual chi-square for variables not in the equation= 7.23, Df= 3, P= 0.065
e.Number of cumulative outliers (MV Phase I & II) removed to obtain this model : 21

The variables that were not selected in the equation are : deceased had living siblings; carer's age; and carer had perceptions of unmet needs for more help in caring for deceased.

4.3.4.1. Summary

With the exception of perception of caring, similar predictors were selected by both models, with (table D.4.) and without outliers (table 4.33.). The models without outliers correctly classified 70.18% of cases and has a goodness-of-fit chi-square of 974.72 with P= 0.91, indicating that the designed model fits the data well.

The model shows that carers who are highly satisfied with hospital doctors' services are those who perceived caring for the deceased at home as a burden, who perceived their post-bereavement health as excellent or good, who reported that deceased had a choice about the treatment, who perceived that deceased had enough privacy all the time while in hospital, and who indicated that doctors provided treatment when the deceased had breathlessness problems.

4.3.5. Satisfaction with health and social services in general

In this part of the analysis, no specific service characteristics were considered. The aim of this analysis was to assess the non-service characteristics which are predictors of overall carers' satisfaction with care delivered. In addition, investigations into the role of the service characteristics in predicting satisfaction were done at the level of specific providers.

Table E.5. shows the multivariate associations at MV-I between the non-service related factors and carers' satisfaction with health and social services with no outliers removed, while table E.6. presents the multivariate associations at MV-II between the non-service related factors and carers' satisfaction with no outliers excluded.

Table 4.34. presents the results at MV-I level when the outliers were removed, while table 4.35. shows results obtained at MV-II level when outliers were excluded.

Table 4.34. Multivariate associations at MV-I of the non-service related factors in predicting informal carers' satisfaction with the health and social services, with outliers removed

Selection criteria : Enter
Number of cases : 1055

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-5.59	0.001	
Non-service characteristics :			
Deceased's housing tenure (owner-occupier)			
yes vs no	+0.63	0.010	1.87 (1.32 to 2.67)
Deceased had financial problems which resulted from illness			
no vs yes	+0.90	0.009	2.47 (1.25 to 4.89)
Duration of functional limitation experienced by deceased			
short vs long	-1.03	0.001	2.80 (0.28 to 0.56)
Duration of psychological & cognitive functioning symptoms experienced by dec.			
short vs long	+0.26	0.106	1.30 (0.94 to 1.80)
Strength of the carer's religious faith			
strong vs some or no faith	+0.33	0.047	1.40 (1.00 to 1.94)
Carer's self-assessment of post-bereavement health		0.001	
excellent vs fair/poor	+1.14	0.001	3.14 (1.96 to 5.02)
good vs fair/poor	+0.42	0.048	1.52 (1.00 to 2.32)
Carer had perceptions of need for more help in caring for the deceased at home			
no vs yes	+0.97	0.001	2.64 (1.89 to 3.67)
Carer's perception of caring for deceased		0.047	
rewarding vs burden	+0.79	0.077	2.19 (0.92 to 5.25)
other but not burden vs burden	+0.31	0.491	1.36 (0.56 to 3.29)
no practical help vs caring is a burden	+0.56	0.252	1.76 (0 67 to 4.62)

a.Cases correctly classified : 74.41%
b.Model chi-square= 186.85, Df=23, P< 0.001
c.Goodness-of-fit chi-square=953.77, Df=1031, P=0.958
d.Number of outliers with SRESID of 2.00 or more removed to obtain this model : 18

The variables that were in the model but had a significance level greater than 0.1 are : deceased's place of death; deceased had children; intensity of functional limitation; duration of respiratory symptoms; relationship of respondent to deceased; carer's age; carer lives alone; carer's psychological functioning; carer had bereavement-related psychological problems; carer had practical worries/anxieties which resulted from deceased's death; carer's perception of deceased home as an easy place for care; and the level of restriction in the carer's activities as a result of caring.

Table 4.35. Multivariate associations at MV-II of the non-service related factors independently predicting satisfaction at MV-I with informal carer's satisfaction with the health and social services, with outliers removed

Selection criteria : Forward stepwise
Number of cases : 1213

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-4.38	0.001	
Non-service characteristics :			
Deceased's housing tenure (owner-occupier)			
yes vs no	+0.92	0.003	2.52 (1.37 to 4.61)
Deceased had financial problems which resulted from illness			
no vs yes	+0.44	0.045	1.56 (1.15 to 2.11)
Duration of functional limitation experienced by deceased			
short vs long	-0.90	0.001	0.41 (0.29 to 0.56)
Duration of psychological & cognitive functioning symptoms experienced by dec.			
short vs long	+0.33	0.022	1.40 (1.05 to 1.86)
Strength of the carer's religious faith			
strong vs some or no faith	+0.38	0.011	1.47 (1.09 to 1.97)
Carer's self-assessment of post-bereavement health		0.001	
excellent vs fair/poor	+0.96	0.001	2.61 (1.70 to 3.90)
good vs fair/poor	+0.36	0.054	1.43 (0.99 to 2.06)
Carer had perceptions of need for more help in caring for the deceased at home			
no vs yes	+0.92	0.001	2.50 (1.87 to 3.34)
Carer's perception of caring for deceased		0.003	
rewarding vs burden	+0.84	0.039	2.31 (1.04 to 5.11)
other but not burden vs burden	+0.32	0.445	1.37 (0 61 to 3.08)
no practical help vs caring is a burden	+0.37	0.389	1.45 (0.62 to 3.38)

a.Cases correctly classified : 74.44%
b.Model chi-square= 164.03, Df=11, P< 0.001
c.Goodness-of-fit chi-square=1216.90, Df=1201, P=0.368
d.Number of cumulative outliers (MV Phase I & II) removed to obtain this model : 32

All the variables that significantly predicted informal carer's satisfaction with the health and social services at P< 0.1 at MV Phase-I were selected in the equation

Further analysis

One of the important association presented in table 4.35. was that between deceased's social status as measured by housing tenure and carers' satisfaction with health and social services in general. Results have indicated that carers reporting for people who had been owner-occupiers were 2.52 times more likely to be highly satisfied with the district nurses' services than those whose deceased were not owner-occupiers. However, it might be that this association is the result of owner-occupiers receiving higher level of services.

To control for this, three variables were forcibly entered in the model presented in table 4.35. These variables are : (1) the period of time for which deceased had help, if any, from a district nurse, (2) the number of times deceased saw the GP at home or in the surgery in the last year of life, and (3) whether deceased had home help from social services. Results are presented in table 4.36.

Table 4.36. Multivariate associations at MV-II of the non-service related factors independently predicting satisfaction at MV-I with informal carer's satisfaction with the health and social services, controlling for a set of service characteristics

Selection criteria : Enter
Number of cases : 1102

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-5.72	0.001	
Non-service characteristics :			
Deceased's housing tenure (owner-occupier)			
yes vs no	+0.55	0.002	1.74 (1.23 to 2.46)
Deceased had financial problems which resulted from illness			
no vs yes	+1.39	0.002	4.03 (1.95 to 8.35)
Duration of functional limitation experienced by deceased			
short vs long	-0.80	0.001	0.45 (0.45 to 0.65)
Duration of psychological & cognitive functioning symptoms experienced by dec.			
short vs long	+0.37	0.021	1.45 (1.06 to 2.00)
Strength of the carer's religious faith			
strong vs some or no faith	+0.47	0.005	1.59 (1.15 to 2.20)
Carer's self-assessment of post-bereavement health		0.001	
excellent vs fair/poor	+1.14	0.001	3.14 (2.02 to 4.88)
good vs fair/poor	+0.41	0.043	1.51 (1.01 to 2.26)
Carer had perceptions of need for more help in caring for the deceased at home			
no vs yes	+1.12	0.001	3.05 (2.21 to 4.23)
Carer's perception of caring for deceased		0.065	
rewarding vs burden	+0.69	0.106	2.00 (0.86 to 4.62)
other but not burden vs burden	+0.24	0.587	1.27 (0.54 to 2.97)
no practical help vs caring is a burden	+0.51	0.266	1.67 (0.67 to 4.14)
Service-related characteristics :			
Deceased had home help from social services			
yes vs no	+0.19	0.401	1.21 (0.77 to 1.89)
Period for which deceased had help, if any, from a DN			
1 month or less vs no help from DN	+0.09	0.697	1.09 (0.70 to 1.42)
1-3 months vs no help from DN	+0.42	0.089	1.52 (0.94 to 2.48)
3-6 months vs no help from DN	+0.49	0.100	1.63 (0.91 to 2.91)
6-12 months or more vs no help	+0.94	0.001	2.56 (1.54 to 4.25)
Period for which deceased saw a GP at home or in surgery		0.001	
less than 20 times vs never	-0.01	0.952	0.98 (0.67 to 1.45)
20 times or more vs never	+0.62	0.001	1.85 (1.27 to 2.29)

a.Cases correctly classified : 77.00%
b.Model chi-square= 219.17, Df=18, P< 0.001
c.Goodness-of-fit chi-square=999.43, Df=1083, P=0.9663

4.3.5.1. Summary

When compared, the model presented in table 4.35. was found to better predict carers' satisfaction with health and social services in general than the one presented in table D.6., for it includes, in addition to the duration of cognitive and functioning symptoms experienced by the deceased, all the predictors obtained without removing the outliers. Furthermore, this model has a higher percentage of correctly classified cases (74.44%), and a higher P value (P= 0.37) for the goodness-of-fit chi-square statistic (X^2= 1216.90).

The model presented in table 4.35. indicates that carers who are highly satisfied with the health and social services tend to be those who have strong religious faith, who perceived their post-bereavement health as excellent or good, who perceived caring at home for the deceased as rewarding, who perceived no need for more help in caring for the deceased at home, who were reporting for deceased who were owner-occupiers, who perceived that the deceased had no financial problems as a result of illness, who perceived that the deceased had experienced, and for a short period of time, functional limitation, and psychological and cognitive functioning symptoms.

When the three service-related characteristics were controlled for in the analysis (table 4.36.), none of the associations between the individual categories of the "perception of caring" variable remained significant, though the variable as a whole was. Additionally, and even though that of the deceased's housing tenure decreased, the odds ratio of carers being highly satisfied with the health and social services in general when the deceased had no financial problems that resulted or made worse by the illness increased markedly. This variable had a more predictive effect on carers' satisfaction when the service provision characteristics were controlled for.

4.3.6. Comment on the results

The results at the bivariate level have indicated the presence of significant associations between carers' satisfaction and both service and non-service related factors. These significant associations by no means indicate a causal relationship between the two variables, independent and dependent, bearing in mind that other factors might have influenced such a relationship. Additionally, no judgment can be made regarding the strength of these associations for the size of chi-square and P only indicate the evidence against the null hypothesis of no association (Altman, 1991). However, this does not undermine the importance of this stage of analysis for it has firstly reduced the number of variables subjected to multivariate analysis, and secondly outlined the possible predictors of carers' satisfaction.

The aim of the analysis was to explore the importance of different sets of non-service related characteristics in predicting carers' satisfaction with services, independently of the characteristics of these services. The designed final models have indicated that both the service and non-service characteristics affect the way carers perceive the quality of care delivered by the different providers. The non-service characteristics were also proved to be of importance in predicting carers' satisfaction with health and social services in general.

4.4. Summary of results

4.4.1. Summary tables

Table 4.37., 4.38., 4.39., and 4.40. summarizes the number of variables that were significant at each stage of the analysis. PVS-I and PVS-II are two indicators that were designed to show the importance of the different sets of variables in predicting satisfaction. PVS is an abbreviation of "Proportion of Variables Selected".

PVS-I is the ratio of the number of variables that were selected in the final logistic model at MV-II and which were significant at P< 0.1 to the number of variables that were significantly associated with satisfaction at P< 0.1 at the bivariate level. For example, the number of non-service related variables that were selected at MV-II in the model assessing carers' satisfaction with HDs' services was 2, while the number of non-service related variables that were significant at the bivariate level was 16. Thus, PVS-I is equal to 0.13 which is 2 divided by 16 (table 4.39.)

PVS-II is the ratio of the number of variables that were selected in the final logistic model at MV-II and which were significant at P< 0.1 to the number of variables that were initially considered for analysis. For example, the number of service-related variables that were selected at MV-II in the model assessing carers' satisfaction with HDs' services was 3, while the number of service-related variables that were initially considered for analysis was 12. Thus, PVS-II is equal to 0.25 which is 3 divided by 12 (table 4.39.)

Table 4.37. Number of non-service and service variables that significantly associated with carers' satisfaction with district nurses' services at the different phases of the analysis

Variable	Total number (1)	Bivariate P< 0.1 (2)	MV-I no outliers (3)	MV-II no outliers P< 0.1 (4)	PVS-I (4/2) P< 0.1	PVS -II (4/1)
A. Non-service characteristics	35	19	8	6	0.32	0.17
-Deceased sociodemographic characteristics	9	5	3	2	0.40	0.22
-Deceased clinical characteristics	8	3	0	0	0.00	0.00
-Carer sociodemographic characteristics	9	4	2	1	0.25	0.11
-Carer bereavement experience	5	4	1	1	0.25	0.20
-Carer experience of caring	4	3	2	2	0.66	0.50
B. Service characteristics	7	7	5	5	0.71	0.71
C. Total	42	26	13	11	0.42	0.26

Table 4.38. Number of non-service and service variables that significantly associated with carers' satisfaction with general practitioners' services at the different phases of the analysis

Variable	Total number (1)	Bivariate P< 0.1 (2)	MV-I no outliers P< 0.1 (3)	MV-II no outliers P< 0.1 (4)	PVS-I (4/2)	PVS-II (4/1)
A. Non-service characteristics	**36**	**26**	**14**	**11**	**0.42**	**0.31**
-Deceased sociodemographic characteristics	9	6	1	1	0.17	0.11
-Deceased clinical characteristics	8	5	4	3	0.60	0.38
-Carer sociodemographic characteristics	10	7	3	2	0.28	0.20
-Carer bereavement experience	5	4	4	3	0.75	0.60
-Carer experience of caring	4	4	2	2	0.50	0.50
B. Service characteristics	**8**	**7**	**2**	**2**	**0.29**	**0.25**
C. Total	**44**	**33**	**16**	**13**	**0.39**	**0.30**

Table 4.39. Number of non-service and service variables that significantly associated with carers' satisfaction with hospital doctors' services at the different phases of the analysis

Variable	Total number (1)	Bivariate $P< 0.1$ (2)	MV-I no outliers $P< 0.1$ (3)	MV-II no outliers $P< 0.1$ (4)	PVS-I (4/2)	PVS-II (4/1)
A. Non-service characteristics	**35**	**16**	**5**	**2**	**0.13**	**0.06**
-Deceased sociodemographic characteristics	9	1	1	0	0.00	0.00
-Deceased clinical characteristics	8	6	0	0	0.00	0.00
-Carer sociodemographic characteristics	9	5	0	0	0.00	0.00
-Carer bereavement experience	5	2	2	1	0.50	0.20
-Carer experience of caring	4	2	2	1	0.50	0.25
B. Service characteristics	**12**	**8**	**3**	**3**	**0.38**	**0.25**
C. Total	**47**	**24**	**8**	**5**	**0.63**	**0.11**

Table 4.40. Number of non-service variables that significantly associated with carers' satisfaction with health and social services at the different phases of the analysis

Variable	Total number (1)	Bivariate P< 0.1 (2)	MV-I no outliers P< 0.1 (3)	MV-II no outliers P< 0.1 (4)	PVS-I (4/2)	PVS-II (4/1)
A. Non-service characteristics	**35**	**23**	**8**	**8**	**0.35**	**0.23**
-Deceased sociodemographic characteristics	10	5	2	2	0.40	0.20
-Deceased clinical characteristics	8	4	2	2	0.50	0.25
-Carer sociodemographic characteristics	9	6	1	1	0.17	0.11
-Carer bereavement experience	5	4	1	1	0.25	0.20
-Carer experience of caring	4	4	2	2	0.50	0.50

4.4.1.2. Comparison of PVS-I and PVS-II across providers

The above tables indicate that for the non-service related characteristics, we have the following relationships :

1. PVS-I (GP) > PVS-I (HSS)> PVS-I (DN) > PVS-I (HD) [*]
2. PVS-II (HSS)> PVS-II (GP) > PVS-II (DN) > PVS-II (HD)

Additionally, for the service-related characteristics, the following relationships were found :

1. PVS-I (DN) > PVS-I (HD) > PVS-I (GP)
2. PVS-II (DN) > PVS-II (GP) = PVS-II (HD)

Other important relationships :

1. In the model predicting carers' satisfaction with district nurses, the highest PVS-I and PVS-II were for carers' experience of caring.

2. In the model predicting carers' satisfaction with GPs, the highest PVS-I and PVS-II were for carers' bereavement experience.

3. In the model predicting carers' satisfaction with hospital doctors , the highest PVS-I and PVS-II were for carers' experience of caring.

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[*]. The sign > is used to denote the value "greater"

4. In the model predicting carers' satisfaction with hospital doctors , the highest PVS-I and PVS-II were for carers' experience of caring, followed by the second highest (highest PVS-I and second highest PVS-II) deceased's clinical characteristics.

4.4.1.3. Remark on the summary tables

It is to be noted that using the PVS-I and PVS-II for comparison purposes among providers is faced by one major limitation, which is that the number and type of service characteristics investigated in the analysis differ from one provider to the other, and that the PVS-I and PVS-II value for a particular set of independent variables, the sociodemographic characteristics for instance, is directly proportional to the number of variables selected in the model, which is by itself a function of all the variables subjected to multivariate analysis, including the service characteristics.

4.4.2. Common predictors

Some characteristics were found to be predictors of carers' satisfaction with more than one provider. This emphasizes the importance of these characteristics, and strengthen their role in predicting satisfaction. In this section, common predictors with significant odds ratio are discussed.

4.4.2.1. Across all providers

Carers' perception of caring for deceased at home was found to be a common predictor of carers' satisfaction across all providers considered in our investigation. Carers who perceived caring for the deceased at home as rewarding compared to a burden were more likely to be highly satisfied with district nurses, general practitioners, and health and social services in general. Carers who perceived caring at home as a burden were more likely than others to report high satisfaction with hospital doctors.

4.4.2.2. District nurses and GPs

Carers who had no bereavement-related psychological problems, and those who reported that the deceased had had 20 or more home visits from their DN and their GP were more likely than others to report high satisfaction with the services delivered by DNs and GPs.

4.4.2.3. Hospital doctors, GPs, and health and social services in general

Carers who perceived their post-bereavement health as excellent compared to fair or poor were more likely than others to report high satisfaction with the hospital doctors, GPs, and health and social services in general.

4.4.2.4. DNs, GPs, and health and social services in general

Carers who perceived no unmet need for more help while caring for the deceased at home were more likely than those who perceived that need to report high satisfaction with the services delivered by the DNs, GPs, and the health and social services in general.

4.4.3. Important predictors specific to providers

In this section, the predictors which were specific to each provider and which had high odds ratio in the final model compared to other variables in the model will be presented.

4.4.3.1. District nurses

The frequency and the number of home visits made by the district nurses had, and compared to the other variables in the model, high odds ratio predicting carers' satisfaction. The two groups of carers who were highly satisfied with district nurses' services were those : (1) whose deceased had had very frequent home visit from the district nurse, and (2) whose deceased had had 20 or more home visit from the DN.

4.4.3.2. General practitioners

Two non-service and two service-related variables were found to have high odds ratio predicting carer's satisfaction. Four groups of carers were found to be highly satisfied. These are : (1) carers who have the same GP as the one deceased had, (2) carers who are reporting for deceased who experienced incontinence for a short period of time, (3) carers whose deceased had had 20 or more home visits from their GP, and (4) carers who knew the diagnosis from the GP.

4.4.3.3. Hospital doctors

Two service-related predictors had high odds ratio compared to the other variables in the model. The two groups of carers who were highly satisfied are those (1) who reported that deceased had enough choice about the treatment he/her had in the hospital, and (2) those who indicated that deceased had enough privacy all the time while he/her was in hospital.

4.4.3.4. Health and social services in general

Two non-service related variables were found to have high odds ratio compared to other variables in the model. Thus, the two groups of carers who were highly satisfied were those (1) who perceived no need for more help while caring for the deceased at home and those (2) whose deceased was an owner-occupier. When the level of service was controlled for, housing tenure was of less importance compared to whether deceased had financial problems which resulted from the illness; the latter had a remarkably higher odds compared to the former. Thus, the third highly satisfied group consists in this case of carers who perceived that deceased had no financial problems that resulted from the illness.

4.5. Conclusion

The results have indicated the presence of both service and non-service related predictors of carers' satisfaction with palliative care services. They have also shown the importance of the carers' experience of bereavement and of caring vis a vis other non-service factors in predicting carers' satisfaction. Finally, some of the non-service predictors were common to two or more providers while others were provider specific.

CHAPTER 5

DISCUSSION

5.1. Introduction

In this chapter, results presented at both the bivariate and multivariate level of the analysis will be discussed. Discussion of the main findings and the comparison of these findings with those reported in the literature on satisfaction with medical and palliative care will be made. The importance of the service and non-service related factors in predicting carers' satisfaction will be assessed. But first, the main limitations of the analysis will be stated.

5.2. Limitations of the analysis

The main limitations of the analysis are as follow :

1. The RSCD is a retrospective survey whereby interviews with bereaved carers were conducted from ten to thirteen months after deceased's death. A major shortcoming of retrospective design is the selective memory of the subjects; retrospective panel design is also open to the possibility that people will re-interpret the past in the light of the present and that their answers can be perceived and not real (De Vaus, 1991). In palliative care, comparisons

of rating made by the family members before the death and seven months after bereavement suggest that family members alter their assessments during bereavement, and that compared to concurrent assessments, bereaved family members' memories of symptoms and pain were polarised, the patient was remembered as being less anxious and memories of their own anxiety were of higher anxiety (Higginson et al, 1994).

2. Face-to-face interviews were conducted with carers. As indicated by De Vaus (1991), such interviews have limitations. Firstly, respondents might give socially desirable answers to sensitive questions. Secondly, interviewers might place their own interpretation on questions and reveal their opinions. Thirdly, interviewers might fabricate results. To account for these limitations, and before any data collection, RSCD interviewers were carefully trained to limit the effects of interviewer bias.

3. Interviews were conducted by different interviewers and the degree of which the style of the interviewer in conducting the interview predisposed carers in their answers is not known. However, analyses conducted on sample A showed no significant associations at the 95% probability level between carers' satisfaction with DNs, GPs, HDs, and the health and social services in general on one hand, and the interviewer's sex, interviewing experience, and the length of interview on the other (Tables F.1., F.2., F.3. and F.4.).

4. Since the RSCD study was not originally designed to explore the determinants of satisfaction, the analysis conducted in this thesis was restricted to those aspects of services covered by the questionnaire. We might have missed important service characteristics, the presence of which might have affected the variable profile of that model. However, the analyses conducted in this thesis focused on a comprehensive set of service and non-service characteristics, and covered all the non-service characteristics that were depicted in the literature as possible predictors of patient satisfaction with medical care as well as a considerable number of service and non-service variables that are specific to the palliative care field.

5. The data do not allow us to draw causal inferences from the observed associations between the various independent variables and satisfaction. Like all cross-sectional surveys, the RSCD suffers from "time ordering of data". Some inferences could have been made if the data could be modelled with path analytic techniques (Berkanovic and Marcus, 1976). Path analysis is a procedure used for testing causal models; it makes use of R^2 in linear regression, and enables researchers to specify how much effect each variable has and to work out the mechanisms by which variables affect one another (De Vaus, 1991). Path analysis is based on linear regression whereby the dependent variable is continuous, and since both the dependent and independent variables used in the analysis were categorical, path analysis could not be used.

6. The questionnaire used by the RSCD is a structured one and allows quantitative analysis and lacks any qualitative material which could have helped us understand the meaning of the associations revealed.

7. Sample bias might have resulted when the number of cases was reduced at the multivariate level of analysis (Table 5.1.). This decrease in number is due to that cases with valid answers on **all** variables subjected to logistic regression are selected for the analysis. It was virtually impossible to check for this bias since the number of variables considered at this level of the analysis was too high.

Table 5.1. The reduction in the number of cases at the multivariate level of the analysis

Analysis	Original # of cases	Number of cases in final model	Per Cent reduction
District Nurses	1076	904	16.0
General Practitioners	1782	1096	38.5
Hospital doctors	1539	1043	32.2
Health and social services	1836	1213	33.9

7. Some developed scales obtained from factor analysis and used in the analysis have a reliability coefficient alpha less than 0.70, the level recommended as indicating a reliable scale (De Vaus, 1991). A reliable scale is defined as the one on which individuals would obtain much the same scale score on two different occasions; one way of assessing the reliability of a scale is to look at reliability alpha which measures the consistency of a person's response on an item compared to each other scale item (item-item correlation) (De Vaus, 1991).

Table 5.2. Standardized reliability alpha coefficients of scales developed from factor analysis and used in the analysis

Scales	Standardized Alpha Reliability Coefficient
Intensity of functional limitation	0.92
Duration of functional limitation	0.92
Duration of gastro-intestinal symptoms	0.55
Duration of incontinence	0.55
Duration of cognitive and psychological functioning symptoms	0.56
Duration of respiratory symptoms	0.55
Carers' perception of need for more help while caring at home	0.45
Carers' bereavement-related psychological problems	0.60
Carers' practical worries/anxieties resulting from deceased's death	0.47
Carers' adjustment to bereavement	0.68

5.3. Discussion of the main findings

5.3.1. Satisfaction level

The results indicate that in general the level of satisfaction was high. The percentage of carers who gave a rating of excellent or good for services delivered by the district nurses, general practitioners, hospital doctors, and health and social services in general, was respectively 85.3%, 68.5%, 72.0%, and 67.0% (table 3.4.).

This high level of satisfaction is in agreement with previous findings in the patient satisfaction literature. Several studies have reported relatively high levels of patient satisfaction with medical care (Hulka et al, 1975; Fox and Storm, 1981; Williams and Calnan, 1991; Hjortdahl & Laerum, 1992; Stein et al, 1993). Additionally, researchers into palliative care have reported high levels of carers' satisfaction with services delivered to their dying patients (Cartwright et al, 1973; Jones, 1984; Cartwright, 1990; Blyth, 1990; Herd, 1990; Higginson et al, 1990; Sykes et al, 1992; Butters et al, 1993).

Several explanations have been given by researchers for the observed high level of satisfaction. Tessler and Mechanic (1975) suggests that most people are satisfied most of the time, and that those who are not may opt out of the system by changing the provider. Hulka et al (1971) indicated that the high level of satisfaction could be explained by the reluctancy of people to express negative perceptions. Lebow (1974) raised the issue of social desirability, and indicated that reactivity, which is the changes in response because the subject knows he is being evaluated, may cause responses to inaccurately reflect patients' real opinions. Prescott-Clarke et al (1988) argued that people are more likely to express perceptions of satisfaction rather than dissatisfaction because they believe that nothing will change as a result of complaining about care. Thompson (1993) indicated that one reason for this kind of finding may be the lack of specificity in the satisfaction questions, leading to the patients' inability to discriminate between different experiences of care. The problem of item-wording was also mentioned by Lebow (1974), Pope (1978) and French (1981).

The results have also shown that informal carers were more satisfied with the district nurses' services than with services delivered by GPs, hospital doctors, and health and social services in general. This finding is in agreement with what Neale (1991) has reported in her review on informal carers' needs that the most commonly reported praise from informal carers and patients goes to nurses. As discussed by Neale (1991), this may be the result of the growth of the "whole person" approach in the nursing process, and developments in nurse training which place emphasis on psycho-social care (Griffin, 1991), and that a further underlying reason may be the predominance of women in the nursing workforce, with their supposedly natural informal caring qualities (Graham, 1983; James, 1989). It may also be related to the role nurses play in integrating other services in ways that serve the patient's needs (McClure and Nelson, 1982).

When compared to community care, hospital care was perceived by carers as less highly satisfying. A rating of excellent was given by 32.7% of carers commenting on services delivered by hospital doctors, by 37.3% of those commenting on the general practitioners' services and by 50.7% of those commenting on district nurses' services (table 3.4.). This finding is in agreement with other research findings (Herd, 1990; Higginson et al, 1990; Addington-Hall et al, 1991). Addington-Hall et al (1991) indicated that dissatisfaction with hospital care stemmed from carers' perception that the hospital gave insufficient information about the patient's condition, that the carer had not been warned that the death was imminent, that pain was inadequately controlled, and that the number of nurses allocated to the ward was too small to provide adequate care. Herd (1990) reported problems with transport, lack of support, hospital nurses and doctors, and cited few quotations of complaints formulated by carers about hospital care :

> *" ..My husband was treated so badly that I pity anyone having to go through the same ordeal... his diagnosis surely should have been made much sooner, and surely his pain, vomiting and sickness should have been better controlled.*
>
> *" ..He was very distressed with pain for two days, until they started the syringe pump, why didn't they use it earlier ?"*
>
> *" ..The ward was too busy and noisy.."*
>
> *" ..When there was no help for my husband from surgery or radiotherapy...the doctors finished him off.."*

When asked about their overall perceptions of the quality of health and social services in general, carers were less highly satisfied with these services as compared to those delivered by specific providers, i.e. district nurses, GPs, and hospital doctors. This might be because carers are more reluctant to criticize the specific providers that delivered care to deceased but are less reticent when asked about health and social services in general. It might also be that the less specific the question or statement, the more likely the carer is to express negative views about the services (Wilkin et al, 1992). Hall & Dornan (1988c) addressed the issue of specificity in their meta-analysis and indicated that the specificity of the health care being judged was linearly related to satisfaction, with more specific events receiving higher scores, and that studies which asked about care in general reported lowest satisfaction scores than those that focused on a particular kind of care.

Overall, the findings suggest the hypothesis that carers' higher satisfaction with community care as compared to hospital care is related to the actual delivery of a better quality of services at the community level. On the other hand, the provision of services that meet the expectations of carers may be shaped by their experience of community care. In other words, is it a problem of quality of care or unrealistic expectations ?. It might be that carers have higher expectations of what the hospital staff should deliver from services to dying patients as compared to district nurses and GPs. If these expectations are not met, dissatisfaction with the service is most likely to be formulated.

Assessing expectations is beyond the scope of our work and, as noted by Carr-Hill (1992), it is not easy to measure people's expectations and goals. Therefore, another alternative was chosen to detect whether carers' satisfaction is a reflection of the carers' perceptions of the services delivered. This approach, as mentioned in Chapter 2, rests on identifying the service and non-service related characteristics that are significantly associated with carers' satisfaction, and on comparing the importance of the non-service vis a vis the service characteristics in the prediction of carers' satisfaction.

5.3.2. Non-service characteristics

5.3.2.1. Deceased sociodemographic characteristics

The literature on patient satisfaction with medical care has shown a great deal of controversy regarding the effects of the patient characteristics. Some of the studies on patient satisfaction with medical care have indicated significant associations between some of these characteristics and patient satisfaction while others have not (section 1.5.3.1.).

Our findings add to the controversy of the literature on the effects of patients' sociodemographic characteristics. At the bivariate level, and as summarized in section 4.2.1.1.1., sex, age and religious denomination of deceased had no significant association with carers' satisfaction with any of the providers considered.

Even though ethnicity of the deceased was not included in the multivariate stage (section 4.3.3.), it is still an important finding at the bivariate level which deserves discussion. The literature on the effect of ethnicity on patient satisfaction with medical care conflict, with "white" patients (Hulka et al, 1975; Gray, 1980), and sometimes "black" patients (Linn et al, 1982; Zastowny et al, 1983) reporting more satisfaction than dissatisfaction with medical care.

In the analysis, carers of "white" patients were more likely than others to report high satisfaction with GPs' services. This may have a two-fold explanation. Firstly, GPs might have been providing "white" patients with a better quality of care than their "non-white" counterparts, and secondly, "non-white" patients might have been more critical of GPs' services because of social differences in terms of culture, social behaviour, and so on, especially if care was delivered at home and necessitated frequents contacts with the provider. This requires a deeper understanding of the culture and background of patients and their families by the provider for the care to be positively perceived by the family, and in this case, the carer.

Even though the National Health Services (NHS) has made some attempts to improve access and to address language problems (Jofre, 1988), Mind (1987) and Donovan (1986) have reported the persistence of the lack of awareness of cultural practices and principles of ethnic minority individuals amongst some health professionals.

The Black Report (ed. by Townsend and Davidson, 1987) also highlighted the presence of unmet needs for the different ethnic minorities groups :

> *"..there is evidence of some lack of appreciation among health services staff of the special needs of some immigrant groups, as well as a clear lack of adequate facilities in some of the areas in which they have been obliged to concentrate.."*

Thus, the needs of these minority groups need to be addressed if we are to ensure equal utilization of the services by the different ethnic groups in the society, for satisfaction with the service is an important determinant of future utilization of this service (Hays, 1985). Additionally, as prior experience with health providers affects people's expectations of care (Oberst, 1984), and thus affects satisfaction, and afterwards utilization of the services, GPs should take into account the cultural background as well as the social norms and values of the patients and their families while delivering care at home.

The housing tenure of the deceased is a proxy measure of social class that measures the accumulation by an individual or family of fixed property or assets and says something about familial attitudes and priorities (Black Report, ed. by Townsend and Davidson, 1988). It was found to be significantly associated at the bivariate level with the carers' satisfaction with district nurses, general practitioners and health and social services in general, with carers reporting for deceased who were owner-occupiers being more highly satisfied. The same direction of association was found with carers' satisfaction with hospital doctors but the association failed to reach the 90% significance level. This finding is in agreement with Cartwright (1992) who found that carers of working class patients were less satisfied with district nurses services than were respondents for middle-class patients. Additionally, the relationship between housing tenure and carers' satisfaction with the general practitioner agrees with the literature on the inequalities in the availability and use of health services which indicates that middle-class patients receive better and higher quality of services than their working-class contemporaries (Black Report, ed. by Townsend and Davidson, 1987).

Another plausible explanation is that patients who are not owner-occupiers, i.e. living in rented accommodation or council flats and houses, may have higher needs because of the more difficult conditions under which they are living. These needs are not only medical but also social and economic. They may genuinely have had less adequate facilities, e.g. overcrowding, bad housing conditions, difficulties in paying bills, worries about daily living, which translated into higher needs. These high needs might have led to unrealistic expectations on the part of the carer of the services and care that should be delivered by the community staff, and by the health and social services in general. If these providers were unable to address these needs, carers are more likely to report less satisfaction with their services.

In addition, and because of the above mentioned social and economic problems which non-owner occupiers are more likely to experience, carers reporting for deceased who were not owner-occupiers might have been dissatisfied with the life deceased had, this dissatisfaction being translated into all facets of the deceased's life, including the care the deceased had received from their providers. The association between satisfaction with life and satisfaction with medical care has been well documented in patient satisfaction literature (section 1.5.3.2.).

Housing tenure, when the effects of the service provided by district nurses and those provided by the general practitioners were controlled for statistically, failed to reach statistical significance at the multivariate level. However, this variable was selected as an important predictor of carers' satisfaction with health and social services in general, even after controlling for the provision of services by district nurses, general practitioners, and the provision of home help by the social services. This finding might suggest that housing tenure, when considered with other characteristics, is of no importance in predicting carers' satisfaction with specific providers, but of prime importance when carers' satisfaction with health care and social services in general is assessed.

Carers reporting for deceased who had financial difficulties that resulted from the illness were found to be less satisfied with the health and social services in general. This variable was found to be an important predictor of carers' satisfaction with health and social services delivered to the deceased, especially after controlling for the provision of services by district nurses, general practitioners, and the provision of home help by the social services. Controlling for these services has reduced the odds ratio of "housing tenure" and increased markedly that of "deceased had financial difficulties that resulted from the illness". This might suggest that carers reporting for deceased who were owner-occupiers were more likely than others to report high satisfaction with services delivered by the health and social services in general partially out of differences in the provision of these services. Housing tenure, as a variable, seems to have a partial masking effect on the variable "deceased had financial difficulties that resulted from the illness". That is why when the effect of "housing tenure" decreased that of "deceased had financial difficulties" increased.

Still, carers reporting for deceased who had no financial difficulties were more likely to be highly satisfied with the health and social services in general. This might be because carers were satisfied with the life deceased had in general, and this was translated into satisfaction with health and social services in general (section 1.5.3.2.). It might also be that those with no financial difficulties are less dependent on the health and social services due to their ability to purchase services, if needed, to complement those delivered by the local and health authorities and were, therefore, less critical of the quality and/or quantity of these services.

The place of death was found to be a significant predictor of respondents' satisfaction with both district nurses, and general practitioners (section 4.3.2. and section 4.3.3.). Carers' satisfaction with district nurses, general practitioners, and health and social services was higher when the deceased died at home and lower if they died in other places. Though statistically significantly associated with carers' satisfaction at the bivariate level, deceased's place of death was not found to be a significant contributor to the prediction of satisfaction with health and social services in general when other characteristics were considered. Additionally, carers reporting for deceased who died in hospital were not statistically significantly more satisfied with hospital doctors than those reporting for deceased who died elsewhere.

These findings suggest that the association between place of death and carers' satisfaction is specific to providers at the community level. This association was found to be independent of whether the carer perceived the need of more help while caring for the deceased at home, and of how carers perceived caring as an activity (section 4.3.2. and section 4.3.3.). Additionally, the association was independent of some clinical characteristics of the deceased that were found to be predictors of carers' satisfaction with general practitioners (section 4.3.3.), and also independent from some aspects of services delivered by both district nurses and general practitioners. The possible explanation of these findings is that carers might have perceived themselves as co-workers in the delivery of care at home. They might have helped the district nurse with the practical aspects of the services, and also might have participated with the district nurse in implementing the GPs' treatment plan. This contribution towards the delivery of care might have restricted the carer from criticising services delivered by the community staff because by criticising them, they would be criticising the care delivered at home in general, to which they have contributed.

Another explanation could be that carers reporting for deceased who died at home were dependent on the community staff for the care delivered to the deceased, and hence were less likely to criticize the quality of that care. Not surprisingly, carers were less satisfied when patient died in an institution. Patients may be most likely to be admitted to a hospital, for example, when carers are no longer able to continue coping with the deceased at home. It has been reported that terminally ill cancer patients that are admitted to hospitals usually suffer from medical and nursing problems that their carers could not manage satisfactorily at home (Walsh and Kingston, 1988), and that those who died in a hospital or institution usually needed help with self-care and night care at home for somewhat longer that those dying at home, emphasizing that the longer the needs persist, the higher the probability there is of some crisis in the lives of those caring for people at home which may necessitate admission to a hospital or an institution (Cartwright et al, 1973). Thus, carers of patients dying at home might have high expectations of the role of the community staff in caring for deceased. If these expectations are not met, or if the carers are unable to complement the community staff activities in caring for the patients at home, it is more likely that the patient will be admitted to an institution. However, the patient's admission to an institution may very well be the result of inadequate services delivered by the community staff, and that dissatisfaction with district nurses and general practitioners is the end-product of a process of evaluation of these inadequate services by the lay carer.

This latter explanation of the association between dying at home and carers' high satisfaction with the district nurses and GPs' services does not contradict the finding that this association was independent of carers' perception of needs for any more help while caring for the deceased at home. Studies into informal carers' needs have indicated that carers who are fully engaged in their role of caring may be reluctant to acknowledge and address problems or ask for help (Lewis and Meredith, 1988; Blyth, 1990; Addington-Hall, 1991). Additionally, some of the respondents in these studies felt inadequate or disloyal if they admitted the need for help. This might suggest that regardless of whether they needed any help in caring for the deceased, carers might have reported higher satisfaction with these services out of fear that, if they asked for any help, they might be criticized for their inability to care for the deceased at home.

Carers reporting for deceased who had living children were more likely to be highly satisfied with the services delivered by the district nurses, general practitioners and the health and social services in general. However, when other characteristics were controlled for at the multivariate level, the association remained significant only for carers' satisfaction with district nurses' services. It is quite difficult to explain this association for it is independent of the relationship of carer to deceased (Table 4.27.). The explanation for this association, which is a mere speculation, could be that children of deceased play a positive role in the provision and coordination of district nursing services so that these services are delivered in such a way as to meet the patients' needs.

5.3.2.2. Deceaseds' clinical characteristics

An unexpected association at the bivariate level was found between the site of malignant neoplasm and carers' satisfaction with hospital doctors. However, this variable failed to reach the 90% significance level at the multivariate level. At the bivariate level, carers reporting for deceased who died of lymphatic and haematopoietic tissue, or bone, breast and connective tissue were more likely than others to express high carers' satisfaction with hospital doctors services. Least satisfaction was expressed by carers whose deceased had neoplasms of the genito-urinary organs or respiratory and intrathoracic organs. Even though it is not easy to explain such a relationship, one could make several suggestions. Firstly, symptoms of the genito-urinary cancers are somewhat different from those of bone, breast, and connective tissue or lymphatic and haematopoietic tissue. For instance, gynaecological cancer patients often experience abnormal and offensive vaginal discharge; prostate cancer patients suffer from increased frequency of passing urine or difficulties of emptying the bladder, and getting up frequently at night to pass urine; patients with kidney or bladder neoplasms experience pain in passing urine and bladder irritability (Williams, 1989). In contrast, the types of symptoms experienced by patients suffering from lymphatic or haematopoietic tissue cancer include pain, loss of weight and loss of appetite (Hodgkin's disease, myeloid leukaemia), tiredness and shortness of breath (multiple myeloma, lymphocytic leukaemia, myeloid leukaemia), and symptoms from involvement of nerves, the spinal cord, or brain (lymphocytic leukaemia) (Williams, 1989).

In summary, those with lymphatic/haematopoietic cancer experience more pain, while those with genito-urinary cancer have symptoms related to bodily functioning. Therefore, it might be that hospital doctors were more able to manage symptoms related to lymphatic and/or haematopoietic tissue cancers than those associated with genito-urinary cancers, and that the management of symptoms might have acted as a precursor to carers' satisfaction. This explanation is supported by findings from other research on the effectiveness of symptom management. For example, Dunlop (1989) indicated that in hospital, and as result of the success in controlling pain in the last decade, pain ranked ninth in the analysis on distressing symptoms experienced by patients with far advanced cancer. Additionally, Addington-Hall et al (1991) have indicated that pain, itchy skin and constipation were the three symptoms which carers perceived to be most relieved by treatment given to their patients in the last week of life. Palliative treatment given to diarrhoea, difficulty passing urine or urinary incontinence, dysphagia, cough, breathlessness, and vomiting was perceived by less than 50% of carers to have helped alleviate these problems (Addington-Hall et al, 1991).

Williams (1992) indicated that leukaemias, lymphomas, Hodgkin's disease, sarcomas of bone and soft tissue are potentially curable cancers but do require a combination of surgery, radiotherapy or chemotherapy. Therefore, carers reporting for deceased who had such types of cancer might have valued all these interventions and perceived the hospital doctors as adopting all possible strategies of treatment to save their patients' lives. Consequently, these perceptions might have been translated into satisfaction with the hospital doctors' services.

Research has shown that lung cancer patients, who constitute the majority of patients with respiratory organs cancer, were more likely than patients with other types of cancers to report unmet psychological, social and economic needs, community-type unmet needs, unmet needs in relation to medical staff, and a large number of general unmet needs (Houts et al, 1986). A diagnosis of uterine cancer was also associated with both psychological and social unmet needs, and with unmet needs in relation to medical staff (Houts et al, 1986). Therefore, carers whose deceased had respiratory or genito-urinary organs cancers might have been less satisfied than other carers with hospital doctors' services because hospital doctors did not deliver the services that would meet the high needs of the deceased.

The intensity and duration of functional limitation were found to be associated with carers' satisfaction at the bivariate level. Carers reporting for deceased who experienced low functional limitation in terms of intensity (measured by the number of tasks the patient could not perform) were more likely to report high satisfaction with all four providers. These findings agree with the literature of medical care in general (Romm et al, 1976; Linn et al, 1982; Hall et al, 1990), for it might be that the more restricted the activities of the patient, the higher the patients' unmet needs and demands for care that would help them lessen these restrictions, and thus the lower the satisfaction. However, the intensity of functional limitation was not found to significantly predict carers' satisfaction with any of the providers at the multivariate level, showing that it had no independent relationship with satisfaction.

Carers reporting for deceased who experienced long duration of functional limitation were more likely to report high satisfaction with general practitioners, hospital doctors, and health and social services in general. When the effects of the other variables were controlled for statistically, the duration of functional limitation was found to only predict carers' satisfaction with GPs and health and social services in general. However, the association with satisfaction was a negative one, i.e. the longer the duration of the functional limitation, the higher their satisfaction with the GPs and the health and social services in general. It might be that carers reporting for deceased who had functional limitation for a short period of time had higher expectations of the services delivered by the GPs and the health and social services compared to those whose deceased were restricted in their activities for a longer period of time. The latter might have had longer contacts with these services, and might have shaped their expectations according to their experience with these services while the former entered into the system for a short period of time, and might not have had the chance to adjust their demands to what the system could deliver from services and hence were more critical of these services. It might also be that carers' satisfaction with GPs and health and social services in general when the deceased had a longer duration of functional limitation is a reflection of the long period of dependency of the carers and patients on these services, and hence the reluctancy of carers to criticize the main source of care.

These findings suggest that in the palliative care field, intensity and duration of functional limitation have different impacts on carers' satisfaction. Duration of functional limitation seems to be more related to the clients', carers or patients, adjustment of their needs to the delivered services, while intensity is more associated with what people demand from the providers regardless of what services these providers can actually deliver.

One of the main findings in this section is the absence of a significant association at the bivariate level between carers' perception of the duration of pain and their satisfaction with services delivered by any of the providers considered. However, the trend was for carers reporting for deceased who had a short duration of pain to be slightly but not significantly more likely to be highly satisfied with the services delivered by any of the providers.

This finding is, in fact, contrary to initial expectations. Pain control or level and prevalence of pain are viewed by researchers as important outcomes of palliative care (Mor and Masterton-Allen, 1987). Pain control, as an independent variable, was also found to be an important predictor of carers' satisfaction with hospice care

(Wilkinson, 1986). In our analysis, the duration of pain seems to have no effect on how carers' perceived the quality of services delivered to the deceased. It might be that experiencing pain, regardless of its duration, is within the realm of carers' expectations of the sufferings of cancer patients. Pain has always been associated with cancer and, as Levin et al (1985) noted, cancer patients are expected to experience pain. This association between cancer and pain might have predisposed carers to view pain as a natural manifestation of having cancer and thus to perceive no limit on the duration for which it should be experienced by the patient. Therefore, carers might have considered the duration of pain as a cancer characteristic, a factor related to the disease itself, and which has nothing to do with whether the provider delivered good or bad services.

It might also be that satisfaction is related to the perception of success of the intervention to relieve pain during that period and not to the mere existence of pain over that period of time. In other words, the period of time over which pain existed might not have been of importance to carers if pain was perceived to be effectively managed by the providers. This explanation seems plausible given that relieving cancer pain is the main target of health providers, and that, as Sykes et al (1992) noted, it could nowadays be effectively controlled in about 95% of cases.

It is worthy to note that no analysis on the association between carers' perception of the severity of pain and their satisfaction with the different providers was conducted. This is because when the different symptoms were subjected in terms of their severity to factors analysis, and unlike the duration of these symptoms, they failed to group into meaningful factors. Additionally, "severity" and "duration" of a particular symptom were expected to be highly inter-correlated, and hence, only one of them was to be kept for multivariate analysis. Therefore, the decision was to use duration and not severity in the analysis as an indicator of symptom distress across all symptoms reported by carers, including the experience of pain.

The significance of the associations at the bivariate level between carers' satisfaction and the duration of gastro-intestinal, respiratory, psychological and cognitive functioning symptoms, and incontinence varied across providers. However, two important points are to be made. Firstly, the duration of psychological and cognitive functioning symptoms was significantly associated at the bivariate level with carers' satisfaction across all providers, but it only significantly predicted carers' satisfaction with health and social services. Secondly, the duration of respiratory symptoms and that of incontinence experienced by the deceased were found to be significant predictors of carers' satisfaction with general practitioners services.

It might be that carers reporting for deceased who had a long duration of cognitive and psychological functioning symptoms experienced more emotional burden. Caring by itself might have been more demanding, for such symptoms are difficult to manage and cope with. Hence, carers' might have had higher expectations of the way health professionals are supposed to act to alleviate these symptoms. Symptoms such as general feelings of weakness, anorexia, depression, and insomnia have been reported by cancer patients in both hospitals and hospices to be the most distressing (Dunlop, 1989), and perceived by carers to be poorly controlled by providers

(Addington-Hall et al, 1991). Therefore, experiencing these symptoms over a long period of time, coupled with a lack of effective management of these symptoms might have predisposed carers to report less satisfaction with general practitioners, hospital doctors, and health and social services in general. When other characteristics were considered, the duration of psychological and cognitive functioning symptoms remained an important predictor of carers' satisfaction with health and social services in general.

Finally, the duration of incontinence was found to be associated at the bivariate level with carers' satisfaction with general practitioners and hospital doctors, while duration of respiratory symptoms was found to be associated with all the providers except hospital doctors. However, the duration of incontinence and that of respiratory symptoms were found to be predictors of carers' satisfaction with general practitioners' services. Keeping other things constant, carers whose deceased had experienced incontinence and respiratory symptoms over a long period of time were significantly less likely to report satisfaction with the GPs' services. Similarly to the interpretation given earlier, experiencing these symptoms over a long period of time, coupled with poor management of these symptoms by the GP might have predisposed carers in their dissatisfaction with the GPs' services.

5.3.2.3. Carers' sociodemographic characteristics

The sex of carers was not found to be statistically significantly associated with carers' satisfaction with any of the four providers. However, male carers were more likely, though not significantly, to report higher satisfaction with the services compared to female carers. Evidence suggests that male carers receive more help and support than female carers (Blaxter, 1976; Hunt, 1970; Neale, 1992). This discrepancy in terms of service delivery might have led to the observed slightly, though not significantly, higher levels of satisfaction to be reported by "male" carers.

The age of the carers was significantly associated at the bivariate level with their satisfaction with GPs, hospital doctors and health and social services in general. This finding is in agreement with other findings in the literature on patient satisfaction with medical care, with older patients being more satisfied with medical care (Fox and Storm, 1981; Linn et al, 1982; Patrick et al, 1983; Treadway, 1983; Wartman et al, 1983; Kaim-Caudle, 1987; McCarthy et al, 1988; Hall et al, 1990a; Williams and Calnan, 1991). Several explanations have been given for this. Some of these explanations related to the expectations of the elderly of the services delivered, while others focus on the attitude of doctors towards young or old patients. McIver (1991) indicated that the elderly have much lower expectations than younger people, and that surveys often pick up this uncritical attitude. Fox and Storm (1981) reported that the elderly desire different affective relationships with the health care provider than do younger people. Hall and Dornan (1990a) indicated that older patients might have been treated in a more thorough and responsive manner than younger patients. Harris et al (1985) mention that internal medicine residents and staff physicians were found to have more negative attitudes towards younger patients. A similar finding was reported by Street et al (1988) who indicated that physicians were less communicatively dominant, more non-verbally responsive as listeners, and more egalitarian in their interactions with middle-aged and older patients, relative to their encounters with younger patients.

However, when considered with other variables at the multivariate level, the age of the carers failed to reach the significance level in predicting satisfaction, and was not selected in the final models.

The relationship of the carer to the deceased, whether the carer lived with the deceased, and the marital status of carers were all found to significantly associate with carers' satisfaction across all providers at the bivariate level (table 4.9., 4.10., 4.11., and 4.12) , and were also found to be highly inter-correlated (section 4.3.1.). As mentioned earlier, "relationship of respondent to deceased" was kept for analysis at the multivariate level. However, when other characteristics were controlled for, this variable did not contribute significantly to the prediction of satisfaction in the final models. At the bivariate level, carers who were spouses of deceased were significantly more likely to report high satisfaction with the services across providers than non-spouses of deceased. Several explanations could be given. Firstly, it might be that spouses were more aware of the quality and quantity of the services delivered to deceased because they have lived with the deceased during that period, and hence were less prone than other carers to give a negative judgment of these services. Secondly, because they lived with the deceased, spouses might have been more aware of the deceased's needs, and therefore might have been better able to pursue the services that would best meet these perceived needs. Thirdly, it might also be that health professionals treat carers who are spouses of deceased differently from other carers, taking into account the vulnerability of bereaved spouses in developing bereavement problems (section 1.6.1.). It might also be that after the deceased's death, bereaved spouses more than any other group of bereaved carers feel defenceless, and try to get sympathy from their social surroundings by expressing less critical attitudes. Finally, it might be that they are too afraid to criticise the care they depended on.

The religious denomination of the carer had no significant association with carers' satisfaction across providers. The strength of religious faith was significantly associated, at both the bivariate and multivariate level, with carers' satisfaction with general practitioners and health and social services in general. This variable was one of the significant predictors of carers' satisfaction with GPs and health and social services in general. The relationship between religion, as a background variable, and patient satisfaction has rarely been investigated by researchers (Hall et al, 1990a). In our analysis, carers who had strong religious faith were more likely to be highly satisfied with GPs' services than those who had some or no faith at all. A plausible explanation of this association could be that carers with strong religious faith, and compared to those with some or no faith, have different expectations of the services delivered by the GPs and the health and social services in general. Kristjanson (1986) reported that carers with religious affiliation were more interested in spiritual care than in medical care per se in contrast to families with no religious affiliation who were more interested in the technical aspect of medical care. Therefore, carers with some or no religious faith might have had higher needs than those with strong faith related to the clinical management of the disease, which the GPs may have failed to meet. This dissatisfaction with medical care at the community level might have also predisposed them to formulate less satisfaction with health care in general. On the other hand, religious individuals may be generally reluctant to criticize people, having been exhorted to "love thy neighbour" all the time.

Finally, carers' having the same GP as that of the deceased was found to be the most important predictor in this set of independent variable. Carers who have the same GP as the deceased were 2.70 times more likely to be highly satisfied with GPs' services. Hulka et al (1975) indicated that patients who are highly dissatisfied with care will either change doctors or avoid medical care altogether, whereas positive experiences with a particular doctor will enhance a positive attitude. Therefore, carers might have changed the GP if they were highly dissatisfied with the services delivered by that GP to their loved ones. Thus, one would expect more satisfaction than dissatisfaction with GPs' services from carers who still have the same GP as the deceased. Additionally, having the same GP might have predisposed carers to be less critical, as they still depend on this GP for the delivery of care. In other words, carers might have been giving socially desirable answers (Snyder and Ware, 1975). Furthermore, carers with a different GP might have intuitively compared their GPs with the deceased's GPs, and felt that their GPs would have delivered better services if he/she was the one who provided the deceased with care, regardless of the quantity and quality of care delivered by the deceased's GP.

5.3.2.4. Carers' bereavement experience

The findings summarized in section 4.2.1.4.1. indicate that, on the whole, carers with better bereavement outcomes were more likely to report high satisfaction with services delivered. When the bereavement variables that were significantly associated with satisfaction at the bivariate level were considered with other variables at the multivariate level, three bereavement characteristics remained significantly associated with carers' satisfaction. Firstly, carers' self-assessment of post-bereavement health was found to significantly predict carers' satisfaction with GPs, hospital doctors, and health and social services in general, with those perceiving their health as excellent being more highly satisfied with the services than those who rated their health as fair or poor. Secondly, carers who reported having no bereavement related psychological problems were more likely than those who reported having at least one such problem to be highly satisfied with community services. Finally, carers who were less adjusted to bereavement were more likely to be highly satisfied with GPs' services.

The association between perception of overall health status and patient satisfaction has been investigated by many researchers (section 1.5.3.2.). However, it has never been researched in the palliative care field where the subjects are carers of the deceased rather than patients. Still, our finding is in agreement with the literature. In the analysis, it is not sure whether carers' self-assessment of post-bereavement health reflects the carers' actual health status, or the carers' subjective perception of their health. It might be that carers who perceive their health as fair or poor have real medical and psychological problems which predisposed them to be dissatisfied with their own health, and to extend this dissatisfaction into the different aspects of their life including health care in general (Linn and Greenfield, 1982; Roberts et al, 1983; Hall et al, 1990), and that delivered to deceased.

It might also be that these carers are generally dissatisfied with their life, especially after the deceased's death, and this dissatisfaction have predisposed them to be dissatisfied with care delivered to them, and with medical care in general including that delivered to deceased, and which consequently led them to develop poor health (Hall et al, 1990), if they had real medical problems. It might also be that these carers are not happy in their life which predisposed them to have a negative attitude towards themselves which was manifested in a negative perception of their own health, and also towards the health care system in general, including the care delivered to deceased. Finally, Judge and Solomon (1991) reported that people who perceive their health status as poor might have a strong personal stake in the health care system and adverse indicators of health status could be expected to be strongly associated with views about health care.

In the analysis, two measures of carers' psychological well-being were used. The carers' general psychological functioning as measured by the GHQ was found to be significantly associated with carers' satisfaction across all four providers. Carers with a low GHQ score were more likely to report high satisfaction with the services delivered by the different providers compared to those with a high score. However, when the effects of other variables, including other bereavement-related variables, were controlled for, this variable was not selected in the final models predicting carers' satisfaction with the different providers.

The carers' general psychological well-being as measured by their reporting of having bereavement-related psychological problems emerged among the non-service characteristics as a predictor of carers' satisfaction with community staff, both district nurses and GPs. Carers who reported having no such problems were more likely to be highly satisfied with the services delivered by the community staff than those who reported having at least one problem. It might be that carers who reported having bereavement-related psychological problems had high needs for support and care at the bereavement level from district nurses and GPs. They might have had high expectations of the services delivered to bereaved carers. If these expectations were not met given the limited resources of the health authorities, carers were more likely to report low rather than high satisfaction with these services. In other words, carers' experience with the services after the deceased's death might have predisposed them in their evaluation of these services.

However, another explanation could be given. The experience of grief differs from one person to another and, as indicated by Parkes (1986), grief can be weak or strong, brief or prolonged, immediate or delayed. Some bereaved develop an "atypical" grief, resulting in psychological illness. This special form of grief is manifested, among other symptoms, by having severe depression, hypochondriacal symptoms, phobic symptoms, insomnia, self-reproach and expression of guilt, identification symptoms, and delay in the onset of grief of more than two weeks' duration. These symptoms can be reasonably considered as indicators that the reaction to bereavement may take a pathological course (Parkes, 1986).

Although no proper judgements can be provided on the psychological state of carers who reported having bereavement-related psychological problems, although those with low GHQ scores were more likely to report high satisfaction with services across providers, it can be presumed that their experience of grief differed from that of other carers. Parkes (1965), in his Bethlem study on bereaved psychiatric women of less than 60 years of age, indicated that people with atypical grief feelings of guilt and self-reproach were more likely to express marked hostility towards other individuals, usually doctors, nurses and clergy. Parkes (1986) reported a psychiatric case to reinforce the argument :

> *"Mr M was sixty-eight when his wife died. She died unexpectedly after a brief illness. For several days he was stunned. He shut himself up at home and refused to see anyone. He slept badly, ate little, and lost interest in all his customary pursuits. He blamed himself for failing her, and for sending her to the hospital, fearing that she had picked up an infection on the ward...He was generally irritable, and blamed the hospital for his wife's death..'*

Bowlby (1969) indicated that death is personalized as something that has been done to the bereaved and they seek someone to blame. The blame, Bowlby continues, is directed against anyone who might have contributed to the suffering or death of the loved ones, especially God and doctors, since both are seen as having power over life and death. Bowlby (1969) reported several examples of "anger", resulting in blaming others for the deceased's death, and particularly those who had attended the deceased during his illness :

> *" One widow felt angry with the hospital authorities for sending her husband home by bus when he was not fit to travel; she also expressed great anger towards a nurse who had hurt her husband by ripping off an adhesive dressing. Another widow reported consistent memories of the way doctors behaved and treated her husband; she accused them of ignoring significant symptoms..."*

However, even though this criticism and anger may have been justified, Parkes (1986) noted that much of it seemed as irrational as its opposite, an uncritical adulation of the medical profession. Parkes (1986) reported the following comment:

> *"One widow who was very angry with the hospital staff at the time of her bereavement later retracted her accusations and added ruefully, I wish there was something else I could blame..."*

Thus, it is quite possible that carers who reported having bereavement-related psychological problems have had a more difficult grieving process than other bereaved people, and that their dissatisfaction with GPs and district nursing care might have been the result of guilt, self-reproach and anger directed towards the community staff. The reasons why this anger might have been directed towards the community staff are not known. However, two suggestions could be made. Firstly, carers might have found it easier to criticise the less specialized community care than to criticise the highly technological hospital care. Secondly, the bulk of care might have been provided at the community level, and therefore, carers were likely to blame the providers at the community level than those at the hospital level for the death of the deceased.

Finally, adjustment to bereavement was found to be a predictor of carers' satisfaction with GPs' care. Carers who had good adjustment to bereavement were more likely to report less satisfaction with GPs' care than those with poor adjustment to bereavement. Such finding is difficult to interpret. The association between carers' satisfaction with care and their adjustment to bereavement has never been investigated by researchers. It might be that the more the bereaved person accepts the reality of the death event and comes to terms with it, the more he/she will be able to give a clear judgment of the quality of care outside their feelings of despair and loss. Thus, a negative judgment of the GPs' services by persons with good adjustment to bereavement could be a reflection of the actual quality of care delivered by the GPs. In contrast, it might also be that the more the individual is adjusted to bereavement, the more he/her overcomes the feelings of anger and guilt, and thus try to be more positive of the role the medical profession had in caring for the deceased in the period of illness. Therefore, we would expect a linear positive relationship between adjustment to bereavement and respondents' satisfaction. Our finding supports the former rather than the latter explanation.

5.3.2.5. Carers' experience of caring

Two characteristics predicted carers' satisfaction. These are : (1) carers' perception of caring and (2) carers' perception of needs for more help while caring. Carers who perceived caring as rewarding were more likely to report high satisfaction with the district nurses, GPs, and health and social services in general than those who perceived caring as a burden. In contrast, high satisfaction with hospital doctors was expressed by carers who perceived caring as a burden. It might be that those who perceived caring as a rewarding task were happy with their role which they shared with the community staff, and that this satisfaction with their caring role might have led to a satisfaction with care and support delivered by the health care and social services in general, and by the community staff in specific. McHorney and Mor (1988) reported that the dissatisfaction of primary care persons (PCPs) with their caring abilities was related to their dissatisfaction with the patient medical and support care. McHorney and Mor also suggested that dissatisfaction with caring abilities may be considered as an indicator of self-reproach, and that those dissatisfied with their caring abilities may have felt that they somehow contributed to the patient's death or inadequate care by lack of attention during the terminal caretaking period.

In contrast, those who perceived caring as a burden might have been unable to cope in a continuous manner with caring for the patient and hence looked for other alternatives, such as hospital services, that would release them from caring. Admitting the patient to a hospital might have given the carer who perceived caring as a burden a break from caring, and might have allowed them to undertake the activities which were restricted as a result of caring.

Perceiving no need for more help while caring for the deceased at home was found to be a significant predictor of carers' satisfaction with district nurses, GPs, and health and social services in general. Two explanations could be given for this association. It might be that carers who perceived no needs for more help while caring for the deceased at home were actually satisfied with the quantity and quality of services delivered to their patients by the community staff and the health and social services in general. It might also be that carers tended to be less critical of the services delivered at home out of fear that their caring role will be criticised if they formulate any negative criticism towards the care delivered at home in general, and to which they are expected, as informal carers, to have contributed.

5.3.3. Service characteristics

5.3.3.1. District nurses' services

Five out of seven service characteristics were selected in the final model predicting carers' satisfaction with district nurses' services. The main predictor was the frequency of home visits made by the district nurses, followed by the number of these visits, the perception that the district nurse contacted other services, the reporting that district nurse visited the carer after the deceased's death, and that the district nurse gave the deceased help at night.

Since there appear to be no studies in the literature depicting the predictors of either patients' or carers' satisfaction with district nurses' services delivered at the patients' home, it is impossible to compare results. However, the analysis has shown that carers' satisfaction is strongly predicted by how frequently the district nurse was perceived by carers to have visited deceased at home, and to a lesser degree by the total number of home visits. This might have been the result of a difference between carers' and district nurses' perception of the patients' needs. Carers of deceased who reported that the district nurse visited fairly frequently or infrequently as compared to those who indicated that the district nurse visited very frequently might have perceived their patients' needs for district nursing services to be much higher than was perceived by the district nurse. In other words, the district nursing service might have been delivered very frequently to patients who were perceived by the district nurse to have higher needs for it, regardless of the carer's perception of these needs.

Another explanation takes into account the possibility that the relationship between the district nurse and the carer might have strengthened as a result of the frequent home visits. The district nurse might not only have been viewed as a health professional, on which carer and patient depended for the delivery of nursing care, but also as a friend and a source of social and emotional support. Such a relationship might have predisposed carers to be less critical of the district nurses' services. In contrast, when carer had a limited contact with the district nurse, the nurse-carer relationship might have been restricted to the delivery of the main practical care provided to patients, and that the short-time contact might have not been enough for the carer to break the barriers for a supportive relationship to develop.

It might also be that the more the carers had contact with the district nurses' services, either in terms of frequency or number of visits, the more they were able to shape their expectations to what the district nurse can provide from services given the limited resources under which health authorities are functioning. As such, carers who reported that deceased had very frequent visits might have had enough time to shape their expectations of the district nursing services to the actual service delivered by the district nurse.

5.3.3.2. General practitioners' services

Two characteristics were found to powerfully predict carers' satisfaction with GPs' services. These were : (1) the number of home visits made by the GP, and (2) the provision of information regarding diagnosis to carer.

The suggestions formulated earlier to explain the association between the frequency and number of home visits by the district nurse on one hand and carers' satisfaction with district nurses' services on the other apply to the association between the number of GP's home visits and carers' satisfaction with GPs' services.

The finding about the association between the number of home visits and carers' satisfaction with GPs' services is in agreement with Cartwright's (1990) finding that respondents' summing up of the different aspects of care the people who died got from their general practitioner was strongly related to the number of home visits they had had: the proportion describing the care as fair or poor (rather than excellent or good) was 28% for those who had had less than five home visits in the year before they died, 16% for those with five to nine home visits and 5% for those with ten or more visits.

The provision of information about diagnosis by GPs to carers was found to be an important predictor of carers' satisfaction with the GPs' services delivered to their loved ones. The lay carer might have interpreted the lack of provision of such information by the GP as either due to (1) the ignorance of the GP about the diagnosis, or to (2) the inability of the GP to communicate such information. In either cases, carers are more likely to have reported less than high satisfaction with GPs' services. The role of the GP in providing information regarding diagnosis, prognosis and the imminent death of patient has been reported by Seale (1991) to be changing over time. Seale (1991) noted that between 1969 and 1987, there was a move towards greater openness between hospital doctors and dying patients and their families, and that the role of the GP might have changed from being the first in "breaking the news" to helping to support the person afterwards. Such a change in the role of the general practitioner might not have been congruent with the carers' expectations of GPs as providers of information, which had consequently led to carers' dissatisfaction when such role was not performed.

In addition, research has indicated that cancer patients, compared to patients with other diagnosis, have a greater desire for information about diagnosis, prognosis, treatment, results of tests, etc. (McIntosh, 1974; Cassileth et al, 1980; Molleman et al, 1984; Newall et al, 1987). Therefore, if GPs did not provide the information desired, carers were more likely to report low than high satisfaction with the GPs' services.

5.3.3.3. Hospital doctors' services

Two service characteristics were powerful predictors of carers' satisfaction with hospital doctors : (1) the perception that deceased had enough choice about the treatment given by doctors, and (2) the perception that deceased had enough privacy all the time while in hospital.

Carers who perceived that deceased had enough choice about the treatment given to them while in hospital might have valued the participation of the deceased in the decision-making process, especially given that patient autonomy is nowadays viewed as an important component of a successful patient-doctor relationship (McCullough, 1988).

Several models have been designed by researchers to understand the nature of the doctor-patient relationship. Parsons (1951) described an "ideal type" model where patients have a "sick role" while doctors have a "professional role" which grants them with certain rights, placing them in a strong, powerful and dominant position in the medical encounter. Szasz and Hollender (1956) described three models : (1) activity-passivity model, (2) guidance-cooperation model, and (3) mutual participation. In the first two models, patients are not allowed to take part in the interaction and are expected to obey the instructions provided by the doctors. In the third model, a mutual participation is expected from both doctors and patients. McCullough (1988) indicated the presence of two models: (1) the beneficence model of moral responsibility, and (2) the autonomy model of moral responsibility; the former allows doctors to impose judgments on their patients in violation of their autonomy, while the latter allows doctors to share information with patients, play a counselling role with the emphasis on the exercise of choice-autonomy by the patient, and if possible, implement the patient's value-based preference. Based on these two models, McCullough suggested an alternative model which assigns equal weight to both professional judgment and patient autonomy.

Our findings support the autonomy of the cancer patient regarding the choice of treatment, and indicate the importance of such perception to carers when evaluating services delivered by hospital doctors.

The association between the carers' perception that the deceased had enough privacy all the time while in hospital and carers' high satisfaction with HDs' services is in agreement with Blanchard et al's (1990) finding that establishing privacy during physical examination was one of four predictors of cancer patient satisfaction with the oncologist morning round. Cassidy (1991) indicated that hospital ward consultations by palliative care doctors frequently involve the breaking of bad news and a discussion of prognosis, as well as the assessment of patients' suitability for transfer to a hospice or at home, and that ward consultations should follow a certain process in which "seeing the patient in privacy", i.e. not just behind curtains, is an important component for having a good relationship with the patient.

The provision of treatment for respiratory symptoms was also selected in the final model. Carers were 1.47 more likely to report high satisfaction with the hospital doctors' services when deceased had treatment for breathlessness than when the deceased had not. This characteristic is not an important predictor, as an odds ratio of 1.47 is not high when compared to the odds associated with other service and non-service characteristics. However, two explanations could be given for this association. Firstly, this association might be an artifact resulting from the fact that those deceased who were given treatment for breathlessness had lung cancer, and that lung cancer patients, compared to other group of carers, might have been given more attention and care by the hospital doctors, which led to the high levels of carers' satisfaction. However, this explanation is contradictory to the earlier finding that carers whose deceased had a respiratory organs cancer were less likely to be highly satisfied with the hospital doctors' services. The second explanation takes into account that breathlessness, as a symptom experienced by cancer patients in general, might have been perceived by carers as life-threatening, and therefore carers might have valued any intervention to manage it.

5.4. Importance of the non-service vis a vis the service characteristics in predicting satisfaction

Introduction

The results have indicated that carers' satisfaction is predicted by both service and non-service related characteristics. Even though higher odds ratio were associated with the service characteristics than with the non-service ones, the importance of the non-service characteristics in predisposing carers' perception of the quality of care should not be underestimated.

The effects of the patient sociodemographic characteristics, which are the characteristics most frequently studied by previous researchers, on satisfaction were often inconsistent. As Fox and Storm (1981) summarize the situation :

> *" The literature on satisfaction with health care presents contradictory findings about sociodemographic variables... The situation has grown so chaotic that some writers dismiss the sociodemographic characteristics as reliable predictors of patient satisfaction".*

For this reason, Hall and Dornan (1990) conducted their comprehensive meta-analysis of patient sociodemographic characteristics as predictors of satisfaction with medical care. The results of this meta-analysis are reported elsewhere in the thesis (sections 1.5.3.1., 1.5.3.2., and 1.5.3.3.). In their discussion of the findings, Hall and Dornan (1990) emphasized the importance of not underestimating the effects of these characteristics and mentioned that :

> *" Sociodemographic characteristics are a minor predictor of satisfaction, at best. It is important, nevertheless to place these small correlations in proper perspective by noting that established correlates of satisfaction such as the patients' health status (Pascoe, 1983), the physician's communication behaviours (Hall et al, 1988a), and the physician's technical competence (Hall et al, 1988a) achieve average magnitudes of quite modest size. Indeed, small size effects are the rule not the exception in much health sciences research; for example, well established risk factors for cardiovascular disease account for only about 2% of variation in occurrence of the disease (Locker and Dunt, 1978)."*

The importance of the patient attributes in affecting satisfaction was earlier stressed by Tessler and Mechanic (1974) who indicated that :

> *" Differences in satisfaction with different practice plans are often the product of varying expectations, experiences, and personal attributes as well as a feature of the actual services provided. Among the factors considered in addition to health plan are sociodemographic variables, health status, life distress, and attitudes towards various facets of medical care.. "*

The importance of the non-service vis a vis the service characteristics in the palliative care field

In this section, three criteria were used to assess the importance of the service and the non-service related factors in predicting carers' satisfaction. These were : the strength of the odds ratio as all the variables in the models were significant predictors; the PVS-I and PVS-II values for each set of independent variables (tables 4.37., 4.38., 4.39., 4.40.); and having an odds ratio of 2.00 or more. This third criterion by no means underestimates the importance of the variables with an odds ratio less than 2.00. This value of the odds ratio was arbitrary chosen for comparison purposes and for an easier interpretation of the importance of the different predictors especially since the final models contain a considerable number of significant service and non-service predictors.

In the final model predicting carers' satisfaction with district nurses, six non-service characteristics and five service characteristics were selected. However, the highest values of PVS-I and PVS-II were for the service characteristics (table 4.37.). In addition, four service characteristics had an odds ratio greater than 2.00 compared to two non-service characteristics. The highest odds ratio among all eleven variables in the final model was that of the frequency of home visits made by the district nurse (odds ratio= 10.86 for the perception that district nurses visited very frequently). The two most important predictors at the non-service level pertained to the carers' caring and bereavement characteristics. These were : carers' perception of caring as rewarding (odds ratio= 3.66) and carers' reporting having had no bereavement-related psychological problems (odds ratio= 2.36).

In the final model predicting carers' satisfaction with general practitioners' services, eleven non-service characteristics and two service-related characteristics were selected. The highest PVS-I and PVS-II values were for the non-service characteristics (table 4.38.). In addition, both service characteristics and three non-service characteristics had an odds ratio greater than 2.00. However, the highest odds ratio was associated with the number of home visits made by the general practitioner (odds ratio of 5.57 for 20 or more home visits), followed by the GP as the source of the carer's knowledge about the diagnosis (odds ratio= 3.29). The most important predictor at the non-service level was carers' having same GP as the deceased (odds ratio=2.70), followed by the carers' self-assessment of his/her post-bereavement health as excellent (odds ratio= 2.22), and finally, carers' perception that deceased had a short duration of incontinence (odds ratio=2.08).

In the final model predicting carers' satisfaction with hospital doctors' services, two non-service and three service-related characteristics were selected. The highest

PVS-I and PVS-II values were for the service characteristics. One non-service and two service-related characteristics had an odds ratio greater than 2.00. The highest odds ratio was associated with carers' perception that deceased had enough privacy all the time while in hospital (odds ratio= 4.52), followed by carers' perception that deceased had a choice about the treatment given in hospital (odds ratio= 3.10). At the non-service level, the most important predictor was carers' self-assessment of their post-bereavement health as excellent (odds ratio= 2.54). However, carers' perception of caring was also selected as an important predictor, but was negatively associated with high satisfaction (odds ratio less than 1).

At the level of the health and social services in general, eight out of the twenty-three non-service related variables that significantly associated with satisfaction at the bivariate level were selected in the final model (PVS-I= 0.35). Of the eight variables, four had an odds ratio greater than 2.00. The highest odds ratio was associated with carers' self-assessment of their post-bereavement health as excellent (odds ratio= 2.61), followed by deceased's housing tenure status (odds ratio= 2.52), the carers' perception of no needs for more help while caring for the deceased at home (odds ratio= 2.50), and finally, the carers' perception of caring for the deceased as rewarding (odds ratio= 2.31).

However, when some service characteristics were introduced into the model predicting carers' satisfaction with health and social services in general, carers' perception that deceased had no financial difficulties that were caused by the illness had an odds ratio of 4.03, the highest among all variables in the model. The other variables that had an odds ratio greater than 2.00 were : carers' self-assessment of their post-bereavement health as excellent (odds ratio= 3.14), followed by the carers' perception of no needs for more help while caring for the deceased at home (odds ratio= 3.05), and finally, the carers' perception of caring for the deceased as rewarding (odds ratio= 2.00).

5.5. Concluding remarks

The analysis has shown that :

1. carers' satisfaction with palliative care delivered to deceased in the last year of life is a reflection of **both** service and non-service related characteristics.

2. the service characteristics are **relatively** more important than the non - service ones in predicting carers' satisfaction.

3. on the whole, carers' bereavement and caring characteristics are **relatively** more important than other non-service characteristics in predicting carers' satisfaction.

Therefore, in post-bereavement surveys evaluating palliative care services, carers' satisfaction reflects service characteristics but it is also partly determined by carer and patient characteristics.

CHAPTER 6

CONCLUSION AND FURTHER PROPOSALS

6.1. Conclusion

As indicated earlier, Lebow (1974) stated that :

> *" A major methodological concern about perception of care studies is the extent to which patient opinions accurately reflect care given. Here the issue is external validity. It is unfortunately quite difficult to assess whether patient opinion does reflect the quality of care... "*

The analysis presented in this thesis addressed the issue of the external validity of carers' satisfaction as an outcome measure in post-bereavement studies of palliative care. In the palliative care field, carers are considered as an important source of information on the care delivered to their terminally ill patients even though it has been reported in the literature that carers' and patients' views about the care delivered may differ (Ahmedzai et al, 1988; Cartwright and Seale, 1990; Higginson et al, 1990). Higginson et al (1994) mentioned that assessments by bereaved family members may be valid for some items related to service provision, but not as the sole assessments of patient's pain, symptoms or anxiety. Higginson et al (1994) suggested that :

> *"..studies which rely on the ratings of bereaved family members should assess the validity of their responses and record more information about the mood and grief of the family members.."*

Still, research into the quality of palliative care is often conducted retrospectively and has to rely on assessing carers' perception for the simple reason that dying patients are sometimes too ill or confused to be interviewed (Seale, 1991), and that terminally ill patients' perceptions of the quality of care is expected to be influenced by many factors including their medical and psychological status, as well as their dependency on the medical and nursing services.

In order to rely on carers' evaluation of the quality of the services in planning new services, or changing the present ones to meet the carers' or patients' needs, researchers must be sure that carers' satisfaction is a true manifestation of the service characteristics. The analysis has shown that carers' satisfaction with palliative care is a reflection of both service and non-service characteristics. Non-service characteristics were found to be of less importance compared to the service-related ones in predicting satisfaction, but they were nevertheless significant.

The analysis has also indicated the importance of the carers' bereavement and caring characteristics as predictors of carers' satisfaction with palliative care. The relationship between these characteristics and carers' satisfaction has never been investigated before. The presence of these associations, independently of a large set of deceased and carer sociodemographic characteristics, reinforces our suggestion that palliative care is a unique field of medical care.

In summary, the findings support using carers' satisfaction as an outcome measure while taking into account that part of it is actually influenced by powerful non-service related predisposing factors.

6.2. Implications of this research

This research into carers' satisfaction with palliative care has :

1. opened the field of palliative care to an area of research neglected by researchers

2. given the field of health services research new insights into the determinants of satisfaction.

3. assessed the appropriateness of using carers' satisfaction as an outcome measure to evaluate services.

4. provided health planners with information on the different factors predisposing carers' satisfaction with palliative care services.

5. investigated, for the first time, the association between a comprehensive set of carers' bereavement and caring characteristics and carers' satisfaction with palliative care

6. revealed the determinants of carers' satisfaction with three important providers of palliative care (district nurses, GPs, and hospital doctors).

7. revealed the determinants of carers' satisfaction with health and social services in general

6.3. Future research

This work has raised several issues which future research should tackle :

1. The relationship between ethnicity and carers' satisfaction with GPs' services should be further investigated. It is of prime importance to investigate the source of dissatisfaction of ethnic minorities so that their needs are properly addressed.

2. Carers of patients with respiratory or genito-urinary cancers were found to be significantly more dissatisfied with hospital doctors' services than other carers. Research should be carried out to assess the reasons of their dissatisfaction and to detect whether the deceased had unmet nursing and medical needs.

3. More comprehensive research should be done on the relationship between carers' bereavement outcome and carers' satisfaction with services delivered to the deceased. The cross-sectional nature of the RSCD survey and the exploratory nature of the analysis provided the observational associations between carers' bereavement outcome variables and their satisfaction. More research should be undertaken to understand these associations.

4. The association between carers' perception of caring at home as a burden and their high satisfaction with hospital doctors indicate the importance of conducting future research to assess the needs of these carers.

5. The associations between carers' perception of the deceaseds' clinical characteristics and carers' satisfaction with GPs' services highlight the need of more research into the management of symptoms at home. It is important to reveal the factors predisposing these associations.

6. Our research focused on hospital and community care and did not tackle the predictors of carers' satisfaction with hospice services. It would be interesting to assess the predictors of dissatisfaction with hospice services given that very high levels of satisfaction are reported for hospice services.

7. Research into carers' satisfaction with palliative care should follow the pattern of research on patient satisfaction with medical care in general. In other words, structural and process elements of the quality of palliative care

should be identified for a particular setting, and the associations between these elements and carers' satisfaction, controlling for important background variables, should be intensively investigated.

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APPENDICES

Appendix A

Table A.1. Relationships of sociodemographic variables to patient satisfaction with medical care

Reference	Sample	Variable (direction of satisfaction)
Hulka et al (1975)	pregnant women and mothers of infants attending primary care clinic in a single community	pregnant women : education (+) social class (-) mother of infants: education (-) social class (NS)
Romm & Hulka (1979)	patients with diabetus mellitus	age (NS) education (NS) social class (NS)
Fox & Storm (1981)	survey conducted using telephone interviews	sex (female) age (+) race (NS) education (-) work status (retired & homemakers) (+) income (-)
Linn et al (1982)	chronically ill patients (no specific illness)	age (+) race (blacks and hispanics) (+) education (-) work status (retired) (+) marital status (married, widowed) (+)
Greenly et al (1983)	psychologically ill patients	age (+) education (-) adult household role
Patrick et al (1983)	disabled patients	sex (female) (+) age (+) work status (unemployed) (+) place of birth (NS) household composition (NS)

continue, table A.1.

Reference	Sample	Variable (direction of satisfaction)
Treadway (1983)	patients attending a general practice	sex (NS) age (+) social class (NS) years of education (NS)
Wartman et al (1983)	patients attending a private clinic	age (+) education (-) social class (middle to upper)
Zastowny et al (1983)	five different samples used in five different surveys on utilization of care in the U.S.	sex (female) (+) education (-) race (black)
Kaim-Caudle (1987)	patients attending a general practice	age (+)
Like and Zyzanski (1987)	adults patients attending a family practice	sex (female) age (NS) race (NS) marital status (NS) education (NS) employment (NS) occupation (NS) annual income (NS)
McCarthy et al (1988)	patients attending a general practice	age (+)
Weiss (1988)	patients attending primary medical care setting	sex (NS) age (NS) education (NS) race (NS) income (NS)

continue, table A.1.

Reference	Sample	Variable (direction of satisfaction)
Hall et al (1990)	older patients in a Health Maintenance Organization (HMO)	sex (NS) age (NS) education (NS) occupation (NS) living alone (NS) marital status (NS) year joining HMO (+) income sufficiency (+)
Hall et al (1990, a)	meta-analysis on 110 american studies	sex (NS) age (+) education (+) ethnicity (NS) social status (upper class) (+) marital status (married) (+) family size (NS)
Williams & Calnan (1991)	randomly selected people from the electoral register	GP's care : sex (female) (+) age (+) education (NS) social status (NS) dental care : sex (NS) age (NS) education (NS) social status (NS) hospital care : sex (NS) age (+) education (NS) social status (NS)
Stein et al (1993)	HIV patients attending AIDS Health Services Programs	sex (NS) education (college) (-) race (NS)

*. When the relationship between satisfaction and the sociodemographic variables was not significant, the abbreviation "NS" was used.

Table A.2. Relationships of predispositional characteristics to patient satisfaction with medical care

Reference	Sample	Variable (direction of satisfaction)
Romm et al (1976)	patients with congestive heart failure	activity status (+) symptomatology (-)
Fox & Storm (1981)	survey conducted using telephone interviews on patient satisfaction with medical care	health status : disability days (NS) having a chronic condition (+)
Greenly et al (1982)	psychologically ill patients	number of symptoms (-) admit and discuss problems (+) not admit problems (-)
Linn et al (1982)	Chronically ill patients	health status : disability days (-) general health (+) social health (NS) physical abilities & limitations (-) self-rated depression (-)
Patrick et al (1983)	disabled and non-disabled patients	overall satisfaction measure : practical assistance (NS) emotional support (NS) adverse life events (-) self-rating of health status (+) physical disability (NS) psychosocial disability (NS) specific satisfaction measure : practical assistance (+) emotional support (NS) adverse life events (NS) self-rating of health (+) physical disability (NS) psychosocial disability (-)
Oberst (1984)	cancer patients attending chemotherapy	anxiety (-) seriousness of illness (-)

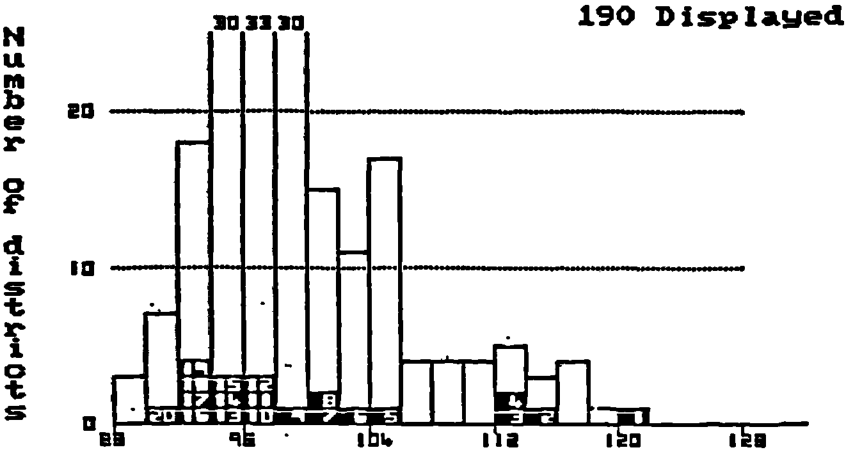
continue, table A.2.

Reference	Sample	Variable (direction of satisfaction)
Weiss (1988)	patients attending a primary care setting	confidence in medical system in own community (+) confidence in medical care system in general (NS) regular source of care (+) life satisfaction (+) internal locus of control (NS) satisfaction with own health (NS)
Hall et al (1990)	Old patients in a health maintenance organization	overall health (+) emotional distress (-) social activity (+) physical function (+) cognitive function (NS) number of diagnoses (NS) physician rating of patient health (NS)
Stein et al (1993)	HIV-patients attending Aids Health Services Programs	number of symptoms (-) frequency of symptoms (-)

*. When the relationship between satisfaction and the sociodemographic variables was not significant, the abbreviation "NS" was used.

Appendix B

Figure 1. Frequency of the total number of districts in England (1989/1990), and the RSCD districts by the Department of Health Social Index (DOHSI)



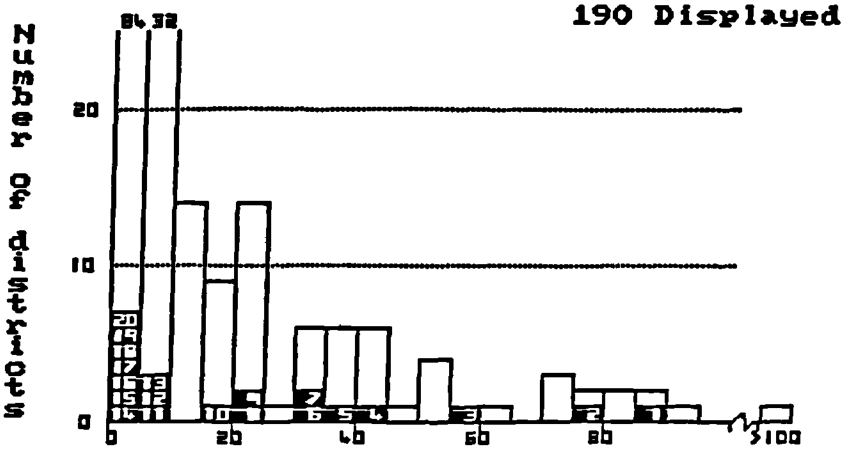
0 Zero vals; 0 Excluded; 0 Missing; 8 No service

—— ucl districts

1	City and Hackney	2	Bloomsbury	3	Newham
4	North Manchester	5	Newcastle	6	Canterbury
7	Bristol & Weston	8	Cornwall	9	Great Yarmouth
10	Dudley	11	Norwich	12	Redbridge
13	Bromley	14	Dartford	15	Hillingdon
16	Bexley	17	Frenchay	18	Tunbridge Wells
19	West Berkshire	20	Mid Essex		

exc Excluded values, mis Missing data, nos No service

Figure 2. Frequency of the total number of districts in England (1989/1990), and the RSCD districts by the population density*



0 Zero vals; 0 Excluded; 0 Missing; 8 No service
—— ucl districts

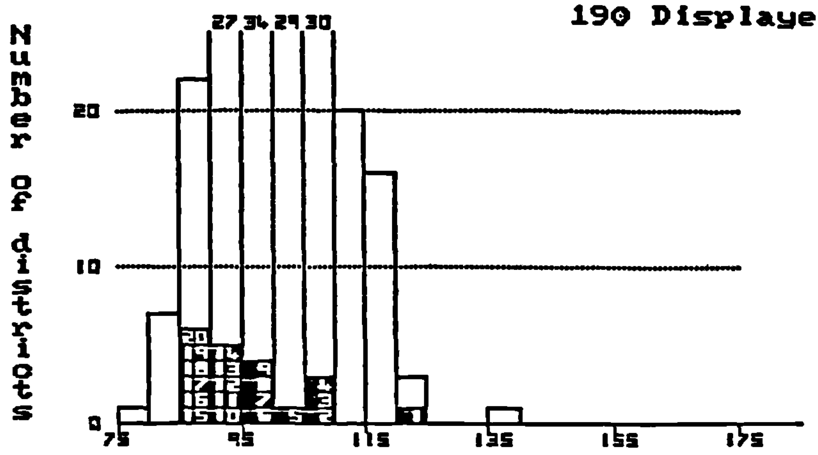
1 City and Hackney	2 Bloomsbury	3 Newham
4 Redbridge	5 Bexley	6 Dudley
7 North Manchester	8 Hillingdon	9 Newcastle
10 Bromley	11 Bristol & Weston	12 Frenchay
13 Dartford	14 Canterbury	15 Cornwall
16 Great Yarmouth	17 Mid Essex	18 Norwich
19 Tunbridge Wells	20 West Berkshire	

exc Excluded values, mis Missing data, nos No service

---

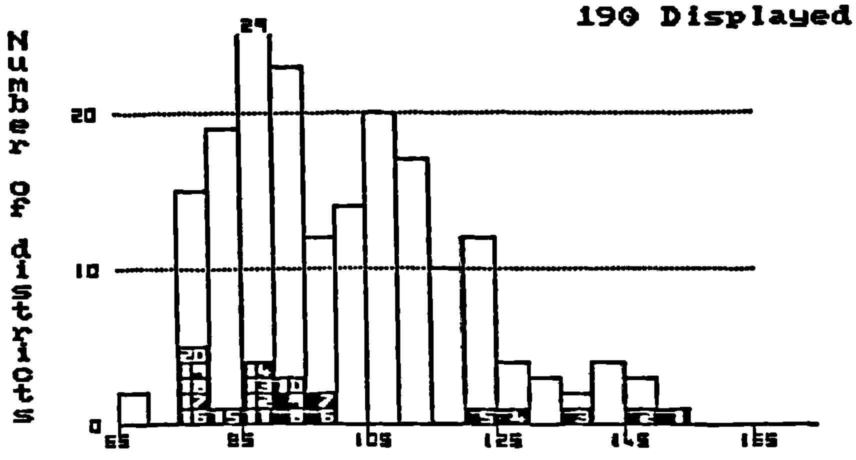
*. Population density is measured by the estimated number of people per hectare resident in the district

Figure 3. Frequency of the total number of districts in England (1989/1990), and the RSCD districts by the annual standardized mortality ratio of deaths from all causes of District residents aged 65 years or more



```
   0 Zero vals;     0 Excluded;     0 Missing;     8 No service
 ____ ucl districts
   1  North Manchester  2  Dartford          3  Newcastle
   4  Newham            5  Dudley            6  Canterbury
   7  Cornwall          8  Tunbridge Wells   9  West Berkshire
  10  Bristol & Weston 11  City and Hackney 12  Great Yarmouth
  13  Mid Essex        14  Norwich          15  Bloomsbury
  16  Bexley           17  Frenchay         18  Bromley
  19  Hillingdon       20  Redbridge
 exc  Excluded values, mis  Missing data, nos  No service
```

Figure 4. Frequency of the total number of districts in England (1989/1990), and the RSCD districts by the annual standardized mortality ratio of deaths from all causes of District residents aged 15-64 years

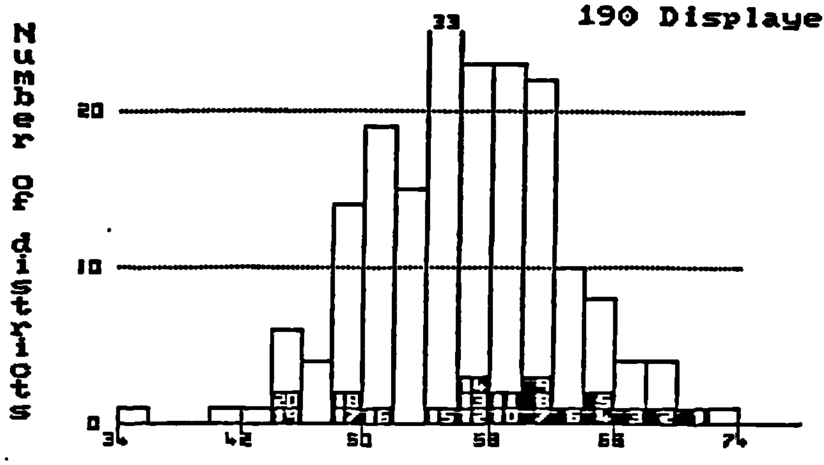


0 Zero vals; 0 Excluded; 0 Missing; 8 No service

—— ucl districts

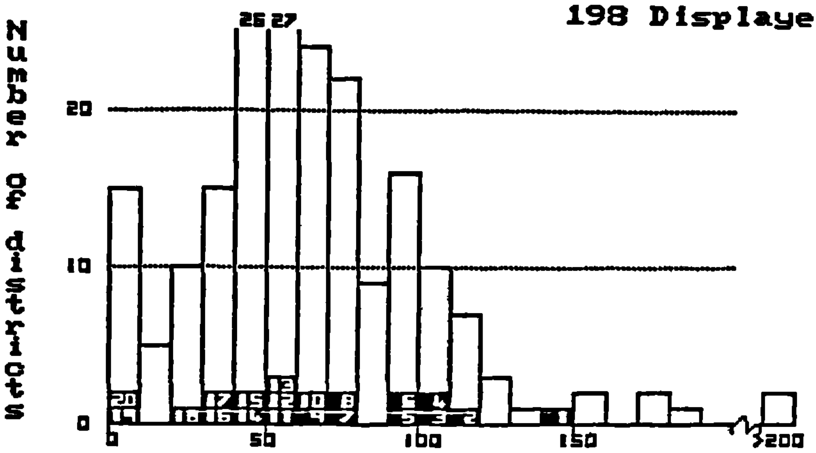
1	North Manchester	2	Bloomsbury	3	City and Hackney
4	Newcastle	5	Newham	6	Dudley
7	Hillingdon	8	Bristol & Weston	9	Dartford
10	Great Yarmouth	11	Bexley	12	Canterbury
13	Cornwall	14	Redbridge	15	Frenchay
16	Bromley	17	Mid Essex	18	Norwich
19	Tunbridge Wells	20	West Berkshire		
exc	Excluded values,	mis	Missing data,	nos	No service

Figure 5. Frequency of the total number of districts in England (1989/1990), and the RSCD districts by the percentage of deaths of District residents that occurred in NHS hospitals



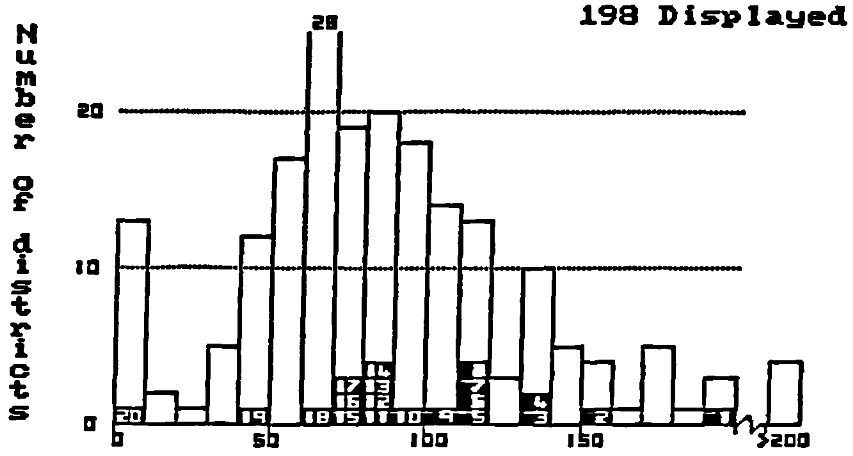
```
     0 Zero vals;    0 Excluded;    0 Missing;     8 No service
  ___  ucl districts
     1 Hillingdon         2  Newham               3  Redbridge
     4 Bexley             5  City and Hackney     6  Dartford
     7 Bloomsbury         8  Bromley              9  North Manchester
    10 Mid Essex         11  West Berkshire      12  Frenchay
    13 Newcastle         14  Norwich             15  Great Yarmouth
    16 Dudley            17  Canterbury          18  Tunbridge Wells
    19 Bristol & Weston  20  Cornwall
   exc Excluded values, mis  Missing data, nos  No service
```

Figure 6. Frequency of the total number of districts in England (1989/1990) and the RSCD districts by the total number of District nurses (WTE) including bank/agency staff



```
    9 Zero vals;    0 Excluded;     0 Missing;     0 No service
 ___ ucl districts
  1 Norwich             2 Bristol & Weston  3 Newcastle
  4 West Berkshire      5 Frenchay          6 Cornwall
  7 Canterbury          8 Dudley            9 Bexley
 10 Redbridge          11 City and Hackney 12 Great Yarmouth
 13 North Manchester   14 Mid Essex        15 Newham
 16 Bloomsbury         17 Hillingdon       18 Dartford
 19 Bromley            20 Tunbridge Wells
exc  Excluded values, mis  Missing data, nos  No service
```

Figure 7. Frequency of the total number districts in England (1989/1990), and the RSCD districts by the total number of available bed days in geriatric medicine



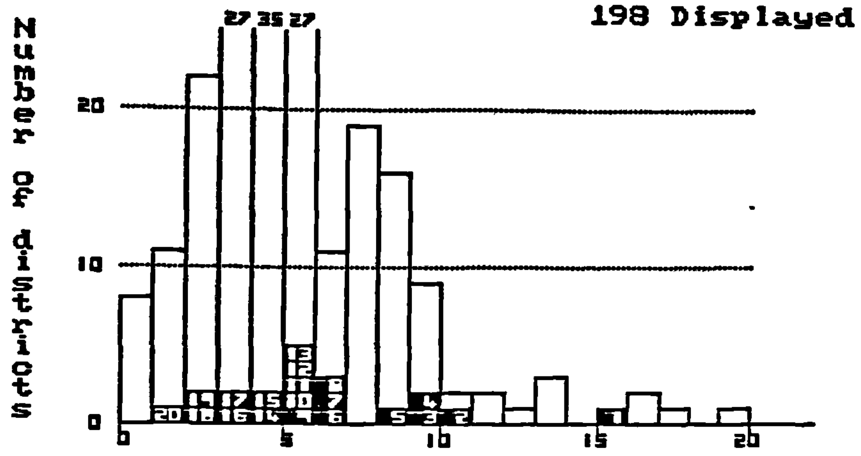
13 Zero vals; 0 Excluded; 0 Missing; 0 No service

—— ucl districts

1	Norwich	2	Cornwall	3	Frenchay
4	Newcastle	5	Bromley	6	Canterbury
7	Mid Essex	8	West Berkshire	9	Newham
10	City and Hackney	11	Great Yarmouth	12	Hillingdon
13	North Manchester	14	Redbridge	15	Bloomsbury
16	Dudley	17	Tunbridge Wells	18	Bexley
19	Bristol & Weston	20	Dartford		

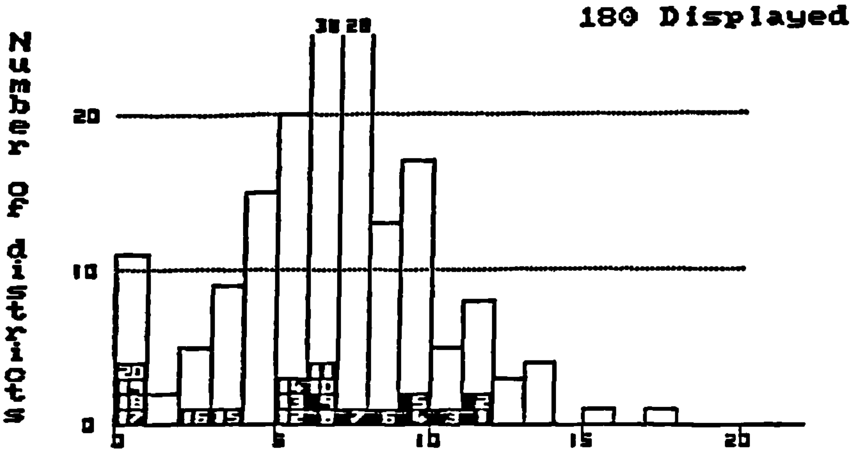
exc Excluded values, mis Missing data, nos No service

Figure 8. Frequency of the total number of districts in England (1989/1990) and the RSCD districts by the total number of senior medical and dental staff in WTE in geriatric medicine



```
  6 Zero vals;    0 Excluded;     0 Missing;      0 No service
 ___  ucl districts
  1 Newcastle          2 Bromley             3 North Manchester
  4 Norwich            5 Canterbury          6 Bloomsbury
  7 Dudley             8 Hillingdon          9 Bexley
 10 Frenchay          11 City and Hackney   12 Mid Essex
 13 Newham            14 Bristol & Weston   15 West Berkshire
 16 Cornwall          17 Tunbridge Wells    18 Dartford
 19 Redbridge         20 Great Yarmouth
exc  Excluded values, mis  Missing data, nos  No service
```

Figure 9. Frequency of the total number of districts in England (1989/1990) and the RSCD districts by the total number of consultants in geriatric medicine per 100,000 District catchment population



9 Zero vals; 2 Excluded; 0 Missing; 16 No service

—— ucl districts

1	Bloomsbury	2	North Manchester	3	Bexley
4	Bromley	5	Newham	6	Newcastle
7	Hillingdon	8	Dartford	9	Norwich
10	Redbridge	11	West Berkshire	12	Canterbury
13	Dudley	14	Mid Essex	15	City and Hackney
16	Tunbridge Wells	17	Bristol & Weston	18	Frenchay
19	Cornwall	20	Great Yarmouth		
exc	Excluded values,	mis	Missing data,	nos	No service

Appendix C

Letter sent to inform potential interviewees about the study

We are making a study of the care and services received by dying people and their relatives. University College London are helping with this study. We want to know what people feel about the services that were received. We also want to find out whether there are any ways in which things could be better. The findings will help us plan better care for people in the future.

I understand from the register of deaths that (the deceased's name) died recently. We would like to talk to someone who can tell us about (the deceased's name) health and the care he received in the last year of life.

I am writing to this address because this was registered as the usual address of the deceased. Our interviewer, Ms XXXX, will be contacting you soon to ask whether you would be the best person to tell us about the care that (the deceased's name) received.

If you are willing to help with this study, she will make an appointment to come and talk to. It is entirely up to you whether you decide to take part. If you decide to do so, all your answer will be completely confidential. If you decide not to take part, we will not contact you again.

If you have any queries about the study, you may wish to telephone us beforehand.

Thanking you in advance for your help

Dr XXXXXXXX

CONFIDENTIAL

DISTRICT. :

INTERVIEW. :

INTERVIEWER :

PERSON WHO DIED
NAME :
ADDRESS :

MARITAL STATUS(M/S)? :

YEAR OF BIRTH? :

AGE? :

PERSON WHO REGISTERED DEATH
NAME AND ADDRESS :

QUALIFICATION :

CONTACTS

DATE.	TIME.	PHONE?.	NOTES.

STRICTLY CONFIDENTIAL

District: ☐☐
Interview: ☐☐☐
Interviewer: ☐
Order sent in: ☐☐

CARE OF DYING - MAIN QUESTIONNAIRE

INTRODUCTION

1. I am ____________ , and I am working for University College London and for _________ Health Authority.

2. We are doing a study of the care and services received by dying people and their carers. We want to find out about 2 things: firstly, we want to find out what people think about the services that were received, and secondly we want to find out about how people cope with death and illness.

3. I understand from the register of deaths that _________ died recently, and we would like to talk to someone who can tell us about ________'s health and the last year of his/her life.

4. Anything you tell us will be treated as completely confidential - I will not write your name on the interview schedule and no names will be mentioned in the reports we are planning to write.

5. I would like to ask you a number of questions. If you would rather not answer one of the questions, we will go on to the next one. If you decide you don't want to answer any more questions, tell me and we will finish the interview.

6. Do you have any questions about the interview, or shall I begin my questions?

TIME INTERVIEW STARTED: ☐☐☐☐

1. (a) I believe you are __________'s:-
(code all that apply)

Husband / wife	1	
Son / daughter	2	} —> 3
Brother / sister	3	
Son-in-law / Daughter-in-law	4	
Brother-in-law / Sister-in-law	5	
Parent	6	} —> 3
Other relative *(specify)*:	7	
Friend *(if also neighbour friend takes precedence)*	8	—> (b)
Neighbour	9	
Official of home	10	
Coroner, Environmental Health Officer, Lawyer	11	
Warden (sheltered housing)	12	
Official *(specify)*:	13	

(b) *If Friend (8)* Would you say he/she was a close friend of yours or not?

Close friend	1
Not*	2

2. How long had you known him/her?

Less than a year	1
1 year < 2 years	2
2 years < 5 years	3
5 years < 10 years	4
10 years < 15 years	5
15 years < 20 years	6
20 years < 30 years	7
30 years or more	8

3. *(Code)* Sex of respondent

Male	1
Female	2

4. Could you tell me about ________'s death - had he/she been ill for some time before he/she died?

5. So what did he/she die of? *(Probe for details of accidents, heart problems, type of cancer etc.)*

6. *Check - do not ask.*

Sudden death with no illness or warning or time for care *	1
Other death	2

7. How old was he/she when he/she died?

Under 25	1
25 - 34	2
35 - 44	3
45 - 54	4
55 - 64	5
65 - 74	6
75 - 84	7
85 or more	8
(Don't know)	9

8. Could you tell me his/her exact date of death?

9. (a) Where did __________ die?

His/her own home	1	} —> 10
Other person's home specify:	2	
Hospital	3	
Hospice	4	
Old people's home or nursing home	5	
Other Institution *(specify)*:	6	
Ambulance, Street etc	7	} —> 10
Other *(specify)*:	8	

(b) How long was ______ in there before he/she died?

Less than 24 hours	1	
1 day < 1 week	2	
1 week < 1 month	3	
1 month < 3 months	4	
3 months < 6 months	5	
6 months < 1 year	6	
1 year or longer*	7	—> 20
(Don't know	9)	

10) ***Ask only if sudden death of person under 65. If not —> 11.***

Before he/she died was __________ restricted in any way in what he/she could do, or in his/her ability to look after him/herself?

Yes	1	
No	2	} —> 20
DK	9	

11. I'd like to ask you about a number of things people sometimes have difficulty with as they get older or become ill. Up until the time ________ (died/ went into hospital/hospice for the last time) could he/she manage to do these things without any help?

Ask for each one		When did he/she start to <u>need</u> help with this?
Get in and out of bath or shower?	Yes .... 1 No .... 2 DK 9	Less than a week before death/ last admission ..... 1 3 months < 6 months ..... 4 1 week < 1 month .... 2 6 months < 1 year ...... 5 1 month < 3 months ..... 3 1 year + ... 6 (DK .... 9)
Dress and undress - including shoes and fastenings?	Yes .... 1 No .... 2 DK 9	Less than a week before death/ last admission ..... 1 3 months < 6 months ..... 4 1 week < 1 month .... 2 6 months < 1 year ...... 5 1 month < 3 months ..... 3 1 year + ... 6 (DK .... 9)
Go to the toilet - cope on own when there?	Yes .... 1 No .... 2 DK 9	Less than a week before death/ last admission ..... 1 3 months < 6 months ..... 4 1 week < 1 month .... 2 6 months < 1 year ...... 5 1 month < 3 months ..... 3 1 year + ... 6 (DK .... 9)
Wash (and shave)?	Yes .... 1 No .... 2 DK 9	Less than a week before death/ last admission ..... 1 3 months < 6 months ..... 4 1 week < 1 month .... 2 6 months < 1 year ...... 5 1 month < 3 months ..... 3 1 year + ... 6 (DK .... 9)
Cut own toe nails?	Yes .... 1 No .... 2 DK 9	Less than a week before death/ last admission ..... 1 3 months < 6 months ..... 4 1 week < 1 month .... 2 6 months < 1 year ...... 5 1 month < 3 months ..... 3 1 year + ... 6 (DK .... 9)
Make himself/herself a hot drink?	Yes .... 1 No .... 2 DK 9	Less than a week before death/ last admission ..... 1 3 months < 6 months ..... 4 1 week < 1 month .... 2 6 months < 1 year ...... 5 1 month < 3 months ..... 3 1 year + ... 6 (DK .... 9)
Did he/she need any help at night? there?	Yes .... 1 No .... 2 DK 9	Less than a week before death/ last admission ..... 1 3 months < 6 months ..... 4 1 week < 1 month .... 2 6 months < 1 year ...... 5 1 month < 3 months ..... 3 1 year + ... 6 (DK .... 9)

IF NO PROBLEMS —> 20

12. (a) Who helped with these/this (before he/she died/ went into hospital/hospice for the last time). What about:-

	Helped? Y	N	DK
1. You? *	1	2	9
2. (Other relatives living with _____ ?)	1	2	9
3. Any relatives not living with _____ ?	1	2	9
4. Friend or neighbour?	1	2	9
5. District nurse?	1	2	9
6. Bath attendant?	1	2	9
7. Chiropodist?	1	2	9
8. Staff in nursing or residential home, or sheltered housing?	1	2	9
9. Homehelp?	1	2	9
10. Anyone else? *(specify)*:	1	2	9

(b) *IF 2,3 or 4*
So how many different relatives or friends helped to look after _____ ?

Number ☐☐

(c) Who would you say bore the brunt (main part) of caring for _____ ? *(Code one only)*

1. Respondent	1
2. Other relatives living with _____	2
3. Any relatives not living with _____	3
4. Friend or neighbour	4
5. District nurse	5
6. Bath attendant	6
7. Chiropodist	7
8. Staff in nursing, residential home or sheltered home	8
9. Other *(specify)*	9

13. (a) Could (you or) _____ (deceased) have done with (any more) help with these things?

Yes	1	
No	2	--> 14

(b) In what way? *(ring all that mentioned)*

Bathing	1
Toe nails	2
Help at night	4
Other *(specify)*:-	8

☐

14. (a) Was any special equipment to help in caring for _____ ordered?

Yes	1
No	2
Don't know	9

(b) Would it have helped to have had some (more) equipment to help you care for _____ ?

Yes	1
No	2

(c) *Ask only if equipment ordered (a)*
Else ---> 15.

Did it arrive when it was needed?

Yes, all arrived when needed	1	---> 15
No, none arrived when needed	2	
Some arrived when needed, some didn't	3	
Don't know	9	

(d) Could you explain? *(ring all that apply)*

Arrived too late to be of use (died or deteriorated)	1	--->15
Never arrived	2	
Other *specify*:-	4	

15. ***Ask only if respondent helped (Q12) and is not an official.***
If respondent did not help at all, or if interviewing official —> Q20.

During the time you were looking after ________
was there anything you gave up or did less of because of that - what about:

	GAVE UP	DID LESS	SAME
Visiting friends or neighbours?	1	2	3
Going out to social activities?	1	2	3
Going on holiday?	1	2	3
Entertaining people at home?	1	2	3
Going to work?	1	2	3
Looking after someone else?	1	2	3
Anything else? *(specify):*	1	2	3

16. So would you say your activities were:-

Severely restricted	1
Fairly restricted	2
A little restricted	3
or Not restricted?	4

17. On balance, would you say you found looking after ________ more rewarding or more of a burden - or were they equally balanced, or what?

Rewarding	1
A burden	2
Equally balanced	3
Other *specify:-*	4

18. Did - or do - you have any health problems which made it difficult for you to do things for ________?

Yes	1
No	2

19. Some people find it helpful to get in touch with groups set up for people coping with illnesses and disabilities or for their families. I mean groups like Cancer Relief, the MS Society, Arthritis Care and Help the Aged. Did you get in touch with a group like these?

Yes	1	
No	2	-> 20

Ask for each group mentioned Did you find them very helpful, helpful or not very helpful?

a) Name:

Very helpful	1
Helpful	2
Not very helpful	3

b) Name:

Very helpful	1
Helpful	2
Not very helpful	3

c) Name:

Very helpful	1
Helpful	2
Not very helpful	3

20. ALL INTERVIEWS CONTINUE HERE

Can I ask you now about any symptoms ____________ may have had in the last twelve months of his/her life
(that is including any time he/she was in a hospital or hospice during that year)

Ask for each symptom	Did he/she have any ______?			*(If Yes)* Do you think he/she found it:-				How long did he/she have it?							Can I just check, did he/she have it in the week before he/she died?		
	Yes	No	Dk	Very distressing	Fairly distressing	or Not very distressing?	(DK)	<1wk	1 wk < 1 mth	1 mth < 3 mths	3 mths < 6 mths	6 mths < 1 year	1 year plus	(DK)	Yes	No	DK
Pain	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Trouble with breathing	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Vomiting or feeling sick	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Sleeplessness	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Dry mouth/thirst	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Mental confusion	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Feeling low or miserable	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Anxiety or trouble with nerves	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Loss of appetite	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9

CONTINUED ON NEXT PAGE

20. (continued)

Ask for each symptom	Did he/she have any ______?			Do you think he/she found it:-				How long did he/she have it?							Can I just check, did he/she have it in the week before he/she died?		
	Yes	No	Dk	Very distressing	Fairly distressing	or Not very distressing?	(DK)	<1wk	1 wk < 1 mth	1 mth < 3 mths	3 mths < 6 mths	6 mths < 1 year	1 year plus	(DK)	Yes	No	DK
Difficulty swallowing	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Constipation	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Persistent cough	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Bed sores	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Loss of bladder control	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Loss of bowel control	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Unpleasant smell	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9
Any other symptom he/she found distressing *specify*:-	1	2	9	1	2	3	9	1	2	3	4	5	6	9	1	2	9

HOME AND CIRCUMSTANCES

I'd like to ask you a few questions about ________, and about his/her home and circumstances.

21. What ethnic group did he/she belong to. Can you tell me which of these groups he/she belonged to? *(show card)*

White	1
Black Caribbean	2
Black African	3
Black other *(specify)*	4
Indian	5
Pakistani	6
Bangladeshi	7
or Chinese?	8
(Other	9)

22. Before ________ died (or went into a home or hospital for the last time) did he/she live in a:-

House	1
Bungalow	2
Flat	3
Sheltered housing	4
or where? *specify:-*	5
(Don't know	9)

23. Who owned that?

Deceased and/or husband/wife	1
The Council	2
Housing Association	3
Private Landlord	4
Relative of deceased *specify:-*	5
Other *specify:-*	6
(Don't know	9)

If sudden death of person under 65 with no restrictions (Q10) —> 63

If in hospital or hospice for a year or more before died (Q9) —> 97

If in old peoples home or nursing home for a year or more before died (Q9) —> 40 with introduction: 'I'd like to ask you some questions about the nursing home/ residential home'.

24. *Check.* Did ________ live alone or with others?

Alone	1	
With others	2	—> 27

25. At any time during the last year of his/her life did ________ get any help at home with:- *(ring all that apply)*

Shopping	1	☐	
Cooking	2		
or Cleaning?	4		
(None of these	0)		—> 26
(Don't know	9)		

(b) *If any*
Who helped. What about:-

	Y	N	DK
1. You?	1	2	9
2. (Other relatives living with ________?)	1	2	9
3. Any relatives not living with ______?	1	2	9
4. Friend or neighbours?	1	2	9
5. Home help from Social Services?	1	2	9
6. Privately paid help?	1	2	9
7. Meals on wheels?	1	2	9
8. Luncheon Club?	1	2	9
9. Or anyone else? *specify:-*	1	2	9

(c) *If home help from social services (5)*
Did he/she have to pay for this?

Yes	1
No	2
Sometimes	3
Dk	9

(d) *If meals on wheels (7) or luncheon club (8)*
Did he/she have to pay for this?

Yes	1
No	2
Sometimes	3
Dk	9

26. (a) Do you think ________ needed any (more) help with these?

Yes	1	
No	2	—> 32
DK	9	

(b) In what way? *(ring all that apply)*

(More) help with shopping	1	—> 32
(More) help with cooking	2	
(More) help with cleaning	4	

☐

27. (Can I just check) who did _____ live with before he/she died (or went into hospital for the last time)?
(record details for each member of household)

Relationship to deceased	Sex	Age in years
A	M F	
B	M F	
C	M F	
D	M F	
E	M F	

Code 27 as follows:
Lived with:

alone	1
spouse only	2
spouse and others	3
others only	4

Age of household:

all > 75	1
all 65-74	2
all < 65	3
other	4

28. *Check.* a) Respondent lived with deceased?

Yes	1	
No	2	—> 29

b) *Respondent is which letter on above grid?*

29. Up until when he/she died or became ill (if this was in the last year of life) did he/she do any or most of the:-

	Most	Some	None
Shopping?	2	1	0
Cooking?	2	1	0
Cleaning?	2	1	0

30. a) Who (else - if any one) helped with or did these. What about:-

	Y	No	DK
1. You?	1	2	9
2. Other person living with him/her?	1	2	9
3. Relative not living with him/her?	1	2	9
4. Friend/neighbour?	1	2	9
5. Home help from Social Services?	1	2	9
6. Privately paid help?	1	2	9
7. Meals on wheels?	1	2	9
8. Luncheon club?	1	2	9
9. Anyone else? *(specify)*:-	1	2	9

(b) *If home help from social services (5)*
Did he/she have to pay for this?

Yes	1
No	2
Sometimes	3
Dk	9

(c) *If meals on wheels (7) or luncheon club (8)*
Did he/she have to pay for this?

Yes	1
No	2
Sometimes	3
Dk	9

31. (a) Do you think you/they needed (more) help with these?

Yes	1	
No	2	} --> 32
Dk	9	

(b) In what way?
(ring all that apply)

(More) help with shopping	1	☐
(More) help with cooking	2	
(More) help with cleaning	3	

32. Were there any (other) financial problems related to ________'s illness/age?

Yes	1
No	2
DK	9

33. Did he/she get any financial help from:-

	Yes	No	DK
Mobility allowance?	1	2	9
Attendance allowance?	1	2	9
Disability pension?	1	2	9
Income support/ supplementary benefit?	1	2	9
Relative?	1	2	9
Heating allowance?	1	2	9
Rent or rate rebate?	1	2	9
Anything else? *specify:-*	1	2	9

34. Could he/she have done with any (more) financial help?

Yes	1
No	2
DK	9

35. Was ________'s home an easy place for someone like him/her?

Yes	1
No	2
DK	9

36. (So can I check) Were there any problems with:-

	Yes	No	DK
Stairs?	1	2	9
The position of the lavatory?	1	2	9
The distance from the shops?	1	2	9
Anything else? *specify:-*	1	2	9

37. (a) Did ________ have a telephone at home?

Yes	1	--> 39
No	2	
Don't know	9	

(b) Do you think he/she would have liked one?

Yes	1
No	2
DK	9

NURSING / RESIDENTIAL HOME

39. Did _____ live or stay in a nursing home or an old people's home or a residential home at any stage in the last twelve months of his/her life?

Yes	1	
No	2	--> 48

40. What was it? *(ring all that apply)*

Old people's home	1
Nursing home	2
Residential home for under 65 years	3
Other *(specify):-*	4

If in more than one, ask questions 41 - 47 about the one in longest. If in doubt, ask about most recent. Make note below.

41. Who was it run by?

Council	1
Private	2
Charity *(specify):-*	3
Other *(specify):-*	4

42.(a) So did _____ have to pay for all, some or none of the cost of living there?

All	1	
Some	2	
None	3	—> 43
Don't know	9	

(b) Was this a problem at all?

Yes	1
No	2
Don't know	9

43. (a) How long was he/she there in the last 12 months of his/her life?

Less than a week	1
1 week < 1 month	2
1 month < 3 months	3
3 months < 6 months	4
6 months < 1 year	5
> 1 year	6
(Dk	9)

(b) Was that so you or the person looking after him/her, could have a rest?

Yes	1
No	2

44. Do you feel that the help and care _______ got from the (nurses and other) staff there was:-

Excellent	1
Good	2
Fair	3
or Poor?	4
(Don't know)	9

If interviewing official of institution
—> 48 for old people's home/residential home
OR —> 63 for nursing home

45. Did you visit _____ while he/she was in there?

Yes	1
No	2
DK	9

If respondent never visited
—> 48 for old people's home/residential home
OR —> 63 for nursing home

46. Thinking of the following aspects of the home, from _________'s point of view, would you say they were good or not so good. What about:-

	Good	Not so Good	OTHER	DK
The food?	1	2	3	9
The heating?	1	2	3	9
_________'s room?	1	2	3	9
The bathroom & lavatory facilities?	1	2	3	9
The stairs or lift?	1	2	3	9
Other things about the building?	1	2	3	9
The way the home was run?	1	2	3	9

47. So, taking everything into account, how would you rate it as a place for _________ to live towards the end of his/her life?
Would you say it was:-

Excellent	1
Good	2
Fair	3
Poor	4
or Dreadful?	5

DISTRICT NURSES

If in nursing home for whole year before death (Q9 Q40) —> *63*

All others (including those in old people's home or residential home) continue here.

48. I'd like to ask some questions about any help _______ had from a district nurse or other nurse at home (including any district nurses coming to the residential home).

(a) Did ____ have any help from a district nurse, or any other sort of nurse, at home in the 12 months before he/she died?

Yes	1 —> 49
No	2
Don't know	9

b) Could he/she have done with any help from such a nurse during that time?

Yes	1 —> (c)
No	2 } —> 63
Don't know	9 } —> 63

(c) What with? *(ring all mentioned)*

washing/bathing	1 } —> 63
dressings	2 } —> 63
medicines	3 } —> 63
counselling/support	4 } —> 63
other *(specify)*	8 } —> 63

49. (a) What sort of nurse came to help?

1. District nurse/ nurse from general practice	1
2. Health visitor	2
3. Nurse from hospital *(if hospital based Macmillan nurse code as 4)*	3
4. Nurse from hospice (Macmillan nurse, Hospiscare nurse, hospice at home nurse)	4
5. Other nurse *(specify)*:-	5

Probe Any others?

(b) *If more than two* - Which were the two sorts of nurses that helped most?

District nurse/ nurse from general practice	1
Health visitor	2
Nurse from hospital	3
Nurse from hospice (Macmillan nurse, Hospiscare nurse, hospice at home nurse)	4
Other nurse *(specify)*	5

Ask QS 50 - 60 about nurses that helped most, and those on pink sheets about those that helped next most.

Can we talk about ____ *(code)* (first).

50. For how long did he/she have help from that/those nurse(*s*)?

Less than a week	1	
1 week < 1 month	2	
1 month < 3 months	3	
3 months < 6 months	4	
6 months < 1 year	5	
1 year +	6	
(Don't know	9)	

51. How often did they/she come - at the most frequent?

More than once a day	1	
Every day	2	
2 - 6 times a week	3	
Once a week	4	
2 - 3 times a month	5	
Less often	6	
(Don't know	9)	

52. Did that/those nurses mainly provide practical care, or did she/they mainly spend time talking?

Mainly practical	1	
Mainly talking	2	
(Don't know	9)	

53. (a) Was there anything else you or ____ would have liked her/them to do or to do more often?

Yes	1	
No	2	--> 54

(b) What? *(ring all mentioned)*

Washing/bathing	1	
Dressings	2	
Medicines	3	
Counselling/support	4	
Other *(specify)*	8	

54. When she/they came, do you feel she/they had enough time to do the things she/they did or did she/they hurry over them?

Enough time	1	
Hurried over them	2	
(DK	9)	

55. Would you say she/they gave __________ :-

A lot of reassurance and support	1	
Some reassurance and support	2	
or Hardly any?	3	
(DK	9)	

56. (a) Did she/they get in touch with any other services on __________'s behalf?

Yes	1	
No	2	} --> 57
Don't know	3	

(b) Which other services?

General practitioner	1	
Hospital	2	
Hospice	3	
Social services	4	
Other *specify:*	5	

57. (a) And did she/they give any advice?

Yes	1	
No	2	} --> 58
Don't know	3	

(b) Would you describe it as:-

Very helpful	1	
Fairly helpful	2	
or Not helpful?	3	

58. (a) Did she/they give ____ or you any help at night - between 8pm and 8am - at anytime during the year?

Yes	1	--> 59
No	2	
Dk	9	

(b) Would this have been helpful?

Yes	1	
No	2	
Dk	9	

59. Do you feel that the help and care ____ got from this/these nurse(s) was:-

Excellent	1	
Good	2	
Fair	3	
or Poor?	4	
(Don't know)	9	

60. About how many times did ____ have help from this/these nurse(s) at home in the last 12 months of his/her life?

1 - 2	1	
3 - 5	2	
6 - 11	3	
12 - 19	4	
20 - 49	5	
50 - 99	6	
100 - 199	7	
200 +	8	
Living in	9	

If more than one sort of nurse (Q49)
ask QS 50 - 60 on pink sheets about sort of nurse who helped next most often

61. (a) Do you think he/she had nursing help as often as necessary or would it have been better if he/she'd had it more often?

As often as necessary	1	—> 62
Prefer more often	2	
Other comment: *specify:-*		

(b) Did you or ________ ask for more help?

Yes	1	
No	2	}—> 62
Dk	9	

(c) What happened?

Refused by nurses	1
Not available	2
Other *(specify)*	4

62.

If received help at home from a hospice nurse (Macmillan nurse, hospiscare, hospice at home nurse) —> 63

(a) Was he/she offered the chance to see a hospice (Macmillan,Hospiscare,Hospice at home) nurse at any time during the year before he/she died?

Yes	1	
No	2	}—> 63
Dk	9	

(b) Did he/she meet them?

Yes	1	
No	2	—> (d)

(c) *If yes*

complete Qs 50 - 60 on green sheets

(d) Why not? Was it because:

The nurse was too busy	1
________ died before the nurse could meet them	2
________ did not want to meet them	3
You did not want to meet them	4
or what? *specify*	8

GENERAL PRACTITIONERS

63. Now can we talk about ________'s general practitioner.

Did ________ have a GP under the NHS whom he/she saw when he/she needed a doctor?

Yes	1
No	2
Don't know	9

IF NO GP —> 68 THEN —> 95

64. Was the doctor a man or a woman?

Male	1
Female	2
(Don't know	9)

65. In the 12 months before he/she died how many times did he/she see his/her doctor - or a partner, locum or assistant - professionally either at home (including residential home) or in the surgery?

Not at all	1	—> 68
Once	2	
Two - Four	3	
Five - Nine	4	
Ten - 19	5	
20 +	6	
(DK	9)	

66. And how many times was that at his/her home (including residential home)?

Not at all	1	—> 68
Once	2	
Two - Four	3	
Five - Nine	4	
Ten - 19	5	
20 +	6	
(DK	9)	

67. Did the doctor - or a deputy come to visit him/her at night - between 8 p.m. and 8 a.m. - at all during that year? How many times?

Not at all	1
Once	2
Two - Four	3
Five - Nine	4
Ten - 19	5
20 +	6
(DK	9)

68. When was the last time ________ saw a general practitioner before he/she died?

Within 24 hours	0
1 day < 3 days	1
3 days < 1 week	2
1 week < 1 month	3
1 month < 3 months	4
3 months < 6 months	5
6 months < 1 year	6
1 year < 2 years	7
2 years +	8
(Don't know	9)

For sudden deaths of people under 65 with no restrictions (Q10) —> 72

If ________ did not have a GP (Q63) —> 95

69. Did you feel that __________'s doctors were:-
Willing to do home visits 1
or Rather reluctant to do home
visits? 2
(Don't know) 9

70. (a) Do you feel it would have been helpful if the doctor(s) had visited ________ (more often) at home?
Yes 1
No .... 2 } --> 71
Dk 9

(b) Was he asked?
Yes 1
No .... 2 -->(d)

(c) What happened? *(ring all that apply)*
Doctor refused 1
Receptionist refused .... 2 } --> 71
Other *specify:* 4

(d) Why not? *(ring all that apply)*
Didn't want to bother doctor 1
Couldn't contact doctor 2
Previous bad experience
put them off 4
Other *specify:* 8

71. (a) And what about visits at night - were there any (other) occasions when you feel it would have been helpful for a doctor to come and see ________ at night?
Yes 1
No 2
Dk .... 9 } ---> 72

b) Was he asked?
Yes 1
No .... 2 ---> (d)

(c) What happened? *(ring all that apply)*
Doctor refused 1
Doctor gave telephone advice .... 2 } ---> 72
Other *specify:*.............................. 4

(d) Why not? *(ring all that apply)*
Didn't want to bother doctor 1
Couldn't contact doctor 2
Previous bad experience
put them off 4
Other *specify:* 8

72. (a) Did you have the same doctor as ________ or one in the same group?
Same doctor .... 1 ---> 73
Another doctor in same group 2
Different doctor 3

(b) Do you know ________'s doctor at all?
Yes 1
No .... 2 ---> 75

73. Do you think ________'s doctor is an easy person to talk to or not?
Easy 1
Not easy 2

74. Do you think he/she has time to discuss things or not?
Has time 1
Not 2

75. Would you describe the way ________'s general practitioners looked after him/her as:-
Very understanding 1
Fairly understanding 2
Not very understanding 3
Or what? *specify:-* 4

(Don't know) 9

76. Altogether what do you think about the different aspects of care ________ got from his/her general practitioners in the last year of his/her life. Would you describe the care as:-
Excellent 1
Good 2
Fair 3
or Poor? 4
(No care) .... 5 ---> 95
(Don't know) 9

If no care (5) or no symptoms at Q20 ---> 95

77. Can I just check, did ________ have any pain whilst he was at home in the last 12 months of his life?
Yes 1
No 2
Don't know .... 9 } ---> 82

78. (a) Did the general practitioners give ________ any treatment for pain, or arrange for him/her to have any treatment for that, during the last year of his/her life?
Yes .... 1 ---> 79
No 2
Don't know 9

(b) Do you think they should have?
Yes 1
No .... 2 } ---> 82

79. What sort of treatment did the general practitioners give, or arrange for ________ to have, for the pain - was it:- *(ring all that apply)*

Given by mouth	1	
By injection	2	
By syringe driver	3	
Or what? *specify:-*	4	

☐

80. Did the treatment relieve the pain: -

Completely all the time	1	
Completely some of the time	2	
Partially	3	
or Not at all?	4	
(Don't know	9)	

81. Do you think the general practitioners tried enough to relieve ________'s pain?

Yes	1	
No	2	
Uncertain	3	

82. Can I check, did ________ have any trouble with breathing whilst he/she was at home?

Yes	1	
No	2	}
Don't know	9	} —> 86

83. (a) Did the general practitioners give ________ any treatment for his/her trouble with breathing or arrange for him/her to have any treatment for that in the last year of his/her life?

Yes	1	—> 84
No	2	
Don't know	9	

(b) Do you think they should have?

Yes	1	}
No	2	} —> 86

84. Did the treatment relieve the trouble:-

A lot	1	
Some	2	
A little	3	
or Not at all?	4	
(Don't know	9)	

85. Do you think the general practitioners did enough to help ________ with his/her breathing?

Yes	1	
No	2	
Uncertain	3	

86. Can I check, did ________ have any vomiting or feelings of sickness whilst he/she was at home?

Yes	1	
No	2	}
Don't Know	9	} —> 90

87. (a) Did the general practitioners give ________ any treatment for his/her vomiting or feeling sick or arrange for him/her to have any treatment for that in the last year of his/her life?

Yes	1	—> 88
No	2	
Don't know	9	

(b) Do you think they should have?

Yes	1	} —> 90
No	2	}

88. Did the treatment relieve the vomiting and feeling sick:-

A lot	1	
Some	2	
A little	3	
or Not at all?	4	
(Don't know	9)	

89. Do you think the general practitioners tried enough to help ________ with his/her vomiting and feeling sick?

Yes	1	
No	2	
Uncertain	3	

90. Can I check, did ________ have any constipation whilst he/she was at home?

Yes	1	
No	2	}
Don't know	9	} —> 94

91. (a) Did the general practitioners give ________ any treatment for his/her constipation or arrange for him/her to have any treatment for that in the last year of his/her life?

Yes	1	—> 92
No	2	
Don't know	9	

(b) Do you think that they should have?

Yes	1	}
No	2	} —> 94

92. Did the treatment relieve the constipation: -

A lot	1	
Some	2	
A little	3	
or Not at all?	4	
(Don't know	9)	

93. Do you think the general practitioners did enough to help ________ with his constipation?

Yes	1
No	2
Uncertain	3

94. Do you think the general practitioner's understanding of the different problems ______ had in the last year of his/her life was:-

Good	1
Fair	2
or Poor?	3

95. (a) Apart from a general practitioner, did any (other) doctor from a hospital or hospice or anywhere else come to visit ________ at home during the twelve months before he/she died?

Yes	1
No	2 } —> 96
Don't know	9 } —> 96

(b) Where was from the doctor from?

Hospital	1
Hospice	2
Other specify:-	3

(c) So do you think the visit was:-

Very helpful	1
Fairly helpful	2
or Not helpful?	3
(Don't know	9)

HOSPITAL AND HOSPICE CARE

96. *Check.* Was ________ in a hospital or hospice at any time during the last twelve months of his/her life (including when died)?

Yes	1
No	2 —> 137

97. How many different hospitals or hospices was in during the last twelve months of his/her life?

☐☐

98. (a) How long was he/she in a hospital or hospice (altogether) in the 12 months before he/she died?

Less than 3 nights	1
3 nights < 1 week	2
1 week < 1 month	3
1 month < 3 months	4
3 months < 6 months	5
6 months < 1 year	6
All the year	7
(Don't know	9)

(b) (Can I check) was _____ in a hospice at anytime during the last 12 months of his/her life?

Yes	1
No	2 } —> 99
Don't know	9 } —> 99

(c) How long was he/she in a hospice (altogether) in the 12 months before he/she died?

Not at all	0
Less than 3 nights	1
3 nights < 1 week	2
1 week < 1 month	3
1 month < 3 months	4
3 months < 6 months	5
6 months < 1 year	6
All the year	7
(Don't know	9)

If died in hospital or hospice (Q9) —> 100

99. How long before ________ died did he/she leave hospital for the last time?

Less than a week	1
1 week < a month	2
1 month < 3 months	3
3 months < 6 months	4
6 months < 1 year	5
(Don't know	9)

I'd like to ask you some questions about the care and treatment ________ received while he/she was in hospital or hospice that last year.

100. Can you tell me the name of the hospital or hospice he/she was in?

(If more than one, ask about one died in - or was in longest)

a) Name

b) Address

If died in accident and emergency (casualty) —> 136

101. *Check.* Was that a hospital or hospice?

Hospital	1
Hospice	2

102. And was he/she in there under the NHS or privately or what?

NHS	1
Privately	2
Other *specify:-*	3

103. (a) Was ________ admitted to that hospital (or hospice) just once in the year before he/she died - or did he/she go in more than once?

Once .... 1 --> 104
More often 2

(b) How many times?

☐☐ --> 105

104. *Ask if admitted once and died elsewhere (Q9), Else --> 106*

Looking back now, do you think that he/she was discharged too soon, or at the right time - or do you think he/she should have been discharged earlier?

Too soon .... 1 }
At the right time .... 2 } --> 106
Too late .... 3 }

105. Looking back now, do you think that he/she was (ever) discharged too soon, or (always) at the right time - or do you think he/she should (ever) have been discharged earlier?

All too soon 1
All at the right time 2
All too late 3
Some too soon, some at the right time 4
Some too late, some at the right time 5
Other (*specify*) 6

(Don't know 9

106. *Ask only if in more than one hospital or hospice. If only in one hospital or hospice (Q97) --> 107*

How long was he/she in that hospital/hospice (altogether) in the last year of his/her life?

Less than 3 nights 1
3 nights < 1 week 2
1 week < 1 month 3
1 month < 3 months 4
3 months < 6 months 5
6 months < 1 year 6
(Don't know .... 9)

107. What was the reason for _____ going into (that) hospital/hospice. Was it mainly:- (*ring all that apply*)

To find out what was wrong 1
To relieve his/her symptoms 2
To try and cure his/her illness 3
Or what? *specify:-* 4

108. (a) While _______ was in ______ hospital did he/he have any pain?

Yes 1
No .... 2 }
Don't know .... 9 } --> 112

(b) Did he/he receive any treatment for this?

Yes .... 1 --> 109
No 2
Don't know 9

(c) Do you think they should have?

Yes .... 1 }
No .... 2 } --> 112
Don't know 9 }

109. What sort of treatment did he/she have for the pain - was it:- (*ring all that apply*)

Given by mouth 1
By injection 2
By syringe driver 4
Or what? *specify:-* 0

☐

110. Did the treatment relieve the pain:-

Completely all the time 1
Completely some of the time 2
Partially 3
or Not at all? 4
(Don't know) 9

111. Do you think the doctors at _________ tried enough to relieve _______'s pain?

Yes 1
No 2
Uncertain 3

112. (a) While ________ was in ______ hospital, did he/she have any trouble with his/her breathing?

Yes 1
No .... 2 }
(Don't know) .... 9 } --> 115

(b) Did he/she receive any treatment for this?

Yes .... 1 --> 113
No 2
(Don't know) 9

(c) Do you think he/she should have received any?

Yes .... 1 }
No .... 2 } --> 115

113. Did the treatment relieve the trouble:-

A lot 1
Some 2
A little 3
or Not at all? 4
(Don't know) 9

114. Do you think the doctors at ________ tried enough to help ________ with the trouble with his/her breathing?

Yes	1	
No	2	
Uncertain	3	

115. (a) While ________ was in ______ hospital did he/she have any trouble with vomiting or feeling sick?

Yes	1	
No	2	—> 118
(Don't know)	9	

(b) Did he/she receive any treatment for this?

Yes	1	—> 116
No	2	
(Don't know)	9	

(c) Do you think he/she should have received any?

Yes	1	—> 118
No	2	

116. Did the treatment relieve the vomiting and feeling sick:-

A lot	1
Some	2
A little	3
or Not at all?	4
(Don't know)	9

117. Do you think the doctors at ________ tried enough to help ________ with his/her vomiting or feeling sick?

Yes	1
No	2
Uncertain	3

118. (a) While ________ was in ________ hospital, did he/she have any constipation?

Yes	1	
No	2	—> 121
Don't know	9	

(b) Did he/she receive any treatment for this?

Yes	1	—> 119
No	2	
Don't know	9	

(c) Do you think that he/she should have?

Yes	1	—> 121
No	2	

119. Did the treatment relieve the constipation:-

A lot	1
Some	2
A little	3
or Not at all?	4
(Don't know)	9

120. Do you feel the doctors at ________ tried enough to help ______ with his/her constipation?

Yes	1
No	2
Uncertain	3

121. (a) Was there any (other) treatment you think they should have given to __________ but did not?

Yes	1	
No	2	—> 122
Don't know	9	

(b) What? *(ring all mentioned)*

Symptom control (not operation) ...	1
An operation to cure condition	2
An operation to alleviate symptoms ..	3
Drug treatment to cure condition	4
Radiotherapy (X-Ray) treatment	5
Physiotherapy	6
Other *specify:-*	8

122. Do you think __________ had any unnecessary treatment (or operation) while he/she was in ________ hospital?

Yes	1
No	2
Uncertain	3

123. Do you think that __________ had as much choice about his/her treatment as he/she wanted?

Yes	1
No	2
Other *specify:*	3
DK	9

124. Do you feel the doctors were able and willing to give the time to ________ that he/she needed?

Yes	1
No	2
Uncertain	3

125. Altogether what do you feel about the different aspects of care __________ got from the doctors while he/she was in ___________ .
Would you describe it as:-

Excellent	1
Good	2
Fair	3
or Poor?	4
(Don't know	9)

126. What about the nurses and other staff there - do you think the care ________ got from them was:-

Excellent	1
Good	2
Fair	3
or Poor?	4
(Don't know	9)

127. Would you say ________ had enough privacy while he/she was in ________ ?
Yes, all the time 1
Some of the time 2
No 3
Don't know 9

128. (a) Did he/she have a room of his/her own:-
All the time .... 1 —> 129
Some of the time 2
or Not at all? 3
(Don't know) 9

(b) Would he/she have liked one (all the time)?
Yes 1
No 2
Uncertain 3

(c) How many beds were there in his/her room/ward?

☐☐

129. Would you describe the room where he/she was when he/she died/was most of the time as:-
Very peaceful and quiet 1
Fairly peaceful and quiet ... 2
or Not at all peaceful and quiet? 3

If interviewing official of that hospital/ hospice —> Q136

130. Did you visit ________ while he/she was in ________ ?
Yes 1
No .... 2 —> 136

131. How many times (in that year)?
1 - 4 1
5 - 9 2
10 - 19 3
20 - 49 4
50 + ... 5
(Don't know .... 9)

132. How long did it usually take you to get there?
Less than 15 minutes 1
15 minutes < 30 minutes 2
30 minutes < 45 minutes 3
45 minutes < 60 minutes 4
1 hour < 2 hours 5
2 hours + *specify:-* 6

133. Did you find the journey tiring?
Yes 1
No 2
Sometimes 3

134. When you were there would you describe the way you were treated at ________ as:-
Very kindly 1
Fairly kindly 2
Indifferent 3
or Rather hostile? 4

135. (a) While you were there did you take part in ________'s care?
Yes 1
No .... 2 —> 136
Sometimes 3

(b) What did you do? Did you:-

	Y	No	DK
Give medicines?	1	2	9
Feed ______ or give him/her drinks?	1	2	9
Wash him/her?	1	2	9
Take him/her to the lavatory?	1	2	9
(Help) lift him/her?	1	2	9
Or anything else? *specify:-*	1	2	9

136.

If in more than one hospital/hospice complete yellow pages (Q100 - 135) about one he/she was in for longest or next longest. Else continue here.

Sudden Deaths —> 138

137. *Ask only if ___ was not inpatient in hospice (Q98b). If an inpatient in a hospice —> 138*

(a) Did anyone suggest that he/she might go into a hospice at any time in the last year of their life?
Yes 1
No .... 2 } —> 138
Dk .... 9 }

(b) Why didn't he/she go into one. Was it because:-
There were no beds available 1
The hospice felt it wasn't the right place for ________ 2
________ did not want to go into one 3
or because you did not want him/her to go into one? 4
(Other - *specify* .... 8)

138. *Check. Sudden deaths of people under 65 with no restrictions (Q10) —> 145*

People in hospital or hospice or nursing home all year (Q98) —> 150

DAY HOSPITALS

139. (a) Did______ go to a day hospital at all during the year before he/she died?

Yes	1	—> 140
No	2	
Don't know	9	

(b) Would it have been helpful if he/she had been able to go?

Yes	1	} —> 145
No	2	

140. Was it at, or run by, a:-

Hospital	1
Hospice	2
or What? *specify:-*	3

If run by local authority, skip to Q145

141. How long was he/she going there for?

Less than a week	1
1 week < 1 month	2
1 month < 3 months	3
3 months < 6 months	4
6 months < 1 year	5
1 year +	6
(Don't know	9)

142. How many times did he/she usually go each week during this time?

Once a week	1
Twice a week	2
Three	3
Four	4
Five +	5
Less often	6
(Don't know	9)

143. Did he/she enjoy the days at the centre:-

A lot	1
Some	2
A little	3
or Not at all?	4
(Don't know)	9

144. What about for you or others looking after him/her - were the visits:-

Very helpful	1
Fairly helpful	2
or Not helpful?	3
Other comment *specify:-*	4
(Don't know)	9)

OUT-PATIENTS

145. Did ________ go to hospital as an out-patient at all during the last year of his/her life?

Yes	1	
No	2	} —> 149
DK	9	

146. How many times did he/she go to out-patients during that time?

Once	1
2 - 4	2
5 - 9	3
10 - 19	4
20 +	5
Uncertain	6

147. (a) How did he/she (usually) get there?

Ambulance	1
Hospital car	2
Public transport	3
Own car	4
Lift in other person's car	5
Walked all the way	6
Other *specify:*	7

(b) How long did the visit (usually) take from the time he/she left home until he/she got back?

Less than an hour	1
1 hour < 2 hours	2
2 hours < 3 hours	3
3 hours < 4 hours	4
4 hours < 6 hours	5
6 hours + *specify:-*	6
(Don't know	9)

148. Would you say _____'s visit(s) to out-patients were:-

Easy	1
A little difficult	2
Fairly difficult	3
or Very difficult?	4
(Don't know	9)

149.

For sudden deaths of people under 65 with no restrictions (Q10) —> 173 with introduction 'can we talk about when ________ died'

For sudden deaths of people over 65 with no restrictions, no hospital admissions or out-patients visits —> 153

150. (a) Did ________ have any operations in the year before he/she died?

Yes	1	
No	2	} —> 151
Dk	9	

(b) How many operations did he/she have?

Number: ☐☐

(c) Thinking now about the (last) operation he/she had *(ask questions below about each operation)*

	Was it intended to:- *(ring all that apply)*		Looking back, do you think it was a good idea for him/her to have this operation?	
Last Op	relieve his/her symptoms	1	Yes	1
	cure his/her condition	2	No	2
	find out what's wrong	3	DK	9
	or what? *specify:-*	4		
	(Don't know)	9		
Previous Op	relieve his/her symptoms	1	Yes	1
	cure his/her condition	2	No	2
	find out what's wrong	3	DK	9
	or what? *specify:-*	4		
	(Don't know)	9		
Op Before That	relieve his/her symptoms	1	Yes	1
	cure his/her condition	2	No	2
	find out what's wrong	3	DK	9
	or what? *specify:-*	4		
	(Don't know)	9		

151. (a) Can I just check, did _____ have any chemotherapy or hormone therapy in the year before he/she died. By that I mean, drug treatment given by doctors in hospital to stop cancer cells growing, or to kill cancer cells?

Yes 1
No .... 2 } --> 152
Dk .... 9 } --> 152

(b) Was it intended to cure his/her condition or to improve his/her symptoms?

Cure condition 1
Improve symptoms 2
(Don't know .... 9)

(c) Looking back now, do you think it was a good idea for him/her to have this treatment?

Yes 1
No 2
Dk 9

(d) How long before he/she died was he/she last given chemotherapy or hormone therapy?

Less than a week 1
1 week < 1 month 2
1 month < 3 months 3
3 months < 6 months 4
6 months < 1 year 5
(Don't know .... 9)

152. (a) Can I just check, did ______ have any radiotherapy in the year before he/she died. By that I mean X-ray treatment from a special machine which was intended to limit cancer or help with _______'s condition in some way.

Yes 1
No .... 2 } --> 153
Dk .... 9 } --> 153

(b) Was it intended to cure his/her condition or to improve his/her symptoms?

Cure condition 1
Improve symptoms 2
(Don't know) 9

(c) Looking back now, do you think it was a good idea for him/her to have this treatment?

Yes 1
No 2
Dk 9

(d) How long before he/she died was he/she last given radiotherapy?

Less than a week 1
1 week < 1 month 2
1 month < 3 months 3
3 months < 6 months 4
6 months < 1 year 5
(Don't know .... 9)

Can I change the subject slightly now?

153. (a) Would you say ________ had:-

A strong religious faith 1
Some religious faith 2
or No religious faith? .... 3 } --> 154
(Don't know) .... 9 } --> 154

(b) Do you think his/her faith was a help to him/her in the time before he/she died?

Yes 1
No 2
Uncertain 3
Other *specify:-* 6

(c) To what faith or denomination did he/she belong?

Roman Catholic	1
Church of England	2
Other Protestant	3
Jewish	4
Moslem	5
Hindu	6
Other *specify:-*	7

INFORMATION

Check. No illness or incapacity at all (Qs 4-6,11) —> 173

154. (a) Can we move onto another subject now. During_______'s illness or incapacity were you able to find out all you wanted to know about his/her illness and how it was likely to affect him/her?

Yes	1
No	2 —> 155
No illness or incapacity	3 —> 173

(b) Was there anything else you would have liked to have explained to you in more detail?

Yes	1 —> 155
No	2

(c) Were you able to find out about things as soon as you wanted to?

Yes	1 —> 156ii
No	2

155. What would you have liked to know about/in more detail/earlier? *(ring all mentioned)*

Probe Is there anything else you would have liked to know about in more detail or earlier?

How to cope with, or care for patient	1
What was wrong ie diagnosis or cause	2
Reasons for decisions about medical care / treatment	3
The likely outcome of condition	4
More information about medication or treatment (ie what given for, side-effects, name etc)	5
Other *specify:-*	6

156i. (a) Did you ask anyone about this/these?

Yes	1
No	2 —> 156ii

(b) Whom did you ask? *(ring all that apply)*

General practitioner	1
Hospital doctor	2
Hospital sister/nurse	3
Hospice doctor	4
Hospice sister/nurse	5
Home nurse *specify:-*	6
Other *specify:-* ...	7

(c) What happened?

Did not understand answer	1
Person too rushed	2
Other *specify:-*	3

156ii. (a) Who did you talk to about ________'s illness and what might happen. What about a:-

	Y	NO	DK
1. General practitioner?	1	2	9
2. (Hospital doctor?)	1	2	9
3. (Hospital nurse?)	1	2	9
4. (Hospice doctor)	1	2	9
5. (Hospice nurse)	1	2	9
6. (Home nurse *specify:-*)	1	2	9
7. Vicar, priest etc?	1	2	9
8. Other professional? *specify:-*	1	2	9
9. _______ (person who died)? ..	1	2	9
10. Relative of yours?	1	2	9
11. Friend/neighbour?	1	2	9
12. Anyone else? *specify:-*	1	2	9

(b) *Ask only if talked to more than one. Else —> Q157*

Who gave you the most information?
(code one only using number from (a))

☐

(c) And who did you find the most helpful or supportive?
(code one only using number from (a))

☐

157.

Nearly sudden deaths —> 173.

Did _______ know he/she was likely to/might die?

Yes, certain	1	
Yes, probably	2	
Probably not	3	—> 164
No, definitely	4	
Unable to say	5	—> 166

158. (a) Had anyone told him/her. Who?

No-one	0	—> 159
General practitioner	1	
Hospital doctor	2	
Hospital sister/nurse	3	
Hospice doctor	4	
Hospice sister/nurse	5	
Home nurse *specify:-*	6	
Respondent	7	
Other *specify:-*	8	
Don't know	9	—> 159

(b) Did he/she ask them?

Yes	1
No	2
Other *specify:-*	3
Dk	9

(c) How did you feel about the way he/she was told?

Well done/happy	1
Went against carers wishes	2
Other criticism *specify:*	3
Other comment *specify*	4

159. (a) Do you think that what _______ knew was best as it was?

Yes	1	—> 160
No	2	

(b) What would have been better?

Better not to have known	1
Better to have known definitely	2
Best as it was	3
Uncertain	4

160. How long before he/she died had he/she (or might he/she) have known that he/she was going to die?

Less than 24 hours	1
24 hours < 1 week	2
1 week < 1 month	3
1 month < 3 months	4
3 months < 6 months	5
6 months < 1 year	6
1 year +	7
(Don't know)	9

161. Would you describe him/her as:-

Definitely accepting	1
Fairly accepting	2
Not at all accepting?	3
(Don't know)	9

162. Did you and he/she talk about his/her death?

Yes	1
No	2
Other *specify:-*	3

163. How do you feel about that now?

Glad talked about it	1	—> 165
Sorry talked about it	2	
Glad did not talk about it	3	
Wish had talked about it	4	
Other *specify:-*	5	

164. Do you think that what _______ knew was best as it was?

Yes	1
No	2
Uncertain	3

165. (a) Did he/she ask anyone?

Yes	1	
No	2	—> 166
Don't know	9	

(b) Who? *(ring all that apply)*

General practitioner	1
Hospital doctor	2
Hospital sister/nurse	3
Hospice doctor	4
Hospice sister/nurse	5
Home nurse *specify:-*	6
Other professional *specify:-*	7
Other *specify:-*	8

(c) What did they say? *(ring all that apply)*

Changed subject	1
Referred him/her to someone else	2
Told him/her but he/she didn't take it in	4
Other *specify:-*	8

166. (a) (Can I check) Did you know, half know, or not know, what was wrong with _______ ?

Knew	1	
Half knew	2	—> 167
Didn't know	3	

(b) Did anyone tell you. Who?

No-one	0	
General practitioner	1	
Hospital doctor	2	
Hospital nurse	3	
Hospice doctor	4	
Hospice nurse	5	
Home nurse *specify:-*	6	
Other professional *specify:-*	7	
Deceased	8	
Relative etc. *specify:-*	9	

167. And did you know, half know, or not know that ____ was likely to/might die?

Knew	1	
Half knew	2	—> 172
Didn't know	3	—> 171

168. (a) Had anyone told you. Who?

No-one	0	—> 169
General practitioner	1	
Hospital doctor	2	
Hospital nurse	3	
Hospice doctor	4	
Hospice nurse	5	
Home nurse *specify:-*	6	
Other professional *specify:-*	7	
Deceased	8	
Relative etc. *specify:-*	9	

(b) Did you ask them - or what happened?

Ask them	1
Other *(specify)*	2

(c) How did you feel about the way you were told?

Well done/happy	1
Went against carers wishes	2
Other criticism *specify:*	3
Other comment *specify:*	4

169. How long had you known that he/she was going to die?

Less than 24 hours	1
1 day < 1 week	2
1 week < 1 month	3
1 month < 3 months	4
3 months < 6 months	5
6 months < 1 year	6
1 year or more	7

170. Would you have preferred not to know or do you think it was better that you did?

Preferred not	1	—> 173
Better that knew	2	
Uncertain	3	

171. (a) Would you have liked to have known or do you think it was better you didn't?

Liked to have known	1	
Glad didn't	2	—> 173

(b) Did you ask anyone?

Yes	1	—> (d)
No	2	

(c) Why not?

Didn't know who to ask	1	—> 173
Aware of people waiting	2	
Doctor/nurse rushed	3	
Other *specify:-*	4	

(d) Who?

General practitioner	1
Hospital doctor	2
Hospital nurse	3
Hospice doctor	4
Hospice nurse	5
Home nurse *specify:-*	6
Other *specify:-*	7

(e) What did they say?

Changed subject	1	—> 173
Referred him/her to someone else	2	
Other *specify:-*	3	

172. Would you have preferred to know definitely or not to have known at all or do you think it was best as it was?

Like to have known definitely	1
Prefer not to know at all	2
Best as it was	3

<u>Now can we talk about when ________ died</u>

173. *<u>Check</u>* Were you with ________ when he/she died?

Yes	1	—> 174
No	2	

(b) Would you have liked to be there or not?

Liked to have been there	1
Not	2

(c) When was the last time you saw ________ before he/she died?

Within 24 hours	1
1 day < 1 week	2
1 week < 1 month	3
1 month < 3 months	4
3 months or more	5

174. (a) Was anyone (else) there when he/she died?

Yes	1
No	2 —> 175

(b) Who?

(Other) relative	1
Friend	2
Nurse	3
Other professional	4
Other specify:-	5

175. *If interviewing official —> 187*

Looking back to the circumstances of _______'s death now: is there anything that happened that you feel pleased about? What?

176. And is there anything you wish had happened differently? What?

Sudden deaths (Q6) —> 193

Hospital/institutional deaths (Q9) —> 182

HOME DEATHS

177. How do you feel about _______ dying at home rather than in hospital?

178. Did you at any stage feel it would have been better for ________ to be in a hospital or hospice or other institution (again) - either from his/her point of view or from the point of view of the people looking after him/her?

Yes	1
No	2 —> 187

179. So was that for:-

_________'s sake	1
Or the sake of those looking after him/her	2
Or both?	3

180. (a) Did you discuss this with _______'s general practitioner?

Yes	1
No	2 —> 181

(b) So couldn't the G.P. get _______ admitted or was the doctor unwilling to try or what?

Unable to get admission	1
Unwilling to try	2
Other *specify:-*	3

181. Would you have preferred him/her to be in a:-

Hospital	1	—> 187
Hospice	2	
Old people's home	3	
or Where? *specify:-*	4	

DEATHS IN HOSPITALS/ OTHER INSTITUTIONS

182. How did you feel about ________ dying in a hospice/hospital/institution rather than at home?

183. Did you at any stage feel it would have been better for _______ to be at home?

Yes	1
No	2 —> 185

184. (a) Did you discuss this with ________'s general practitioner or with anyone at the hospital/hospice/institution?

Yes	1
No	2 —> 185

(b) Who?

General practitioner	1
Hospital doctor	2
Hospital nurse	3
Hospice doctor	4
Hospice nurse	5
Home nurse	6
Other *specify:-*	7

(c) What did they say?

185. *Check.* I think you said you visited/did not visit ______ around the time (within a week) he/she died?

Visited	1	
Did not visit	2	—> 187

186. Would you describe the way the staff at the hospital/ institution treated you around the time ______ died as:-

Very kind and understanding	1
Fairly kind and understanding	2
or Not kind and understanding?	3
Other *specify:-*	4

187. Do you think that ______ had enough choice about where he/she died?

Yes	1
No	2
Not sure	3
Other *specify:*	4

188. What about his/her carers/family - did you have enough choice about this?

Yes	1
No	2
Not sure	3
Other *specify:*	4

189. Looking back now, and taking ______'s illness into account, do you think he/she died at the best time - or would it have been better if he/she died earlier or later?

Died at best time	1
Better earlier	2
Better later	3
(Don't know	9)

190. (a) What about ______ ? Did he/she ever say that they wanted to die sooner?

Yes	1	
No	2 }	—> 191
Not sure	3 }	—> 191

(b) Did he/she ever say that he/she wanted euthanasia?

Yes	1
No	2
Not sure	3

191. Altogether, would you describe the quality of ______'s life in the year before he/she died as:-

Good	1
Fair	2
or Poor?	3
(Other *specify:-*	4)

192. Altogether, and taking all things into consideration, would you say that the care ______ received in the year before he/she died, from the health and social services was:

Excellent	1
Good	2
Fair	3
or Poor	4
(Other *specify:-*	5)

Officials, neighbours friends who were not close —> 220

193. (a) After ______ had died, did you see his/her body at all (after it had been washed and prepared)?

Yes	1	
No	2	—> (d)

(b) Are you glad or sorry you saw him/her - or how do you feel?

Glad	1
Sorry	2
Other *specify:-*	3

(c) *Ask if death in hospital/institution (Q9). Else —> 194*

Were there any problems about seeing him/her?

Yes	1 }	
No	2 }	—> 194

(d) Would you have liked to do so?

Yes	1
No	2

(e) Did anyone suggest that you might like to?

Yes	1
No	2

194. Since _______ died have any of these people visited you at home:-

Visited?		Did you find the visit helpful or not?	
Your own doctor?			
Yes	1	Yes	1
No	2	No	2
DK	9	Dk	9
Other GP?			
Yes	1	Yes	1
No	2	No	2
DK	9	Dk	9
District nurse?			
Yes	1	Yes	1
No	2	No	2
DK	9	Dk	9
Hospice (Hospiscare, Macmillan) nurse?			
Yes	1	Yes	1
No	2	No	2
DK	9	Dk	9
Welfare or social worker?			
Yes	1	Yes	1
No	2	No	2
DK	9	Dk	9
Minister, vicar or priest?			
Yes	1	Yes	1
No	2	No	2
DK	9	Dk	9
Any other professional person?			
Yes	1	Yes	1
No	2	No	2
DK	9	DK	9
specify:-			

A few questions about you and your health.

195. How has your health been since____ died?

196. Would you describe your health for your age as:-

Excellent	1
Good	2
Fair	3
or Poor?	4

197. *Check* And how old are you?

Under 25	1
25 - 34	2
35 - 44	3
45 - 54	4
55 - 64	5
65 - 74	6
75 - 84	7
85+	8

198. Since________ died have you had problems with any of these things that you think have been caused or made worse by ___'s (illness and) death:-

	Yes	No
Sleeplessness?	1	2
Nerves or depression?	1	2
Loss of appetite?	1	2
or Any other symptom? *specify:-*	1	2

199. (a) And have you consulted a doctor for yourself at all since _____ died?

Yes	1
No	2 —> 201

(b) How many times?

Number: ☐

(c) Did the doctor prescribe anything that might help you sleep or help you feel less miserable?

Yes	1
No	2

(d) How did you feel about that?

Pleased prescribed	1
Pleased not prescribed	2
Wished prescribed	3
Rather not prescribed	4
Other *specify:-*	5

201. *Check (Q72)* I think you said you had:-

The same doctor as ______	1 —> 205
A different doctor to ______	2

202. Is your doctor a man or a women?

Man	1
Woman	2

203. Do you think your doctor is an easy person to talk to or not?

Easy	1
Not easy	2

204. Do you think he/she has time to discuss things or not?

Has time	1
Not	2

205. Would you describe him/her as:-

Very understanding	1
Fairly understanding	2
Not very understanding	3
or What? *specify:-*	4

206. (a) Since ________ died have you talked to any of these people about your feelings about ______'s death:-

	Talked to?	Did you find the talk helpful or not?
Your own doctor?	Yes 1 No 2 DK 9	Yes 1 No 2 Dk 9
Other GP?	Yes 1 No 2 DK 9	Yes 1 No 2 Dk 9
A nurse? *specify:-*	Yes 1 No 2 DK 9	Yes 1 No 2 Dk 9
A minister, vicar or priest?	Yes 1 No 2 DK 9	Yes 1 No 2 Dk 9
Friend or neighbour?	Yes 1 No 2 DK 9	Yes 1 No 2 Dk 9
Relative? *specify:-*	Yes 1 No 2 DK 9	Yes 1 No 2 Dk 9
Anyone else? *specify:-*	Yes 1 No 2 DK 9	Yes 1 No 2 Dk 9

(b) *Ask if more than one helpful. Else —> 206*

Who did you find most helpful?

Your GP	1
Another doctor	2
A nurse *specify:-*	3
A minister, vicar or priest	4
Friend or neighbour	5
Relative *specify:-*	6
Anyone else *specify:*	7

206. Do you feel you would have liked to talk to anyone (else) about your feelings?

Yes	1
No	2

207. (a) Would you say you had:-

A strong religious faith	1
Some religious faith	2
or No religious faith	3 —> 208

(b) Has it been a help to you over ________'s death?

Yes	1
No	2
Other *specify:-*	6

(c) To what faith or denomination do you belong?

Roman Catholic	1
Church of England	2
Other Protestant	3
Jewish	4
Moslem	5
Hindu	6
Other *specify:-*	7

208. *Check* You are now:-

Widowed	1
Married	2
Single	3
Separated or divorced	4

209. (a) *Check* And you now:-

Live alone	1 —> 210
with others	2

(b) *If with others record:*

Relationship to informant	Sex	Age (in years)
A	M F	
B	M F	
C	M F	
D	M F	
E	M F	

CODE Q209 AS FOLLOWS:

Living with:

alone	1
spouse only	2
spouse and others	3
others only	4

210. *Check* Used to live with deceased?

Yes	1
No	2

211. *Check* And who owns your home?

Self or spouse	1
Council	2
Private landlord	3
Other *specify:-*	4

212. Do you miss ____________:-

A great deal	1
Quite a lot	2
or Not very much?	3

213. Before__________(became ill and) died would you describe your relationship with him/her as:-

Very good	1
Good	2
Fairly good	3
or Poor?	4

214. (a) What about loneliness - do you find this a problem for you or not?

Yes	1
No	2 —> 215

(b) Do you think this is a big problem or one that you will get over fairly soon - or what?

Big problem	3
Will get over soon	4
Other <u>specify</u>:-	5

215. Do you find now that you can look forward to things in the same way as you used to before_____died?

Yes	1
No	2

216. Do you feel you have come to terms with _________'s death yet?

Yes	1
No	2
Uncertain	3

217. Taken together, would you describe the way things are going for you these days as:-

Reasonable	1
Not very well	2
or not at all well?	3

218. Since _________ died have you had any practical worries or anxieties which have been caused by or made worse by _______'s death such as:-

	Yes	No
Financial worries?	1	2
Legal ones?	1	2
Problem with ownership of house, or tenacy?	1	2
Anything else? *specify:*	1	2

219. Here are some statements about how you have been feeling in yourself recently. Please read them carefully and underline the answer which best shows how you have been feeling recently.

[Give GHQ]

(Interviewers - do not code this)

1 ☐☐

2 ☐☐

3 ☐☐

4 ☐☐

220. I've got one or two more questions about ______ 's family.

(a) Can I check, did he/she have any children alive at the time of death?

Yes 1
No .... 2 —> 221

(b) How many sons?

☐

(c) How many daughters?

☐

221. (a) And did he/she have any brothers or sisters who were alive when he/she died?

Yes 1
No .... 2 —> 222

(b) How many brothers?

☐

(c) How many sisters?

☐

222. *If sudden death of people under 65 —> 223*

Were there any relatives who you feel might have helped more - or visited him/her more often?

Yes 1
No 2

223. That's all my questions. Is there anything else you'd like to tell us about ________'s death, or about your feelings?

224. Is there anything else you'd like to ask me about the study?

<u>**Thank you very much for all your help and patience with our questions.**</u>

225. I've got a handout I'd like to leave with you that explains a bit about the study. It also gives the University's telephone number in case you'd like to say anything after I've gone.

226. *Only if you do not have their telephone number*

One final thing - have you got a telephone here and would you be prepared to give the number in case I find I've missed anything out when I check through the interview schedule?

No telephone 0
Not prepared to give number 1

Telephone number ________________

TIME INTERVIEW
FINISHED

☐☐☐☐

TO BE COMPLETED AT END OR IMMEDIATELY AFTER INTERVIEW

227. Sex of deceased

Male	1
Female	2

228. Marital status of deceased at time of death.

Married	1
Single	2
Widowed	3
Divorced or separated	4

229. Informant cried or expressed emotion in other ways during interview.

Cried	1
Other	2
Both	3
Neither	0

230. Place of interview.

Deceased's residence	1
Address of person who registered death	2
Both	3
Other *specify full address*	4

231. Others present during interview?

None of the time	1 —> 229
Some of the time	2
All of the time	3

(b) Who? specify relationship to informant

232. Length of interview(s).

Less than 30 minutes	1
30 mins < 1 hour	2
1 hour < 1 hr 30 mins	3
1 hr 30 mins < 2 hours	4
2 hours < 2hrs 30 mins	5
2 hrs 30 min < 3 hours	6
3 hours + specify	7

233. Informant asked spontaneously to be informed of the study results?

Yes	1
No	2

234. Date of interview(s) (Day, month, year)

First ☐☐☐☐☐☐

Last ☐☐☐☐☐☐

235. Number of calls to complete interview

Number ☐☐

236. Was the informant the most appropriate person to tell is about the last year of __________'s life?

Yes	1 —> 234
No	2
Uncertain	3

(b) Who might/would have been better (relationship to the deceased)

(c) Reason for not interviewing them?

237. (a) Was GHQ completed?

Yes	1 —> 235
Yes, partly	2
No	3

(b) Reason for not completing it

238. Any other comments about interview.

239. ***Put serial number on pink, yellow, green and blue sheets, and on GHQ.***

Appendix D

Table D.1. **Frequency distribution of deceaseds' sociodemographic characteristics (N=1858)**

Variable	n	Per cent
Sex		
male	961	51.7
female	897	48.3
Age		
under 55	198	10.7
55-64	307	16.5
65-74	524	28.2
75-84	609	32.8
85 or more	220	11.8
Ethnicity		
white	1835	98.8
non-white	22	1.2
missing information	1	0.1
Marital status		
married	1024	55.1
single/separated/divorced/widowed	814	43.8
missing information	20	1.1
Had living children		
yes	1504	80.9
no	343	18.5
missing information	11	0.6
Had living siblings		
yes	1346	72.4
no	485	26.1
missing information	27	1.5
Housing tenure		
owner-occupier	1130	60.8
not an owner-occupier	666	35.8
missing information	62	3.3
Lived alone		
yes	499	26.9
no	1326	71.4
missing information	33	1.8
Religious denomination		
Roman Catholic	180	9.7
Church of England	1049	56.5
other Protestant	177	9.5
other (including Islam & Judaism)	72	3.9
no faith/missing information	380	20.5
Place of death		
home	571	27.9
hospital	937	50.4
hospice	257	13.8
other institution	88	4.8
ambulance/street	5	0.3
Had financial problems as a result of illness[*]		
yes	194	10.4
no	1595	85.8
missing information	69	3.7

*.This variable is only used in analyses conducted on satisfaction with health and social services

Factor analysis : Duration of functional limitation

Table D.2a. **Variables used in the factor analysis**

Variable name	Variable formulation
Durbath	Duration for which help was needed in getting in/out of bath or shower *
Durdress	Duration for which help was needed in dressing/undressing
Durtoilet	Duration for which help was needed in going to toilet/coping on his own
Durwash	Duration for which help was needed in washing/shaving
Durtoe	Duration for which help was needed in cutting own toe nails
Durdrink	Duration for which help was needed in making a hot drink
Durnight	Duration for which help was needed at night

*. < 1 wk, 1 wk-1 mth, 1 mth-3 mth, 3 mth-6 mth, 6 mth-1 year, 1 year +

Table D.2b. **Factor matrix, communalities, eigenvalues, and per cent of explained variance in the factor solution**

Variable	Factor matrix	Communalities	Eigenvalue	% variance
Durbath	0.80	0.64	4.82	69.0
Durdress	0.89	0.79		
Durtoilet	0.86	0.73		
Durwash	0.84	0.71		
Durtoe	0.73	0.73		
Durdrink	0.86	0.74		
Durnight	0.82	0.67		

Table D.2c. **Reliability statistics of developed scale**

Number of items	Reliability Alpha	Standardized Alpha
Seven	0.92	0.92

Factor analysis : Duration of symptoms experience

Table D.3a. Variables used in the factor analysis

Variable name	Variable formulation
Durbladder	Duration for which deceased had bladder incontinence*
Durbowel	Duration for which deceased had bowel incontinence
Dursmell	Duration for which deceased had a bad smell
Durbedsore	Duration for which deceased had bedsore
Dursick	Duration for which deceased had vomiting or feeling sick
Durappetite	Duration for which deceased had loss of appetite
Durswallow	Duration for which deceased had difficulties in swallowing
Durmouth	Duration for which deceased had a dry mouth
Durconst	Duration for which deceased had constipation
Durnerves	Duration for which deceased had problems with nerves or anxieties
Durlow	Duration for which deceased felt low or miserable
Durconfuse	Duration for which deceased was mentally confused
Dursleep	Duration for which deceased had sleeplessness
Durcough	Duration for which deceased had coughing problems
Durbreath	Duration for which deceased had breathing problems

*. < 1 wk, 1 wk-1 mth, 1 mth-3 mth, 3 mth-6 mth, 6 mth-1 year, 1 year +

Table D.3b. Communalities, eigenvalues, and per cent of explained variance in the factor solution

Variable	Communalities	Factor	Eigenvalue	Cumulative % of variance
Dursick	0.51	1	2.94	19.6
Durappetite	0.41	2	1.64	30.5
Durswallow	0.36	3	1.21	30.6
Durmouth	0.33	4	1.10	46.0
Durconst	0.34			
Durbladder	0.65			
Dursmell	0.40			
Durbowel	0.62			
Durbedsore	0.17			
Durnerves	0.56			
Durlow	0.57			
Durconfuse	0.33			
Dursleep	0.34			
Durcough	0.68			
Durbreath	0.60			

Table D.3c. Factor matrix of rotated solution :

Variable	Factor 1	Factor 2	Factor 3	Factor 4
Dursick	0.70	0.05	0.06	-0.15
Durappetite	0.63	0.01	0.12	0.08
Durswallow	0.56	0.11	-0.04	0.18
Durmouth	0.50	0.15	0.17	0.18
Durconst	0.37	-0.04	0.36	-0.27
Durbladder	-0.06	0.80	0.11	-0.01
Durbowel	0.04	0.78	0.09	-0.03
Dursmell	0.28	0.56	-0.09	0.04
Durbedsore	0.22	0.33	0.10	-0.07
Durnerves	0.08	0.06	0.74	0.06
Durlow	0.19	0.07	0.72	0.09
Durconfuse	0.03	0.37	0.44	0.03
Dursleep	0.39	0.03	0.43	0.08
Durcough	0.05	-0.06	0.12	0.81
Durbreath	0.23	-0.01	0.07	0.74

a. Quartimax rotation of factor
b. Listwise deletion of cases

Table D.3d. Reliablilty statistics of developed scales

Items in the scale	Reliability Alpha	Standardized Alpha
Gastro-intestinal symptoms	0.54	0.55
Dursick		
Durappetite		
Durswallow		
Durmouth		
Durconst		
Incontinence	0.56	0.55
Durbladder		
Durbowel		
Dursmell		
Durbedsore		
Cognitive and psychological functioning symptoms	0.56	0.56
Durnerves		
Durlow		
Durconfuse		
Dursleep		
Respiratory symptoms	0.55	0.55
Durcough		
Durbreath		

Table D.4. Frequency distribution of deceaseds' clinical characteristics (N=1858)

Variable	n	Per cent
Site of malignant neoplasm		
digestive organs/peritoneum	508	27.3
respiratory organs/intrathoracic	420	22.6
bone/breast/skin/connective tissue	228	12.3
genito-urinary organs	297	16.0
lymphatic/haematopoietic tissue	138	7.4
neoplasm of other unspecified site	258	13.9
neoplasm of unidentified behaviour	9	0.5
Intensity of functional limitation*		
low	886	47.7
high	797	42.9
missing information	175	9.4
Duration of functional limitation*		
short	869	46.8
long	722	38.9
missing information	267	14.4
Duration of pain*		
short	1163	62.6
long	609	32.8
missing information	86	4.6
Duration of gastro-intestinal symptoms*		
short	835	44.9
long	673	36.2
missing information	350	18.8
Duration of incontinence*		
short	880	47.4
long	821	44.2
missing information	157	8.4
Duration of cognitive and psychological functioning symptoms*		
short	835	44.9
long	799	43.0
missing information	224	12.1
Duration of respiratory symptoms*		
short	943	50.8
long	868	46.7
missing information	47	2.5

*. The cut-off point is the median (Table D.15).

Table D.5. Frequency distribution of carers' sociodemographic characteristics (N=1858)

Variable	n	Per cent
Relationship of respondent to deceased		
spouse	868	46.7
not spouse (children/relatives/friends)	990	53.3
Sex		
male	626	33.7
female	1232	66.3
Age		
less than 65 years	1199	64.5
65 years or more	635	34.2
missing information	24	1.3
Marital status		
married	661	35.6
single/separated/divorced/widowed	1174	63.2
missing information	23	1.2
Housing tenure		
owner-occupier	1286	69.2
not an owner-occupier	542	29.2
missing information	30	1.6
Living alone		
yes	831	44.7
no	1007	54.2
missing information	20	1.1
Lived with deceased		
yes	1145	61.5
no	698	37.6
missing information	15	0.8
Religious denomination		
Roman Catholic	171	9.2
Church of England	1054	56.7
other Protestant	175	9.4
other (including Islam & Judaism)	84	4.5
no faith /missing information	374	20.1
Strength of religious faith		
strong	483	26.0
some/no faith	1345	72.4
missing information	30	1.6
Have the same GP as deceased had[*]		
yes	965	51.9
no	873	47.0
missing information	20	1.1

*. This variable is only used in analyses conducted on satisfaction with GP services

Factor analysis : Perception of need for more help in caring at home

Table D.6a. **Variables used in the factor analysis**

Variable name	Variable formulation
Homecare	Need for more help with domestic services
Self-care	Need for more help with deceased's self-care activities
Help	Some relatives should have visited and helped

Table D.6b. **Factor matrix, communalities, eigenvalues, and per cent of explained variance in the factor solution**

Variable	Factor matrix	Communalities	Eigenvalue	% variance
Homecare	0.80	0.64	1.45	48.4
Self-care	0.78	0.61		
Help	0.45	0.20		

a. Unrotated one-factor solution
b. Listwise deletion of cases

Table D.6c. **Reliablilty statistics of developed scale**

Number of items	Reliability Alpha	Standardized Alpha
Three	0.44	0.45

Table D.7. Frequency distribution of carers' experience of caring (N=1858)

Variable	n	Per cent
Perception of caring		
rewarding	702	37.8
a burden	93	5.0
other but not a burden	526	28.3
no provision of practical help to patient	520	28.0
missing information	17	0.9
Level of restriction in activities		
severely restricted	866	46.6
little/no restriction	453	24.4
no provision of practical help to patient	520	28.0
missing information	19	1.0
Have perception of need for more help in caring at home		
yes	830	44.7
no	905	48.7
missing information	123	6.6
Perception of deceased's home as a place for care		
easy place for care	1288	69.3
not an easy place for care	503	27.1
missing information	67	3.6

Factor analysis : Bereavement-related psychological problems

Table D.8a. **Variables used in the factor analysis**

Variable name	Variable formulation
Sleep	Since deceased died have you had problems with sleeplessness
Nerve	Since deceased died have you had depression or nerves problems
Appetite	Since deceased died have you had loss of appetite problems
Other	Since deceased died have you had any other symptom caused or made worse by the death

Table D.8b. **Factor matrix, communalities, eigenvalues, and per cent of explained variance in the factor solution**

Variable	Factor matrix	Communalities	Eigenvalue	% variance
Sleep	0.76	0.57	1.84	46.0
Nerve	0.73	0.53		
Appetite	0.69	0.48		
Other	0.50	0.25		

a. Unrotated one-factor solution
b. Listwise deletion of cases

Table D.8c. **Reliablilty statistics of developed scale**

Number of items	Reliability Alpha	Standardized Alpha
Four	0.60	0.60

Factor analysis : Practical worries resulting from deceased's death

Table D.9a. **Variables used in the factor analysis**

Variable name	Variable formulation
Financial	Since deceased died have you had financial problems
Legal	Since deceased died have you had legal problems
Ownership	Since deceased died have you had problems with house ownership
Other	Since deceased died have you had any other worry

Table D.9b. **Factor matrix, communalities, eigenvalues, and per cent of explained variance in the factor solution**

Variable	Factor matrix	Communalities	Eigenvalue	% variance
Financial	0.73	0.39	1.57	39.2
Legal	0.68	0.52		
Ownership	0.63	0.46		
Other	0.43	0.19		

a. Unrotated one-factor solution
b. Listwise deletion of cases

Table D.9c. **Reliablilty statistics of developed scale**

Number of items	Reliability Alpha	Standardized Alpha
Four	0.46	0.47

Factor analysis : Carer's adjustment to bereavement

Table D.10a. **Variables used in the factor analysis**

Variable name	Variable formulation
Miss	Do you miss deceased great deal, quite a lot or not at all ?
Loneliness	Do you find loneliness a problem for you or not ?
Forward	Do you look forward to things the same way as before deceased's death?
Term	Do you feel you have come to terms with deceased's death or not yet ?
Reasonable	Would you describe the way things are going for you as reasonable, not very well, or not at all well ?

Table D.10b. **Factor matrix, communalities, eigenvalues, and per cent of explained variance in the factor solution**

Variable	Factor matrix	Communalities	Eigenvalue	% variance
Miss	0.65	0.43	2.22	44.3
Loneliness	0.71	0.50		
Forward	0.79	0.61		
Term	0.69	0.47		
Reasonable	0.46	0.21		

a. Unrotated one-factor solution
b. Listwise deletion of cases

Table D.10c. **Reliablilty statistics of developed scale**

Number of items	Reliability Alpha	Standardized Alpha
Five	0.69	0.68

Table D.11. **Frequency distribution of carers' bereavement characteristics (N=1858)**

Variable	n	Per cent
Self-assessment of post-bereavement health		
excellent	430	23.1
good	934	50.3
fair/poor	470	25.3
missing information	24	1.3
Adjustment to bereavement*		
poor	796	42.8
good	986	53.1
missing information	76	4.1
Have bereavement-related psychological problems		
at least one problem	1231	66.3
no health problems	600	32.3
missing information	27	1.5
Have post-bereavement practical worries		
at least one worrying problem	626	33.7
no worrying problems	1186	63.8
missing information	46	2.5
Psychological functioning*		
low GHQ score	870	46.8
high GHQ score	801	43.1
missing information	187	10.1

*. The cut-off point is the median (Table D.15).

Table D.12. **Frequency distribution of district nurses' services delivered to deceased in the last year of life (N=1100).**

Variable	n	Per cent
Number of times DN visited deceased in last 12 months		
less than 20 times	503	45.7
20-49 times	285	25.9
50 times or more	298	27.1
missing information	14	1.3
Frequency of visits		
nurse visited deceased very frequently (more than once a day/ every day)	543	49.4
nurse visited deceased fairly frequently (2-6 times a week/ once a week)	427	38.8
nurse visited deceased infrequently (2-3 times a month/ less often)	117	10.6
missing information	13	1.2
Type of care provided		
practical	814	74.0
talking	199	18.1
both equally	61	5.5
missing information	26	2.4
Nurse gave advice		
yes	606	55.1
no	387	35.2
missing information	107	9.7
Nurse contacted other services		
yes	475	43.2
no	566	51.5
missing information	59	5.4
Nurse visited at night		
yes	226	20.5
no	861	78.3
missing information	13	1.2
Nurse visited carer after deceased's death*		
yes	295	26.8
no	794	72.2
missing information	11	1.0

Table D.13. **Frequency distribution of general practitioners' services delivered to deceased in the last year of life (N=1854)**

Variable	n	Per cent
Number of times GP visited deceased at home		
less than 20 times	1484	80.0
20 times or more	275	14.8
missing information	95	5.2
GP visited at night		
yes	681	36.7
no	1121	60.5
missing information	52	2.8
GP told the carer about the diagnosis		
yes	341	18.4
no	1481	79.9
missing information	32	1.7
GP provided treatment for pain		
yes	1277	68.9
no / deceased had no pain	468	25.2
missing information	109	5.9
GP provided treatment for breathlessness		
yes	447	24.1
no / deceased had no breathing problems	1325	71.5
missing information	82	4.4
GP provided treatment for vomiting		
yes	590	31.8
no / deceased had no vomiting	1141	61.5
missing information	123	6.6
GP provided treatment for constipation		
yes	749	40.4
no / deceased had no constipation	945	51.0
missing information	160	8.6
GP visited carer after deceased's death		
yes	33	1.8
no	1804	97.3
missing information	17	0.9

Table D.14. **Frequency distribution of hospital doctors' services delivered to deceased in the last year of life (N=1648)**

Variable	n	Per cent
Deceased had enough privacy while in hospital		
yes, all the time	869	52.7
sometimes/never	693	42.1
missing information	86	5.2
Deceased had a room on his/her own		
yes, all the time	215	13.0
sometimes/never	1402	85.1
missing information	31	1.9
Carer's perception of the journey to visit deceased in hospital		
tiring	426	25.8
not tiring	1110	67.4
missing information	112	6.8
Doctor provided treatment for pain		
yes	1085	65.8
no / deceased had no pain	319	19.4
missing information	244	14.8
Doctor provided treatment for breathlessness		
yes	459	27.9
no / deceased had no breathing problems	1015	61.6
missing information	174	10.6
Doctor provided treatment for vomiting		
yes	398	24.2
no / deceased had no vomiting	924	56.1
missing information	326	19.8
Doctor provided treatment for constipation		
yes	395	24.0
no / deceased had no constipation	745	45.2
missing information	508	30.8
Deceased had a choice about treatment		
yes	837	50.8
no/other non-affirmative answers	653	35.2
missing information	158	9.6
Deceased had an operation(s) in a hospital in the last year of life		
yes	673	40.8
no	960	58.3
missing information	15	0.9
Deceased had chemotherapy/hormone treatment in a hospital in the last year of life		
yes	370	22.5
no	1217	73.8
missing information	61	3.7
Deceased had radiotherapy in a hospital in the last year of life		
yes	453	27.5
no	1151	69.8
missing information	44	2.7
Carer knew the diagnosis from a hospital doctor		
yes	706	42.8
no	911	55.3
missing information	31	1.9

Table D.15. Measures of central tendency and variance of scales derived from variables (N= 1858)

Variables	Median	Mean	S.D.	Variance	Skewness	Range (Min-Max)
Intensity of functional limitation	5.00	4.15	2.80	7.86	-0.38	0.00-7.00
Duration of functional limitation	14.00	13.96	11.47	131.64	+0.51	0.00-42.00
Duration of pain	5.00	4.04	2.01	4.04	-0.80	0.00-6.00
Duration of gastro-intestinal symptoms	12.00	12.05	6.19	38.31	+0.34	0.00-30.00
Duration of incontinence	2.00	3.61	4.26	18.16	+1.51	0.00-24.00
Duration of psychological and cognitive functioning symptoms	8.00	8.65	6.09	37.06	+0.41	0.00-24.00
Duration of respiratory symptoms	2.00	3.54	3.95	15.57	+0.83	0.00-12.00
Psychological functioning	19.00	22.47	13.25	175.57	+1.27	0.00-80.00
Adjustment to bereavement	2.00	2.24	1.52	2.32	+0.90	0.00-5.00

Appendix E

Table E.1. Multivariate associations at MV-I of the service and non-service related factors in predicting carers' satisfaction with the general practitioners' services, with no outliers removed.

Selection criteria : Enter
Number of cases : 909

Variable	Regression coefficient	P value	Odds(95% C.I.) ratio
Constant	-2.81	0.001	
Non-service characteristics :			
Place of death			
home vs institution	+0.37	0.033	1.44 (1.03 to 2.02)
Intensity of functional limitation			
low vs high	+0.43	0.054	1.54 (0.99 to 2.39)
Duration of functional limitation			
short vs long	-0.72	0.002	0.49 (0 31 to 0.77)
Duration of incontinence			
short vs long	+0.19	0.018	1.21 (1.03 to 1.43)
Duration of respiratory symptoms			
short vs long	+0.30	0.059	1.35 (0.54 to 1.83)
Carer's age			
65 years or more vs less than 65	+0.34	0.077	1.41 (0.96 to 2.05)
Carer's strength of religious faith			
strong vs some or no faith	+0.30	0.079	1.35 (0.97 to 1.87)
Carer's self-assessment of post-bereavement health		0.061	
excellent vs fair/poor	+0.47	0.046	1.60 (1.01 to 2.53)
good vs fair/poor	+0.06	0.781	1.06 (0.71 to 1.57)
Carer had bereavement related health problems			
no vs yes	+0.40	0.042	1.50 (1.01 to 2.21)
Carer has the same GP as deceased			
yes vs no	+0.70	0.001	2.01 (1.46 to 2.78)
Carer's perception of caring		0.093	
rewarding vs a burden	+0.24	0.527	1.27 (0.60 to 2.67)
other but not burden vs a burden	-0.23	0.555	0.80 (0.39 to 1.69)
no practical help vs caring is a burden	-0.08	0.851	0.92 (0.39 to 2.16)
Carer had perception of need for more help in caring at home			
no vs yes	+0.29	0.081	1.33 (0.96 to 1.84)
Service-related characteristics :			
Number of home visits made by GP			
20 or more vs less than 20 visits	+1.37	0.001	3.93 (2.48 to 6.23)
GP told carer about diagnosis			
yes vs no	+0.96	0.001	2.63 (1.78 to 3.87)

a.Cases correctly classified : 70.40°•
b.Model chi-square= 78.28, Df-7, P< 0.001
c.Goodness-of-fit chi-square=920.31, Df-876, P=0.145
d.Number of outliers with SRESID of 2.00 or more : 21.

The following variables were in the model but had a significance level greater than 0.1 : deceased housing tenure; deceased had living children; deceased had living siblings; duration of psychological and cognitive functioning symptoms; relationship of carer to deceased; carer lives alone; carer's adjustment to bereavement; carer's psychological functioning; carer's perception of deceased home as an easy place for care; the level of restriction in the carer's activities as a result of caring; GP visited carer after deceased's death; GP visited deceased at night; GP provided treatment for pain; GP provided treatment for constipation; GP provided treatment for vomiting; and GP provided treatment for breathing problems.

Table E.2. Multivariate associations at MV-II of the service and non-service related factors independently predicting satisfaction at MV-I with carers' satisfaction with the general practitioners' services, with no outliers removed

Selection criteria : Forward Stepwise
Number of cases : 1232

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-2.16	0.001	
Non-service characteristics :			
Place of death			
home vs institution	+0.33	0.019	1.39 (1.05 to 1.82)
Duration of respiratory symptoms			
short vs long	+0.32	0.016	1.37 (1.06 to 1.76)
Carer's strength of religious faith			
strong vs some or no faith	+0.31	0.026	1.37 (1.04 to 1.81)
Carer's self-assessment of post-bereavement health		0.005	
excellent vs fair/poor	+0.52	0.005	1.69 (1.17 to 2.43)
good vs fair/poor	+0.05	0.757	1.05 (0.76 to 1.43)
Carer had bereavement-related psychological problems			
no vs yes	+0.36	0.014	1.43 (1.07 to 1.90)
Carer has the same GP as deceased			
yes vs no	+0.78	0.001	2.19 (1.68 to 2.85)
Carer's perception of caring		0.006	
rewarding vs a burden	+0.38	0.227	1.46 (0.79 to 2.72)
other but not burden vs a burden	-0.09	0.786	0.91 (0.49 to 1.72)
no practical help vs caring is a burden	-0.11	0.741	0.90 (0.47 to 1.72)
Carer had perception of need for more help in caring at home			
no vs yes	+0.32	0.017	1.37 (1.06 to 1.78)
Service-related characteristics :			
Number of home visits made by GP			
20 or more vs less than 20 visits	+1.28	0.001	3.60 (2.51 to 5.16)
GP told carer about diagnosis			
yes vs no	+0.92	0.001	2.51 (1.83 to 3.44)

a.Cases correctly classified : 69.48%
b.Model chi-square= 220.44, Df=13, P< 0.001
c.Goodness-of-fit chi-square=1227.86, Df=1218, P=0.416
d.Residual chi-square for variables not in the equation= 19.31, Df=5, P= 0.002
e.Number of outliers with SRESID of 2.00 or more : 25.

Five variables were not selected in the equation. These are : intensity of functional limitation; duration of functional limitation; duration of incontinence; carer's age; and carer's adjustment to bereavement.

Table E.3. Multivariate associations at MV-I the service and non-service related factors in predicting informal carers' satisfaction with the hospital doctors' services, with no outliers removed

Selection criteria : Enter
Number of cases : 672

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-2.33	0.001	
Non-service characteristics :			
Carer's age			
65 years or more vs less than 65	+0.41	0.067	1.50 (0.97 to 2.32)
Carer's self-assessment of post-bereavement health		0.011	
excellent vs fair poor	+0.71	0.009	2.04 (1.19 to 3.49)
good vs fair/poor	+0.13	0.590	1.14 (0.71 to 1.81)
Carer's psychological functioning			
low vs high GHQ score	+0.43	0.026	1.54 (1.05 to 2.25)
Carer's perception of caring		0.067	
rewarding vs a burden	-0.63	0.119	0.53 (0.24 to 1.18)
other but not burden vs a burden	-1.04	0.013	0.35 (0.15 to 0.80)
no practical help vs caring is a burden	-0.73	0.104	0.48 (0.20 to 1.16)
Service-related characteristics :			
Carer perceived that deceased had a choice about the treatment given			
yes vs no	+0.83	0.001	2.30 (1.57 to 3.37)
Carer perceived that deceased had enough privacy in hospital			
all the time vs sometimes/never	+1.20	0.001	3.31 (2.22 to 4.94)
Carer perceived that doctor provided treatment for respiratory symptoms			
treatment was provided vs treatment not provided/did not have such symptoms	+0.59	0.004	1.78 (1.20 to 2.66)

a.Cases correctly classified : 69.64%
b.Model chi-square= 68.42, Df=7, P< 0.001
c.Goodness-of-fit chi-square= 651.59, Df=642, P=0.388
e.Variables in the model with significance level greater than 0.1 :
d.Number of outliers with SRESID of 2.00 or more : 10.

The following variables were in the model but had a significance level of P greater than 0.1 : site of malignant neoplasm; deceased had siblings; relationship of respondent to deceased; intensity of functional limitation; duration of incontinence; duration of functional limitation; duration of gastro-intestinal symptoms; duration of psychological and cognitive functioning symptoms; carer lives alone; carer's perception of need for more help in caring at home; deceased had a room on his/her own; deceased had chemotherapy; deceased had operation(s); carer knew the diagnosis from doctor; and the carer's perception of the journey to visit deceased as tiring.

Table E.4. Multivariate associations at MV-II of the service and non-service related factors independently predicting satisfaction at MV-I with carers' satisfaction with the hospital doctors' services, with no outliers removed

Selection criteria : Forward Stepwise
Number of cases : 1114

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-2.30	0.001	
Non-service related characteristics :			
Carer's self-assessment of post-bereavement health		0.001	
excellent vs fair/poor	+0.76	0.001	2.15 (1.47 to 3.13)
good vs fair/poor	+0.18	0.284	1.20 (0.86 to 1.66)
Service-related characteristics :			
Carer perceived that deceased had a choice about the treatment given			
yes vs no	+0.95	0.001	2.57 (1.95 to 3.39)
Carer perceived that deceased had enough privacy in hospital			
all the time vs sometimes/never	+1.27	0.001	3.55 (2.68 to 4.69)
Carer perceived that doctor provided treatment for respiratory symptoms			
treatment was provided vs treatment not provided/did not have such symptoms	+0.33	0.024	1.39 (1.04 to 1.84)

a.Cases correctly classified : 67.86%
b.Model chi-square= 166.66, Df=5, P< 0.001
c.Goodness-of-fit chi-square=1096.37, Df=1108, P=0.592
d.Residual chi-square for variables not in the equation= 9.95, Df= 5, P= 0.077
e.Number of outliers with SRESID of 2.00 or more : 17.

The following variables were not selected in the equation : carer's age; carer's psychological functioning; and the carer's perception of caring.

Table E.5. Multivariate associations at MV-I of the non-service related factors in predicting informal carers' satisfaction with the health and social services, with no outliers removed

Selection criteria : Enter
Number of cases : 1073

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-4.51	0.001	
Non-service characteristics :			
Deceased's housing tenure (owner-occupier)			
yes vs no	+0.43	0.010	1.54 (1.11 to 2.14)
Deceased had financial problems which resulted from illness			
no vs yes	+0.57	0.057	1.77 (0.98 to 3.19)
Duration of functional limitation experienced by deceased			
short vs long	-0.77	0.001	0.46 (0.30 to 0.70)
Strength of the carer's religious faith			
strong vs some or no faith	+0.29	0.071	1.34 (0.97 to 1.83)
Carer's self-assessment of post-bereavement health		0.001	
excellent vs fair/poor	+0.99	0.001	2.69 (1.72 to 4.21)
good vs fair/poor	+0.41	0.044	1.50 (1.01 to 2.22)
Carer had perceptions of need for more help in caring for the deceased at home			
no vs yes	+0.77	0.001	2.17 (1.59 to 2.96)
Carer's perception of caring for deceased		0.039	
rewarding vs burden	+0.70	0.087	2.02 (0.90 to 4.54)
other but not burden vs burden	+0.22	0.591	1.25 (0.55 to 2.84)
no practical help vs caring is a burden	+0.52	0.257	1.68 (0.68 to 4.14)

a.Cases correctly classified : 73.63%
b.Model chi-square= 142.30, Df=23, P< 0.001
c.Goodness-of-fit chi-square=1049.46, Df=1049, P=0.490
d.Number of outliers with SRESID of 2.00 or more : 18

The variables that were in the model but had a significance level greater than 0.1 are : deceased's place of death; deceased had children; intensity of functional limitation; duration of psychological/cognitive functioning symptoms; duration of respiratory symptoms; relationship of respondent to deceased; carer's age; carer lives alone; carer's psychological functioning; carer had bereavement-related health problems; carer had practical worries/anxieties which resulted from deceased's death; carer's perception of deceased home as an easy place for care; and the level of restriction in the carer's activities as a result of caring.

Table E.6. Multivariate associations at MV-II of the non-service related factors independently predicting satisfaction at MV-I with carers' satisfaction with the health and social services, with no outliers removed

Selection criteria : Forward stepwise
Number of cases : 1365

Variable	Regression coefficient	P value	Odds (95% C.I.) ratio
Constant	-3.39	0.001	
Non-service characteristics :			
Deceased's housing tenure (owner-occupier)			
yes vs no	+0.29	0.037	1.33 (1.02 to 1.75)
Deceased had financial problems which resulted from illness			
no vs yes	+0.48	0.048	1.61 (1.00 to 2.59)
Duration of functional limitation experienced by deceased			
long vs short	-0.64	0.001	0.53 (0.39 to 0.70)
Strength of the carer's religious faith			
strong vs some/no faith	+0.35	0.012	1.42 (1.08 to 1.87)
Carer's self-assessment of post-bereavement health		0.001	
excellent vs fair/poor	+0.90	0.001	2.45 (1.70 to 3.53)
good vs fair/poor	+0.33	0.047	1.39 (1.00 to 1.93)
Carer had perceptions of need for more help in caring for the deceased at home			
no vs yes	+0.83	0.001	2.28 (1.76 to 2.97)
Carer's perception of caring for deceased		0.001	
rewarding vs burden	+0.82	0.022	2.28 (1.13 to 4.60)
other but not burden vs burden	+0.25	0.496	1.28 (0.62 to 2.64)
no practical help vs caring is a burden	+0.37	0.329	1.45 (0.69 to 3.07)

a.Cases correctly classified : 73.55%
b.Model chi-square= 136.36, Df=10, P< 0.001
c.Goodness-of-fit chi-square=1377.98, Df=1354, P=0.319
d.Number of outliers with SRESID of 2.00 or more : 24.

All the variables that significantly predicted informal carer's satisfaction with the health and social services at P< 0.1 at MV Phase-I were selected in the equation

Appendix F

Table F.1. **Carers' satisfaction with district nurses' services with interviewer's sex, interviewing experience, and length of interview**

Interviewer characteristics	Satisfaction with service				
	high		low		total
	n	(%)	n	(%)	n(100%)
Sex					
male	56	(56)	44	(44)	100
female	502	(51)	474	(48.6)	976
X^2= 0.75, Df=1, P= 0.384					
Interviewing experience					
OPCS/MRC/other professional training	288	(49.8)	290	(50.2)	578
market research	218	(55.3)	176	(44.7)	394
no previous experience	52	(50.0)	52	(50.0)	104
X^2= 3.00, Df=2, P= 0.223					
Length of interview					
less than 2 hours	267	(50.2)	265	(49.8)	532
2.00-2.30	144	(52.0)	133	(48.0)	277
2.30-3.00	89	(61.0)	57	(39.0)	146
3.00 +	50	(48.1)	54	(51.9)	104
X^2= 6.03, Df= 3, P= 0.110					

Table F.2. Carers' satisfaction with GPs' services with interviewer's sex, interviewing experience, and length of interview

Interviewer characteristics	Satisfaction with service				
	high		low		total
	n	(%)	n	(%)	n(100%)
Sex					
male	67	(40.1)	100	(59.9)	167
female	624	(38.6)	991	(61.4)	1615
X^2= 0.14, Df=1, P= 0.708					
Interviewing experience					
OPCS/MRC/other professional training	345	(37.5)	576	(62.5)	921
market research	284	(41.9)	394	(58.1)	678
no previous experience	62	(33.9)	121	(66.1)	183
X^2= 5.29, Df=2, P= 0.071.					
Length of interview					
less than 2 hours	361	(38.0)	588	(62.0)	949
2.00-2.30	178	(41.1)	255	(58.9)	433
2.30-3.00	85	(39.9)	128	(60.1)	213
3.00 +	56	(35.4)	102	(64.6)	158
X^2= 2.06, Df= 3, P= 0.559.					

Table F.3. Carers' satisfaction with hospital doctors' services with interviewer's sex, interviewing experience, and length of interview

Interviewer characteristics	**Satisfaction with service**				
	high		**low**		**total**
	n	**(%)**	**n**	**(%)**	**n(100%)**
Sex					
male	51	(37.2)	86	(62.8)	137
female	484	(34.5)	918	(65.5)	1402
X^2= 0.29, Df=1, P= 0.589					
Interviewing experience					
OPCS/MRC/other professional training	266	(32.8)	545	(67.2)	811
market research	204	(35.7)	368	(64.3)	572
no previous experience	65	(41.7)	91	(58.3)	156
X^2= 4.86, Df=2, P= 0.088.					
Length of interview					
less than 2 hours	303	(37.5)	506	(62.5)	809
2.00-2.30	110	(29.3)	266	(70.7)	376
2.30-3.00	61	(33.9)	119	(66.1)	180
3.00 +	53	(35.6)	96	(64.4)	149
X^2= 7.70, Df= 3, P= 0.052.					

Table F.4. Carers' satisfaction with health and social services in general with interviewer's sex, interviewing experience, and length of interview

Interviewer characteristics	**Satisfaction with service**				
	high		**low**		**total**
	n	**(%)**	**n**	**(%)**	**n(100%)**
Sex					
male	48	(28.4)	121	(71.6)	169
female	456	(27.4)	1211	(72.6)	1667
X^2= 0.08, Df=1, P= 0.771					
Interviewing experience					
OPCS/MRC/other professional training	251	(26.4)	699	(73.6)	950
market research	202	(29.1)	493	(70.9)	695
no previous experience	51	(26.7)	140	(73.3)	191
X^2= 1.47, Df=2, P= 0.479.					
Length of interview					
less than 2 hours	282	(28.6)	70.3	(71.4)	985
2.00-2.30	102	(23.3)	336	(76.7)	438
2.30-3.00	66	(30.7)	149	(69.3)	215
3.00 +	44	(26.2)	124	(73.8)	168
X^2= 5.77, Df= 3, P= 0.123.					