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Executive Summary

An Evaluation of Informal Carers' Experiences of Hospital Support

Purpose

The purpose of this study was to evaluate the support that informal carers receive from the East Sussex Hospitals NHS Trust (The Conquest Hospital site).

Aims and Objectives

The aims of the research were to:

- Examine carers' experience of the care and support provided by the NHS Trust.
- Advise on ways in which services for carers can be improved and developed.

The objectives of the research were to examine:

- Carers' expectations of the types of support and information which they should receive when the person they are caring for is admitted to hospital.
- The extent to which the East Sussex Hospitals NHS Trust Code of Practice for involving carers is being implemented.
- The extent to which carers feel that their expectations have been met, their needs and interests have been taken into account and they have been involved as active partners in the care provided in hospital.

Methodology

A literature review was conducted to examine the concept of caring and place informal care within the policy context, the review provides a sound evidence base for inclusion of the standards within the code. The empirical study used a combined methodology in the form of focus group discussions, and a survey to determine carers experiences of hospital support when the person for whom they care is an inpatient, or attending for emergency or outpatient treatment and to explore whether their expectations were met.

A total of six focus groups were held with carers from the three main carer groups: carers of older people, carers of young adults, and parent carers. One of the groups was a reference group, which was conducted to set the research parameters and ensure the carers concerns were addressed. As a result of the focus group discussions a questionnaire was developed to explore the views of carers in the Hastings and Rother. The questionnaire was piloted on a sample of members of the focus groups to test its validity. The survey was distributed to 600 carers in the Hastings and Rother area.

The response rate to the survey was low (30.7%) however the demographic data from the survey was compared to the findings from the General Household Survey (2000) and suggests that the sample is largely representative of the carers in the general population. Furthermore comments written on the survey form echoed the views expressed in the focus groups.

Main findings and recommendations on the ways in which services for carers and patients could be improved and developed:

The research findings confirm that through implementing the Code of Practice for Involving Carers some of the main concerns and difficulties experienced by carers could be addressed.

Action Required

Recognition of carers.

Identifying the carer provides staff with the opportunity of learning about the patient's home circumstances, the carer's expertise in the care of the patient, and the carer's own needs and preferences. As part of involving carers the Trust should ensure that:

- **Where there is a full-time carer this is identified on the patients' notes.**
- **Relatives accompanying patients to outpatients or accident and emergency are asked if they are carers.**
- **The carers contribution to the patients care is acknowledged by staff**
- **Carers are treated as individuals in their own right.**

Information needs

To allow carers to be involved in decision-making, they need to be provided with sufficient and appropriate information. This could be achieved by the Trust ensuring that:

- **When admissions are planned the named nurse is identified as soon as possible preferably before the patient is admitted.**
- **A procedure is put in place to ensure that when a named nurse is off duty carers have an alternative person they can speak to.**
- **There is recognition that information needs vary over time, and that information sharing is an important part of support.**
- **The level of information required by carers is not assumed.**

Patients with special needs

Although there is no reference in the code to carers of people with specific disabilities carers of children and young adults identified a number of areas where the Trust could improve services:

- **People with learning difficulties should be seen promptly for appointments.**
- **When parents are with a child with a disability on the children's ward there should be a member of staff on each shift responsible for ensuring that those parents feel confident about leaving their child whilst they have a break.**
- **There should be staff trained in the use of sign language.**

Problems with Access

Again although access and parking is not included within the code both in the focus groups and the survey, access to the hospital was raised as a problem. Practical measures the East Sussex Hospitals NHS Trust could adopt to improve services for carers and patients would be to:

- **Address the problem with parking at the hospital, particularly taking account of those requiring disabled access.**
- **Review access for people in wheel chairs and comments about wheelchair access should be shared with the Disability Discrimination Working Group.**
- **The Trust needs to ensure that issues around public transport are fed into the Hasting Community Strategy.**
- **The Trust should review the number of missed appointments caused by transport difficulties**

Training

A survey by Carers UK (CNA 2001) found that readmission rates, (the proportion of people having to go back to hospital within two months of being discharged) in the population studied had almost doubled between 1998 and 2001. To ensure that carers have the necessary level of skills when the patient is discharged they should have access to training in relevant treatment practises and thus potentially reduce readmissions. Therefore the Trust should ensure that:

- **Where carers need training in treatment practises, staff try to ensure that the carer feels competent to carry out the tasks unaided before the patient is discharged.**

Care for the Carer

One of the aims of the code is to ensure that care for the carer is incorporated into care for the patient in a holistic manner. From the study the following findings emerged:

- **The carer should be asked about the types of personal care provided for the patient at home, and the amount of help the patient requires when eating and drinking, in recognition of the carer's expertise in providing care for the patient.**
- **Carers want to be treated as an individual in their own right.**
- **Carers require support at different times, for example when their relative is in hospital or after discharge.**
- **Following discharge an assessment of the home situation should be made to ensure appropriate services are being delivered and the carer is able to cope.**
- **The appointment of a carers' support or liaison officer should be considered.**
- **The wording on the code relating to carers involvement should take account of the views expressed by the carers and the bold typeface should be altered.**

Acknowledgements

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An Evaluation of Informal Carers Experiences of Hospital Support.

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Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid (Carers UK 2001).

Introduction

The purpose of this study is to evaluate the support that informal carers receive from the East Sussex Hospitals NHS Trust. It is an empirical study that uses a combined methodology to determine the support that carers experience during the inpatient, emergency or outpatient treatment of the person for whom they care and explores whether their expectations are met.

The first section is a literature review which examines the concept of caring and places informal care within the policy context examining why carers have become a focus of government policy. It then examines the East Sussex Hospitals NHS Trust Code of Practice for Involving Carers, exploring the literature which supports the inclusion of items within the code. The second section outlines the methods that were adopted giving a rationale for the choice of methodologies. The main findings of the study are then presented in the third section, and the findings are linked to recommendations for developing the support provided for carers by the Trust.

1. A Review of the Literature

1.1. The Concept of Caring

It is the degree of dependency rather than the membership of a specific category of user that creates a need for care. A common characteristic of those needing care is that their condition is not amenable to curative treatment; there is a potential cost of long-term use of medical and social services and needs are often multiple and not the responsibility of a single profession or agency (Allsop 1995).

Twigg and Atkin (1994) conceptualised caring in terms of a combination of elements. For them care involves:

- the performance of tasks beyond those normally expected, that is doing things for people that they cannot do for themselves, often involving hard physical labour.
- caring almost always takes place within a context of kinship, that is within the family.
- carers do not simply do the physical tasks but they also support those for whom they care emotionally.
- caring involves a feeling of being responsible for the cared-for person, this sense of responsibility is rooted within the obligations of the relationship, and carers are bound into the relationship that means they do not simply give up when the balance of interest turns against continuing.

Twigg and Akin (1994) identify four models of response that service providers adopted towards carers:

- carers as resources,
- carers as co-workers,
- carers as co-clients
- superseded carers.

- Carers as resources

In this model there is an assumption among service providers that in some sense informal care comes first, and that there is only a need for the social care system to step in when informal care is unavailable. This model places the cared for person as the centre of focus, and the carer only features as part of the background.

- Carers as co-workers

In contrast to the carers as resources model, this sees the carers interests and well-being considered by the providers, however this is essentially on an instrumental basis and the primary aim is to provide high quality care for the cared for person.

- Carers as co-clients

Carers are regarded as people in need of help in their own right and services are provided with the aim of relieving their situation and enhancing their morale. Support is aimed at those who are most highly stressed and in some cases the interests of the carer are pursued at the expense of the cared for person.

- Superseded carers.

The final model sees the carer as being replaced in the care-giving relationship. This may be due to concern for the independence of the cared for person, or out of concern for the carer. In these cases the term 'carer' is replaced by 'family' or 'relatives' as being less evocative of the level of responsibility assigned to the role of the carer.

1.2. Policy Background

Carers as a resource has been the predominate model upon which government policy has been based. Britain has an estimated 5.7 million carers and one in six households (17%) contains a carer (DoH 1999). Since the 1960s successive governments have emphasised the need to provide community care. The main objective being to enable individuals to remain in their own homes, rather than being cared for in long-stay institutions or residential establishments. The initial emphasis was on “care in” the community but during the 1970s there was a shift to “care by” the community (Finch 1990). By the end of the 1970s informal family care had become the central plank of service provision. (Allen 2001). These changes in policy reflected a growing number of different pressures:- the ageing population, public expenditure contraction, Left-wing critiques of the repressive nature of institutional care and Right-wing policies on self-help and the importance of the family.

During the 1980s there were a number of reviews of community care which identified a lack of strategy. For example the Audit Commission (1986) and the Griffiths Report (1988) found that arrangements for community care were in disarray. In response to these criticisms the government published *Caring for People* (DHSS 1989). This put particular stress on supporting care-givers in practical ways to enable people to stay at home, and was therefore a major shift in health and social care policy. It moved carers from a position in the wings where they were virtually ignored to one where they were almost centre-stage (Baldwin and Parker 1989 cited in Pickard 2001).

The proposals in *Caring for People* were implemented in the 1990 NHS and Community Care Act. The Act required local authorities to take account of carers when undertaking assessments of needs. The key objective for service delivery was that “service providers make practical support for carers a high priority”. However, this concern for carers was essentially instrumental with the knowledge that helping carers to maintain their contribution to care was a sound investment (Pickard 2001). Family carers therefore continued to be seen as a resource and the measures were primarily aimed to “keep carers caring”.

The Government responded to further political lobbying with The Carers (Recognition and Services) Act (1995), which for the first time provided certain carers with a statutory right to an assessment of need (Nolan 2001). However the Act was limited in a number of ways, no rights to services were conferred on carers, and carers could not request an assessment unless the person for whom they were caring was also being assessed. In addition to be eligible for assessment carers had to be providing substantial care on a regular basis, however neither ‘substantial’ nor ‘regular’ were defined and so could be subject to interpretation. Furthermore no additional resources accompanied the Act so local authorities struggled to address carers needs in the face of competing demands. Evaluation of the Carers (Recognition

and Services) Act found its implementation to be piecemeal and patchy (Nolan 2001) and realisation that the Act was only partially effective resulted in the launch of the Carers National Strategy – “*Caring about Carers*” (DoH 1999). This was intended to mark a substantial shift in policy and culture so that carers were not only recognised but also respected and admired. The primary objective of the strategy was...

focussed on enabling those who choose to care, and those whose care is wanted by another person, to do so without detriment to the carers inclusion in society and to their health. Our aim is to support people who choose to be carers (DoH 1999).

The Carers (Recognition and Services) Act failed to address the well-being of carers in their own right. This was addressed in the Carers and Disabled Children Act (2000) which gave carers the right to an assessment of their needs even where the person cared for had refused an assessment for, or the provision of, community care services, provided the person cared for would be eligible for community care services.

In 1999 the Royal Commission on Long Term Care reported, and recommended that government should “ensure that services become increasingly ‘carer blind’...,” meaning that “the existence of a carer will not lead to the failure to offer services”. In contrast the main emphasis in *Caring for Carers* was on the development of systems to provide carers with short breaks.

The implementation of these policies has gradually shifted the balance of responsibility for meeting users on-going care needs from the hospitals to the community. Hospital discharge and the process of organising ‘continuing care’ in the community are integral parts of government policy. The emphasis has been on enabling patients with continuing care needs to be discharged home from hospital wherever possible, without unnecessary delays and discontinuities in their care (Heaton et al.1999). Recent studies however have indicated that hospital discharge is a key point where carers face difficulties. Many carers still feel that their views are not listened to, that they are not prepared for or understand the likely future needs of the cared-for person and they have not been informed of other service options (Henwood 1998). For the NHS hospital discharge is becoming more of a focus with the increasing pressures on beds and waiting list targets placing more pressure for patients to be discharged quickly. Within today’s fiscal constraints in health care, effective discharge has increased importance for health professional and clients (Bull and Roberts 2001). Successive policies on hospital discharge and continuing care have stressed the need for patients and their carers to be included in the discharge planning process. But until recently the main emphasis has been on patients (Heaton et al. 1999), however the Carers Act (1995) and the Carers National Strategy (1999) in theory have given priority to the consideration of carers individual requirements alongside those of the patients. Carers are pivotal in the process (Twigg and Atkin 1994) and this could help to explain why hospitals are taking more interest in policy making in this area.

1.3. The East Sussex Hospitals NHS Trust Code of Practice for Involving Carers

There are currently are a number of local policies in place within the Trust that are concerned with supporting carers when the person for whom they care is hospitalised.

For example Kipling ward has a philosophy of holistic care for children which includes a commitment to Family Centred Care, there are guidelines for the management of clients admitted to the Conquest Hospital with a verified learning disability. Care for the Carers has also implemented a Carers' Emergency Alert Card Scheme, this is a credit card sized source of identification for carers. Its purpose is to raise awareness and alert health care professionals in the event of the carer being suddenly taken ill and unable to tell anyone about their dependent, so help can be arranged to assist the dependent person whilst the carer is receiving attention.

The East Sussex Hospitals NHS Trust has developed a code of practice for involving carers, and has adopted the definition of a carer provided in the Annual Report of the Department of Public Health for East Sussex Health Authority ...

“A carer is anybody who is helping to look after a partner, relative or friend, who because of illness, old age or disability is unable to manage at home without care” (Public Health Report 2000).

The East Sussex Hospitals NHS Trust code focuses on involving carers when their dependent is hospitalised or attending outpatient appointments. Extensive review of the literature and Internet searches has only produced evidence of one other such code of practise for carers in existence, this was at St Bartholomew's Hospital. This code was produced in the early 1990s and further enquiry at this hospital determined that it was not currently in use.

The East Sussex Hospitals NHS Trust code of practice (see appendix) identifies a range of standards for the service to be provided to carers and a commitment to identifying the carer when a person is assessed, and ensuring that the carer has access to the patients named nurse.

- **Staff will identify the main carer or carers during the initial assessment of the patient's needs.**
- **In the case of inpatients there will be a meeting arranged between the carer and the named nurse carer as soon as possible, preferably within 48 hours of assessment. This will be an opportunity to learn about the patients' home circumstances as well as to identify the carers' needs, insight and preferences and expertise in the care of the patient. If a face-to-face meeting cannot be achieved within 48 hours then the designated nurse on duty will carry out a telephone interview as soon as possible. This will provide essential information for discharge planning.**

The aspects of the code are grounded in current policy and Department of Health practise guidance. It is recognised that carers in the course of their care-giving develop considerable expertise. The expert carer like the expert patient develops a special knowledge of the cared for person's needs. This knowledge is derived from their particular circumstances and from their experience of the way in which the person for whom they care responds to their illness (Allen 2000). Not only is the carer able to inform staff about the patient in this context but also the carer has knowledge about the facilities that are available at home, and what services may be needed on discharge.

The notion of named nursing was introduced in the Patient's Charter (1991), the charter standard stated that patients should have a named qualified nurse, midwife or health visitor responsible for their nursing or midwifery care. This concept was further defined by the DoH (1993), when it was stated that the named nurse should ensure that his/her name and responsibilities are known to the patients and should work in partnership with the patient. The basic principles of named nursing propose that the named nurse should assess plan and evaluate care for the named patients and must be accountable for the care he/she gives to the patient and is responsible for co-ordinating the overall plan of nursing care (Wright 1993) In the case of patients with carers to enable this planning to take place effectively the named nurse needs to communicate with the carer to learn about the patient's home circumstances and take account of the carer's expertise in the care of the patient.

Discharge planning is a process in which patients needs are identified and plans written to facilitate continuity of health care from one environment to another (Driscoll 2000). Effective discharge planning has the potential to ensure the quality and continuity of care from hospital to home, whilst also reducing the length of hospital stay and readmission rates (Draper 1992). A survey by Carers UK (CNA 2001) found that readmission rates, (the proportion of people having to go back to hospital within two months of being discharged) in the population studied had almost doubled between 1998 and 2001. Discharge planning is important to ensure that the necessary services are in place when the patient leaves the hospital, as delay in provision of facilities can affect the patients' levels of independence and consequently increase the burden of care on the carer (Kerr and Smith 2001). From the carer's perspective an effective discharge entails them being actively involved in the discharge planning process (Arskey et al. 1997).

The second part of the code deals with the carers' involvement with the patients' care in hospital. It states that whilst the responsibility for the care of the patient remains with the nursing staff the carer's concerns should be noted, but that the involvement of the carer should be subject to the consent of the patient.

- **The carer will be given the room to explore what they can or cannot contribute within nursing care. The carer's expectations and concerns should be noted; it is our aim that the carer is welcome to collaborate with staff and can negotiate their input into the care of the patient which will be incorporated into the care plan.**
- **However, the carer must be aware that the responsibility for the care remains with the nursing staff. Involvement of the carer must be subject to the consent of the patient, where appropriate. The level of involvement by the carer must also be agreed by the patient.**

Again these parts of the code relate to current best practise guidance. Involvement means being able to participate in an activity.

Participation means getting involved or being allowed to become involved in a decision-making process or the delivery of a service or even simply to become one of a number of people consulted on an issue. (Brownlea 1987 p.605)

Involvement is not actually a straightforward concept to implement because carers and patients are subject to health care professionals' perceptions of how and when they should be involved (Walker and Dewar 2001). 'Involvement' has been conceptualised through drawing on the analogy to a ladder (Arnstein 1969, Taylor et al. 1992 cited in Myers and Macdonald 1996). Although the descriptions of the different intermediary steps on the 'ladder' may vary, essentially they describe the same process of movement from a low level of participation in which decisions are imposed on an individual with little or no discussion, through to a high point of user autonomy in decision-making. In Arskey et al. study (1997) carers' involvement was found to range along a continuum from being actively involved, that is having their needs prioritised and being given choices in the decision making process through to more passive forms of involvement. This would include being given information but not being included or consulted in the discharge planning process. Carers generally placed a premium on active involvement, but carers can often feel excluded from, rather than part of the decision making process. A survey by Warner and Wexler (1998 reported in Walker and Dewar 2001), concluded that carers were seldom consulted even on such basic issues as the hospital discharge of the person for whom they care. This lack of involvement may be due to a number of factors. In a study of mental health users by Warner et al. (2001) many carers felt that practitioners were reluctant to take their views seriously and wrongly used the issue of confidentiality to justify their exclusion. If the discharge planning process is patient centred and the patient controls the agenda without consideration for the carer and other family members, carers can be placed in a difficult position, particularly if the patient wishes to leave the hospital as soon as possible and the carer is not ready for the patient to come home (Heaton et al. 1999). A further difficulty facing carers is due to cultural differences and the traditional roles that lay people in hospital have either adopted or been placed in. This may lead to carers finding it difficult to negotiate an active role in the hospital environment, that is an environment that is both alien to them, and weighted in favour of the service providers (Walker and Dewar 2001).

The code stresses the active involvement of carers in decision-making and clearly states that carers are provided with explanations of treatment regimens.

- **Information sharing between nurse, patient and carer will be our goal, which we will incorporate onto each ward's philosophy of care with the aim of involving the patient and carer in all decision making. As the carer will resume responsibility following discharge it is in everyone's interest to ensure that the carer has the relevant information and skills to manage at home with appropriate support. This will not only aid patients and carers but also help to prevent some readmissions. It is important that the views and capacities of the carer be fully documented.**
- **"Explanations of probable treatment regimens and practices will be given to the carer enabling anxieties and fears to be acknowledged and explored. Treatment regimes seeking to promote independence can seem harsh to patients and carers and cause concern unless properly put in context".**

- **Carers can often have valuable experience of the impact of medication on the person they care for. The type, frequency and administration of medication, especially any form of sedation will be discussed and all appropriate information given by staff. Where medication is given against the judgement of the carer they will have the right to register this viewpoint in the medical notes.**

Provision of information can be seen as a pre-condition of involvement. Information is described by Heaton et al. (1999) as being the key mechanism for involving carers in the process of discharge planning. Kirk and Glendinning (1998) found that the provision of the fullest possible information is an essential pre-requisite for informal carers on which to base their decision as to whether they could provide hospital care at home. This information should include details of the length of time for which their involvement would likely to be needed and the support they could expect to receive from the statutory services. Carers also wanted to have the time to consider the implications for their work, family and other commitments, the provision of information enables the carers to be actively involved in the planning of continuing care and to exercise choice in the arrangements that are made.

How information is provided and by whom was addressed in the literature. Ward and Cavanagh (1997) found that in the first instance when carers were new to the role they wanted to hear the information from health professionals particularly from GPs and/or Consultants, but as they became more experienced in their role they were willing to be informed by other less specific sources. The information required by carers has been found to be broader in scope than that generally believed to be sufficient by health practitioners. Carers require technical knowledge such as advice as to what constitutes signs of relapse in the patient's condition, the possible side effects of medication, and advice on how rehabilitation should be continued at home. Knowledge was also desired on other topics, ranging from details of aids for daily living, and dietary information through to coping with the psychological needs of the person for whom they care (Heaton et al. 1999, Driscoll 2000). However there are also informal sources of information described in the literature, for example Kerr and Smith (2001) found that information on benefits appeared to be passed word of mouth via informal support networks.

Sometimes in practise ward staff need to administer sedation. Sedation may be given to elderly patients to prevent them getting out of bed and wandering about the ward (Akid 2002). In some cases physical restraints are used in the form of cot rails or bed sides (Lee et al.1999), however there are risks associated with these devices, with patients falling over the rails and in some cases suffocating when becoming trapped between the mattress and the rails (Akid 2002), an alternative is the use of a chemical restraint. Within the literature the use of chemical restraints are described in nursing homes and in the mental health field, but there is little empirical evidence of the use of such restraints being used in the acute sector. However the expertise of carers in all areas of the dependents care is recognised (Allen 2001) and needs to be taken into account when medication is administered. In the case of very vulnerable individuals ward staff may feel the need for some procedures for the purpose of protection. The code identifies the tensions and provides for consultation with carers but gives the responsibility for the final decision to the ward staff.

The importance of information to families and carers is seen as a vital part of social support. However where some members of a family are told something which is withheld from others this can diminish the mutual support mechanisms which patients and carers can provide for one another (Rose 1999). The Code acknowledges the need to document the capacities of the carer and studies of carers of stroke patients have highlighted the necessity of providing information tailored to the needs of the individual carers, and not making assumptions about how much different carers can understand, assimilate and retain (Rose 1999). It is also necessary for professionals to be aware that an individual's information needs can also vary over time (Timmermans 1994).

The code provides for specific training for carers, and for a holistic approach to carers to be incorporated into the treatment of the patient.

- **All carers will have access to appropriate training in any relevant treatment practices e.g. giving drinks, helping with correct positioning or specialist feeding techniques.**
- **Care for the carer should be incorporated into any treatment of the patient in a holistic manner. The role of the carer should be explored sensitively to ensure that all available help is given to complement their role both in hospital and the community. It is the nurses' responsibility to ensure that all available channels of help are discussed with the carer; in the event that the carer wishes to relinquish their role then the final responsibility is with health and social services.**

Again there is research evidence to support this approach. Kerr and Smith (2001) reported that carers had had to teach themselves the physical skills necessary to help their relative at home, and that following discharge carers commonly felt isolated and abandoned by the system. It was suggested that there were a basic set of skills that should be taught in the hospital setting and then practised at home under the supervision of an occupational therapist and/or physiotherapist before the relative was fully discharged. The acquisition of practical knowledge is important to carers, but in Heaton et al. (1999) study some carers felt that they weren't given any training because the staff were aware of their previous caring experience and wrongly assumed that further training wasn't needed or required. It was also noted that where training in lifting and handling was provided in the hospital it wasn't always relevant to the domestic physical environment.

Those requiring care have a wide spectrum of conditions and therefore of needs, similarly those providing care are a heterogeneous group and do not necessarily find the same problems troublesome and this variability in carers' needs should be taken in to account by service providers (Syron and Shelley 2001). In Ward and Cavanagh's (1997) study carers felt it was difficult to distinguish their own needs from their dependants but actually felt that it was important that their needs were recognised as distinct from their dependants needs. They also wanted recognition and support for their own roles, not as additional recipients of care, but as peers with professionals in the caring process being able to influence their dependants' treatment plans as they were formulated. In addition they wanted professionals to recognise and to provide

the help that carers themselves needed (Ward and Cavanagh 1997). Finally carers want to be asked whether they can cope and not for health professionals to assume that they will continue with the caring role (Kerr and Smith 2001).

1.4. Comment

Research on the ways in which carers are treated have been reviewed and a number of areas of concern that have been identified;

- quantity and quality of the information provided,
- level of involvement experienced by carers,
- consideration of the carer as an individual,
- effectiveness of discharge procedures.

The East Sussex Hospitals NHS Trust Code of Practise for involving carers appears to take account of these points. It provides clear guidance on the ways in which carers should be involved in care and where there is potential for disagreement, for example in the area surrounding the use of medication it makes it clear that the final decision rests with ward staff but provides a mechanism for carers to register their concern. In the next section the methodology that was used to explore the carers awareness of the code will be outlined.

2. Researching Informal Carers Experiences of Hospital Support

2.1. Introduction

In this section the choice of research methods that were used is outlined. There is in health services research a tension between qualitative research which involves the intensive collection of data from a limited number of people with quantitative research which involves an extensive strategy, collection of limited, quantifiable data from large groups of people. In this research both approaches were utilised to develop a robust source of information. The research team started with an initial reference group to help to identify the key points, and on the basis of this, focus groups, an intensive and open method were used to collect data. These results were analysed in order to develop a more structured and extensive data collection in the form of a questionnaire survey. The study was subjected to ethical review by the East Sussex Local Research Ethics Committee.

2.2. User Involvement in the research process

The research team started with a reference group to facilitate the research process and help identify the right questions to ask. It was an exploratory process, to develop ideas and research hypotheses rather than gather facts and statistics, and was concerned with trying to understand how people think and feel about the topics of concern to the research. The team saw the reference group as involvement of lay people at an early stage in the research.

In recent years, the involvement of lay people in shaping services has become central to government policy in the public sector (DOH 1999). The term 'lay' refers to people who are neither health care professionals nor health service researchers, but who may have specialist knowledge related to health, this includes patients, the general public, and consumer advocates (Entwistle et al. 1998). Lay involvement in research is an important way for people to influence practice within health and social care (Baxter et al. 2001). Furthermore lay involvement may help to ensure that the right questions are asked in ways that make sense to participants and eliminate professional bias.

To ensure confidentiality the reference group was recruited through the Care for Carers database and a letter (see appendix) was sent via the organisation, to a random sample of 100 carers requesting their involvement in setting the parameters for the research. It was decided to send this number of letters to reach a cross-section of carers who would be representative of the main categories of carers in the study. That is: parents or guardians who care for a child who has been hospitalised, carers of young and middle aged adults who have physical or mental disabilities, and carers of older people. By asking the carers to state the disability and whether the person they cared for was an adult or child it was hoped that it would be possible to establish a group with representatives from each of the main categories. It was also stipulated that only carers whom the person they cared for had attended the Conquest Hospital as an inpatient or outpatient within the last twelve months should reply.

16 replies were received from the letters of invitation, and from these a group of six people were selected to represent the three main groups: 2 parents, 2 carers of elderly people and 2 carers of young adults.

The meeting with the reference group took the form of a focus group. We facilitated the meeting by identifying a number of topic headings. The schedule that was used for the group is in the appendix.

(i) Introduction

This was a person-by-person introduction and each participant was asked to describe how they had become a carer and what sort of caring this involved.

(ii) Experience of Caring

Carers were asked to describe difficulties they faced in caring and also whether there were any positive elements to being a carer.

(iii) Support from Services

Carers were asked about the level of support they received from primary care and social services, hospital, or other sources

(iv) Carers Code

The carers were asked whether they had heard about the Code of Practice and what items they would like to see in the Code.

(v) Structure of Focus groups

To conclude the group was asked to comment on the format of discussion, and whether other elements should be included or given greater emphasis to. Finally they were asked what feedback would they like, and whether they would like any further involvement in the project.

The meeting was tape recorded and transcribed and an experienced researcher and project research officer analysed the data and themes were identified. An outline of the findings was sent to all the group members for comments on the structure and format of the group. As a result of the reference group meeting it was decided to retain the format of the meeting but to alter the order so that positive aspects of caring were raised before the difficulties faced by carers. This was because it appeared that any positive aspects of caring became submerged by the difficulties that the carers faced. The data from the reference group was included in the final analysis and some quotes are used within this report.

2.3. Focus Groups

Focus groups were defined by Powell et al. (1996) as

A group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research

Focus groups are distinguished from group interviews in that they rely on the interaction between the group and can elicit a multiplicity of views and emotional processes within a group context (Gibbs 1997). They are considered to be an

established way of collecting rich qualitative data including experiences and opinions in a non-threatening and efficient manner (Barbour and Kitzinger 1999). The groups typically involve 5-10 participants and a facilitator, the role of the facilitator is to guide the group's discussion. The facilitator starts with a number of questions, which are intended to provide a focus for the discussion and to ensure all major areas are covered. Prompts may be used to stimulate discussion of specific issues. A second facilitator provides technical support, takes notes on the discussion, and provides prompts if necessary

Recruitment for the focus groups was also organised through a sample from the Care for the Carers database and through support groups affiliated to the hospital. Staff in specific hospital areas were also asked to recruit carers to the groups, the criteria for inclusion in the groups was that the carers dependent had been to the hospital as an inpatient or outpatient within the past 12 months, this was to ensure recent experiences could be explored. Carers were given or sent an information letter and consent form with an SAE and once a signed consent form had been received they were contacted and asked to attend the group on a specified day.

Six focus groups were planned with between 6 and 8 participants in each. There were two groups selected from each of the main carer categories: parents or guardians of children who have been hospitalised, carers of young and middle aged adults who have physical or mental disability in need of care, and carers of older people.

In total five focus groups were held, the composition of the groups is shown in Table 2.1. Unfortunately, we were unable to identify enough parents caring for children to justify holding a second focus group. This perhaps is not surprising because the actual numbers of parent carers in the population is relatively small, indeed in the National Statistics 2002 (ONS) only 8% of carers were caring for a child. Furthermore not all parents who are carers would necessarily see their role beyond that of being a parent and would therefore not describe themselves as a 'carer'

Table 2.1. Composition of focus groups

Type of Carer	Group A	Group B
Carers of elderly adults	5	7
Carers of young adults	4	8
Carers of children	5	-

The participants were informed on the information sheet that the groups would be tape-recorded, and this did not cause concern for any individual. Each discussion lasted approximately 1 hour and 30 minutes and used the same format as appendix 1. At the end of the discussion participants in the focus groups were asked whether they would be willing to pilot the survey. The tapes were transcribed and were subject to content analysis. Both facilitators analysed the transcriptions for validity. The main themes identified informed the development of the questionnaires used in the third part of the research.

The questionnaire was developed using the themes identified in the focus groups and explored the experiences of people in outpatients, accident and emergency and as inpatients. All but two of the focus group participants returned the pilot questionnaires and there was positive feedback to the nature of the questions

2.4. Diaries

In the original proposal it was stated that diaries would be used in this study. However although extensive efforts were made to inform staff about the study and to ask for possible diarists to be recruited to the study it was not possible to recruit subjects within the project time-scale. Therefore following discussions with the steering group we agreed not to proceed with this part of the study.

2.5. The Survey

In social surveys information is collected from specific units, using a standard set of data collection procedures such as questionnaire or structured form. The researcher aims to minimise his or her impact on the phenomena being studied. Surveys, especially those using questionnaires are seen by social scientists as a cost effective way of generating large quantities of good quality data. Denscombe (1998) noted that surveys 'can produce a mountain of data in a short time for a fairly low cost' and 'can generate large volumes of quantitative data that can be subject to statistical analysis'.

The design of the questionnaire was informed by the results of the focus groups and was piloted on focus group members (a copy of the questionnaire can be found in appendix 2). There were questions about the condition of the cared for person, attendances at the Conquest Hospital; as an outpatient, inpatient or in accident emergency, medication, discharge planning and what improvements carers would like to see.

The total population targeted was 600 carers and questionnaires were sent out using contact details from the Care for Carers database. It was planned that 200 questionnaires would be sent to each main group of carers: parents, carers of elderly people and carers of young adults. However the necessary information was only available for 180 people looking after people aged over 65 years, 64 people looking after young adults (less than 65) and 77 parents caring for children therefore the rest of the sample was taken randomly from the database. The total response rate to the questionnaire was 191 or 30.7% (including those who had not attended the Conquest Hospital in the past year). This was disappointingly low as the expected response to an initial mailing of questionnaires is normally around 35% (de Vaus 1991). There are a number of possible explanations for this. Firstly, nine people who returned the questionnaire stated that they had never been carers and were uncertain why they had been approached, others had been carers and the person for whom they had cared for had died. This reflects the limitations of using databases for obtaining samples. Secondly, to ensure the confidentiality of the respondents no reminder letters were sent. However although the sample is small, those questionnaires that were completed did support the findings of the focus groups. The data was entered into the statistical package SPSS and was analysed, descriptive statistics and cross tabulations were produced. In the following section the results of the survey and data from the focus groups are presented.

2.6. Comment

This section has outlined the methods adopted in the study. They were chosen on the basis of rigour to provide consistent and informative data to answer the research questions within an ethical framework. In the following section the main research findings are presented focussing on the data from the focus groups supported by the survey findings.

3. The Research Evidence:

3.1. Who is caring for whom?

Characteristics of the Carers in the survey

The data from the General Household Survey (GHS) 2000 (ONS 2002) will be used to compare the data generated in the current study to help determine whether the characteristics of the sample were representative of the caring population. The GHS has collected information on the extent and nature of care-giving in Britain at five-yearly intervals since 1985 (ONS 2002). In the GHS 2000 'carers' were defined as people who were looking after, or providing some regular service for, a sick, disabled or elderly person living on their own or in another household.

- **Age of Carers.**

The GHS survey found that there were no consistent age trends in the percentages of carers over the past 15 years. In this study over of third of the 34.6% of the carers were themselves aged over 75 years. This could be due to the nature of the sample with more people known to be caring for those aged over 65 being sent a questionnaire than the other groups.

- **Gender Differences**

The GHS (2000) found that women were more likely to be carers than men and this was found in the current study with 63.6% of the sample being female.

- **Marital Status**

72% were married or co-habiting compared with 73% in GHS 2000.

- **Pattern of caring responsibility**

91.6% of the sample were looking after someone in the same household therefore the following figures are compared with the GHS questions linked with those carers living in the same household (GHS figures are in brackets). 26.2% (27%) were caring for a parent, 55.3% (55%) were caring for a spouse and 7.8% (20%) were carers of children.

- **Caring Commitment**

The survey asked how many people the carer looked after and the number of hours spent on caring activities, but details of the activities undertaken were not asked for. 89.7% of the sample were looking after one person, and 74.8% described themselves as providing 24 hour care. Caring is often a long term commitment and in the GHS 45% of carers had been caring for someone for 5 years or more in the current study this rate was slightly higher with 60.6% caring for more than 5 years. This again could be linked to the age profile of the sample.

- **Characteristics of those being cared for**

The carers were asked to relate the survey questions to the person for whom the carer spent most time on caring activities. 54.2% of the sample being cared for were aged over 65 years (again this could be linked to the way in which the

sample was stratified). The most common condition requiring care was physical disabilities (54.3%), followed by neurological impairment (29.5%) and from the comments on the questionnaire this was most usually due to stroke, the next most common condition was frail elderly 27.6% (carers could tick more than one option which is why the total is over 100%).

Although the response to the questionnaire was low the data presented above suggests that the sample is representative of the wider population of carers in the UK. Furthermore the comments that carers wrote on the survey echoed those of carers in the focus groups and some of these have also been used in the text to draw a composite picture of carers' experiences.

In the following sections the data from the focus groups will be presented in conjunction with the survey findings to describe the carers' experiences of hospital support. This section is organised in such a way as to take account both of the items in the code of practice and the other issues raised in the focus groups which were then incorporated into the questionnaire.

3.2. Identified as Carer.

The East Sussex Hospitals Code of Practice specifies that staff will identify the main carer at the initial assessment of the patients needs and that in the case of inpatients a meeting will be arranged between the carer and named nurse as soon as possible, preferably within 48 hours of assessment. The data from the focus groups suggested that carers were not asked whether they were carers by the staff and often found that it was necessary to identify themselves as such to the staff. This was confirmed by the survey as only 28.3% of the sample had been asked whether they were carers when the person they care for was an inpatient (16.3% in outpatients, 17.6% in accident and emergency). Although staff may have identified the carer through the patient assessment, carers were not asked about their role as carers and therefore the caring role was not confirmed.

I have never been asked if I am his carer. Whether they just take that for granted because I don't have to be his carer, I can go out to work full-time and have someone in (Carer of young adult FGD 1).

The code of practice states that the purpose of identifying the carer is to provide the staff with an opportunity to learn about the patients' home circumstances as well as to identify the carers' needs, insight and preferences and expertise in the care of the patient. Established family carers form a distinctive category of carer and often have a special knowledge of the cared for person's needs. Carers in the focus groups recognised themselves as being experts in the area of their dependents disability and also in the needs of that person however they did not feel that this was acknowledged.

But they will not listen to you because they are the professionals. We're not. I mean what the hell, they don't know what we did in our life. They forget that. They forget our own knowledge and they forget we've got the internet. So if I don't know something rather than go to someone who's not going to give me the full facts because they probably don't even know them I'm going to check

it on the internet. So I am armed with my information. (Carer young adult. Group5).

A similar point was made by one of the respondents in the survey:

To make sure that the doctors listen to what we are telling them and to act on it-who knows the person you are caring for better than we do (Respondent 078 survey)

To establish whether carers were asked about the level of care they provided at home the survey asked whether they had been questioned about the amount of help they gave the patient at home. Only 30.3% had been asked for this information. In the focus groups the issue of professional/lay demarcations was introduced by the participants as a reason why the staff did not always ask for information about the patient.

I feel sorry for the medical profession because they have to be on their guard all the time but they could reap enormous rewards when you think we have been caring for that person for years, 24 hours a day, we are willing to come in we are not there to criticise we are in fact there to co-operate they don't seem to expect that and the culture is wrong (Carer of young adult FGD 1).

Carers felt that where there was a full-time carer this should be marked in some form on the patients' notes. One of the respondents to the questionnaire sent a copy of a care plan or "care passport" that he had developed using his computer for his wife. This gave details of her condition, the medication she was taking and also information about the assistance she required for eating and drinking. In addition his name as her carer was on the passport with his contact details.

In the survey, of those carers whose dependents had been in hospital 49.1% had been aware of the named nurse responsible for their relative. However in the focus groups there were problems identified with named nurses who were often not available due to shift patterns and holidays. Carers had found in these circumstances that other staff were unable or unwilling to answer questions relating to the patient. It was therefore suggested that when the named nurse was off duty that a 'deputy' should be nominated to answer questions about the patients condition.

The thing is though you are given a named nurse, which is lovely, but they go off-duty and you are left with nobody... (Parent FDG3).

I found in [name] unit I could see the sister or the nurse or whoever, and ask them a specific question, 'Oh I am not looking after him, I'll find the nurse who is looking after your husband', and they don't find them and its 'oh she'll be down the corridor' and she's not there. You cannot find anybody when you want somebody and the nurses desk is empty (Carer of elderly husband FDG2).

The code also specifies that the named nurse should make contact with the carer within 48 hours of assessment. Carers in the Focus groups suggested that when admissions were planned the named nurse should be known to the patient and the

carer beforehand as it was suggested that any problems or questions would be likely to occur within the first 48 hours of admission.

Another reason given within the code for identifying the carer and establishing home circumstances is to facilitate discharge planning, the process which facilitates the continuity of health care from one environment to another. To assist with the continuity of care, "care packages" may be arranged and full arrangements may involve primary care teams and social services so that when a patient returns home their needs are met. In the focus groups it was evident that there were instances where "care packages" had been arranged for some patients but once the patient returned home no help materialised and when GP surgeries had been contacted they were unaware of either the patient's return home or that assistance was required. With discharge planning there is potentially a conflict of interests, with the hospital wanting to discharge patients as soon as possible, patients wanting to return home and carers being concerned and uncertain about the level of care they would be required to provide at home.

That's the difficulty with patients they want to get home so badly [name] can cope, yes she can do that and the problem is you can't really but they want to come home so badly, and get back to normality, as much as they can (carer of young adult FDG1)

Carers need to be involved in the discharge planning, so that they are aware of the needs of the patient, have the opportunity to discuss their concerns as to whether they could cope at home, and also to discuss the level of assistance that may be necessary from outside agencies. Patients often want to go home and sometimes this can put pressure on carers to accept the patient home, particularly if a care package has been arranged.

I have never been asked, never been consulted about his homecomings, can you manage at home, we will send him out today (carer 2 of young adult FDG1)

This carer went on to say...

But then of course you have got the person in hospital saying to you I want to come home, you are under a great deal of pressure, don't leave me here I am *better now, but better in hospital is not the same as better at home. It's a fantasy if you like, [in hospital] you are on the flat, there's someone at hand the toilet's just two yards away. When they come home the person at home has got the house to run, and may be a part-time job whatever, they are not well themselves*

The focus on patient-centred care may preclude the carer from discussions relating to the patient's discharge. Although there are issues of patient's confidentiality here, if the patient is dependent on another person being able to provide care at home then that person's ability to provide that care must be established and not assumed. This can only be accomplished through frank and open discussions between the parties involved.

For some in the focus groups the timing of the actual discharge itself was another area where problems occurred both in terms how much notice of discharge was given, and also the time of day when people came home.

I can never understand why it is they come home so late when they are discharged. They wait until 8 o'clock at night-time to send them home and they are disorientated anyhow, and when they get out of the ambulance they are absolutely lost. (Carer of elderly person group 2).

In the survey 53.1 % of the carers thought that the notice given for discharge was acceptable although there were instances where people had felt 'very angry' or 'very upset'. Just over half (53.1%) of carers had been consulted about the discharge and 49% felt their views had been listened to, with 44.9% being helped by the staff to prepare for the discharge. A written discharge plan was given to 28.6% of carers but although 44.9% were told about the sort of after care the patient would need at home only 40.8% were asked whether they would be able to cope. The same percentage (40.8%) were given a contact number to phone for advice once the patient had been discharged.

Carers in the focus groups had had bad experiences of their dependent being discharged, with short notice, patients being sent home undressed, and in one case with bare feet in winter time. There was however also examples of good practise.

...one thing I'm very agreeably pleased about was that before she came out of hospital 2 ladies came out from the physiotherapy department, with my wife, for a day out, for a visit. And they came to see me and asked whether I would be a good housewife or not. They did. They came out here to look at the stairs to see if they were negotiable for her. Once she was settled they came and visited again to see if she was OK and then we had a few phone calls to see how we were getting on which I thought was.... As far as the follow up procedures were concerned I was impressed. She had a good liaison with her GP and with the hospital and that has continued and they keep a check on whether it is going to order. (Carer 2 of young adult FGD 5)

Some carers in the focus groups had been involved in the discharge planning process and had a 'care package' in place for when the patient was discharged. However when the patient was home the promised help sometimes did not materialise, this happened with carers of both children and adults.

He couldn't do a thing for himself. He was on a zimmer frame and they told me that I would have a district nurse in to help me and when I got home on the Saturday I would have a district nurse come in that day. No one came. No one came on the Sunday. No one came on the Monday. I rang my doctor and he said 'oh are we supposed to give you some care?' I said well it was supposed to have been arranged and I had nothing (Carer young adult group 4).

Carers referred to the lack of communication between the different agencies and that there was 'no joined upness' of care. It is difficult to suggest actions that a hospital can take to ensure planned care packages deliver what is promised when they have no authority over the community sector, but equally it is unacceptable that carers take

their relatives home believing that they will receive some assistance, when those expectations will not or cannot be met. A mechanism should be put in place to ensure that the patients and carers do get the services that have been promised and to ensure that carers are coping with the situation. Since The Carers and Disabled Childrens Act (2000), carers are entitled to assessment of their needs, and following discharge of the dependent would appear to be an appropriate time for this to occur.

Someone to visit the home situation and check up on the carer to see if and how they are coping. I had no one at all. I just muddled along on my own and even though I had worked with strokes for years it is different in the home on your own and without any aids. (Survey respondent 079)

Actions

From these findings it is possible to identify a number of areas in which the Conquest Hospital can improve the services which it provides to improve services for carers.

- Where there is a full-time carer he/she should be clearly identified on the patients' notes.
- When admissions are planned the named nurse should be identified as early as possible preferably before the patient is admitted.
- A procedure should be put in place to ensure that when named nurse is off duty carers have an alternative person they can speak to.
- Following discharge an assessment of the home situation should be made to ensure appropriate services are being delivered and the carer is able to cope.

3.3. Involvement

Contributing to care

The second main point in the code refers to the carers being given room to explore what they can/cannot contribute within nursing care. During the discussions it emerged that carers felt that their presence on the ward was important to their relatives in the sense that because they spent so much time with them the patient relied on them being there and felt more confident when the carer was present. Carers obviously have knowledge of the individual patient's preferences and are therefore able to anticipate the patient's needs. The nursing staff on the other hand need time to become familiar with the patients preferences, furthermore whilst the carer had been providing care on a one-to-one basis the hospital staff have other patients to consider. On the wards carers often acted as advocates for the patients being attentive to their needs and bringing those needs to the attention of the nursing staff. One carer described her role in the following way:

but actually that person is entirely dependent on the carer and the fact that they are there makes the world of difference, I mean we are immensely important in that situation and I think that is something they could recognise

as an advantage and it is part of the subtly of medicine (Carer of young adult reference group).

Carers can actively contribute to the treatment and care of the patient if the staff are willing to allow them to do so. However in some circumstances carers felt they were overused even exploited. For example some parents on the children's ward reported that they were expected to provide much of the care for their children to the extent that they felt unable to leave the children to get meals for themselves or even to go to the toilet. This was particularly the case of parents of children with special needs.

I think that carers need to be acknowledged on the ward and their contribution to that person's stay in the ward ought to be acknowledged, by *the services, like meals for example, you can't leave the room although in a way its quite nice to get out once in a while. But if you can't, I mean I have had experience when I haven't even been able to go to the loo so really we are providing a service we come along and we provide a service* (Carer parent reference group).

This was not the only example of a parent finding that they were providing the personal care for the child when in hospital. Parents actually wanted to be involved in the care of their child but did not want to be taken for granted and want to be acknowledged and allowed breaks for meals. It was suggested in the survey that there should be a member of staff with special needs training whose time was 'ring fenced' so that they could provide assistance to parents in the form of caring for the child to allow the parents a break. A parent in the survey also commented

On the children's ward, every mother was totally exhausted. It's right for mothers to stay with their sick child, but it should be 'as well as' not instead of full nursing care. The staff spent most of their shift chatting round the nurse station. (Respondent 080)

It was not only parents who found themselves undertaking elements of care, other carers found themselves washing the patient and providing bedpans, some even were shown how to use suction by the staff. For the most part this was not a problem as the carers wanted to contribute to the care, however as participants in the caring process, they perhaps not unreasonably want to be informed of the patient's condition.

The issue of consent

One element of the code that caused some concern to carers was the statement "Involvement of the carer must be subject to the consent of the patient, where appropriate. The level of involvement by the carer must also be agreed by the patient." There were a number of issues raised by this, firstly the fact that it was in bold type meant that it stood out from the rest of the code and the eye was immediately drawn to it. Secondly, although consent of the patient is required "where appropriate" it was felt some patients either through their condition e.g. Alzheimers or through being unconscious would be unable to give valid consent. One carer noted:

The bottom paragraph of page one is obviously a...I know what you are saying but of course unfortunately a lot of the time the patient is unable to give consent because of their situation and that there by definition gives cart blanche to the nursing staff to say well we think its best because you know...and that is not necessarily the case. I do feel, and I don't know whether you agree, that the carer has so much knowledge of the patient that they have a meaningful contribution to the patient, to look after the patients interests when they are unable to. So that statement there really, I feel could be elaborated because to me it gives cart blanche to the nurse authority to say well he hasn't consented but he can't because he's unconscious (carer young adult group 4)

There are a number of legal and ethical issues surrounding consent, but in light of the feelings this statement provoked within the groups then a change of wording could be appropriate or even simply the bold type face should be removed.

The level of involvement

Involvement is a difficult concept because of different expectations and how individuals perceive they are or can be involved in a process. From the focus group discussions the level of involvement carers experienced or wanted ranged along a continuum from relatively minimal, i.e. they wanted to be informed about the patients' condition and for staff to be accessible so that they could ask for the information that they wanted, but they did not want to be actively providing care on the ward. At the other extreme some carers wanted to participate actively and collaboratively in providing care for the patient.

I think to sum it up in one word and that's involvement and if you take that across the board if people talk to you and you are allowed to talk to them its so much easier for everyone (Carer young adult FGD 1)

From the survey data 70.1% of carers felt that they had enough opportunity to speak to the staff. If information and communication are taken as a measure of involvement then for most people in the study communication and therefore the level of involvement is not always a problem. However there were a number of comments on the survey relating to the wish for more information from staff, which echoed those feelings expressed in the focus groups. The concerns related to information sharing will be discussed more fully below.

For carers of children with learning difficulties the level of involvement was at the collaborative end of the spectrum. This relates to their involvement on the ward that was described above where they are very much involved in the personal and nursing care of the children. In the focus groups of carers of children with particular disabilities, there was agreement that they were very well informed about their child's condition and felt they acted as advocates and collaborators in the care for the child.

I think it is a collaborative thing caring for someone in the medical environment, it's collaboration between that person, yourself as the primary carer, we are advocates we speak on behalf, we are [name] lifeline. People have no idea how to relate to him so we bridge that gap so it has to be when

you, if they understand that there is a disability involved then it has to be a process of collaborative treatment (Carer of young adult reference group).

The issue of communicating with children with learning disabilities was raised by several carers not just from the point of view of staff being able to relate to the children but also being able to use appropriate language. This was particularly the case where the children communicated through sign language because the parents reported that there were no staff who understood sign language. Carers also gave anecdotal evidence of there being no staff working in adult services able to communicate with patients with hearing impairments. In the focus groups and the survey there was a feeling that there was no real understanding of how to approach the care of children with learning disabilities, and the difficulties faced by parents caring for these children. Parents felt that there should be additional training for staff in handling and communicating with children with disabilities.

To have somebody you could... A team nurse that has got experience and some sort of training with disabilities that they can come and actually understand what you are saying because we don't want to sit and talk to somebody that says oh I don't know how you cope Mrs [name] I don't want to hear that. (Parent group 3)

Responsibility

The code refers to the carer being aware that responsibility for the care of the patient remains with the nursing staff, this was commented on by the carers who sometimes found it difficult to hand over responsibility of care to the nursing staff. There was also a sense of belonging, that the cared for person belonged in some way to the carer. As was noted in the first sections a sense of responsibility is an integral part of caring, and carers experience general anxiety about how the cared for person fares in their absence.

I don't think doctors or nurses realise when you hand a person over who is your responsibility and the amount of time and effort you put in its very very difficult to see someone else doing the jobs you have been doing and doing them wrong (Carer young adult group 1)

When a relative or dependent is in hospital, health care professionals may see it as an opportunity for carers to get respite from caring however in reality this is rarely the case. Carers have a sense of responsibility towards the cared for person which for some means that they feel they have to remain with the person where possible to look after their interests. Furthermore transport to the hospital is discussed later but visiting the hospital is tiring and time consuming and carers also have to cope with the anxiety of the condition of the cared for person, and the possible life changing implications of the hospitalisation of that person.

Actions

Again there are a number of ways in which the Conquest Hospital can improve its services.

- When parents are with a child with a disability on the childrens' ward there should be a member of staff on each shift responsible for ensuring that those parents feel confident about leaving their child whilst they have a break.
- There should be staff trained in the use of sign language
- The wording on the code relating to carers involvement should take account of the views expressed by the carers and the bold typeface should be altered.
- The carers contribution to the patients care should be acknowledged by staff.

3.4. Information

Information sharing between the nurse, patient and carer is a goal that is stated in the code of practise with the aim of involving the patient and carer in decision-making. The Kennedy Report (2001) found that face-to-face communication with professionals who are able to engage with patients on an emotional level, to listen to and assess how much information a patient wants to know and convey the information with clarity and sympathy is highly valued by both patient and carers. In this study carers expressed the desire for information from professionals about their dependents. There is a close relationship between the giving and receiving of information and the provision of emotional support (NICE 2002). Information from staff was also mentioned in the survey as an area where services could be improved, and within the focus groups it was thought that there was a need to be articulate or to have a 'loud voice' in order to get the information required.

I think I sense the same as what you sense that there is obviously this terrible period of where everything is going on and you want information and it seems not to be very forthcoming unless you really stamp your feet (Carer of a young adult group 4)

When their relative is on the ward there does not appear to be a structure in place to enable carers to speak to the doctor in charge about the patient's condition. As stated earlier this did not appear to be a problem for the survey respondents but some participants in the focus groups described having to make appointments to see the doctors on the ward, or waiting to catch the doctor as they were leaving the ward. On the other hand, other group members found that they were well informed by the doctors and nurses and received all the information they required.

No as I say they were very good because they kept me informed and they did actually *tell me...I am not saying they...because it was relevant then but I must admit I got an very well with them its always been a 2-way thing.* (Carer young adult group 5)

Information sharing is a two way process and here again carers felt they contributed to the care of the patient by sharing their knowledge. As discussed earlier carers often see themselves as experts in the condition of the patient and as well as getting information from the professionals carers also obtained information from other sources such as: support groups e.g. the Alzheimers Society, the internet, newspapers and magazines, and indeed other carers. However not all carers will have this information and as good information is a pre-requisite for enabling patients and carers to make decisions about care professionals should ask carers what they want to know and not make assumptions about the existing knowledge or the level of knowledge

required. Carers cannot express preferences or be involved in decision-making unless they are given sufficient appropriate information.

Support

Caring can be a lonely and isolating experience. To be able to talk about their situation to others can help carers to realise they are not on their own, can be a source of information about services, and can also be an opportunity to have someone acknowledge what they are doing. It is not always possible for carers to talk to their families because they do not wish to burden them, and carers described how sometimes friends and family 'disappear' over time which contributes to their isolation. Carers would welcome support when relatives are in hospital and during the focus groups the need for support was raised a number of times, when asked what was meant by support they were referring to emotional support and further probing elicited the types of support that was desired at different times from different people as follows:

- Health care professionals acknowledging what the carers do on a day to day basis
- Acknowledgement by health care professionals of the carers' feelings and needs as individuals in their own right.
- The opportunity to speak to others in a similar situation
- Being kept informed.

Support is required at different points by different carer groups

- When the patient is in ITU there are staff and other relatives to provide mutual support but when the patient is discharged the carers would like support from professionals, and also to have the opportunity to speak to others and 'relieve' their experience.

Support groups can also offer mutual support and the chance to meet people in a similar situation.

Talking about going to carers meeting...

You say what you like everyone has been through it and they all talk, and it does help, you hear and think oh mine does that and other peoples husbands do the same and I realise I am not alone (Carer in elderly group).

This was a woman whose husband had Alzheimers disease talking about a carers support group that met on a regular basis. When carers have their relative in hospital with an acute condition their need for support may follow an unexpected pattern. For example carers of people who had been in intensive care referred to how intense the situation was but there were plenty of staff around and other relatives giving each other support and it was when the patient came home that that they felt in need of the opportunity to talk about their experience with others.

And then I suppose one of the biggest comments I would make is you have to go through this 6 weeks intense emotional stress and trying to keep everything in balance with the families and the children and relations and then your wife in this critical condition and then suddenly you're let out of hospital and it

stops. OK? Even you doctor doesn't come to see you, to see the patient. They don't say we're dreadfully sorry you've had this situation lets keep an eye on it. There was none of that. It just stopped. (Carer young adult group 4).

I think the thing that would help me most is to have a group afterwards of other people who have been through the same thing and you always find somebody who is worse off than you then and I think that helps more than anything because you always feel so isolated don't you, and nobody else could *have experienced this horrific thing, and it never one thing as you all say. It's* so many things and at the time your mind can't accept the different things that happen to you. There are so many crisis and I think the nurses keep cheerful *and I think to meet other people.....As you say even in the intensive care it* helped to know that other people were *in there with their relatives...* (Carer young adult group 4).

Being kept informed and involved in the care of the patient is one way in which carers can be helped to feel supported as part of the process of acknowledging their role in the patients' everyday life. As part of this acknowledgement however carers do not want to have staff telling them they don't know how they cope, but they do want positive suggestions as to how to deal with situations.

One element of the code refers to the explanation of probable treatment regimens and practises being given to the carer to enable anxieties and fears to be acknowledged and explored. There was no particular reference to this within the focus groups and therefore no specific questions were asked about this within the survey. However this all comes under the remit of information and involvement, and if carers are correctly informed and involved in the decision-making processes then misunderstandings about the need for certain treatment regimens will be avoided.

Actions

In this area East Sussex Hospitals NHS Trust could develop its support for carers by ensuring:

- There is recognition that information needs vary over time, and that information sharing is an important part of support.
- The level of information required by carers is not assumed.
- There is recognition that carers may require support when their relative is in hospital and after discharge.

3.5. Training

The code of practise specifies that carers will have access to training in relevant treatment practices. Of those who answered the question as to whether they had been offered any training only 3 people (2.8%) had. The level of training given is not specified, but perhaps the code should specify that training would be given to a required level of competence and also that the carer feels competent to undertake the task. This would be especially important in cases such as the following...

But he still had still got a trachy [tracheostomy-a surgical opening into the trachea held open with a tube] which I had got to master and I had one lesson in how to change this trachy and I was sent out (Carer young adult group 4)

Carers were asked in the survey whether they had been given a contact number in case they wanted to ask for advice about the patients' condition once they were discharged. Kerr and Smith (2001) noted that carers often feel isolated and abandoned by the system, and carers need to be involved in discharge planning to ensure they have the necessary skills and if not to have the opportunity for training. It is not just when people have been inpatients that treatment regimens change, this can also happen during outpatient visits and at this time carers should have the opportunity to access help if they need it.

If you go to outpatients if the person you look after is put on a very new regime, some new diet, medication, injections or something like that, there should be some sort of way of asking for help, if you needed to be trained to deal with it or even if you feel you can cope with it (Carer young adult group 1)

An alternative view expressed within the focus groups, which is also linked to information sharing and acknowledgement of carers expertise was that it is sometimes the carers who need to show staff how best to provide certain types of personal care for the patient.

I feel it's the other way round when they are on the ward and I'm sure we all feel the same carers need training but I feel it should be the other way round I feel that you need to show them how to, when you go in to relatives that can't do it themselves that you need to show them how to do it because they are just left in the bed, they can't do it themselves drinks or food just given to them, Oh don't you want it...Well if they want it or not but we need to go in and show them how to do it (Carer elderly parent group 2)

Action

Within this area East Sussex Hospitals NHS Trust can enhance support for carers by ensuring that:

- Where carers need training in treatment practises staff should ensure that the carer feels competent to carry out the tasks unaided before the patient is discharged.
- The carer is asked about the types of personal care provided for the patient at home, and the amount of help the patient requires when eating and drinking etc.

3.6. Medication

The code of practise refers to the use of sedation and the right of carers to register any concerns about the effects of such medication. There was only one instance raised in the focus groups about the sedative side effects of some drugs, and in this case when the carers concerns were voiced to staff the medication was changed. From the survey

medication appears to raise no particular problems for carers with 44% having the purpose of any medication taken in hospital explained to them and 34% having the purpose of medications taken home explained. The difficulties experienced by carers were of a practical nature, waiting for prescriptions to be made up, not all the drugs being provided at discharge and having to return to the hospital for the full prescription. For some elderly carers the packages of some drugs were too similar to others and this had caused some confusion. However there were also some instances in the hospital when drugs had not been given at the correct time and in one case where a drug had not been given at all during the patients stay. This is a further area where carers' expertise needs to be acknowledged.

Hospital staff need to realise that carers know what medication a person takes -all about it- and when it should be taken. Carers do get immersed in these things especially if the patient is confused and indecisive. Carers need respect for their knowledge. (Respondent 071 survey).

3.7. Transport to Hospital

In the focus groups parking was always raised as an issue not necessarily during the discussion itself but as people arrived for the meeting. It was often raised as an opening topic of conversation and one participant was late for the group because she had been unable to park. In the survey 51.1% of respondents complained about the parking and the subject raised the largest number of comments

Nowhere to park after ten in the morning

Parking is a nightmare even with a disabled badge as non badge holders take places

Parking! Diabolical! You have to unload frail/confused person and then leave them there while you search for place to park.

Parking -Parking-Parking!!

During the group discussions the numbers of parking spaces for the disabled were felt to be inadequate and it was suggested that there should be different grades of parking bays according to the degrees of disability experienced. In addition it was thought that the bays failed to take account of the space needed for wheelchair access to the car. Once parked access with a wheelchair was also found to be difficult because of the kerbs and slopes surrounding the hospital.

Not enough parking spaces for disabled; paths have high kerbs and slopes not suitable for wheelchairs

The parking difficulties at the hospital may be compounded by the lack of provision of public transport in the Hastings area. Buses were thought to be expensive and in some cases unreliable. From some areas buses did not run until after 10.00am, and in others there was no bus service in the afternoon, which meant that those people

wishing to visit relatives would have to rely on taxis or lifts from family and friends, further adding to the pressure on car parking at the hospital.

Action

- The Conquest Hospital could improve its support for carers (and patients) by reviewing parking facilities especially for individuals needing disabled access.
- The Trust needs to ensure that issues around public transport are fed into the Hasting Community Strategy.
- The Trust should review the number of missed appointments caused by transport difficulties
- Comments about wheelchair access should be shared with the Disability Discrimination Working Group.

3.8. Outpatient Services and Accident and Emergency

In the survey 85.4% of respondents had attended the clinic with the person they care for one or more times in the past year. Although 79.4% had been present during the examination only 16.3% had been asked whether they were a carer and 15.2 % had been asked how they were coping with caring.

frequently I have been shown out, and not allowed to go into the room with him, and I have had to say I am actually his carer (Carer of young adult FGD 1).

Following on from the difficulties with parking, access within outpatient clinics for those in wheelchairs was also found to be difficult as the space in the waiting areas was thought to be inadequate, particularly if there were a number of other people in wheelchairs present.

The main problem identified within the focus group in outpatients was concerned with waiting with children or young adults with learning disabilities especially when they had had to wait for a long time. One of the suggested improvements in the survey was that there should be quiet areas where children with behavioural problems could wait. Such a suggestion may not be acceptable to all parents/carers as it may be seen as stigmatising and discriminatory.

In the focus groups some carers had brought their relatives to the Accident and Emergency Department and so it was included in the questionnaire. Those in the focus groups had mainly attended with serious acute conditions and did not raise problems with the care in the Accident and Emergency Department (A&E). In the survey 42.9% of the sample had attended A&E but only 7.8% of these had seen leaflets for carers, but as 60.8% answered “don't know” to this question it may simply be that any leaflets that were there were not in a prominent position, or simply had not been noted by the carers in this situation. The main issues identified in the survey with attendance at A&E was the waiting time, which was linked to staffing levels and for a parent of a child with learning disabilities there were problems with communication.

Action

The East Sussex Hospitals NHS Trust could improve its services for carers by ensuring that:

- Relatives accompanying patients to outpatients or accident and emergency are asked if they are carers.
- Reviewing access for people in wheel chairs.
- People with learning difficulties should be seen promptly.

3.9. Care for the Carers.

The code of practice states that care for the carer should be incorporated into any treatment of the patient in a holistic manner, and that the role of the carer should be explored sensitively to ensure that all available help is given to complement their role both in hospital and the community. The findings from the focus groups very much echoed those of previous studies described in section one. Carers want recognition in their own right as individuals and to be treated as individuals.

To be treated like a person and not just as a carer (Respondent 091).

Nobody cares about me (Carer of young adult FGD5)

Automatic and consistent acknowledgement of the carer's personal role in the continuing health care of the patient (Respondent 053).

In addition to having recognition and support of the work they do, the financial problems facing carers was raised in the focus groups. The allowance they are given for providing care was seen as inadequate and also by some as an insult, with long term financial implications for themselves as individuals. Carers often struggled to find out information about the possible financial support they were entitled to and also had difficulty in accessing this support because of the bureaucratic processes involved. Although it could be argued that the acute hospital environment may not be the appropriate setting for the provision of information about allowances and benefits, staff need to be aware of the problems that carers face and be able to refer appropriately e.g. to the hospital social work team or PALS, as part of a holistic approach to carers needs.

In the survey carers were asked if there were any improvements they would like to see to hospital services and only 54.2% thought that services need improving. Considering the media coverage of problems in the NHS this perhaps is a surprisingly low figure but may reflect the older age group of the survey sample, who tend to be more satisfied with the NHS than other groups. The carers were asked what improvements they would like to see and besides parking and transport most commented on communication and the provision of information. Suggestions that were made relating to improving the experiences of carers were again centred round the issues of communication and information.

More communication with carers (Respondent 058).

Carers in the focus groups were asked to comment on the code of practice and some of their comments have been used within the text to highlight the different areas of the code. There were some more general comments about the code relating to the need for the code to be resourced adequately. The carers wanted reassurance that staff would be made aware of the existence of the code and that it was not a paper exercise. It was also suggested that there should be a liaison person or carers support officer appointed to facilitate both the implementation of the code and its continuing use.

This code of practice seems like it's all taking notice of the carer but there's nothing in there to say how they're going to feed this information back to the nurses on the ground floor. If they talk to a carer and they say...how does that get down to the ground floor? There is nothing in there at all about the management (Carer young adult group 5).

Actions

The East Sussex Hospitals NHS Trust can enhance services for carers by ensuring:

- Carers are treated as individuals in their own right.
- Carers' role in the care of the patient is acknowledged.
- The consideration of the appointment of a carers support or liaison officer.

4. Comment

The purpose of this study was to evaluate the support that informal carers receive from the East Sussex Hospitals NHS Trust. To perform the evaluation focus groups and a questionnaire survey were used to determine the experiences of informal carers in the East Sussex Hospitals area and explore whether their expectations are being met.

The study was supported by a literature review which examined the concept of caring and placed informal care within the policy context, examining why informal carers have come to the fore front of government policy. The review provides a sound evidence base for the code and confirms the importance of the inclusion of the standards provided within the code.

The research found that there were a number of areas where the East Sussex Hospitals NHS Trust could take action to improve the services they provide and thus enhance the support for carers. There were instances for example where carers had not been identified by the staff as the main carer. Carers want to be involved to a greater or lesser degree in the care of the patient, such involvement at the very least means that staff communicate with carers. This includes the sharing of information and asking carers about their home circumstances, this will not only facilitate the discharge planning but help to ensure that carers will be able to cope when the patient returns home, thus reducing the likelihood of readmission.

APPENDIX 1

Hastings and Rother NHS Trust

CODE OF PRACTICE FOR INVOLVING CARERS

A carer is anybody who is helping to look after a partner, relative or friend who, because of illness, old age or disability is unable to manage at home without care-
Public Health Report 2000

1. This code of practice aims to operate within the needs of carers, patients and staff and will require ongoing review with staff, clients and all relevant agencies. We recognise that we have much work to do in involving carers in the planning and delivery of services and in evaluating how well we are performing. We would like to see this code used as the basis for ongoing discussion rather than a definitive statement as to what is achievable.

2. Staff will aim to identify the main carer or carers during an initial assessment of the patient's needs. This may be for inpatient care or emergency or outpatient treatment.

3. In the case of inpatients there will be a meeting arranged between the carer and the named nurse as soon as possible, preferably within 48 hours of assessment. This will be an opportunity to learn about the patient's home circumstances as well as to identify the carer's needs, insight and preferences and expertise in the care of the patient. If a face to face meeting cannot be achieved within 48 hours then the designated nurse on duty will carry out a telephone interview as soon as possible. This will provide essential information for discharge planning.

4. The carer will be given the room to explore what they can or cannot contribute within nursing care. The carer's expectations and concerns should be noted; it is our aim that the carer is welcome to collaborate with staff and can negotiate their input into the care of the patient which will be incorporated into the care plan.

However, the carer must be aware that the responsibility for the care remains with nursing staff. Involvement of the carer must be subject to the consent of the patient, where appropriate. The level of involvement by the carer must also be agreed by the patient.

5. Information sharing between nurse, patient and carer will be our goal, which we will incorporate into each ward's philosophy of care with the aim of involving the patient and carer in all decision making. As the carer will resume responsibility following discharge it is in everyone's interest to ensure that the carer has the relevant information and skills to manage at home with the appropriate support. This will not only aid patients and carers but also help to prevent some readmissions. It is important that the views and capacities of the carer be fully documented.

6. Explanation of probable treatment regimes and practices will be given to the carer enabling anxieties and fears to be acknowledged and explored. Treatment regimes seeking to promote independence can seem harsh to patients and carers and cause concern unless properly put in context.

7. All carers will have access to appropriate training in any relevant treatment practices e.g. Giving drinks, helping with correct positioning or specialist feeding techniques.

8. Carers can often have valuable experience of the impact of medication on the person they care for. The type, frequency and administration of medication, especially any form of sedation will be discussed and all appropriate information given by staff. Where medication is given against the judgement of the carer they will have the right to register this viewpoint in the medical notes.

9. Care for the carer should be incorporated into any treatment of the patient in a holistic manner. The role of the carer should be explored sensitively to ensure that all available help is given to complement their role both in hospital and in the community. It is the nurses' responsibility to ensure that all available channels of help are discussed with the carer, in the event that the carer wishes to relinquish their role then the final responsibility is with health and social services.

DO/07102101

APPENDIX 2

(On University of Kent headed notepaper)

Evaluation of Informal Carers' Experiences of Hospital Support.

My name is Hilary Bungay and I am a Research Associate at the University of Kent. I am conducting a research project on behalf of the Hastings and Rother NHS Trust under the supervision of Prof. Andy Alaszewski. The aim of the study is to examine carers' experiences of the care and support provided by the Trust. In particular it will examine the extent to which the Hastings and Rother NHS Code of Practice for Involving Carers which was developed with the Care for Carers Group is being implemented, so that the Trust can learn from carers' experiences and if necessary improve its services.

I would like to set up some focus groups to find out about the experiences of carers' locally and would like to invite you to attend. A focus group is a group discussion, and its purpose is to generate ideas and topics. These would then be used to produce questions for a survey that would be sent to a large number of carers in the Hastings area. The discussion would take about an hour and would take place at the Conquest Hospital. Reasonable travel expenses and caring costs would be reimbursed. The discussion would be tape-recorded, but would be completely confidential, and the tape would be destroyed once the study was completed.

If you do not want to take part in this study, your relationship with the hospital would not be in any way affected and I will not contact you again with respect to this study. If you would be interested in taking part please complete the attached form and return in the enclosed SAE. If you would like further information before completing the form I can be contacted on XXXXXXXX.

Thank you for taking time to read this and I hope to meet you soon.

Yours sincerely

Hilary Bungay

Evaluation of Informal Carers' Experiences of Hospital Support.

The person for whom I care for has within the last year received treatment as an inpatient or attended clinics at the Conquest Hospital and I would be interested in taking part in the focus group.

I care for my adult/child whose disability/illness is.....
.....

I would prefer Morning/ Afternoon/ Evening (please circle as appropriate).

I understand that I could not be identified in the report, and that the tape recording of the focus group would be destroyed when the study is completed.

I can be contacted at: Telephone No (or address if no phone).....
.....
..

Name.....
Signature.....

Focus Group Schedule

1. Introduction

- Person by person
- Emphasis on how became a carer
- What sort of caring

2. Experience of Caring

- Difficulties with caring.
- What positive aspects are there to caring

3. Support from Services

- Primary care and Social services
- Hospital
- Other

4. Carers Code

- Aware
- Elements (what elements would they want to see in the code)

5. Structure of Focus Groups

- Comments on structure of group today
- What elements would they like to see included or given greater emphasis to.
- What feed back would they like, any further involvement in project?

Evaluation of Informal Carers' Experiences of Hospital Support

Questionnaire Survey

The following questions are about your experiences as someone who cares for a person who suffers from long term illness or disability. Please answer by ticking the boxes or writing your response as requested.

Before you start

Are you at present caring for a relative or friend who suffers from a long term illness or disability who has attended the Conquest Hospital as an outpatient/inpatient/ or as an emergency in the past 12 months?

YES ➤➤ Please turnover and answer the rest of the questions and return the questionnaire in the pre-paid envelope provided. Thank you for your help.

YES I used to but stopped within the last 12 months. ➤➤ please turn over and answer the rest of the questions about the situation as it was when you were caring and return the questionnaire in the pre-paid envelope provided. Thank you for your help.

No, not within the last 12 months. ➤➤ There is no need to answer the questions. Please tick the box and return the questionnaire in the pre-paid envelope provided. Thank you for your help.

The people you care for

- Q1.** How many people with a long term illness or disability do you care for? _____
- Q2.** What is the relationship to yourself of all the people for whom you care? (Please specify e.g. mother/partner/child)

If you are caring for more than one person please could you answer the questions about the person who takes up most of your time.

Q3. How old is the person you care for?

Q4. How long have you been caring for this person?

Q5. Which of the following descriptions fits the person you care for? (Please tick all that apply.)

- | | |
|---|--------------------------|
| Frail Elderly | <input type="checkbox"/> |
| Confused Elderly (e.g. dementia, Alzheimer's) | <input type="checkbox"/> |
| Serious illness (e.g. cancer, HIV/AIDS) | <input type="checkbox"/> |
| Chest problems (e.g. Heart and lung diseases, respiratory illness, asthma) | <input type="checkbox"/> |
| Long term conditions (e.g. sickle-cell anaemia, diabetes, arthritis) | <input type="checkbox"/> |
| Physical disability (e.g. inability to walk unaided, sight or hearing impaired) | <input type="checkbox"/> |
| Learning difficulties (e.g. Down's syndrome, autism, cerebral palsy) | <input type="checkbox"/> |
| Chronic childhood disability (e.g. cystic fibrosis, muscular dystrophy) | <input type="checkbox"/> |
| Neurological (e.g. ms, stroke, Parkinson's, motor neurone disease) | <input type="checkbox"/> |
| Mental ill health (e.g. depression, schizophrenia, eating disorders) | <input type="checkbox"/> |
| Drug/alcohol dependency | <input type="checkbox"/> |
| Other. Please describe _____ | <input type="checkbox"/> |

Q6. Does this person live at the same address as you ? Yes No

Q7. How many hours out of 24 do you spend on a typical day either caring for this person or being available in case they need help?

Q8. Does anyone, such as other family or friends, regularly share caring tasks with you. Yes No .

Hospital Care

Getting to the Hospital

Q9. How do you usually travel to the hospital? (Please tick all that apply)

Public transport Private car Taxi Hospital arranges transport Other

Q10. If the your transport is arranged by the hospital how satisfied are you with this service?

Very satisfied satisfied dissatisfied very dissatisfied

If you are dissatisfied with the service please can you tell us why?

Q11. If you make your own way to the hospital by car or public transport can you tell us any specific problems you face getting to the hospital?

Out patient services

	None	1-2 times	3-5 times	6-10 times	More than 10 times
Q12. How many times in the past year have you been to an outpatient appointment with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If the answer to this question is 'None' please go to question...>>>>>**Q13**

	Yes	No	Don't know
Q12a Did the outpatient department have information leaflets for carers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q12b. Did any of the staff ask if you were a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q12c. Did any of the staff provide information about caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q12d Did any of the staff ask how you were coping with caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q12e Were you allowed to be present when the person you care for was being seen by the doctor or nurse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q12f. If the answer to Q12e was 'no' or 'don't know' would you liked to have been present?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Accident and Emergency Services.

	None	1-2 times	3-5 times	6-10 times	More than 10 times
Q13 How many times in the past year have you been to the accident and emergency department with the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If the answer to this question is 'None' please go to question...>>>>>>>>>**Q14**

	Yes	No	Don't know
Q13a. Did the accident and emergency department have information leaflets for carers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q13b. Did any of the staff ask if you were a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q13c. Did any of the staff provide information about caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q13d Did any of the staff ask how you were coping with caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q13e Were you allowed to be present when the person you care for was being seen by the doctor or nurse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q13f. If the answer to Q13e was 'no' or 'don't know' would you liked to have been present?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Inpatient Care.

	None	1-2 times	3-5 times	6-10 times	More than 10 times
Q14 How many times in the past year has the person you care for been in hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If the answer to this question is 'None' please go to question....>>>>>>>>>**Q20a**

On the Ward

	Yes	No	Don't know
Q14a. Did the ward have information leaflets for carers?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q14b. Did any of the staff ask if you were a carer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q14c. Did any of the staff provide information about caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q14d Did any of the staff ask how you were coping with caring?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

On the Ward

		Yes	No	Don't know
Q14e	Was there one nurse in overall charge of the person you care for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q14f	If yes did this nurse ask you about the help you give the person for whom you care at home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q14g	Were you allowed to be present when the person you care for was being seen by the doctor or nurse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q14h.	If the answer to Q14g was ' no ' or ' don't know ' would you liked to have been present?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q14i	Did the staff discuss the persons you care for medical condition with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q14j	If the answer to Q14i was ' no ' or ' don't know ' would you liked to have been involved?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Discharge from Hospital

Q15 How much notice were you given of when the person you care for would be discharged?

Q16 How did you feel about the amount of notice you were given?

Discharge planning

		Yes	No	Don't know
Q17a.	Were you consulted when plans were made for the person for whom you care was to leave hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q17b	Did you feel that your views were listened to by those arranging his/her discharge?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q17c	Did the hospital staff help you to prepare for when he/she left hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q17d	Were you asked whether you would be able to cope at home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q17e	Were you given a written copy of the "discharge plan" describing what would happen when he/she was discharged?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

After Care

		Yes	No	Don't know
Q18a	Were you told about the sort of care that he/she would need after leaving hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q18b	Were other care options discussed e.g. residential care/nursing home/sheltered housing/hospice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q18c	Were you offered any training to help with caring at home e.g. feeding/giving drinks/lifting and moving?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q18d	Did the hospital staff discuss with you whether the person you care for would need and health or social services after leaving hospital? (e.g. district nurse, care assistant, physiotherapist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q18e	When you left the hospital were you given a contact number at the hospital to ring for advice or help?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Medication This section asks about the medicines prescribed by the hospital.

		Yes completely	Yes to some extent	No	I didn't need an explanation	They had no medicines
Q19a	Did staff explain the purpose of medicines the person you care for was taking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q19b	Did staff explain the purpose of any new medicines the person you care for would be taking home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			Yes completely	Yes to some extent	No	I didn't need an explanation
Q19c	Did staff tell you about medication side effects to watch for when you took the person you care for home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q19d	Were you offered information about what symptoms regarding their illness or treatment to watch for after they went home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q19e	Were you given a contact number in case you needed advice about the medication?			Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>

Communication

This section asks you about communication between you and hospital staff

	Yes always	Yes sometimes	No	I had no need to ask
Q20a If you wanted to speak to the staff did you have enough opportunity do to so?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q20b Did you find someone on the hospital staff to talk through your concerns with?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q20c Were you given enough privacy when discussing the condition or treatment of the person for whom you care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q20d When you had important questions to ask the staff, did you get answers that you could understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q20e If you had any anxieties or fears about the condition or treatment of the person for whom you care did the staff discuss them with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q21 As a carer are there any improvements you would like to see to hospital services?
Yes >>Please answer question **Q22** No >>Please go to question **Q23**

Q22 If the answer to question **21** was **yes** would you like to tell us how the service could be improved?

Q23. Have you heard of a code of practise for involving carers in hospitals?
Yes No

Q24. If you were writing a list of suggestions to improve the experiences of carers when the person they care for is in hospital, what would be top of your list?

Personal details

25. What is your sex? Male Female

26. What is your age?

27. What is your marital status? Single (never married)
Married or living as married
Widowed
Divorced or separated

28. Which of these best describes your ethnic origin?

White	<input type="checkbox"/>	Pakistani	<input type="checkbox"/>
Black Caribbean	<input type="checkbox"/>	Bangladeshi	<input type="checkbox"/>
Black African	<input type="checkbox"/>	Chinese	<input type="checkbox"/>
Black (other)	<input type="checkbox"/>	Other Asian	<input type="checkbox"/>
Indian	<input type="checkbox"/>	Other (please specify) _____	

29. Are you in paid employment? Yes ➤ number of hours per week worked _____
No

**Now please check that you have answered all the questions that apply to you.
Please return the completed questionnaire in the PREPAID envelope provided.**

**Thank you very much for your help, we are grateful for the trouble
you have taken**

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