DISABLED PATIENTS IN ACUTE HOSPITAL WARDS: THE LIMITATIONS OF ROLE THEORY FOR UNDERSTANDING THE PROBLEMS OF PATIENTS AND NURSES

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DECLARATION

This thesis is my own work and no part of it has been submitted for a degree at this or any other University.

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ABSTRACT

This study explores the care provided for physically disabled people who are admitted to acute hospital wards for the treatment of short-term illness. Two groups of 75 disabled and 75 non-disabled patients were recruited for the study on a matched pair basis, and a survey of 205 nurses was undertaken. The study involved an assessment of how well disabled patients could manage eight activities of daily life at home and in hospital. The experiences of disabled and non-disabled patients in acute hospital wards were compared by assessing patient satisfaction with six different aspects of care. The views of nurses about caring for disabled patients in acute hospital wards, their experience and training in the care of disabled patients are also explored.

The study demonstrates no difference in the levels of satisfaction with care experienced by disabled and non-disabled patients. Patient satisfaction with all aspects of care was found to be associated with satisfaction with the communication of information, a factor shown to be equally important for both disabled and non-disabled patients.

It was hoped that the theory of social roles would provide a theoretical framework for understanding the position of the disabled patient on an acute hospital ward. However, in the event, role theory proved not to be entirely adequate for this purpose. An alternative model is developed which takes into account the attitudes and experiences of nurses as well as the experiences of disabled patients on acute hospital wards. This is used to suggest ways in which improvements could be made in the care of disabled patients.

CHAPTER 1

Introduction to the Study and the Formulation of Research Questions

This study began as a direct outcome of questions raised by people with physical disabilities about the care provided for them as inpatients on acute general hospital wards. In 1978 a paper was published in the nursing press (Blackwood, 1978) in which the author, a physically disabled person, gave an account of her experiences as an inpatient in a general hospital ward. The article vividly illustrates many deficiencies in the care provided and the author concluded with the following sentences:

> "In hospital I enter a world alien to my needs. My illness may be cured but at a price my dystrophy finds extortionate".

This material was brought to the attention of the Scottish Council on Disability who pursued the possibility of conducting research into acute hospital care for disabled people. The outcome of their efforts was the commencement of a research project, funded by the Scottish Home and Health Department and carried out by the Nursing Research Unit, University of Edinburgh, in collaboration with the Department of Community Medicine, University of Edinburgh. This thesis is based upon that project.

Exploratory work began for the study during Autumn 1979 with the Scottish Council on Disability arranging for a group discussion on the acute hospital care of people with long-term physical handicaps at its national forum. This was attended by a substantial number of people with various types of long-term disabilities. The main concerns of this group were not only the provision of inpatient care, but also the impact of hospital care upon their lives following their return home. On the basis of the comments made during this discussion, a checklist of items was constructed which provided a loose structure for in-depth exploratory interviews with six people with experience of long-term disablement and who had been inpatients in acute general hospital wards. The items were:

(1) Overall opinions of hospitalisation.

(2) Availability of suitable equipment and facilities.

(3) Perceived quality of nursing care, particularly regarding the individual's disablement.

(4) Communication of information.

(5) Smoothness of interactions with hospital staff.

(6) Maintaining a role in self-care and in the nursing management of the chronic condition.

(7) Smoothness of transfers between the hospital and community care settings.

(8) The impact of the inpatient experience upon the individual after hospital discharge.

Information was also collected on medical and social background, the impact of physical limitation on the individual's life, and the circumstances of hospital admission. These interviews took the form more of a conversation about hospital care than a formal interview on the subject. Very brief notes were taken during the discussions and then a fuller documentation was written up afterwards. All the handicapped individuals seen during this exploratory phase were asked specifically about the positive, as well as any negative experiences they may have had as inpatients.

The body of information obtained from the initial group discussion and the subsequent interviews served to reinforce the impression that disabled patients may be experiencing a range of difficulties both between admission and discharge from hospital, and on transfer from the hospital to the community, including the longer term effects of hospitalisation upon the life of the individual. This report is concerned with the experiences of patients with long-term handicaps between admission and discharge from acute hospital care.

The major concerns of the disabled patients were: the lack of appropriate equipment and facilities in hospital; a general lack of awareness by nurses of the special needs of disabled people; difficulties in communicating their needs to the nursing staff; difficulties in continuing smooth relationships with nurses; difficulties in making a positive contribution in the management of disablement while in hospital; and the anticipation of a possible increase in disability following hospital admission, for example, through the development of pressure sores. Although the evidence which was already available could be said to represent the subjective views of a small minority of disabled people, it was felt that the consistency of information obtained indicated that problems of a similar nature could exist for this segment of the hospital inpatient population.

During the exploratory work, five nurses of different grades who worked in acute wards were interviewed at length about nursing patients with chronic disabilities. A list of topics which complemented the information obtained during the patient interviews was identified to provide a structure for the interviews with nurses. These included the following topics:

(1) The recognition of chronic physical disablement.
(2) The frequency of contact with disability.
(3) The extent of training and instruction undertaken re. disablement.
(4) Difficulties in caring for patients with disabilities.
(5) Perceptions of "special needs" of patients with disabilities.
(6) The effect upon ward routines, patients and nurses when patients with disabilities are admitted to the ward.
(7) The smoothness of interactions with patients with disabilities.
(8) Communicating with patients with disabilities.
(9) The nurse's role in care.

These exploratory interviews suggested that nurses recognised problems in caring for patients with disabilities in acute care settings. For these nurses, difficulties were perceived in terms of inadequate nurse training in the care of patients with disablements. Some felt this had resulted in difficulties in communicating with and interacting with disabled people and that the care they had provided was less than optimal. All five nurses reported that the lack of suitable ward facilities, equipment and low staff numbers aggravated these problems.

The findings of this exploratory work confirmed the need to assess more systematically the extent of these problems, in particular to discover whether the problems reported by nurses and disabled patients were related to one another, and to what extent these problems arose from the general circumstances of acute hospital care of patients, disabled or not.

A literature search was undertaken, involving the use of the International Nursing Index, Index Medicus, and the computer-based bibliographies, Blaise, Dialog and Medline. This search failed to locate any published works relating to the acute hospital care of disabled people. A subsequent survey of 64 voluntary associations concerned with disablement, in relation to a separate project (Sklaroff and Atkinson, to be reported), found only one association produced a pamphlet on this subject for its members (British Association for the Hard of Hearing).

The aims, of what was inevitably an exploratory study, were therefore formulated on the basis of the experiences reported by the disabled people and nurses included in the exploratory work. The study aims were stated as follows:

1. What provisions are made on acute hospital wards to meet the needs of disabled patients, in terms of facilities, equipment and manpower?
2. To what extent are nursing staff trained and experienced in the care of patients with physical disablements?
3. To what extent do changes in care routines affect the patient with chronic physical disabilities?

4. What are nurses' views regarding caring for patients with long-term disablements on acute hospital wards?
5. Are there differences in nurses' and patients' views of the role the patient should take in his care?
6. Do disabled and non-disabled patients experience different levels of satisfaction with nursing care?

In order to further illuminate the findings these practical research questions may provide, the general aims of the study, patients, nurses and disablement are now discussed in the context of a theoretical framework drawn from the social sciences.

CHAPTER 2

Theoretical Framework: Role Theory

Theoretical perspectives which have been applied to further the understanding of the position of disabled people and their interactions with others have often centred upon the notions of stigma and deviance (Goffman, 1963; Comer and Piliavin, 1974). In relation to the acute hospital care of people with disabilities, it was not known whether these factors were of any importance. During the exploratory interviews it was shown, however, that disabled respondents certainly had experienced difficulties in their relationships and interactions with nurses, but these seemed to be related to the problems of maintaining an active role in care rather than to the problems of stigma and deviance. Indeed a great deal of concern was expressed about being able to make a positive contribution to the methods in which nursing procedures and other treatments were carried out for them as inpatients on acute hospital wards.

A review of the literature related to the theory of social roles showed that its concepts could enhance the understanding of the reported difficulty of disabled patients maintaining an active role in care and the effect that this may have upon their relationships and interactions with nurses. Some of the assumptions of role theory and its previous applications to the roles of patients and disabled people could also be empirically tested in a situation to which role theory has not been previously applied.

The following discussion provides an account of the general formulation of role theory, a review of its application to the study of health and illness behaviour, and finally theoretical questions are formulated for empirical testing.

ROLE THEORY

The essence of role theory is that when people occupy social positions their behaviour is largely determined by what the incumbent of a position sees as appropriate behaviour for that position and by what others who interact with the incumbent see as appropriate behaviour. The appropriateness of that behaviour leads to either positive reinforcements or negative sanctions being applied to the incumbent by those with whom he is interacting. The concepts central to the study of roles which are relevant to the present study, i.e. role, role position, role expectations, role conflict and role strain, are now discussed.

Role

Gross *et al*. (1958) distinguish three different conceptions of role. First those conceptions which include normative culture patterns, as used in the work of Linton (1936). For Linton the social system was the sum total of ideal patterns which control the reciprocal behaviour between individuals and between individuals and society. Status and role are here elaborations of these ideal patterns. A status is a collection of rights and duties and role is the dynamic aspect of status. A second conception of role is where it has been treated as how an individual defines his situation with reference to the social position of himself and others. In this sense Sargent (1951) conceived role as social behaviour which seems situationally appropriate to the actor in terms of the demands and expectations of those in his group. The third conception treats role as the behaviour of actors in specific social positions and refers to what the actors actually do. It does not therefore refer to normative elements of behaviour (Davis, 1949).

Gross et al. (1958) concluded that the majority of role definitions appeared to contain three basic elements: (1) individuals in social locations; (2) their behaviour; (3) the expectations of others. The normative element of behaviour is almost always included, expectations are central to role and these can be held on the part of the self, the group, or society as a whole.

Role Position

Role position can be defined as the location of an actor or class of actors in a system of role relations. While some commentators have used the term "status" to denote social location, both Dahrendorf (1968) and Gross et al. (1958) reject the word on the grounds that it infers a system of ranking whereas position is neutral. Gross et al. (1958) outline two dimensions along which role positions should be specified; these are the relational and the situational. Relational specification involves examining positions counter to the focal position, i.e. the position of major interest.

For a given research problem a limited number of counter positions may be described, but a focal position can not be fully described until all counter positions have been considered. One of four models may be utilised to delimit the number of positions considered. The "dyadic model" involves concentrating on only one focal and one counter position, for example patient and nurse. The "position centric model" would, in the context of the previous example, entail a consideration of the patient as focal, and a range of counter positions, possibly including nurse, doctor, physiotherapist and social worker. The third framework is termed the "system model" and is similar to the position centric model only that the relationships between all parties are examined rather than just those between focal and counter positions. Finally the "multiple systems model" refers to a situation where a focal position is considered in the context of several systems. For example, the role of doctor could concurrently involve roles in relation to the systems of hospital, professional organisation and university faculty. The situational specification of positions describes the setting within which the position is studied.

Role Expectations

Gross et al. (1958) define expectations as "an evaluative standard applied to an incumbent of a position", and Sarbin and Allen (1968) define role expectations as being made up of rights, privileges, duties and obligations of the occupant of a position in relation to persons in counter positions. In other words, role expectations can be seen as the conceptual link between the social structure and role enactment or actual behaviour, operating as imperatives for a person's conduct in enacting a role.

Since individuals tend to act in conformity to role expectations the clarity and consensus of expectations determine the degree of appropriateness of behaviour and therefore facilitate social interaction by providing actors with a means of reciprocal prediction of behaviour (Sarbin and Allen, 1968). Role expectations also provide constraints upon the individual's behaviour. Dahrendorf (1968) distinguishes three types of expectation, each of which is associated with a particular type of constraint or category of sanctioning behaviour.

If role expectations are unclear actors are uncertain as to what constitutes appropriate behaviour which will result in unpredictability and ineffective social interaction. Sarbin and Allen (1968) outline three situations pertaining to vague or conflicting expectations. First, expectations may be vague, ill-defined or unclear. Second, there may be lack of agreement among occupants of complementary roles. Third, there may be incongruity between the actor's expectations for his own role (role conception) and the role expectations held by his audience.

Role Conflict

When an actor finds himself in a position where contradictory role enactments are required role conflict is said to occur. Two forms of role conflict have been identified in the literature, inter-role and intra-role conflict. Inter-role conflict refers to the occupancy of two or more role positions which have incompatible role expectations. For example, a salesman would experience such conflict if his employer expected him to entertain clients in the evening while his wife expected him to stay at home. Intra-role conflict occurs when an actor perceives others hold different expectations of him as the incumbent of a single position. For example, local constituents may expect a member of parliament to speak on their behalf while the political party whip may expect him to follow a party line which conflicts with the wishes of his constituents.

Role Strain

The consequence of role conflict is role strain and is experienced by the incumbent of a position to which conflicting expectations apply. Goode (1960) defines role strain as "the felt difficulty in fulfilling role expectations". The state of role strain has been characterised by the terms "anxiety", "frustration", "tension", "apathy" and "futility". Not all commentators use the term "strain" but equivalent states are widely referred to in the literature. For example, Corwin (1961) and Kramer (1968) use the term "role deprivation".

Several studies have examined the effects of conflicting or incongruous role expectations and the associated role strain. In general these works have shown the consequences of this type of situation to be undesirable. In the field of education, Bible and McComas (1962) found that dissatisfaction with social interaction was linked to lack of consensus of expectations between complementary roles, and Greene and Organ (1973) found role conflict to be associated with low job satisfaction. In the context of health care, Larson and Rootman (1976) found that patients whose doctors behaved in accordance with their expectations tended to be more satisfied with their care than those whose doctors did not meet their role expectations.

ROLE THEORY AND THE STUDY OF HEALTH CARE AND ILLNESS BEHAVIOUR

Role theory has been widely applied to the study of health care both from the points of view of patient and professional roles (Hardy and Conway, 1978). The application of role concepts to the field of illness was given a major boost with the publication of Parsons' (1951) seminal discussion of the sick role. Since then much research has been undertaken to verify, refute or to extend the applicability of Parsons' conceptualisation of the sick role.

Parsons' model has been appropriately described by Segall (1976) as an ideal type model of the sick role, rather than as a description of empirical reality. Parsons held that in Western societies institutional uniformities determine a characteristic sick role through four interrelated, normative role expectations. These consist of two major rights accorded to, and two major obligations required of the sick by society. More precisely the four expectations which determine the sick role are: (1) the right of the occupant of the sick role to be exempt from responsibility for his incapacity; (2) the right to be exempt from the responsibilities and obligations of his former roles; (3) the duty to recognise that illness is inherently undesirable, to try to get well and therefore relinquish the sick role as soon as possible; and (4) the duty to obtain help from technically competent persons and to co-operate with them in the process of recovering health.

These are the patterned expectations which define the norms and behaviour of the sick individual and those who interact with him. For the sick person a deviant status is implied, that is deviant from the well population, and his role is characterised by co-operation and motivation to get well.

While the sick role model has been widely accepted as a valid point of departure for much research into sick role behaviour it is subject to severe limitations. Indeed Parsons acknowledged in his original discussions that modifications were required to fit various dimensions of the sick role (Parsons, 1951, p. 436). The major criticism of Parsons' model is its failure to account for the diversity of expectations people hold about illness and the sources of variation in these expectations.

It is not surprising that studies of acceptance of sick role expectations have reported somewhat conflicting findings. Twaddle (1969), in a study of sick role expectations, found seven different patterns of acceptance and rejection amongst the four classical sick role expectations. This study was, however, based upon a small sample of 29 and consequently multivariate patterns could not be explored. Several studies have reported variations in sick role acceptance in relation to socio-cultural variation. Segall (1976) reported conflicting expectations between different religious groups in a study of Jewish and Protestant housewives. Mechanic (1962) maintained that age, sex, importance of social roles and learned responses to illness affect sick role behaviour. Arluke et al. (1979) showed that differences in sick role expectation did differ between different segments of society but as significant variations were small, that a high degree of consensus existed. The significance of this study is questionable because there was a low response rate (49%) and any consequent bias is unspecified by the authors.

A further source of variation in sick role expectations lies in the nature and severity of the individual's illness. In Segall's (1976) consideration of the sick role concept he states:

> "... the dimensions of the Parsonian sick
> role model are relative to the nature
> and severity of illness".

Application of the sick role concept to situations other than acute illness has been considered in relation to various human conditions of interest to medicine although not always specifically illness. These include psychiatric illness (Blackwell, 1967; Petroni, 1972); ageing (Lipman and Sterne, 1969); pregnancy (McKinley, 1972); and chronic illness (Thomas, 1966; Kassebaum and Baumann, 1965; Callahan et al., 1966). Each of these situations presents problems for application of the sick role concept. In this study only the case of chronic illness and the sick role is considered.

SICK ROLE AND CHRONIC ILLNESS

The characteristics of chronic illness differ from those of acute illness in terms crucial to the normative expectations associated with the classical sick role. Chronic illness is by definition not temporary and consequently the expected commitment of the role incumbent to get well is either inapplicable or at least requires re-specification.

Many people with chronic illness are not so incapacitated as to relinquish all other roles. The assumption of the dominance of the sick role to the exclusion of other role obligations is unwarranted in the case of chronic illness. Hence the degree to which chronic illness isolates the individual from the norms of the well population becomes questionable (Segall, 1976; Kassebaum and Baumann, 1965).

Callahan et al. (1966) in their consideration conclude the sick role in chronic illness is only partially comparable to the role played in acute illness. In a similar vein Kassebaum and Baumann (1965), reporting research findings, conclude that differences in sick role expectations could not be simply explained by demographic and socio-economic variations alone, but that the person's accustomed roles and the effects of the person's diagnosis on his capacity to perform them also exert important influences.

ROLES AND DISABILITY

The sick role as conceptualised by Parsons has clear limitations and fails to account for behavioural expectations in relation to the chronic sick. Thomas (1966), in a discussion of disability from the perspective of role theory, provides an illuminating extension of sick role in relation to behavioural changes associated with disablement. Thomas delineates and analyses five disability related roles referred to as the:

(1) disabled patient; (2) handicapped performer; (3) helped person; (4) disability co-manager; (5) public relations man. These five roles designate aspects of the disabled person's behavioural repertoire and the behaviours of those with whom he interacts. Thomas maintains that one or more of these roles should apply to every disabled individual at certain times.

The "disabled patient" role is characterised partly by sick role expectations and partly by expectations related to the hospital sub-culture, i.e. patient role. Thomas refers to the expectations of patient role as set out by King (1962) and comprise of dependence and compliance, the non-fulfilment of normal role obligations, the de-emphasis of external power and prestige, the graceful bearing of pain and suffering, and the desire to get well. (Patient roles are considered in greater detail below). The expectation of the patient desiring to get well is elaborated by Thomas to an expectation of the disabled person making the most of his capabilities within the context of the rehabilitation services. In addition to this set of expectations, subsumed under the disabled patient role, Thomas includes the tolerance of prognostic uncertainty and that the individual defines himself as sick.

The role of "handicapped performer" comes directly from a loss in functional capacity which variably limits enactment of other normal life roles. It is a collection of behaviours adopted as substitutes for those lost or impaired.

The "helped person" role refers to the disabled individual's response to becoming an object of aid. The help required may be minimal or otherwise but nonetheless it constitutes a deviation from the Western cultural norm of independence.

The role of "disability co-manager" (a term borrowed from Wright, 1960) refers to the disabled person as becoming actively involved in attending to day-to-day care of his condition, e.g. administration of medication, carrying out exercises and participating in decisions about his care and rehabilitation.

The fifth disabled role considered by Thomas is that of "public relations man" and refers to the need for the disabled individual to inform others about his situation. In the words of Thomas:

> "The relative uniqueness of the particular individual's impaired condition and the associated ignorance of others places a burden of explanation and interpretation upon the disabled over and above that which the non-disabled carries".

The nature of information to be conveyed is broad in scope and relates to the nature of disease, the extent of impairment disability and handicap, management and treatment of the condition and rehabilitation regimes.

As stated above, not all of these roles may be enacted at any one time. In the context of this study it is held that the roles of disability co-manager and public relations man are of particular significance when a disabled person takes up the role of patient on an acute ward.

THE PATIENT ROLE

The patient role can be seen as an extension of the sick role (Tagliacozzo and Mauksch, 1972). Hospitalisation adds further rights and obligations to the sick role which are legitimised by the organisation. That is the sick person takes up a position within an organisation which is accompanied by implications for normative compliance and sanctions. Organisational forces are widely seen as determining a role characterised by patient compliance to hospital regulations and routines, while decisions are made for the patient by medical, nursing and other health care professionals (Mauksch, 1962; King, 1962; Freidson, 1970). Mauksch (1962) states:

> "... the patient's dependency manifestations are, in reality, inevitable, because they are the direct consequences of a social system that forces him to become childlike, to manifest dependent relationships, and to renounce and abdicate the independence that characterises adult human behaviour". (p. 136)

Freidson (1970) maintains that doctors and nurses reduce patient autonomy in order to create a convenient atmosphere in which to deliver care. Hospital rules are for the benefit of the organisation rather than for the convenience of the patient. Freidson argues that in order to maintain patient compliance doctors and nurses rely upon procedures to encourage the patient to adopt a submissive role. These procedures are enacted through the control of information and by diminishing the social status of the patient, or in Goffman's terms, "treating the patient as a non-person" (Goffman, 1961).

Clearly, as a general rule, medical and nursing staff are in possession of a greater depth of knowledge about patient care and treatment than are patients. Despite their professional expertise it has been found that doctors and nurses deliberately limit the flow of information to patients to minimise questioning and interruptions, and to obscure their own shortcomings from the scrutiny of patients (Roth, 1963; Brown, 1966; Skipper, 1965).

Treating patients in a de-personalising manner assists in avoiding difficulties while doctors and nurses carry out the "mechanical service role" in a situation where the patient can observe the quality of care. Goffman (1961) states:

> "One solution is anaesthesia; another is the wonderful brand of non-person treatment found in the medical world, whereby the patient is greeted with what passes as civility, and said farewell to in the same fashion, with everything in between going on as if the patient weren't there as a social person at all, but only as a possession someone has left behind". (p. 298)

In a similar vein Lorber (1976) states:

> "For the medical staff, the more like a helpless object the patient is, the easier they find it to do their job. But if the patient cannot be rendered insensate his or her views are ignored completely, the routinisation of work is helped when the patient is objective, instrumental, emotionally neutral, completely trusting and obedient". (p. 214)

Additional evidence of de-personalising treatment of patients comes from Cartwright (1964) who found doctors neglected even ordinary civilities such as introducing themselves to patients.

Clearly passivity is a major element in the role of a patient and, although it may be resented by the patient, pressures are brought to bear upon him to acopt a submissive position. Tagliacozzo and Mauksch (1972) found that many patients perceived the rules for the proper conduct of patients, were to have trust and confidence in the physician and to co-operate with him. With reference to nurses, patients were convinced "proper conduct" constituted being respectful, not demanding and being considerate. Further many were afraid that if they did not keep quiet and do as they were told, they would not get adequate care. Lorber (1976), in a study of 103 surgical patients, found doctors and nurses termed patients who interrupted routines and made extra work for them as "problem patients". Possible consequences of this were premature discharge, referral to a psychiatrist and being tranquillised. Lorber concludes:

> "Thus the consequences of deliberate deviance in a general hospital can be medical neglect or a stigmatising label, while conformity to good patient norms is usually a return home with only a surgical scar". (p. 224)

Patients would seem to have little choice but to conform to the organisational pressures exerted on them. Any reluctance to conform would gain little support from fellow patients (Freidson, 1970) and Goffman (1961) points out that even visiting relatives may be co-opted by the nursing and medical staff and not fully support the patient's non-conformity.

But not all patients conform to the institutional norm of passivity. Coser (1962) described patients who completely accepted a dependent role as "primary" in orientation while others who felt the patient should be autonomous, critical and well-informed as "instrumental" in orientation. Shiloh (1965) made a similar distinction between passive and actively orientated patients but used the terms "hierarchical" as referring to passive and "equalitarian" as referring to actively orientated patients.

These studies reported that active patients, i.e. equalitarian and instrumental, tended to cause disturbances in hospital routines (Coser, 1962), perceived themselves as equal partners with the hospital to achieve the mutual goal of successful treatment, and tended to complain (Shiloh, 1965). Lorber (1976) found 27% of her sample held attitudes which did not conform to the norm of compliance and submissiveness to hospital routines.

A number of socio-demographic variables have been shown to be associated with an active patient orientation. Cartwright (1964) found that younger patients from the professional groups were more likely to ask questions of the medical staff. Lorber (1976) also found that younger, better educated patients were less likely to express very conforming attitudes. The same study reported no difference in attitude between men and women and that the data suggested some differences in attitude existed between different ethnic-religious groupings.

The stage at which the patient is in the course of his illness, e.g. critically or mildly ill, has implications for nurse-patient relationships. A major expectation of the patient is his desire or motivation to relinquish the patient role as soon as possible and to return to his accustomed way of life. Any signs that the patient lacks this motivation and does not wish to relinquish the position of patient can rapidly lead to labelling as a malingerer by medical and nursing staff.

Branch and Paxton (1976) modified a model developed by Sasz and Hollander (1956) illustrating three phases of the nurse-patient relationship which occur during the course of a patient's recovery. These phases are: (1) when the patient is critically ill, in a totally dependent state and the passive recipient of care from the active nurse; (2) the patient remains ill but is able to co-operate with the nurse who acts as a teacher and enabler, the patient is moving from a dependent to an independent state; (3) the patient is mildly ill and the relationship between patient and nurse is characterised by mutual participation. Consequently the patient gradually prepares himself for independence in the world of the non-sick.

Coser (1962) also considers the changing orientation of the patient through the course of the illness. Coser sees the imperatives of passivity and effort as contradictory, the patient who adjusts best to hospital demands may be the least well-prepared to re-enter society. The level of passivity appropriate for life in hospital may inhibit efforts to regain independence.

The smooth continuum from patient dependence to independence implied by the Sasz and Hollander model has been described as the healthy dynamic of nurse-patient roles (Bradly and Edinberg, 1982, p. 152). The operating mechanism of this continuum, i.e. nurses and patients assuming changing roles, is inhibited not only by nurse and patient perceptions of the patient's capabilities but by institutional pressures to retain the patient's acceptance of hospital routines throughout his admission.

THE ROLE OF THE DISABLED PATIENT IN AN ACUTE CARE SETTING

The individual with a long-term physically disabling condition clearly receives no dispensation from acute illnesses which may require treatment on an inpatient basis. As a hospital patient the disabled person has to concurrently perform the roles associated with being a patient and being a disabled person. Three of the role types set out by Thomas (1966) in his taxonomy of the roles of disabled persons, have particular relevance for the disabled person as a patient. These are the disabled patient, the disability co-manager and the public relations man. Although Thomas did not go on to amplify interactions between these role entities, it seems likely that a disabled person who needs to take on the role of patient will experience conflict with the other roles of disability co-manager and public relations man.

The patient role as discussed above, and as described by Thomas, is a role characterised by submission, acceptance and passivity. If only to prevent the deterioration of a disabling condition, the disabled individual must become an active participant in attending to his own impairment during his life in the community. This may involve the administration of medications, injections, following rehabilitative exercise programmes, selecting physical aids and ensuring they are appropriate for use. In rehabilitation medicine and in the care of chronic illness the individual is positively encouraged to take an active role in his own care (Martin, 1978). Indeed, failure to adopt an active role may result in the ultimate failure of the treatment itself. The role of disability co-manager places the disabled person in a position to acquire a wide knowledge of his condition and its treatment, possibly over a period of many years. Armed with this accumulated knowledge the disabled person is adequately prepared to take on the role which Thomas refers to as that of public relations man.

For the continuing care and treatment of an individual's impairment it would appear that the disabled person must impart explanations about his condition, his rehabilitation regime and the general management of his disablement. Communication of this information may be seen as being of prime importance should the disabled person be admitted to an acute hospital under the care of a new set of carers who are unfamiliar with his particular care routines. The continuation of these routines, although of great importance to the disabled patient, may not fit into the routine of a hospital ward without causing some disruption or inconvenience for nursing staff.

In order to ensure that usual care routines are adhered to in hospital, the disabled patient is to some extent unable to entirely conform to the passive and unquestioning role preferred for the conduct of patients. Therefore the disabled patient who feels unable to adapt to ward routines, or whose own care routines conflict with those of the ward, is placed in a position where conflict with the nursing staff may be difficult to avoid. Even relatively minor nursing procedures, such as being made comfortable in bed, offer countless alternative ways to approach a problem yet only one or two methods may be suitable and these may only be known to the patient himself. Consequently if the disabled patient is going to have an at all comfortable stay in hospital the occasions for requesting alternative equipment, modified treatment techniques and other procedures is seemingly limitless.

THEORETICAL FORMULATION OF STUDY

From the point of view of role theory the present study could be formulated as an investigation into whether the disabled patient admitted to an acute hospital is faced by conflicting role requirements with consequential role strain. It could be that the disabled patient is unable to adapt to the institutional expectation of the passively orientated patient without relinquishing an accustomed active role in the care of his disabling condition. If this is the case, to relinquish his role in long-term care may at best result in unnecessary discomfort during his hospitalisation or at worst a long-term deterioration of his long-term disablement. On the other hand, retaining an active role in his own care may result in the patient being viewed as "demanding" by the nursing staff and a state of conflict may be created between the two parties. In the terms of role theory, the consequences of this conflict could be the creation of role strain, reflected in poor nurse-patient relationships and the ineffective communication of information between nurse and patient.

This study aims to substantiate or refute the following propositions derived from this discussion of role theory:

1. Disabled people will view the patient role as more actively orientated relative to non-disabled people, and nurses will view the patient role as more passive in orientation relative to disabled people.
2. Where nurses' and patients' views of the patient role are incongruent, patients will be less satisfied with their care generally and particularly with their interactions with nurses and the communication of information.
3. That incongruency in views of the patient role will occur more frequently between nurses and disabled patients than between nurses and non-disabled patients and consequently disabled patients will more frequently experience less satisfaction with their interactions with nurses and with the communication of information than non-disabled patients.

The dyadic model of role positions was adopted as a focus for the study, with the patient occupying the "focal" and the nurse occupying the "complementary" roles. The practical context of the research led to the choice of the dyadic model of role positions since the disabled patient and the nursing problems were the dominant interests of the study.

CHAPTER 3

Research Design and Methods

In order to test the theoretical assumptions described and to answer the practical questions set out in the introduction, three groups of respondents were required. First, a group of patients with chronic physical disabilities who had experienced short-term admission to acute hospital wards. Second, for purposes of comparison, a group of patients who had no physical disabilities. Third, a sample of nurses who had cared for disabled patients whilst working on an acute hospital ward (Figure 1).

SAMPLE DEFINITION

Long-Term Disablement

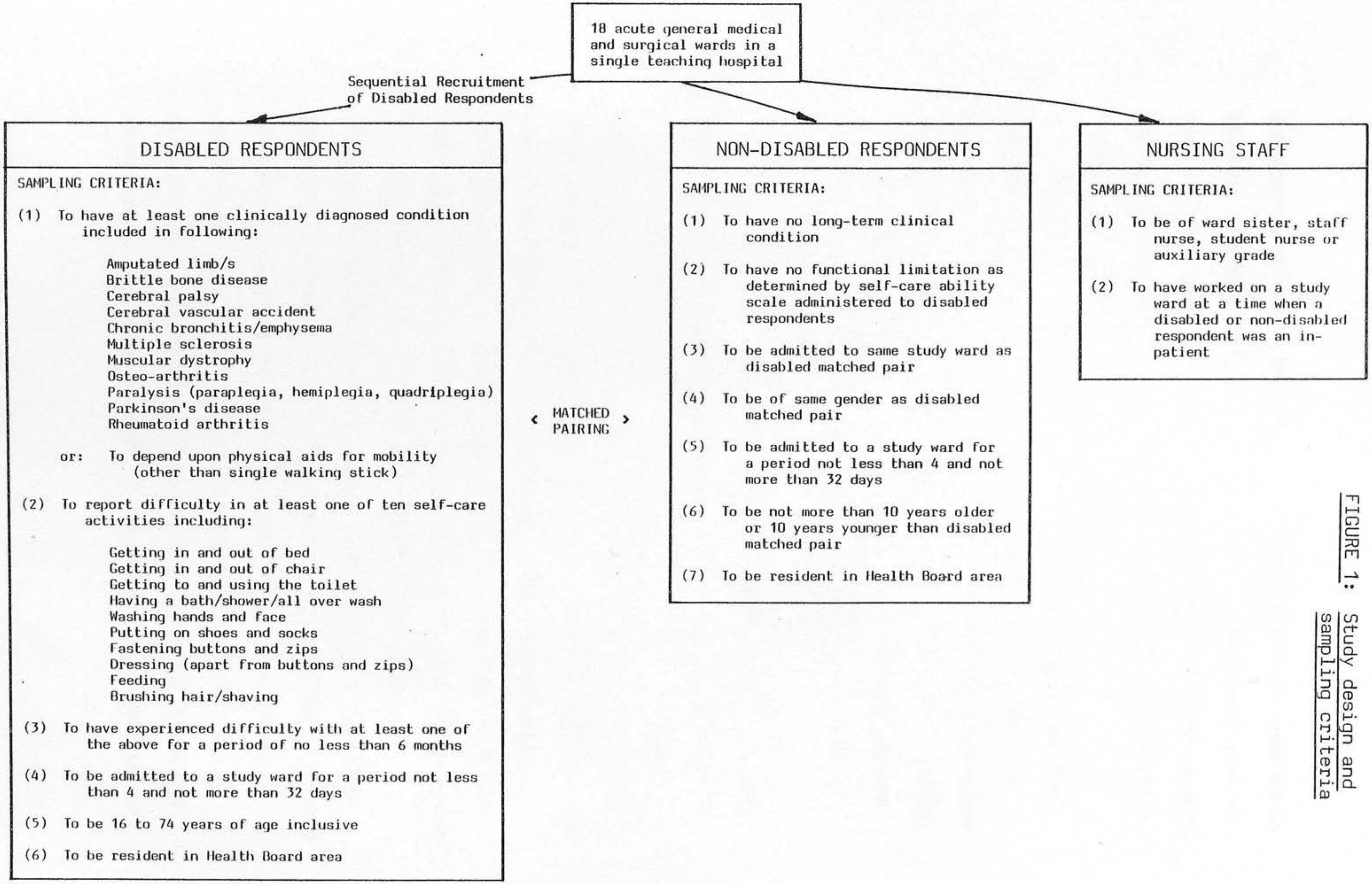
In order to recruit a group of patients who had functional limitations similar to those of the patients interviewed during the exploratory phase, a definition of long-term disability was required. For this study long-term disablement was operationally defined in terms of three criteria:

(1) a specific medically recognised disabling condition, or a known dependence on aids to mobility;

(2) a specified level of functional limitation;

(3) a specific duration.

Medical condition was used to provide a convenient means of rapidly screening for disability a potentially large number of hospital inpatients. The medical conditions were selected to meet the following criteria: their frequency in general hospital wards was sufficient to secure an adequate number of potential respondents for the research; they were known to be associated with



DISABLED RESPONDENTS

SAMPLING CRITERIA:

(1) To have at least one clinically diagnosed condition included in following:

Amputated limb/s
Brittle bone disease
Cerebral palsy
Cerebral vascular accident
Chronic bronchitis/emphysema
Multiple sclerosis
Muscular dystrophy
Osteo-arthritis
Paralysis (paraplegia, hemiplegia, quadriplegia)
Parkinson's disease
Rheumatoid arthritis

or: To depend upon physical aids for mobility (other than single walking stick)

(2) To report difficulty in at least one of ten self-care activities including:

Getting in and out of bed
Getting in and out of chair
Getting to and using the toilet
Having a bath/shower/all over wash
Washing hands and face
Putting on shoes and socks
Fastening buttons and zips
Dressing (apart from buttons and zips)
Feeding
Brushing hair/shaving

(3) To have experienced difficulty with at least one of the above for a period of no less than 6 months

(4) To be admitted to a study ward for a period not less than 4 and not more than 32 days

(5) To be 16 to 74 years of age inclusive

(6) To be resident in Health Board area

NON-DISABLED RESPONDENTS

SAMPLING CRITERIA:

(1) To have no long-term clinical condition

(2) To have no functional limitation as determined by self-care ability scale administered to disabled respondents

(3) To be admitted to same study ward as disabled matched pair

(4) To be of same gender as disabled matched pair

(5) To be admitted to a study ward for a period not less than 4 and not more than 32 days

(6) To be not more than 10 years older or 10 years younger than disabled matched pair

(7) To be resident in Health Board area

NURSING STAFF

SAMPLING CRITERIA:

(1) To be of ward sister, staff nurse, student nurse or auxiliary grade

(2) To have worked on a study ward at a time when a disabled or non-disabled respondent was an in-patient

FIGURE 1: Study design and sampling criteria

long-term functional impairment; and were separately recorded in hospital discharge summaries in Scotland. A provisional list of such conditions was taken from Harris (1971) and included cerebral palsy, multiple sclerosis, osteo-arthritis, rheumatoid arthritis, haemophilia and Parkinson's disease.

Discharge summaries from the medical and surgical wards of the main study hospital were examined. It was found that 346 patients with one or more of these conditions had been discharged over a one year period. This information confirmed the viability of a quantitative and prospective approach to the study and subsequently provided material upon which to base a definition of short-term hospital admission.

This list of medical conditions was modified before it was applied in the screening procedure. Haemophilia was excluded as a specialist unit for its treatment existed within the study hospital area. In its place and to augment numbers, hemiplegia, quadriplegia, paraplegia, amputations and chronic obstructive airways disease were added. Brittle bone disease and muscular dystrophy were also added, despite their rarity, because of the very special nursing requirements of patients with these diagnoses.

The use of a small number of conditions as a patient screening device meant that possibly large numbers of disabled inpatients with other disabling conditions would not be considered eligible for the sample. An additional category was therefore added to the list. Any patients who depended upon aids to mobility, i.e. leg calipers, walking sticks, walking frames and wheelchairs, were also included in the study. The final list of conditions included in the screening phase of the main study is shown in Figure 1.

Level of Functional Limitation

As neither a diagnostic label nor the use of aids to mobility themselves reflect the extent of restriction of activity (Harris, 1971), an assessment of the degree of functional restriction was also required. A similar assessment was also made of the non-disabled respondents in order to exclude any who were experiencing a functional limitation.

It was considered that this assessment should be undertaken using an index based upon abilities to perform the activities of daily life. The criteria by which a measure was chosen were as follows:

(1) It should have been subjected to tests of reliability and validity during its development and preferably have been used in published research.

(2) It should be based upon respondents' self-reporting rather than depend upon physical tests, the latter method being inappropriate for use with acutely ill patients.

(3) It should be brief and simple to administer so as not to over-burden acutely ill people with lengthy questioning.

(4) Preferably it should provide a scaled index reflecting the degree of incapacity.

A review of methods of classification and assessment of disablement was undertaken with these criteria in mind. The self-care ability scale as used by Harris (1971) was finally selected for use in the study. While this scale does have weaknesses, particularly in relation to its additive scoring system and its tendency to under-estimate minor difficulties amongst the more affluent groups, no scale reviewed stood out as being markedly superior to that employed by Harris (see Duckworth (1983) for discussion of the Harris scale). The Harris scale had a major advantage over the other scales in that national statistical data based upon it were available. It also satisfied most of the other selection criteria outlined above. The scale is based upon the self-report of respondents, covers a range of activities of daily life, and provides a score ranging from 1 to 8 indicating the degree of self-care handicap (Figure 2).

The extent of questioning required to complete this scale was greatly increased in the Harris (1971) survey by their need to distinguish three groups amongst those with very severe handicap and in need of special care. For the present study the length of questioning was much reduced by collapsing the three highest levels of handicap to form one group. In view of the very small proportion of the population estimated by Harris to be experiencing such severe degrees of handicap division of this group, in a relatively small sample survey, would have been of little practical value. The modified version of the Harris scale used for the study is reproduced in Appendix 1a.

FIGURE 2: Classification scheme of the Index of Self-Care Handicap (after Harris, 1971)

VERY SEVERE in need of special care	1.	Toilet help every night and feeding and dressing, or washing and toilet.	Classified as one group for purposes of study
	2.	Regular nightly toilet help and help feeding/washing/dressing, or much daytime feeding/washing/toilet help.	
	3.	Bed or chair-fast, or mentally unable to care for themselves - but less help than 1 or 2.	
SEVERE	4.	All items difficult or most difficult and some impossible.	
	5.	Most items difficult or 3-4 difficult and some impossible.	
APPRECIABLE	6.	Difficulty with some items or help needed with some minor items.	
MINOR/NONE	7.	Difficulty one or two items.	
	8a.	(Non-motor): no "physical" impairment problems but main impairment sensory, etc.	Respondents categorised under 8a or 8b were considered as ineligible for inclusion as a "disabled" respondent
	8b.	(Motor): no self-care difficulty.	

Chronic Disablement

The specification of a precise temporal boundary to chronicity is clearly an arbitrary way of separating acute from chronic illness. The main requirement for the study definition was that patients should have been experiencing difficulty in some aspect of self-care long enough to have modified their routines in some way in order to cope with their disablements, by approaching tasks in alternative ways, by modifying their environment, or by obtaining physical aids. Therefore a period of six months was chosen as a sufficiently long period for this to have happened.

For each activity reported as being difficult the patient was asked for how long this had been so. To be eligible for inclusion in the study the difficulty must have been experienced for a minimum of six months for at least one of the activities of self-care.

Short-Term Hospital Admission

The "acute" care setting of the study required that a limit was also placed upon the duration of hospital stay. Studies such as Butler and Pearson (1970) have systematically formulated definitions of "short-term" hospital admission. For the present study the definition of acute was based on an analysis of discharge summary statistics from the study hospital. These data showed the rate of discharge to be relatively high for the first three days following admission after which the rate progressively slowed until the 32nd day when 90% of all patients had been discharged. Patients who remained in hospital after 32 days had elapsed tended to have fairly long spells of inpatient care, their average length of stay being 120 days. For purposes of the study "short-term" admission was therefore defined as being from four to 32 days of inpatient care.

Age of Respondents

Outside the hospital the circumstances and attitudes of disabled people to self-care are obviously different for the very young, the adult and elderly people. The experiences of disability leading to the formulation of the study were those of adults. It was decided therefore to restrict the study to adults between the ages of 16 and 74 years inclusive.

Availability and Interviewing Ability

Two additional criteria were applied in the selection of suitable disabled respondents for the study. First, as interviews were to be the principal method of data collection, respondents who were unable to communicate verbally or in other ways had to be excluded. Secondly, respondents had to be readily available for interview at home following their discharge from hospital. Patients who were resident outwith the health board area in which the study took place were excluded.

Sampling Criteria for Non-Disabled Control Respondents

For purposes of comparison a group of non-disabled patients was required from the same medical and surgical wards to which the disabled patients had been admitted. In order to ensure that both groups of patients had similar age and sex distributions it was decided to use a matched pair sampling procedure. For each disabled patient recruited to the study a non-disabled patient was recruited from the same ward and satisfied the same sampling criteria of length of hospital stay, place of residence and ability to communicate. In addition there had to be no evidence of a chronic medical condition and on interview had to have no functional restrictions in terms of the Harris (1971) self-care ability scale.

Specific matching criteria were that non-disabled patients had to be of a similar sex and age as their disabled partner and in no instance more than ten years older or younger. This rather broad age band was selected in order to ensure that delays in waiting for a control patient would be minimal and that both patients making up a pair would have been on a ward at the same time.

The advantages of matched pair sampling for comparative research are discussed by Fliess (1973) in terms of possible gains in efficiency in a statistical sense. For the purposes of this study a matched pair sampling design was used primarily as a mechanism for locating a group of non-disabled patients who were comparable to the selected disabled patients. Although the possibility of an increase in the power of tests of significance and precision of the estimated degrees of association was of lesser importance, data analysis was facilitated by the equality of age and sex distributions of the two respondent groups.

Sampling Criteria for Nurses

All nurses of the grades of ward sister, staff nurse, student nurse and nursing auxiliary, who had worked on a study ward when either a disabled or non-disabled respondent had been an inpatient were eligible for inclusion in the study. This was to ensure that the responses of the nursing staff were made in the context of the same ward situations as that of the patients in the study.

STUDY METHODS

Data were obtained from the patient groups through the use of structured interviews. This method of data collection provided the opportunity to question respondents about their experiences of hospital so as to ascertain their major concerns. Personal interviews did not require respondents to complete questionnaires, a task which may have caused difficulty for some of those with disabilities. The first patient interview took place in hospital and the second in the patient's own home following his discharge from hospital.

Information from the nurse respondents was obtained by a postal questionnaire for all grades other than ward sisters who were interviewed using a structured interview schedule. The use of postal questionnaires permitted a larger sample of nurses to be included than would have been possible had interviews been used. Ward sisters were seen not only as having a key influence in the provision of care but also as being aware of difficulties in providing care in relation to specific wards.

The collection of data from all nurses began when the survey of patient respondents had been completed. This timing did incur difficulty in tracing some of the nurse respondents. It was felt that interviews with nurses during the patient survey may have influenced the way in which nurses approached the care of disabled patients.

PATIENT INTERVIEW SCHEDULES

Patient Interview in Hospital

The first patient interview was used both for preliminary screening and as a source of basic demographic and hospital information. In addition to items related to sampling criteria and matching criteria, i.e. age, sex, diagnosis, level of self-care, and place of residence, information on the circumstances of hospital admission, i.e. route and reason for admission, were taken from the nursing records. This interview was deliberately made as brief as possible in order not to impose upon the time of acutely ill patients (schedule reproduced in Appendix 1a).

Patient Interview at Home

The schedule used for the patients' home interviews was much longer than the hospital interview. It consisted of four sections which covered: (1) demographic and hospital information; (2) activities of daily living; (3) satisfaction with hospital care; and (4) patient role expectations. With the exception of the section of the schedule dealing with the activities of daily living, which was only used with the disabled patients, the schedules for disabled and non-disabled patients were identical (Patient Home Interview Schedule reproduced in Appendix 1b).

1. Demographic and hospital information:

Data elicited for this section of the schedule completed the demographic information available on patients. Variables which may have influenced the individual's reactions to care, e.g. length of hospital stay and number of previous hospital admissions, were also recorded. This section, which was situated at the beginning of the schedule, also served to create a rapport between the interviewer and the respondent during the discussion of factual biographical material.

2. Activities of daily living:

This part of the schedule served to document how the disabled patient usually managed with up to eight activities of daily living. This included: (1) walking; (2) getting in and out of bed; (3) getting in and out of a chair; (4) using the toilet; (5) having a bath or shower; (6) washing hands and face; (7) dressing; and (8) eating. An 'Other' category was also included for any activities not included in the list with which the patients may find difficulty. The eight activities were chosen in order to broadly cover those included in the Harris self-care assessment scale.

This section of the schedule served to document the nature of difficulty a respondent usually experienced with a particular activity whilst living in their normal place of residence. Information was then obtained about how they coped with each difficult activity and, if the activity was continued in hospital, how appropriate were the provisions available in terms of equipment, facilities and assistance. Although a high degree of structure was incorporated into this part of the schedule, opportunities were given throughout for respondents to make open-ended comments on this aspect of their care.

3. Satisfaction with hospital care:

The purpose of this part of the schedule was to ascertain the extent of satisfaction with care experienced by the patient groups and to explore what underlying factors lead respondents to feel satisfied or otherwise. A schedule to measure patient satisfaction with care was constructed for use in the study. Requirements of this schedule were that it should reflect as accurately as possible the extent to which a patient was content, or otherwise, with several aspects of care. To facilitate statistical comparisons it provided numerical scores for each respondent. It also provided respondents with ample opportunity to make comments about care provision and thereby provide guidance on how improvements in care could be achieved.

The structure of the satisfaction schedule was based on a model suggested by Locker and Dunt (1978). The assessment of satisfaction began with an overall evaluation of care followed by an assessment of six specific aspects of care. These six aspects were selected to reflect the concerns of the disabled people interviewed during the exploratory phase of the study; they also reflected dimensions of care examined in other patient satisfaction studies (Ware et al, 1978). They included: (1) the provision of ward facilities for patient use; (2) ward routines;

(3) relationships with nursing staff; (4) communication of information; (5) nursing care; and (6) discharge arrangements.

Each of these topics was the subject of a series of open-ended and closed questions which were followed by a seven-point scale, ranging from very satisfied to very dissatisfied, for each dimension of care. The questions positioned prior to the seven-point rating scale served to provide qualitative information about the causes of satisfaction and also served as an aid to the respondent's recall of his hospital experiences prior to completion of the scale. Overall satisfaction with care was assessed on a single seven-point rating scale which was completed prior to questioning about the specific aspects of care.

4. Assessment of patient role expectations:

The method for assessing patient role expectations was designed to yield a numerical score reflecting the degree of activity/passivity expected on the part of patients and to be equally applicable to all respondents; disabled patients, non-disabled patients and nurses.

Methods employed in the social sciences to assess role orientations have included sentence completion tests (Anderson, 1973), the role differential (Loh and Triandis, 1968) and, most commonly, Likert summated rating scales (Larson and Rootman, 1976; Kramer, 1968; Lorber, 1976). Each of these techniques were tried during the early phases of the study but finally the Likert scaling method was selected as the method of choice. Sentence completion tests were excluded following their administration to a group of 30 nurses when it was found that an extremely limited range of vocabulary was consistently used to complete the sentences. The role differential, a scale of similar format to the semantic differential of Osgood et al. (1957), only the stimuli are complementary roles, e.g. father/son or patient/nurse, was administered to another 30 nurses. This scale was also found to be of dubious value owing to the high degree of explanation which was required before these respondents were able to complete the scale. A summated rating scale was constructed according to the principles set out by Likert (1932). (For an account of its construction and a discussion of its properties see Appendix 2).

A list of 37 statements related to patient role were derived from the preliminary interviews with disabled patients and nurses. These were then submitted to a pilot group of 35 disabled patients, 30 non-disabled patients and 60 nurses of various grades. The respondents' level of agreement with these statements was then analysed using the SPSS computer programme (Nie, 1975). The eight statements shown to be most highly correlated with the main scale scores were selected for the activity/passivity role scale. (The final scale is reproduced in Appendix 2).

NURSES' QUESTIONNAIRES

This questionnaire consisted of a series of open-ended and closed questions and the activity/passivity role scale described above. Broadly, the questionnaire covered the four main nursing related aims of the study. These were:

(1) to assess the extent of nurses' knowledge of and exposure to disablement;

(2) to assess the extent of nurses' experience in caring for disabled patients;

(3) to establish nurses' views towards caring for disabled patients on acute wards; and

(4) to assess the nurses' orientation towards the patient's role in care on the dimension of activity and passivity .

(Questionnaire reproduced in Appendix 1c).

WARD SISTER INTERVIEW SCHEDULES

The first part of the ward sister interview schedule dealt with the same areas covered by the nurses' questionnaire. The remaining sections were concerned with ward design, equipment and the effect upon the ward of having disabled inpatients. While the first part of the schedule contained a large element of structure it was intended that the latter half should take a much less structured form in order to discuss freely with the sisters their concerns and difficulties in the widest possible sense (see Appendix 1d for list of questions included in the ward sister schedule).

CHAPTER 4

The Pilot Study

The main objectives of the pilot study were:

1. To test the sampling criteria for recruiting disabled patients.
2. To test the matched pairing criteria for the selection of non-disabled respondents.
3. To test alternative methods of assessing patient role perceptions.
4. To obtain a pool of responses from patients and nurses to the list of role-related statements for possible use in the construction of a Likert scale.
5. To ensure that the aspects of care included in the patient satisfaction schedule covered the major concerns of both disabled and non-disabled patients.
6. To ensure that the structure of the interview schedules allowed a smooth flowing interview to proceed.
7. To ensure all questions included in the questionnaires and interview schedules were clear in their meaning and that multiple choice questions included lists of mutually exclusive and totally inclusive alternatives.
8. To carry out a preliminary analysis of the data collected with a view to selecting a method for handling the study data, e.g. computer file or manual sorting system.
9. To reveal any organisational problems which might occur during patient recruitment and interviewing.

Prior to commencement of the pilot interviews a part-time research assistant was recruited to assist with the ward visits to locate respondents and to carry out some of the home interviews.

Twelve acute medical and six acute surgical wards within a large Scottish teaching hospital were used to recruit both the pilot and main study samples of patients. Nurse respondents in the pilot survey were recruited from a non-teaching district general hospital outside the main study health board area. A further sample of nursing final year nursing degree students was used for a final pre-test of the nurses' questionnaire. The pilot study of patients in the main study hospital obviated the need to negotiate access to patients in two hospitals, an important consideration in view of the lengthy access procedures which had to be adhered to. This strategy permitted data to be collected from both nurses and patients without contaminating the setting for the main study.

The pilot work in relation to patient respondents lasted 12 weeks. Each study ward was visited twice weekly to screen the current inpatients. Bi-weekly visits ensured that no potentially eligible disabled respondent could have been admitted for four or more days without having been on the ward during a researcher's visit.

THE PATIENTS' PILOT STUDY

During each visit the ward sister and/or the nursing Kardex was consulted to establish whether or not any patients on the ward had one of the selected disabling conditions, or used aids to mobility, was of an age between 16 and 74 years, and was resident within the health board area. Such patients were then approached and asked if they would take part in the study following a brief explanation of its purpose (see introductory statement, Appendix 1a). The first hospital interview was then completed to establish if the patient satisfied the sampling criteria related to self-care ability and duration of limitation.

As the initial visit to each ward involved screening every inpatient for eligibility and subsequent visits entailed screening only the new admissions, a relatively large number of interviews were anticipated at the beginning of data collection. For this reason only half (9/18) of the wards were visited during the first week. The ward visits were divided, as were the home interviews, between the researcher and the part-time research assistant.

The sampling criteria yielded respondents at a rate which could be managed by the interviewers, although the flow came in peaks and troughs. Over the 12 weeks a total of 88 patients were approached as potential disabled respondents. Thirty five of these satisfied all the sampling criteria and were interviewed a second time at home following their discharge. The availability of this number of respondents alleviated concerns about obtaining a reasonable sample size (target 100) when all the sampling criteria were fully applied. Initial fears that the sample might be swamped by patients with chronic obstructive airways disease did not materialise.

Once a disabled patient had been recruited, a non-disabled matched pair was immediately sought. Non-disabled patients suitable for pairing were not always immediately available. Occasionally this meant that a disabled patient and his non-disabled partner were not inpatients at the same time. However, the biggest gap was only three days. At the end of the patient pilot study five non-disabled patients were still required to complete the matching. Where more than one non-disabled patient was found to be an eligible match, the individual whose age was closest to the disabled respondent was chosen.

The flow of the home interviews was checked and the sections ordered as follows: biographical information; activities of daily living (disabled patients only); satisfaction with care; and the Likert role scale. Questions relating to the activities of daily living were given priority and placed near the beginning of the schedule so as to avoid the possibility that interview fatigue might result in the loss of this information if the section had been placed nearer the end of the schedule.

Minor modifications were necessary to the wording of some questions to clarify their meaning, although the major part of this work had been done through prior discussion of the interview schedules with colleagues. Categories which emerged from the multiple choice questions were added to the schedule in a pre-coded form upon completion of the pilot study.

In the original patient satisfaction schedule, questions dealing with discharge arrangements did not constitute a separate aspect of care with an associated rating scale. During the pilot study, it became obvious that discharge arrangements were a frequent cause of concern to patients. Therefore questioning on this topic was treated as a separate aspect of care and an additional rating scale incorporated into the schedule. Discharge procedures have been considered in other studies as a separate dimension of care for patient satisfaction (Royal Commission on the N.H.S., 1978).

Instruments for the assessment of patient role expectations had already been tested on nurse respondents prior to the commencement of the patients' pilot. This had shown Likert-type scaling to be the most practical procedure (see Chapter 3) and therefore the same list of 37 role-related statements presented to pilot study nurses were also given to the pilot patients. The strength of the patients' agreement or disagreement with these statements was subsequently analysed to construct the eight-item role scale included in the main study interview schedule (see Appendix 2).

The pilot study provided an opportunity to iron out any organisational problems in relation to the study hospital and the scheduling of researchers' time. During the access negotiations, the study was explained to the ward sisters at surgical and medical unit meetings. Each sister was also seen individually to discuss any reservations and to clarify any unclear points. Even so, several weeks of patient recruitment passed before the interviewers were accepted on the wards and times to visit organised when the nurse in charge would be available. As the researchers became more familiar with the nursing staff their level of co-operation increased markedly.

During the pilot study, arrangements were made with the nursing administration to obtain copies of the study ward nursing off-duty rotas to compile the sampling frame for nursing staff. The medical records department agreed to provide daily bed statements from each study ward for use as a check upon how many patients had been screened during the ward visits.

It was found that the workload of hospital visits and home interviews could be handled without difficulty, although, as noted above, some periods were more busy than others. The ward visits involved a minimum of four half days per week and a ward interview took a little over ten minutes to complete. Patients' home interviews lasted, on average, just over one hour. The average return trip to a patient's home was six miles. A maximum of three to four home interviews could be undertaken in a full working day.

Once data from the patients became available, methods for handling the material were tested. Data for the construction of the Likert scale required statistical treatment. The Likert scale data from the patient and nurses' pilot study were coded and put onto a computer using the SPSS computer programme (Nie, 1975) (see Appendix 2). The remaining data were transferred to marginal punch cards for analysis. This mode of data handling seemed to be most appropriate given the quantity of qualitative material on the interview schedules, the relatively small number of cases and the level of any statistical analysis required.

NURSES' PILOT STUDY

Two groups of nurses were included in the pilot study. A first group of 60 nurses, including ward sisters, staff nurses, student, pupil, enrolled and auxiliary nurses, located in a district general hospital assisted with the initial testing of questions included in the nurses' questionnaire. This included the testing of alternative methods for assessing patient role expectations (see Chapter 3) and the construction of the Likert role scale (see Appendix 2). A second group of 20 final year degree students of nursing were used for a final pre-test of the completed nurses' questionnaire, following completion of the main patient study.

CHAPTER 5

The Main Study

PATIENT RESPONDENTS

During the ten-month period of the main patient study, each of the 18 study wards was visited on a twice-weekly basis. During this period, 315 potentially eligible disabled inpatients were invited to participate in the study. These were patients who satisfied the diagnostic groups or use of mobility aids criteria from a total of 11,561 patients admitted to the study wards during the ten months. The majority of these, however, did not satisfy the other selection criteria (209). Most commonly, the level of functional limitation was not high enough for their inclusion as disabled (137) and a substantial minority were excluded by their not being able to communicate adequately* (44) (see Table 1). Five potentially eligible disabled patients refused to co-operate and no further information about their eligibility was available.

TABLE 1: Selection of disabled patients

Patients known to have specified disabling condition and/or known to depend on aids to mobility identified through nursing records	315
Patients co-operating in hospital interview	310
Patients satisfying selection criteria at first interview	101
Patients continuing to satisfy selection criteria at home interview	79
Patients satisfying criteria and co-operating in main home interview	75

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* For definition see page 38

A total of 79 disabled patients satisfied the criteria and were willing to co-operate at the selection stage of the study; four of these were later withdrawn when their circumstances no longer made them eligible, for example, change of address. The study sample therefore consisted of 75 "disabled" patients and their matched non-disabled partners.

Potential matches for the disabled patients were selected from the same wards and, when possible, on the same day as the positive recruitment of the disabled patient. As with the pilot study, some slight delays were encountered in the recruitment of non-disabled partners for the younger disabled respondents.

Of the 75 pairs of respondents, 22 were recruited from surgical and 53 from medical wards. The sample was almost equally divided between the sexes with 38 male and 37 female pairs. The mean age of the total sample (150) was 59.6 years, the majority (90/150) being over 60 years of age. The age distribution of the disabled and non-disabled respondent groups was similar as a result of the age matching during sampling. The mean age of the disabled patients was 60.3 years (range 24-73) and of the non-disabled patients, 59.3 years (range 20-73).

There were no differences in the manual/non-manual occupational grouping of the disabled and non-disabled respondents. Apart from a sub-group of 28 disabled patients who had no primary diagnosis other than their disabling condition, the distribution of primary diagnoses of the disabled patients was not different from that of the non-disabled group of patients (Table 2).

TABLE 2: Primary diagnoses of disabled and non-disabled patients

	Primary Diagnoses	Disabled	Non-Disabled
I	Infectious and Parasitic	2	2
III	Endocrine Nutritional, Metabolic and Immunity	1	2
IV	Blood and Blood Forming Organs	1	2
VI	Nerve and Sense Organs	1	-
VII	Circulatory	16	29
VIII	Respiratory	1	2
IX	Digestive	10	21
X	Genito - Urinary	3	2
XII	Skin	1	1
XIII	Muscular - Skeletal	-	2
XVI	Symptoms (Misc.)	4	6
XVII	Injury/Poisoning	2	1
	Investigations	5	5
	Disabling Condition - Disabled only	28	NA
	Totals	75	75

NURSE RESPONDENTS

During the patient recruitment phase, day duty rotas were collected from each of the wards and a list was drawn up of all nurses who were working on the wards when a patient respondent was actually an inpatient. Once patient recruitment was complete, all staff nurses, student nurses and auxiliary nurses whose names appeared on the list (and were traceable through the nursing administration) were sent a postal questionnaire (Table 3). The ward sisters from each ward where patients had been recruited were interviewed following the return of the postal questionnaires from the other grades of nurse.

The number of nurses participating in the study were less than the number appearing on the sampling list for two main reasons. A substantial minority (94, 23%) of the eligible nurses had changed their employment between the time of their inclusion on the sampling list and the dispatch of questionnaires. As a result, these individuals could not be traced. Of those nurses who were traceable (307) and eligible for a postal questionnaire or an interview, 102 either did not return their questionnaire following two reminders or were unable to undertake an interview. These losses affected mainly the student nurse grade and, to a lesser extent, the staff nurses. From the traceable nurses an overall response rate of 67% (205) was achieved (Table 3).

STATISTICAL TESTS APPLIED TO STUDY DATA

Because of the different ways in which the data were collected for different aspects of the study, several varieties of tests of significance were used for the statistical analysis. For all tests the null hypothesis of no difference or no association was rejected if the significance level of the observed results was 5% or less.

TABLE 3: Response rates of nurses to questionnaires and interviews by grade at time of sampling and response

Nursing Grade (Sampling)	Appearing on First Sampling List	Traceable for Questionnaire/ Interview	Response Rate of Traceable Nurses	Nursing Grade at Time of Response
Sister	16	16 (100%) (interview)	15 (94%)	15
Staff Nurse	78	62 (79%) (questionnaire)	47 (76%)	73
Student Nurse	270	195 (72%) (questionnaire)	122 (63%)	89
Nursing Auxiliary	37	34 (92%) (questionnaire)	21 (62%)	18
Other	NA	NA	NA	10
Totals	401	307 (77%)	205*(67%)	205*

* Sample size

For comparisons between disabled and non-disabled respondents involving paired qualitative data, tables of the exact confidence limits of the binomial distribution were used (Diem and Lentnor, 1970). For other comparisons within samples not involving a disabled and non-disabled comparison, the Chi^2 test was used. Where 20% or more of the expected cell frequencies were less than five, Fisher's exact probability test was used (Siegel, 1956). Comparisons of Likert role scale scores were tested by the one way analysis of variance (Moroney, 1951) and by Student's t-test of difference between means (Yeomans, 1968b). Statistical tests used for the construction of the Likert role scale are noted in Appendix 2.

CHAPTER 6

Disabled Patients and the Activities of Daily Living in Hospital

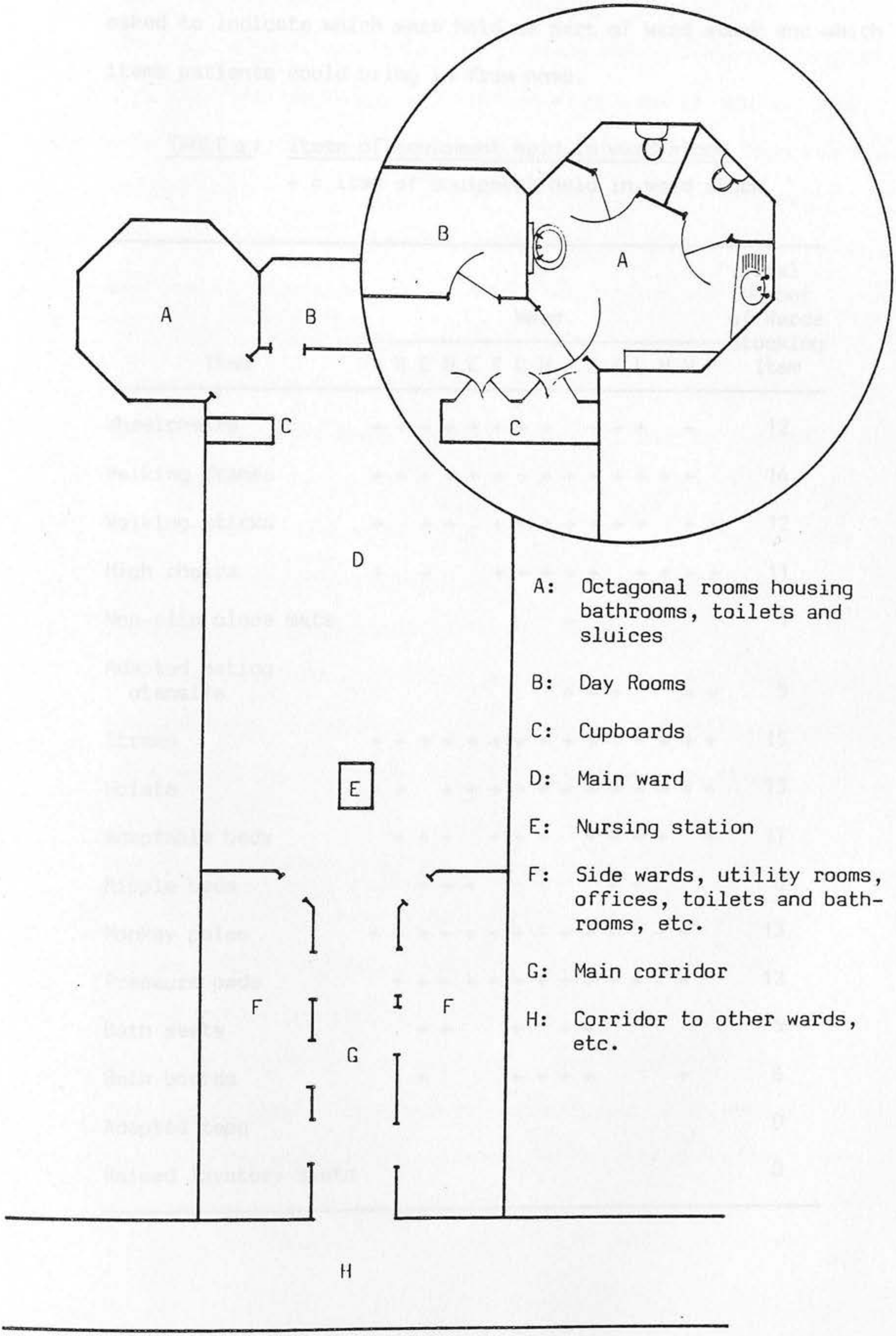
To assess the impact on disabled people of a transition from their usual place of residence to a hospital ward a record was made of the extent to which they were able to continue the daily activities of self-care. The activities of self-care considered included walking, transfer (getting in and out of a bed and chair), using the toilet, bathing, washing hands and face, getting dressed and eating. The means of dealing with activities which usually caused difficulty in the respondent's normal residence were first established. Then, if the activity was continued in hospital, the extent to which the ward environment either handicapped or facilitated the disabled person in self-care activities was explored.

The comparison between self-care abilities at home and in hospital is obviously affected by the severity of the condition for which the individual was admitted to hospital. If a disabled patient specifically mentioned their acute condition had imposed further obstacles to their self-care ability this was documented during the interview.

THE WARD ENVIRONMENT

The 16 wards from which respondents were recruited were all basically of the 'Nightingale' design, although three had been converted to bays as part of a modernisation programme (Figure 3). The average bed complement per ward was 27, but extra beds were often placed in the centre of those wards which had not been converted to bays. The availability of fixed equipment to assist patient mobility was limited to grab-rails in bathrooms and toilets, one ward had a fixed toilet frame. Two wards had bathrooms with fixed hoists but these were not for patient operation.

FIGURE 3: Plan of typical study ward*



A: Octagonal rooms housing bathrooms, toilets and sluices

B: Day Rooms

C: Cupboards

D: Main ward

E: Nursing station

F: Side wards, utility rooms, offices, toilets and bathrooms, etc.

G: Main corridor

H: Corridor to other wards, etc.

* Not drawn to scale

From a list of 16 items of portable equipment used by patient respondents included in the study (Table 4), ward sisters were asked to indicate which were held as part of ward stock and which items patients could bring in from home.

TABLE 4 : Items of equipment held in ward stock

\+ = item of equipment held in ward stock

Item	Ward															Total Number of Wards Stocking Item
	A	B	C	D	E	F	G	H	I	J	K	L	M	N	P	
Wheelchairs	+	+	+	+	+	+	+	+		+	+	+		+		12
Walking frames	+	+	+	+	+	+	+	+	+	+	+	+	+	+		14
Walking sticks	+		+	+		+	+	+	+	+	+	+		+	+	12
High chairs	+		+			+	+	+	+	+		+	+	+	+	11
Non-slip place mats									+							1
Adapted eating utensils									+	+	+			+	+	5
Straws	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	15
Hoists		+		+	+	+	+	+	+	+	+	+	+	+	+	13
Adaptable beds		+	+	+		+	+	+		+	+	+	+		+	11
Ripple beds			+	+	+			+			+	+				6
Monkey poles	+	+	+	+	+	+	+	+	+	+	+		+	+		13
Pressure pads		+	+	+	+	+	+	+	+	+	+	+		+		12
Bath seats			+	+			+		+	+						5
Bath boards			+				+	+	+	+				+		6
Adapted taps																0
Raised lavatory seats																0

Each ward had, on average, nine of the listed items. The least commonly stocked were non-slip place mats, adapted eating utensils, ripple mattresses, bath boards and bath seats; none of the wards had tap handle adaptors or raised toilet seats. When ward sisters were asked if any special equipment had been required for patients on their wards only two reported that they had obtained items of equipment not included on the list, i.e. long arm reacher and raised toilet seat.

Storage space was clearly a factor preventing wards from stocking an extensive range of equipment. Only three of the ward sisters considered their wards had adequate storage capacity. For the remainder, equipment was either crammed into cupboards or stored in day rooms or other utility areas. Few problems were encountered in obtaining equipment from the physiotherapy and occupational therapy departments when needed.

Most ward sisters looked favourably on patients bringing their own equipment to the ward. Only one sister did not encourage patients to use their own aids, other than walking sticks.

FUNCTIONAL PROBLEMS OF DISABLED RESPONDENTS

The most frequently reported self-care difficulties were walking (64/75) and bathing (62/75) (Figure 4). A majority (62/75) of respondents reported difficulty with three or more activities of self-care (Figure 5). As expected, those respondents suffering from C.N.S. related impairments had difficulty with more activities than did those with impairments related to bones and organs of movement (Harris et al, 1971).

FIGURE 4: Number of respondents having difficulty with eight activities of daily living (N = 75)

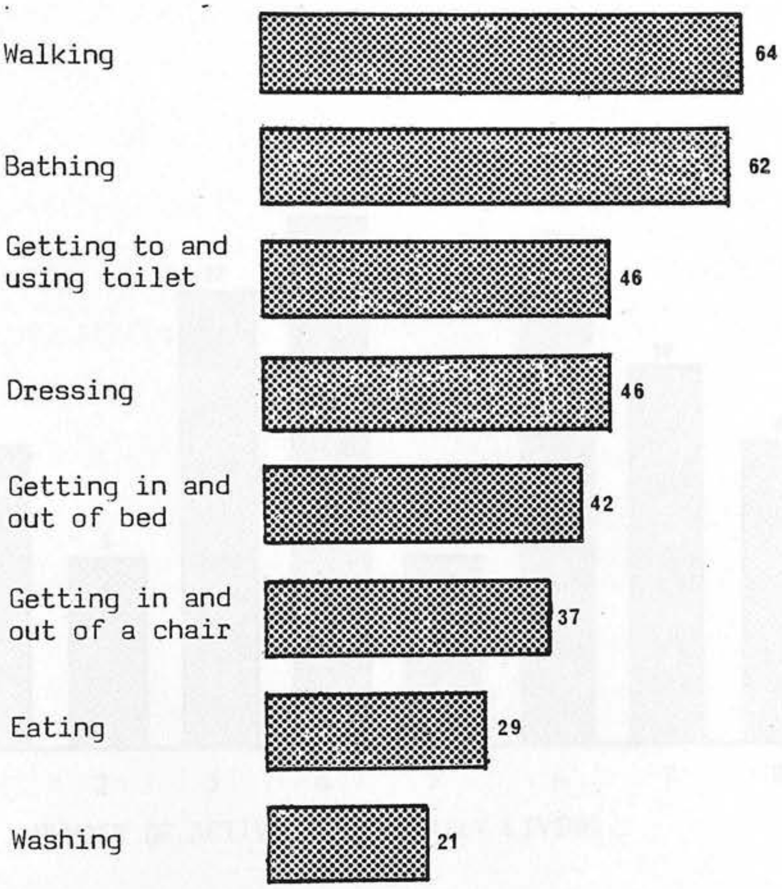
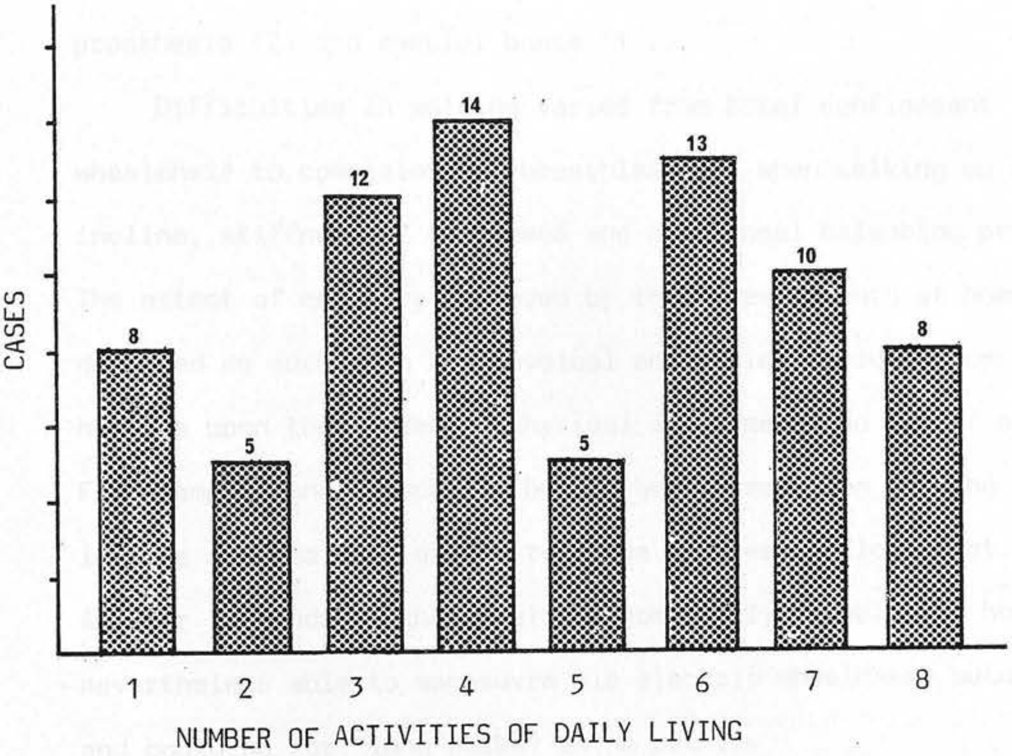


FIGURE 5: Number of activities of daily living causing difficulty per case (N = 75)



Walking

Of the 64 patients who reported difficulty with walking, eight could walk unaided, 47 needed aids and nine required both aids and human assistance to be mobile in their homes (Figure 4). The most frequently used aids were wheelchairs, walking frames and sticks (53/56). The three other patients used a crutch and leg prosthesis (2) and special boots (1).

Difficulties in walking varied from total confinement to a wheelchair to complaints of breathlessness when walking up an incline, stiffness of the knees and occasional balancing problems. The extent of mobility achieved by these respondents at home depended as much upon the physical and social circumstances of the home as upon the patient's physical impairment and use of aids. For example, one respondent became breathless when walking up an incline and was thus unable to leave his second floor flat. Another respondent, though almost completely immobile at home, was nevertheless able to manoeuvre his electric wheelchair outdoors and could go for "long walks" as he put it.

One-third (23/64) were wheelchair users; nine were totally confined to a wheelchair, while 14 used alternative equipment indoors. Nine (9/64) required personal help with mobility. On medical grounds, only nine (9/64) disabled respondents were either bedfast or restricted to transfer from bed to chair during their hospital stay.

The 55 disabled respondents who remained potentially mobile had problems in maintaining their mobility mainly in such patient utility areas as bathrooms and toilets (see sections on Bathing and Toileting). Two respondents had difficulties on the main ward. One patient was afraid to walk on the shiny floor, even though he knew it to be non-slip. Another patient found the ward so full of furniture and fittings that he was unable to use his walking sticks.

The problem of confined space in the main ward was more frequently mentioned by ward sisters than by patients. This problem became most acute when wheelchair-bound patients were on the ward and when extra beds had to be placed in the centre of 'Nightingale' wards. Three patients shared the concern of ward sisters regarding a lack of storage space. The practice of stacking chairs at the entrances of patients' toilets at night hindered or prevented independent access. The changing locations of ward furniture created an obvious hazard for the one blind patient in the study.

The disabled patients' experiences of mobility in hospital were not always negative. For some, the ward design facilitated a greater degree of independence than was possible for them to achieve at home. Two disabled respondents appreciated being able to move around, wash and use the toilet independently. For one patient this was made possible by the single level ward floor and for a second by the presence of more room to manoeuvre than was available in his home.

Forty seven regular walking aid users were potentially mobile in hospital. They maintained their mobility in a number of ways; 19 brought their own equipment to the ward, 22 used hospital equipment and one used both his own and hospital equipment. Five ceased to use any equipment at all but still managed to remain mobile.

Most (14/19) of those who brought in their own equipment maintained their mobility in hospital and reported no special problems. Three respondents claimed that having their own equipment was especially beneficial. One said it gave her a degree of confidence which she felt was badly needed after an operation. Only two patients felt that difficulties had arisen in using their own walking aids on the ward. A patient who preferred to walk in bare feet whilst using her walking frame felt the nurses disapproved of her not wearing shoes. The patient who used sticks and who found difficulty in avoiding ward furniture has already been mentioned.

About a third (8/22) of the disabled patients who were given hospital aids obtained items identical to their own and none reported any problem with them. Two patients, both of whom used walking frames and wheelchairs and who were only issued with walking frames, did not miss having their wheelchairs. Indeed, one thought the wheelchair had been withheld deliberately to encourage him to walk and was, in fact, very pleased about this.

Eight of the 12 patients who used hospital equipment which differed from their own did have difficulties. Six of these explicitly stated that they regretted not having their own aids whilst in hospital. The main reason for not bringing in their aids was simply that it had not occurred to them as being possible. The change of equipment had meant that three of these patients had required the assistance of a nurse in addition to the aid. All of these patients would have preferred independence.

The use of hospital equipment provided an opportunity for some patients to try out alternative types of equipment and to re-assess their own. One patient obtained a second opinion on a new leg prosthesis which he had felt to be unsuitable. This patient's opinion was confirmed by the hospital staff and the patient was given confidence to pursue his case for a more appropriate appliance after his discharge from hospital. One respondent who used a hospital walking frame which was lower than his own found it much superior and, following discharge, purchased one of the same height.

The patient who used both the hospital and his own equipment found he was unable to use the walking frame provided on the ward as it was too low and lacked padded arms. On admission, he had been unable to transport his own frame to the hospital but this was eventually brought in by a social worker.

Five patients who usually used equipment at home, used no equipment in hospital, although they continued to be mobile. Two of these patients regretted not having their aids in hospital but neither had thought about asking for them to be brought in.

Transfer To and From a Bed and Chair

Fifty two disabled patients reported they usually experienced difficulty in transferring to and from a bed and/or chair. Fifteen had difficulty with transfer to and from bed, 11 with transfer to and from a chair, and 26 had transfer difficulties with both of these items (Figure 4). As with mobility, the degrees of difficulty encountered during transfer varied widely from complete inability to transfer to relatively minor difficulties in swinging the legs over the side of a bed.

Of the 17 disabled patients who usually used aids to get in and out of a chair, 14 only required to sit in a high chair to be independent. The remaining three used walking sticks or frames to provide the extra leverage required to get in and out. Of the 14 patients who usually required assistance with transfer to and from a chair, ten were confined to a wheelchair and needed to be lifted in and out.

Getting in and out of bed created more problems than did chairs and consequently a wider variety of aids were usually employed, as well as a greater use of human assistance. Of the 52 patients who had transfer difficulties at home, only two were confined to bed throughout the duration of their hospital stay and 50 disabled patients were therefore faced with transfer problems while in hospital.

The only items of personal equipment brought to the hospital to help with transfer to and from a chair were the walking sticks or frames brought in by three patients. Along with five patients who were provided with high chairs similar to their own, these patients had no difficulty in adapting to the ward situation. Nine patients who usually used a high chair were provided with chairs lower than their own and were consequently made dependent upon the nursing staff when they wanted to sit down and stand up. One tried to bring his own chair from home but was unable to arrange transport. All the patients who required assistance to get in and out of a chair found the help of the nursing staff entirely satisfactory. The six patients who usually managed getting in or out of a chair with difficulty but unaided benefited most by the hospital arrangements. Four were provided with high chairs and all commented on how appropriate for their needs these chairs were.

Most patients who usually had difficulty at home in getting in and out of bed became dependent upon the assistance of nursing staff in hospital for this activity (39/42). The majority (25/39) of these were already dependent upon assistance while at home. Only two patients who did not normally require assistance at home but became dependent in hospital reported that they would have preferred to remain independent. For one patient independence would have been achieved had a brake on a bed been repaired. The two respondents who continued to use their own aids for transfer to and from bed (one sticks and the other a transfer board) reported no difficulties.

Getting To and Using the Toilet

Forty six disabled patients usually had difficulty getting to or using the toilet, 37 of whom relied upon some form of aid or assistance with this activity when at home (Figure 4). The difficulties reported by the disabled patients ranged from inability to remove clothing to a complete inability to transfer from a wheelchair to the toilet. Seven patients who usually had difficulty with this activity at home were restricted to using a bedpan or commode beside the bed in hospital. The most commonly used equipment were commodes (14), raised toilet seats (11), grab-rails (9) and toilet frames (9). Four patients depended upon their walking aids for assistance. Of the 34 who relied on aids to use the toilet, none brought in any equipment other than walking aids.

Raised toilet seats were usually used at home by 11 patients, of whom nine could manage independently. No raised toilet seat attachments were available for any of these patients and consequently seven of the nine users who could normally use the toilet independently became dependent upon the assistance of nurses. Seven patients became dependent upon nurses to use the toilet and all but one disliked what they saw as an unnecessary dependence and wished they had brought their own equipment with them.

Eleven disabled patients usually managed to use their home toilet independently given the provision of a fixed handle or rail. Only four of these patients managed alone in hospital. All but two wards had at least one toilet with fixed grab-rails but their presence did not appear to provide the means to independent use. Two patients noted that the hospital grab-rails provided little help because they were inappropriately positioned. Another two patients complained about the absence of fixed rails in the toilets. As eight wards did not have fixed rails in all their toilet facilities, this experience could have been brought about by the availability or otherwise of a particular toilet when required. Three disabled patients who usually used their home toilet independently, were unable to manoeuvre their equipment inside the hospital facilities and they, too, became dependent upon nurses' help.

Difficulty in gaining access to the toilet facilities was noted by five disabled patients, all of whom used aids. Access became more of a problem at night when furniture was removed from the main ward and stored in the vicinity of toilet entrances. One wheelchair user scraped the skin from his knuckles while trying to get into a toilet, a second was unable to get into the toilet at all after the evening visitors had left and the chairs had been stacked away for the night.

Problems of access to the toilets were mainly due to inadequacies in ward design and the lack of space for storing equipment. As already noted, toilet and bathing facilities were located in octagonal rooms, although additional facilities had been installed elsewhere on most of the wards during modernisation (see Figure 3). The major inconvenience of the octagonal rooms was caused by the angled walls. Where these rooms had been partitioned and used for more than one purpose, particularly as a sluice, the storage of equipment and trolleys accentuated the access problems (Figure 6). A further hazard was created by the positioning of cupboards with doors which opened into the same space as the main entrance doors (Figure 7). Toilet facilities located in other areas of the wards generally made better provision for access. During the survey of the wards, however, it became apparent that where there was plenty of space around access areas, this was very often used to park trolleys or place equipment (Figure 8).

FIGURE 6: Access to patients' toilet

The photograph shows an entrance to a patients' toilet situated in an octagonal room. The room had been partitioned to accommodate both a toilet and a sluice. The sharp angle of the walls was very restrictive, making access with a walking aid, wheelchair or with human assistance virtually impossible. Note also the parked trolley.

FIGURE 7: Patients' toilet

This photograph shows the access route from the main ward to a patients' toilet. The entrance door, which swings through 180º, encroaches upon the space required to open the doors of the cupboards on the right of the picture. The sharp angle formed by the cupboard and the wall restrict space, a problem which is not helped by the parked trolley.

FIGURE 8: Access to patients' toilet

This photograph shows the access route to a modernised patients' toilet and bathroom. In terms of design, the room appeared to be ideal for independent use by patients who required aids. Only the parking of three laundry skips and a waste bin prevented easy access.

Bathing

Sixty two of the disabled patients reported that they usually had difficulty in bathing at home; of these, only 12 could manage the activity without aids or assistance (Figure 4). Three patients had not been in a bath or shower for many years prior to their admission to hospital, largely because their bathrooms were inaccessible. Several patients bathed very infrequently because of the severe problems involved.

During their hospital stay, five patients did not have a bath and three received bed baths only. Bathing in hospital involved a high degree of dependency upon the assistance of nurses. Only seven of the 57 patients who were able to bath could do so without the assistance of nurses. None of the 37 patients who normally used aids for bathing at home brought their personal equipment to hospital.

In hospital, most (41) disabled patients were lifted into a bath by the nursing staff, either manually or with the help of a mechanical hoist (Figure 9). None of the 21 patients who were lowered into the bath with a mechanical hoist expressed any anxiety about the use of this equipment. On the contrary, several patients felt that the installation of a hoist in their own homes would be beneficial. One patient, who had not had a bath for seven years, said:

> "They just put me in the forklift truck,
> up and into the bath I went, a real
> luxury".

This patient recalled that his first thought upon learning of his pending admission was that he would be able to have a bath. Four other patients shared similar feelings and experiences.

FIGURE 9: Bathroom

This photograph illustrates a bath located in an octagonal room. It is well positioned, provides plenty of room for helpers and a fixed swivelling hoist makes patient transfer relatively easy.

Although shower units were used by 13 patients, ten of them still required assistance from the nurses. Six needed help to use the shower because of the high step into the shower unit (Figure 10). Access to shower units on some wards was restricted by a step 6-8 inches high then a step down of 5-6 inches. This restriction, together with the sporadic provision of handrails and presence of tiled surfaces, made the use of shower units understandably difficult (Figure 11). Three patients needed help to sit down and get up from the shower seats which were not adjustable in height.

Washing

Twenty-one disabled patients usually had difficulty at home in washing their hands and face (Figure 4). The levels of difficulty ranged from a complete inability to wash to a difficulty in raising the arms. A long-handled toothbrush used by one patient was the only aid used in conjunction with this activity.

In hospital, eight patients were always washed by the nursing staff and generally they appreciated this help. Although one patient felt able to wash alone, she thought she was helping the nurses by letting them wash her. Only one of the eight patients who usually required some assistance to wash found no assistance was available. This man could not wring out a flannel and would have liked help but made no complaint about his very wet washes.

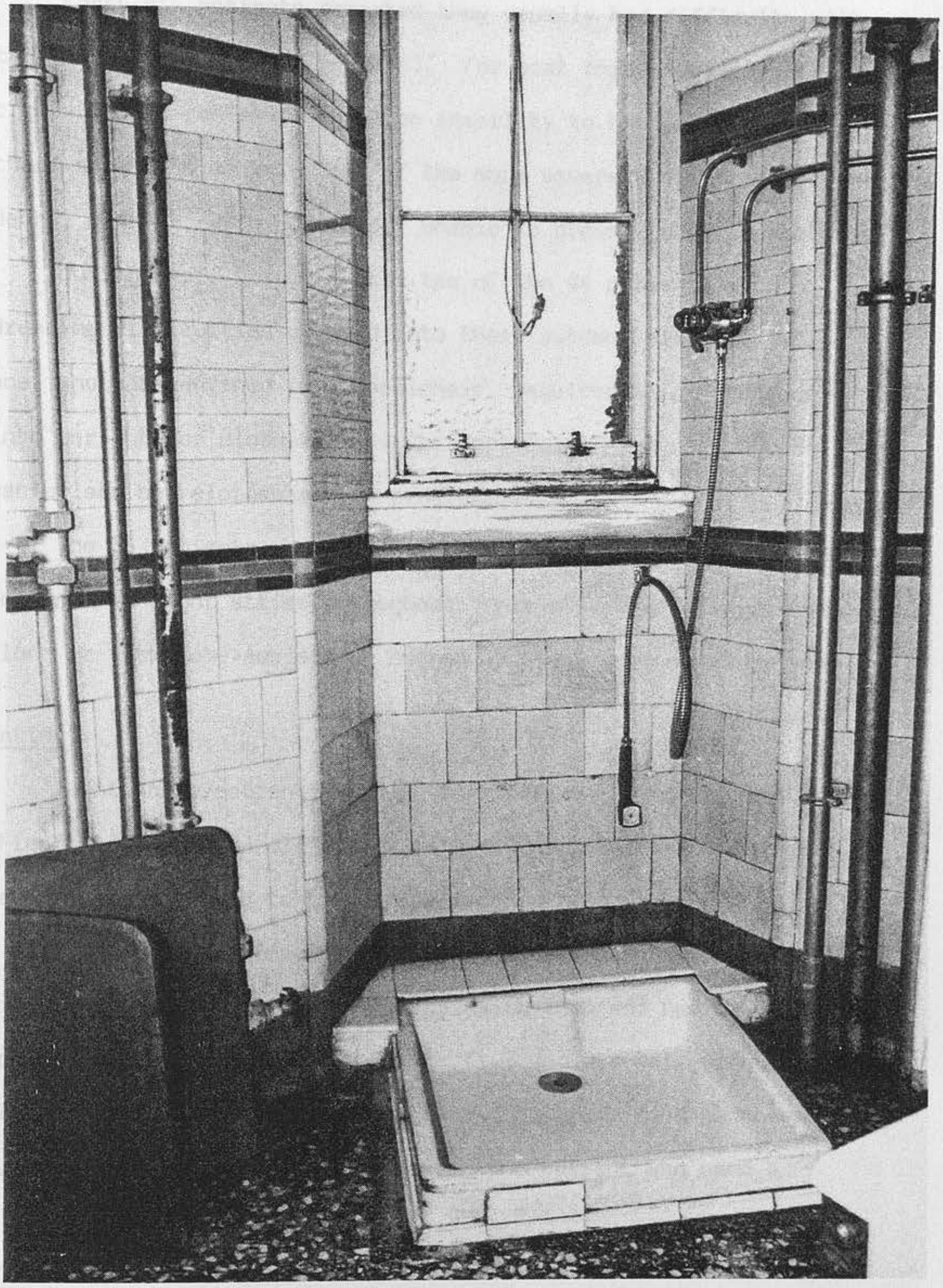
Only one of the 13 patients who usually managed to wash unaided at home experienced any difficulty in hospital. This patient found he could not stand at the wash-hand basin and so

FIGURE 10: Shower unit

The photograph shows a modern shower unit. Although it is fitted with convenient grab rails, the presence of a high step into the shower tray and the absence of an adjustable seat make it difficult for disabled people to use independently.

FIGURE 11: Shower unit

This photograph shows a shower unit which is scheduled for modernisation. In its present state it would be unsuitable for many disabled patients as it lacks a seat, shower head fixture and grab rails. (Note hot and cold water pipes which are used as patient supports). However, despite its ancient appearance, with some minor modification, i.e. an adjustable seat, grab rails and shower head fixture, it would be superior to most of the modern units. It provides space for a helper, or for equipment, and does not have a prohibitively high step into the shower tray.



took to having a shower instead. At home he was unable to bath independently so what may have been a wearisome procedure for many was greatly enjoyed by at least one patient.

Dressing

Forty six patients reported they usually had difficulty with this activity at home (Figure 4). For most this involved relatively minor problems such as an inability to bend down to put on their shoes and socks. Some of the more severely disabled respondents, however, were completely unable to dress without assistance.

During their hospital stay ten of the 46 patients with dressing difficulties changed into their outdoor clothes. Only one, who was confined to a wheelchair, required help to change into her outdoor clothes. This patient told the nurses how to manipulate her clothes and no problems arose.

The 36 patients who usually had a problem with dressing and remained in night attire throughout their stay were able to change alone or with some assistance but no problems were noted by them.

Eating

Twenty-nine patients usually had difficulty when eating (Figure 4). One had difficulty in swallowing and the remainder had problems related to the manipulation of food.

Ten patients normally used aids for eating. Five of these took their personal aids to hospital with them and had no eating problems while in hospital. Of the five who did not bring their aids to hospital, three managed alone once their food had been cut into small pieces by the nurses. One patient who used a non-slip place mat and a plate collar at home and also did not have these in hospital, found it difficult not to push her food off the plate. One patient became completely dependent in the absence of her aids and was fed by the nurses. She felt that this saved her a lot of effort and saved the nurses a lot of clearing up too; consequently, she did not mind being fed.

Two disabled patients who did not use aids for eating at home were given special cups and eating utensils while in hospital. One found them to be of great value and bought a similar set after he was discharged. The second patient, who normally did not use aids and would have preferred not to have had them, said:

> "The nurses were all so nice, and I always like to be polite, so I just used them".

CHAPTER 7

Satisfaction with Hospital Care: The Disabled and Non-Disabled

The interview schedule concerning patient satisfaction was completed after the patients' discharge from hospital. Interviews were undertaken, on average, eight days following discharge. During the interview, information on satisfaction was obtained in the form of scale scores, responses to closed questions and spontaneous comments made by the respondents. Six aspects of care were covered in detail by the interview schedule. These included satisfaction with: (1) ward facilities; (2) ward routines; (3) staff-patient relationships; (4) communication of information; (5) nursing care; (6) discharge arrangements.

The scores obtained from the six satisfaction scales dealing with specific aspects of care, and the scale referring to overall satisfaction with care, all indicated the presence of a high level of satisfaction with hospital care. The distribution of scores for each of the satisfaction rating scales formed positively skewed 'J' curves with 7, i.e. maximum satisfaction, as the modal score for each curve. The tendency of patients to rate the quality of care highly has been noted in other studies of patient satisfaction (Lebow, 1974; Carstairs, 1976).

Of the six specific dimensions of care, personal relationships with staff and nursing care were rated most highly while ward facilities and the communication of information were given the lowest ratings. This finding is in line with the findings of an earlier Scottish study of patient satisfaction (McGhee, 1961). Indeed low levels of satisfaction with the communication of information between patients and ward staff have frequently been reported in other U.K. studies, e.g. Carstairs (1976), Cartwright (1964).

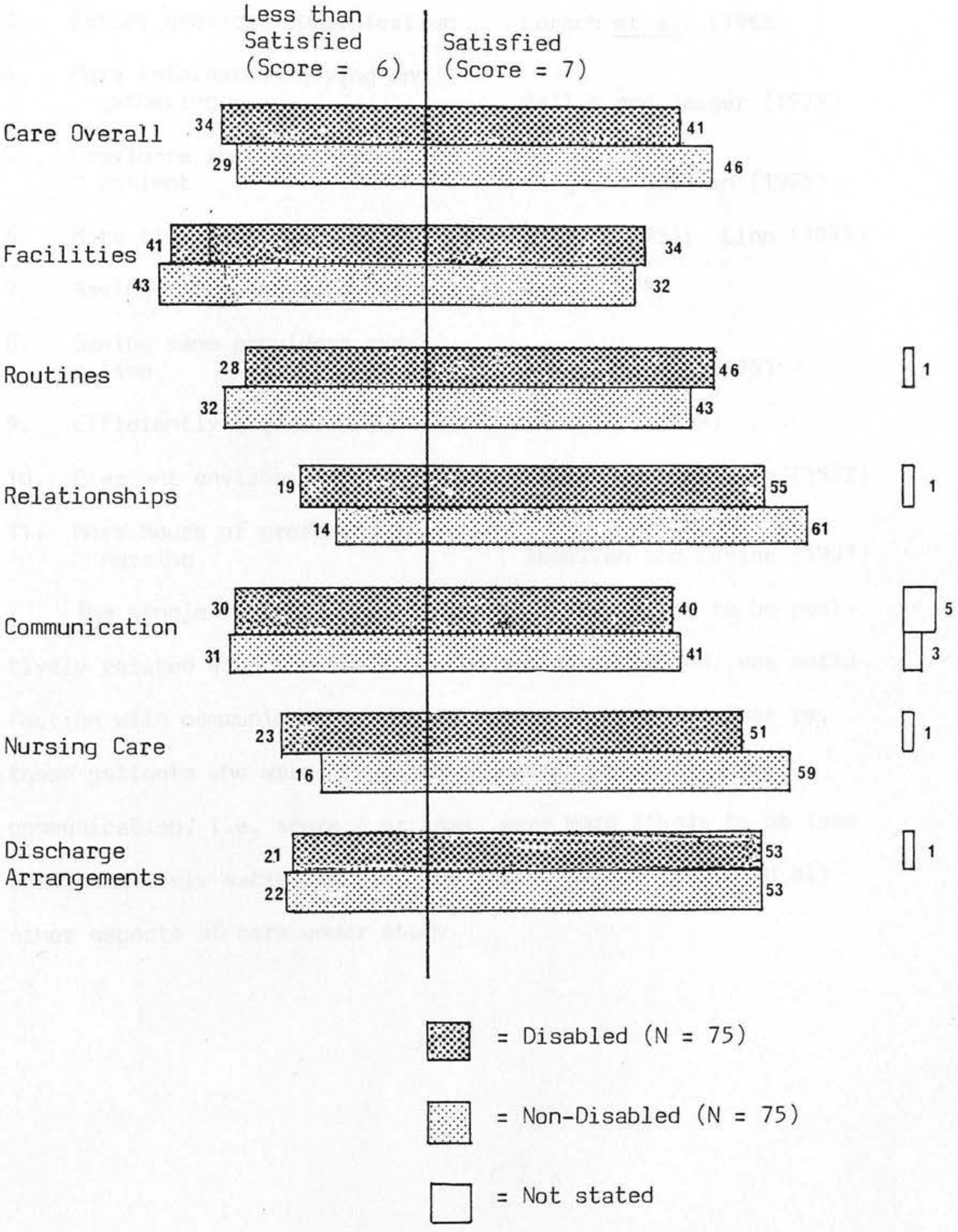
For further analysis, the satisfaction rating scales were split at the modal score to yield two groups; the completely satisfied scoring 7 and the less than completely satisfied scoring 6 or less (Figure 12). There were no significant differences between the disabled and non-disabled groups, either in the overall satisfaction scores or in any of the specific satisfaction scores. Those factors which were liable to confound comparisons between disabled and non-disabled patients, e.g. sex, age, ward of admission, length of admission and area of residence, had been controlled for in the matched pair sampling process.

None of the satisfaction scale scores were associated with the degree of disability as assessed by the Harris scale.

Associations were explored between satisfaction scale scores and age, sex, occupational group, and the extent of previous hospital experiences. None of these factors was shown to have any significant relationship with the satisfaction scale scores.

Evidence available from previous studies of patient satisfaction indicates the major determinant of satisfaction is the nature of care provided. Aspects of care which have been found to be associated with high levels of patient satisfaction include the following:

FIGURE 12: Satisfaction with seven aspects of hospital care - disabled and non-disabled patients



	Characteristic	Investigator
1.	More information given	Houston and Pasanen (1972)
2.	Counselling undertaken by doctor	Linn (1975)
3.	Better provider communication	Korsch *et al*. (1968)
4.	More information giving and gathering	Bellin and Geiger (1972)
5.	Providers showing interest in patient	King and Goldman (1975)
6.	More time spent with patients	Lebow (1975); Linn (1975)
7.	Seeing the same doctor	Linn (1975)
8.	Seeing same providers over time	Hulka *et al*. (1975)
9.	Efficiently organised service	Conforti (1969)
10.	Pleasant environment	Houston and Pasanen (1972)
11.	More hours of professional nursing	Abdellah and Levine (1957)

The single variable of the present study, found to be positively related with all the satisfaction scale scores, was satisfaction with communication of information (Table 5). That is, those patients who were less than completely satisfied with communication, i.e. score 6 or less, were more likely to be less than completely satisfied with their care overall and with all other aspects of care under study.

TABLE 5 : Number of respondents who were satisfied with specific aspects of hospital care among those who were satisfied and those who were less than satisfied with the communication of information

Aspect of Care Rated on Scale	Satisfaction with Communication: Satisfied (Score 7) (n = 71)	Satisfaction with Communication: Less than Satisfied (Score $\leqslant 6$) (n = 71)	Chi^2	df	p
Care overall	56	26	25.9	1	$< .001$
Ward facilities	46	17	23.9	1	$< .001$
Ward routines	62	25	40.6	1	$< .001$
Relationships with staff	70	41	34.2	1	$< .001$
Nursing care	69	35	41.5	1	$< .001$
Discharge arrangements	63	36	24.3	1	$< .001$

Note: The equality of numbers in each group is a feature of the data, not of the design

The nature of patients' dissatisfactions with the six specific aspects of care is now reviewed. For this purpose all the comments made by the patients were reviewed by two judges independently and rated as either positive, negative or neutral in direction.

SATISFACTION WITH WARD FACILITIES

When comparing the responses of disabled and non-disabled respondents in relation to ward facilities, it will be noted that the disabled respondents had already been questioned about the suitability of facilities for continuing the activities of daily life (see Chapter 6). In the interview schedule, questions about ward facilities can be divided into those concerned with social amenities, i.e. provision of television, radio, telephone and day room, and those concerned with items having a more direct bearing upon the patient's physical comfort and personal care, i.e. the condition and layout of bathing, handwashing and lavatory facilities, ward temperature, comfort of the bed and quality of food. Responses to a question asking for any other comments at the end of the section revealed no strong feelings about other aspects of ward facilities.

A large number of comments were made about ward facilities with only 24 respondents making no comment whatsoever. Many of the comments about ward facilities were offered as explanations of the responses to the closed questions which simply asked whether or not a facility was available and if the respondent was satisfied with it. No significant differences were evident between the disabled and non-disabled patients for any of the ten closed questions included in the facilities section of the schedule. Although a majority (71%) of comments about facilities were critical, many respondents were prepared to accept that some things would not be to their liking. As one respondent put it:

> "What can you expect from a hospital, if I'd been a private patient they [facilities] should have been better".

The disabled respondents made a greater number of comments about facilities than the non-disabled. Although disabled patients made a greater number of critical comments than did the non-disabled, they also made more than twice as many positive comments. This may well reflect the fact that disabled respondents had a heightened awareness of their surroundings as a consequence of their disabilities and because they had already been questioned on their activities of daily living.

A majority (14) of the disabled who were unable to use a day room could not do so because they were confined to bed, whereas only four of the non-disabled group were similarly restricted. Two disabled respondents who were confined to wheelchairs were unable to enter the day room while a further 12 preferred not to use it because of tobacco smoke created by other patients. Eighteen non-disabled respondents did not use the room for the same reason. Television and/or radio was available to almost all respondents, although as television sets were situated in day rooms patients who could not or did not use day rooms could only use the radio headphones which, in several instances, were either broken or missing.

There was much dissatisfaction with the provision of lavatory facilities. Although disabled and non-disabled respondents made an almost equal number of complaints in this respect, their reasons for complaint differed. The disabled respondents were concerned about the inconvenient design and lack of suitable aids (see Chapter 6), whereas complaints made by the non-disabled were about the inadequate numbers of lavatories. An equal number of comments were made by both groups regarding standards of hygiene and privacy (Table 6).

TABLE 6: Respondents complaints about lavatory facilities

	Disabled	Non-Disabled
Too few lavatories	13	26
Poor standard of hygiene	3	3
Lack of privacy	1	1
Too small	9	2
Lack of equipment (e.g. hand rails)	7	-
Too cold	1	-
Faulty fixtures	-	2
Access difficulty	3	-
Totals	37	34

Dissatisfaction with bath facilities was expressed by both non-disabled (29) and disabled (22) respondents. The non-disabled respondents were more concerned with the lack of facilities rather than with the quality of what was available. The prime concern of disabled respondents was whether equipment was available to enable them to use the bath or shower and whether there was sufficient space to allow helpers to give them the assistance required (Table 7).

TABLE 7: Respondents' complaints about bathroom facilities

	Disabled	Non-Disabled
Too few bathrooms	7	24
Poor standard of hygiene	-	2
Too small	2	-
Lack of equipment (e.g. hand rails)	10	-
Totals	19	26

In the same way, non-disabled respondents deplored the lack of wash-basins whilst the disabled respondents not only noted inadequacy of provision but also specific difficulties with access and equipment problems (Table 8).

TABLE 8: Respondents' complaints about washing facilities

	Disabled	Non-Disabled
Too few wash-basins	4	14
Poor standard of hygiene	1	1
Lack of privacy	2	1
Access difficulty	2	-
Lack of equipment (e.g. adapted tap handles)	1	-
Totals	10	16

The question about food provoked more comments than did any other question on a specific item. Ninety respondents claimed they were not satisfied with the food and 97 made comments about it. While 19 respondents indicated how much they enjoyed the food, 52 were critical of the provision in terms of quality, presentation and choice. Four respondents who made criticism of the food did so with reference to their medical conditions rather than in terms of its overall appeal. One respondent who was confined to a wheelchair found an ordinary hospital diet too much for an inactive person and requested he should be put on a calorie controlled diet. The remaining three questioned the appropriateness of various foodstuffs they were given following gastrectomy and cholecystitis.

Most patients (134) found the hospital beds comfortable, with only eight disabled and eight non-disabled respondents claiming otherwise. The non-disabled who were not satisfied disliked plastic mattress covers (3) and the hardness of the beds (5). The dissatisfied disabled respondents made similar comments about the hardness of beds (3) and one home user of a Simpson air-bed lamented that an air-bed was not available in hospital. Two paraplegic patients appreciated being able to use Hoskins-type beds identical to those which they had at home.

Although non-disabled respondents could be expected to be experiencing a degree of functional loss as part of their acute conditions, none commented about the ease of use of patient utility areas.

SATISFACTION WITH WARD ROUTINE

Forty four disabled and 41 non-disabled respondents commented on ward routines. There was no indication that negative or positive comments were more frequently made by disabled or non-disabled patients.

A majority of patients (115, 77%) did not have the ward routine explained to them and disabled patients were less likely to receive such an explanation than were the non-disabled ($p = < .05$). None of these respondents expressed any concern about not receiving an explanation of ward routine. Several made comments such as, "I just used my imagination", while others excused the omission by explaining they were admitted during the night or that they had been too ill during their hospital stay to bother about routines. Those respondents who had received some explanation of ward routine, especially from the nursing staff, were very positive in their comments and clearly appreciated the time spent talking to them. As one disabled respondent put it:

> "The nurse who admitted me was marvellous, she told me everything and really made me feel at home".

Many patients (76/150) found that the hospital day started too early, an opinion held by almost equal numbers of disabled and non-disabled respondents. Almost all the respondents (145/150) found they could rest during the daytime if they wanted to. Only three disabled and two non-disabled respondents reported that ward activity prevented them from resting. All the wards included in the study made provision for a resting period, usually in the afternoon, when ward activity was kept to a minimum.

Sleeping at night was difficult for 68 respondents and was a problem which affected disabled and non-disabled patients almost equally. The major causes of sleeplessness were noise and activity on the ward during the night rather than matters related to the patient's medical condition. For some patients the problem of ward activity at night was made worse by having a bed positioned nearby a nurses' station. One disabled and partially deaf respondent reported with obvious pleasure that he had slept undisturbed by lying with his "deaf ear" uppermost. Six disabled and two non-disabled patients could not sleep for reasons related to their medical conditions. Of the disabled respondents, four were bronchitic and had breathing difficulties, one arthritic patient had joint pains and one with a C.V.A. was constantly disturbed as a result of her diuretic therapy or, as she put it, "I was on the water pills and couldn't settle at all". Of the two non-disabled respondents who could not sleep for reasons related to their medical conditions, one had persistent headaches and a second breathlessness caused by a pleural effusion.

A majority of respondents (88/150) found their time in hospital was not boring and no differences between the disabled and non-disabled were apparent in this respect. Neither was this factor influenced by the respondent's age. Whether or not a respondent was able to fill in time in hospital often appeared to depend upon the personality of the individual. Two respondents with multiple sclerosis made contrasting comments. The first, with very severe disabilities, recalled that filling in time was easy, "We had plenty of laughs and got up to plenty of pranks". The second, a respondent with a lesser degree of physical impairment, commented:

> "We all sat around like zombies,
> hospitals seem to do that to people, you
> had no energy to read or concentrate, we
> all felt the same".

On the other hand, disabilities did make filling in time more difficult for at least two respondents. One, a man with multiple sclerosis who suffered from diplopia throughout his hospital stay, found it impossible to read or watch the television. The second, a blind respondent whose only form of entertainment was a radio, found himself in a bed with a broken radio terminal and was not permitted to have his own radio on the ward.

The majority of respondents (133) found visiting times satisfactory in terms of the closed questions and no differences were evident between the disabled and non-disabled groups. Of those respondents who were not entirely satisfied, their major concern was with the serving of an evening meal during visiting.

SATISFACTION WITH WARD RELATIONSHIPS

Respondents were more satisfied with ward relationships than any other aspect of their hospital stay. Most patients had nothing but praise for the ward staff and only in a few instances, where a specific event had in some way spoiled relationships, did respondents offer any qualifications to their praise. A total of 94 respondents made comments about their relationships with ward staff.

Helping a patient to settle on the ward, and relieving any apprehension the patient may have about his admission, was often a part of the explanation of ward routine already mentioned. Although some disabled (15/75) and some non-disabled (7/74) patients reported that no one helped them to settle after their admission, a majority (133/149) thought the nurses had done all they could to set their minds at rest following their admission. For example, a disabled respondent commented:

> "The nurses asked if they could do anything for me and made me feel relaxed"

and a non-disabled respondent said:

> "I have nothing but praise for the nurses, when I first came in the sister made me feel there's someone that's really interested in me".

Those who felt more could have been done to set them at ease were able to offer little explanation as to why it had not been. One non-disabled respondent felt the nurses were unable to do more for him because they were so busy:

> "I felt the nurses could have done more, once I was admitted I was left to get on with things, they [the nurses] were pushed for time though".

Some of the problems arising at the time of admission were common to both disabled and non-disabled respondents. For example, a disabled respondent said, "I felt the nurses were not interested in me", while a non-disabled person said in a similar vein, "They [the nurses] didn't want to know". A second non-disabled respondent had what appears to have been a rather traumatic admission experience:

> "I was just shoved into bed and X-rayed upside down, told nothing, I got told nothing from nobody".

These respondents seem to have been treated in an off-hand manner but this type of problem would seem to be as liable to be experienced by disabled as well as non-disabled patients.

Two disabled respondents, both of whom suffered from Parkinson's disease and had disfiguring impairments in the form of involuntary facial movements, had upsetting experiences following admission. One felt that the nurses would not come near to him while the second said he overheard the nurses whispering about him saying, "What a queer face". It is well-known that visible physical impairment, particularly impairment involving a facial disfigurement, affects interaction (Davis, 1964). It is encouraging that only two disabled respondents made explicit remarks on the felt effects of their impairments upon their interactions with ward staff.

Both disabled and non-disabled respondents reported that they spent little time talking to the nurses during their hospital stay. The limited amount of time the nurses did spend talking was explained by many respondents in terms of how much work they had to get through on the ward. For example, a non-disabled respondent commented:

> "The staff were very friendly and would stop for a chat if they weren't too busy".

A disabled respondent made a similar comment, "The nurses were just too busy to talk". Both groups of respondents appeared to have had very similar experiences and both identified the pressure of ward work as preventing much interaction with nursing staff.

In terms of what interaction with nurses the respondents did have, the majority of both disabled and non-disabled found the interaction very satisfactory. This feeling is reflected in the two following comments made by a disabled and a non-disabled respondent:

> "The nurses went out of their way to be friendly, they were all very good, I loved them". (Disabled)
>
> "There was a friendly atmosphere all round". (Non-Disabled)

Inevitably, not all respondents maintained such cordial relationships throughout their stays. Those who did experience problems usually did so with respect to only certain members of the nursing staff. The non-disabled respondents appeared to have more frank problems in their relationships with nurses. As one non-disabled respondent put it:

> "If you see a nurse you think you'll clash up against, you play dumb, there was one I clashed with. They done all that they could but one or two of them could be very official. Two of them put you in your place, you were only an old horse in for treatment and could'nae do what you wanted to do".

The only adverse comment made by the disabled on the subject of relationships was by a respondent who found the senior nurses "cold and aloof".

The final question in the section on relationships referred to whether the respondent had felt treated as an individual or just another case going through the system. This question was taken from the 'Royal Commission Survey of Patients' Attitudes to the Hospital Service' (Royal Commission on the N.H.S., 1978). For purposes of that investigation, a response indicating that the patient was treated as "just another case" was taken to be an indication of dissatisfaction on the part of the patient. Comments made by respondents during data collection for the study at hand appear to invalidate such a blanket interpretation of responses to this question. One respondent inferred that being treated as just another case was preferable:

> "Definitely I was just another case, the nurses were very professional".

Three respondents equated being treated as an individual with favouritism. As one respondent put it:

> "They [the nurses] have too much to do to have favouritism, the nurses are never finished".

Other respondents did value being treated as an individual; one disabled respondent who resented his felt loss of individuality said, "I felt labelled with a tag, 'in for tests'". No differences were evident in the numbers of disabled and non-disabled who made comments, adverse or otherwise, regarding this aspect of care.

SATISFACTION WITH THE COMMUNICATION OF INFORMATION

Questioning regarding the transfer of information between ward staff and patients was about the patient's medical condition and its treatment, including nursing and medical care. Communications between staff and patients clearly play an important part in all the aspects of patient care (for example, see sections on explanation of ward routines and discharge arrangements) and comments about the communication of information often referred to these different aspects of care.

In terms of satisfaction scores, more respondents were dissatisfied with the communication of information than with other aspects of care, other than ward facilities. Although the majority of comments made about the communication of information were neutral (76), negative (34) comments were more common than positive (5) comments.

Many respondents commented on the nurse's role in communication rather than upon difficulties in obtaining information from nurses. These comments fell into four groups, examples of which are as follows:

(1) Nurses lack information:-

> "The nurses didn't know an awful lot". (Non-Disabled)
>
> "I was in having tests and the nurses didn't know what was happening". (Disabled)

(2) Not the nurses' job to inform:-

> "It's not the nurses' job to tell you about your condition or treatment". (Non-Disabled)
>
> "I had nothing to discuss with the nurses, they only dish out pills and make beds". (Disabled)

(3) Information giving is the doctors' job:-

> "I left all that to the doctors". (Non-Disabled)
>
> "I only asked the people who know, the doctors". (Disabled)

(4) Uncertain whether nurses had information:-

> "Did they [nurses] know anything?" (Non-Disabled)
>
> "Did they [nurses] know?" (Disabled)

Other respondents did see the nurse as a source of information, or at least a conveyer of information between patient and doctor. Ward sisters were recognised by three respondents (two disabled; one non-disabled) as a reliable source of information. For example:

> "I didn't ask the nurses, the ward sister told me most".

Four respondents saw nurses as the carrier of "glad tidings" only. As one respondent put it, "They [nurses] only tell what is good for you", a view which again appears to minimise the nurse's role in this sphere.

Several respondents recalled how their attempts to obtain information were channelled to the doctor:

> "You ask the nurses and they say, 'Ask sister' and sister says, 'Ask the doctor'"

while others simply used the nurses to convey to the doctor a request for information. As one disabled respondent said:

> "The nurses don't know much but they go and ask when you want information from the doctor".

Five respondents explained their felt lack of information coming from nurses in terms of the pressures and constraints upon nurses. For example, one respondent said:

> "The nurses are like speedboats, they have no time to tell you anything".

Of those respondents who depended upon medical staff as information source, six found difficulty in either obtaining or understanding the information they had been given. The following comments made by both disabled and non-disabled respondents illustrate this:

> "The doctor's manner was aloof and I didn't understand the terms". (Non-Disabled)
>
> "I asked the consultant what was the matter with me and he didn't reply". (Disabled)

One disabled and one non-disabled respondent, both of whom had suffered myocardial infarction, felt they had been given inadequate information in order to cope after discharge. Both these respondents had to visit their G.P., one to find out which tablets to take when, and the second to see if he could take exercise.

One disabled respondent who had developed diabetes mellitus was found by the interviewer to have eaten nothing else but the single specimen diet given to her while in hospital since being discharged.*

Three respondents, two of whom were disabled, felt they had more to offer the nurses than vice versa regarding information pertaining to their conditions and treatment. As one put it:

> "No, the nurses asked me a lot of questions about my multiple sclerosis".

In response to the question asking how much information a respondent wished to have about his condition and treatment, the majority (122, 81%) preferred to know all the details, while only a small number of respondents preferred to know only some things (21, 14%) or not to know at all (6, 4%). In terms of this question, the desire for information was equal for disabled and non-disabled respondents. Of those who wanted to know all the details of their condition and its treatment (122), 72% (87) were able to find out all they wanted to know. The reasons most commonly given by the disabled respondents for not finding out what they wanted to know were that they did not like to ask and that no one would say. For the non-disabled respondents, the most common reason was that no one would say.

The medical staff appeared to have played the major role in imparting information about diagnoses and treatment for most patients. Respondents were asked who told them most about the topic and whether or not the nursing staff told them very much. Of the total sample, 128 named the doctor as having told them

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* This respondent was referred to the British Diabetic Association by the interviewer

most, whereas only nine named either the sister or other nurses as having told them most. When asked how much the nurses told them, 123/150 said the nurses had not given them very much information.

The majority of respondents claimed to prefer to leave decisions about treatment and nursing care to the doctors and nurses respectively rather than to discuss the matters with the doctor or nurse. More respondents (45) wished to discuss medical decisions than nursing decisions (26). No differences are evident between the disabled and non-disabled respondents in this respect. Whether or not a respondent was told information or had to ask for it, was related to whether or not he preferred discussion with those who were treating him. Those who preferred discussion were more likely to have asked for information than to have been told without asking ($\text{Chi}^2 = 10.075$, 1 df, $p = <.005$).

When respondents wanted to convey information to the nursing staff, all but one respondent stated that the nurses were ready to listen, always or at least sometimes. Only ten respondents (seven disabled and three non-disabled) said that they never had anything to tell the nursing staff. The only problem noted by the patients about giving information to the nurses was that they were usually busy. One respondent said that there were so few nurses they were difficult to find, while a second recalled feeling that she only told the nurses anything when she knew they would have time to listen.

SATISFACTION WITH NURSING CARE

In terms of the rating scale scores, a high level of satisfaction with nursing care was registered by both disabled and non-disabled respondents. Their comments clearly indicated a feeling of goodwill toward the nurses and an appreciation of the care they provided. In the few instances where respondents had experienced what they considered inadequacies in nursing, explanations were frequently offered which excused the nurse and focused criticism upon the structure of the hospital service in the widest sense.

The quality of critical comments made by disabled and non-disabled respondents differed in that criticisms made by the non-disabled related to specific incidents or events, whereas the disabled respondents tended to consider their whole experience of being nursed and made critical comment in general terms. For example, the comments of two non-disabled respondents were:

> "My intravenous drip stopped and after an hour no nurse had been to adjust it, eventually the doctor put it right".
>
> "A young nurse spilled very hot water on me when I was having a steam inhalation, the matron was very apologetic".

In contrast to this type of statement, the following are two examples of comments made by disabled respondents:

> "There is an enormous fund of goodwill available on the part of the nursing staff, the practitioners of the various therapies and also, certainly not negligible, the ancillary staff. The trouble is that all these categories have certain clearly defined duties to which they have to attend and any additional service and help which they may be called to give to the various types

> of the disabled have to be provided on an ad hoc basis and when time presses this additional help must go by default. On many occasions I was reluctant to press for attention in these circumstances. Busy nurses just do not have the time to decipher the incoherent mumblings of a speech handicapped patient".*
>
> "The nurses weren't aware of the likelihood of breaking my skin when they turned me. You've got to accept the limitations of general hospitals because nurses aren't trained to look after spinal cases and emergencies take priority over me being turned".**

This is not to imply that the disabled respondents made no mention of specific events in the context of critical comment but rather that amongst the non-disabled such incidents formed the sole basis for criticism. Several disabled respondents complained of a lack of awareness, on the part of the nurses, of their underlying disablement. One such respondent who was suffering from hemiplegia and had been admitted for treatment of a myocardial infarction, said:

> "The nurses were very good and did their best but they thought I was able to do things which I can't, like walking to the lavatory. I had to shout I had difficulty walking, the nurses forgot that I had had a stroke".

One disabled respondent with multiple sclerosis had her hopes and expectations raised by a general practitioner saying

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* This comment was part of a statement typed on an electric typewriter by a severely disabled man with rheumatoid arthritis who had suffered a cerebral-vascular accident resulting in speech impairment

** Male paraplegic respondent

she would be "surrounded by nurses and physiotherapists" once in hospital. These expectations were not fulfilled; as she put it:

> "I imagined I would come out of hospital more mobile than when I went in with a tailor-made exercise programme to continue. No exercises were offered and I came home less mobile. My cholecystectomy was definitely a success but my M.S. is definitely worse".

In order to maintain mobility, this respondent walked as much as she could prior to admission. Once hospitalised, she found leg exercise difficult and despite her requests no assistance was given. Two other disabled respondents, one with rheumatoid arthritis and the other with osteo-arthritis, had similar experiences. Both depended upon regular exercise to maintain mobility and found the period of inactivity encountered during their hospital stay effectively reduced their abilities to be mobile.

It is possible that the nurses' efforts to care for the acute condition of their disabled patients might have meant that they were seen to neglect the patient's disabling condition. If this had been the case, then those disabled patients whose primary diagnosis was that of their disabling condition would have expressed greater satisfaction with their care than those disabled patients whose primary diagnosis was not identified as a part of their disabling condition. There was no evidence of different levels of satisfaction for these two groups of disabled patients.

The majority of respondents who commented on their general satisfaction with nursing care were entirely satisfied and praised the nurses highly, both in general terms and in relation to specific events. For example, two non-disabled respondents commented:

> "They [nurses] were always there, even if I scratched my nose".
>
> "When I was washed by staff nurse I felt embarrassed but she was very understanding and put me at ease".

A third non-disabled respondent who felt her appendicectomy wound was "large and ugly" was cheered up immensely by a nurse showing her her own scar from a similar operation. Similar expressions were made by disabled respondents also:

> "The staff were marvellous, nothing was too much trouble".

A respondent suffering from hemiplegia who had a colostomy commented:

> "The nurses were very understanding, they were gentle and didn't rush when lifting me, they understood the pain".

A majority (123) of the total sample of disabled and non-disabled patients saw the nurses as generally being very skilful, while the remainder (26) found the nurses fairly skilful in general (one case not stated). One disabled and one non-disabled respondent qualified their answers by acknowledging that some nurses were untrained or in training. The disabled respondent commented:

> "Most of them [nurses] were fairly skilful, you have a lot of untrained ones but they get help when they need it".

Three respondents felt they could, at times, have been lifted more gently by the nurses. One disabled respondent commented:

> "I found the auxiliaries heavy-handed,
> especially when lifting up the bed"

while a non-disabled respondent said:

> "They pull you up in bed by your arms,
> two nurses of different heights and tell
> you to put your arms around them to
> pull".

Few disabled respondents commented in this section about being lifted, despite the fact that many of them had difficulty with transfer and suffered from conditions liable to make the procedure of being lifted a painful affair. Indeed, it was a non-disabled respondent with a myocardial infarction who perceived a problem in being lifted by two nurses of different height.

The majority (138) of respondents felt that the nurses could have done no more for them than they did; only ten respondents (five disabled and five non-disabled) felt that the nurses could have done more. The areas in which the disabled respondents felt more could have been done for them included assistance with bathing and getting to the lavatory, a paraplegic respondent felt he had not been turned regularly enough, two respondents felt the nurses' general attitude was uncaring and one of these individuals thought he had been ignored by nurses from time to time.

The non-disabled respondents noted a similar range of omissions; insufficient information, a lack of assistance when bathing, delays in receiving pain relieving medication and wound repacking. One respondent felt staff apologies did not fully recompense her for the loss of her false teeth to the incinerator!

A significantly greater minority of disabled respondents (16) felt a nursing procedure should be changed for them than did the non-disabled (1) ($p = <.01$). The type of nursing activity which the disabled respondents requested nurses to change to suit their own particular needs were mainly related to areas of personal care with which they were being assisted. Seven asked if they could follow their usual, often unorthodox, methods to carry out activities. For example, this meant getting in and out a particular side of the bed, doing a "Frisbro flop" to get into bed, or being lifted in special ways. Requests other than for special assistance with A.D.L.s included asking the nurses to note soreness and weakness of limbs, the provision of bed cradles and special positioning in bed. In each case where a special request was made by a disabled respondent, the nurses were able to comply. The only request made by a non-disabled respondent concerned the provision of antacids on a patient's locker.

Significantly more non-disabled respondents (38) felt a nurse had been particularly understanding than did disabled respondents (20) ($p = <.05$). The kind of incident mentioned by respondents in this context varied both for the disabled and non-disabled from a very specific occurrence to general comment. An example of a specific event was a speech impaired respondent who found one nurse particularly understanding when feeling depressed and frustrated with this handicap. Six non-disabled respondents commented upon the high quality of attention and understanding they had experienced as patients in a coronary care unit. Thirteen of the non-disabled respondents could identify an incident in which a nurse was remembered as being especially understanding. For example:

> "Lots of times; I had a pain in my back, they got round me and tried to relieve the pain with pillows".

Few (11) respondents claimed there was ever any occasion when a nurse was not understanding. The instances cited by respondents in the context of this question referred to specific encounters with a single nurse. The experiences of both disabled and non-disabled respondents who claimed that a nurse had not been understanding were similar. For example, a disabled respondent said:

> "The [nurse in charge] was rude, sharp and sarcastic, she belittled me in front of the doctors"

while a non-disabled respondent recounted the following:

> "A nurse told me I was imagining that I was ill".

Only five respondents felt that the maintenance of privacy during examination and treatment had been lacking during their stay, no differences being evident between the disabled and non-disabled groups. Difficulties in maintaining privacy were more related to the structure of the ward and the number of patients present rather than to any lack of diligence on the part of nursing staff. Four respondents who felt privacy was lacking were admitted to beds positioned in the centre of the ward and understandably felt in full view of the whole ward. A fifth respondent noted the problem of rooms used for dual purposes, i.e. lavatory and sluice, divided with a less than full height partition.

SATISFACTION WITH DISCHARGE ARRANGEMENTS

Questions regarding arrangements for discharge elicited only 19 respondents (seven non-disabled, 12 disabled) to make a single comment each, most of which were negative in nature. The focus of criticism amongst non-disabled respondents related to specific experiences concerning the uncertainty of discharge dates and conflicting information from medical and nursing staff in this respect. The following comment exemplifies this:

> "I was sitting by the bed on Monday morning when the doctor passed and said, 'When are you going?'. I asked, 'Going where?'. The doctor replied, 'Home, the chief said you could go home last Friday'".

A second non-disabled respondent understood she was going home on Sunday so had her clothes brought in and put them on. When a nurse realised what was happening she was informed that the staff did not know she was about to be discharged and consequently the respondent, in her own words, was "devastated". As a result of this misunderstanding she took her own discharge.

Although this type of difficulty also arose amongst the disabled group, for example an ambulanceman was given the wrong address to which to take a respondent, the discharge problems encountered by the disabled related to a wider range of topics. Three respondents claimed no ambulances were available to take them home and they had to make their own arrangements for taxis. Another respondent who was taken by ambulance was not allowed to transport her walking frame in the vehicle and eventually her social worker went and collected the equipment from the hospital.

The period of notice given to respondents regarding their impending discharge varied from four days to one hour. A majority (146) of the sample found an adequate amount of time had been given to make arrangements. For those who made the opposite response, the shortage of time did not appear to have had any serious implications.

The majority (133) of respondents returned to their own homes, while 15 went either to stay with a relative or to a convalescent home. Two of the disabled respondents were transferred to another hospital to a unit specialising in rheumatic disease.

As may have been expected, more disabled (35) than non-disabled (15) respondents expected to be visited by community health care staff following their discharge. Of the 50 respondents expecting to be visited, five had not received one or more of their visitors by the time of their interview at home. All of these respondents belonged to the disabled group. Two district nurses failed to arrive to help with bathing, three home helps, an occupational therapist and a physiotherapist failed to materialise. The only respondent who voiced any concern about this failure did so in terms of criticising the hospital for cancelling an existing arrangement for a home help, rather than expressing concern about its implications for maintaining her domestic affairs.

CHAPTER 8

Disabled Patients in Acute Care Settings: The Nurses' Point of View

GENERAL WARDS OR SPECIAL UNITS: NURSES' PREFERENCES FOR ADMISSION OF DISABLED PATIENTS

The extent to which nursing staff viewed acute wards as an appropriate location for the care of the disabled is now examined. These attitudes are explored in terms of the nurse's knowledge and experience in the care of disabled patients.

Nurses in the sample possessed a wide variety of training, skills and experience, and included ward sisters, staff nurses, student nurses and nursing auxiliaries. To obtain an indication of nurses' opinions about caring for disabled patients in acute care settings, they were asked whether acutely ill disabled patients should be admitted to general hospital wards or to special units for the disabled. They were also asked to give the reasons for making their choice.

A majority of nurses (148/205) felt that special units would be more appropriate than general wards for the care of acutely ill disabled people. Preferences were associated with nursing grade (Chi^2 = 17.1672, 6 df, p = <.01) but not in a consistent direction. The proportion of respondents showing preference for admission to specialist units increases with seniority for training grades of nurse and reaches a maximum for third year student nurses. For the qualified grades of nurse, the proportion showing preference for special units decreases with seniority. Ward sisters were the only group within which a majority (8/15) of respondents favoured admission to a general ward. The greatest number of preferences for admission to specialist units were amongst third year student nurses where 35 out of 38 made this response (Table 9).

TABLE 9: Nurses' preferences for admitting acutely ill disabled patients to general wards or specialist units for the disabled by nursing grade at time of completing questionnaire (N = 205)

Grade	Nurses' Preference				Proportion Preferring Special Units (exc. Not Committed Cases)
	Special Units	General Wards	Not Committed	Total	
Ward Sister	6	8	1	15	.428
Staff Nurse	48	22	3	73	.686
3rd Year Student	35	3	1	39	.921
2nd Year Student	28	7	-	35	.800
1st Year Student	9	6	-	15	.600
Nursing Auxiliary	15	3	-	18	.833
Other	7	2	1	10	.777
Totals	148	51	6	205	.744

All but two respondents were able to give reasons in support of their preference for admitting disabled patients to either general wards or specialist units. Another six respondents were unable to make a definite commitment to either of the given alternatives. Although the majority of respondents were able to make a commitment to one of the alternatives given in the question, some respondents qualified their choice.

Of those respondents who felt admission to general wards was most appropriate (51/205), five respondents noted that exceptions to their choice would be likely in view of the variability of disablement. For example, an auxiliary nurse commented:

> "I believe that a disabled person should be allowed to feel as normal as the next person. Therefore, being nursed in a general hospital ward where they are given the same treatment as others would be in their best interests. However, having said that, it really depends upon the disability and condition the patient has been admitted for. I believe there must be lots of cases where it would be more beneficial to the patient to be nursed in a specialist ward".

The sisters who favoured admission to general wards (8/15) did so primarily on the grounds that specialist units would segregate disabled people from non-disabled society. Four of the sisters holding this view acknowledged that acute wards did have deficiencies for the care of disabled patients. They believed these could be overcome given appropriate equipment, facilities and staffing. One sister saw general wards as offering specialist services which would not be so easily available to patients admitted outwith the acute care hospital sector. The main reason given by those ward sisters who supported admitting disabled people to special units was that a higher quality of nursing care could be provided there.

Some nurses who favoured admission to special units (16) qualified their choice in a number of ways. As one staff nurse put it:

> "In a busy general medical ward I have often felt dissatisfied with the amount of care I have given to such patients due to shortage of staff, equipment and facilities. However, I do not wish to alienate such patients, if I felt I could give adequate care then I would certainly say admit to general wards".

The three reasons given most frequently by nurses below the grade of ward sister in support of admitting disabled patients to general wards were: (1) that general wards are more appropriate for the treatment of acute conditions (14/43); (2) that disabled patients are needed on general wards for staff training (6/43); and (3) that segregating disabled from non-disabled patients is not desirable (25/43).

The most frequently given reason for admitting disabled patients to special units was the felt lack of equipment and other facilities on general wards (62/148). A similarly large number of respondents (58/148) felt that the staff on general wards were not adequately trained to care for disabled patients. This view was most prominent amongst second year student nurses (18/28) compared with only 18 out of 48 staff nurses and two out of 15 auxiliaries who made the same point.

The statements that general wards were: (1) too busy to provide high quality care; (2) unable to offer amount of care required by disabled patients; (3) staff/patient ratios too low; and (4) that priorities have to be decided upon which favour the acutely ill patient to the detriment of the disabled patient, all indicate that the pressures of time and high workload render the general ward an inappropriate area for care of the disabled patient. Two examples of such comments are:

> "General wards are understaffed and can barely cope with ambulant patients. Therefore I feel any physical disablement would take up time which should be given to general care and running of the ward". (Second year student)

> "Disabled patients with acute conditions require specialist care. We have all hurried on disabled people in a general ward as they are slower, less skilful and less adept at everyday procedures, for example, washing, and not enough time is spent with them when there are more 'important' patients to see to". (Third year student)

DISABLED PATIENTS AND NURSES' MORALE

The ward sisters were asked if the presence of a disabled patient on their ward affected staff or other patients in any way. All but one sister felt they did affect the ward in some way. Six sisters thought that the nursing staff were detrimentally affected by disabled patients, both in terms of confidence in their professional ability and level of morale. For example, one sister said:

> "Nurses are very unsure how to handle a disabled person and try to avoid doing things for them. If a nurse has to bath a disabled person she wishes she hadn't to".

The following comment illustrates some of the effects on morale noted by the sisters:

> "The nurses' morale is damaged when there is not enough time to do what is needed for a patient, the C.V.A.'s are just left sitting when the ward is busy".

Some of the sisters' comments did relate to a positive influence upon staff. For example, one sister spoke of a young paraplegic patient:

> "A 24-year old paraplegic made everyone think how lucky they were. She was very happy and mobile and cheered everyone up".

Seven ward sisters felt the presence of a disabled patient on the ward had undesirable effects upon the other patients. This was explained by five sisters as being due to the extra attention required to nurse a disabled person. One sister commented:

> "One disabled patient on the ward at present has psychological problems and the consultant came three times over the weekend to see him. The other patients were saying, 'He's getting a lot of attention'. Usually patients don't mention these things, but they feel it".

Two of the sisters felt that non-disabled patients did not accept a disabled person as a fellow patient. In the words of one sister:

> "Sometimes severely crippled people are a problem, other patients ask to be moved from the next bed because they don't want to see them".

Two other sisters had had opposite experiences regarding the conduct of non-disabled patients. For example:

> "Other patients tend to rally round a disabled patient, it makes them more caring".

NURSE TRAINING

In view of the high frequency of statements encountered indicating a perceived lack of training in how to care for disabled people and given as a reason for not admitting them to general wards, the question of nurses' knowledge becomes doubly important. From the total sample of 205 nurses, only five (less than 2½%) claimed to have attended a course of instruction related to physical disability. Nearly all of the courses mentioned were single study days concerned with the care of particular diagnostic groups. The one exception was a ward sister who had attended a symposium on rehabilitation. A little over half (106, 55%) of the respondents claimed to have read one or more books, articles or reports on disability. Predictably, nursing grade was associated with such reading ($Chi^2 = 19.884$, 4 df, $p = < .001$). The higher the nursing grade, the greater the likelihood of having read literature on disability.

There was no association between the nurse's choice of special unit or general wards for acute care of disabled patients and their having read any literature on disability. The areas of literature most frequently read by nurses were those dealing with the nursing care and the psychological implications of disability. No association was apparent between breadth of reading and preferences for special unit or general ward admission policies. While as many as 106 of the sample claimed to have undertaken reading on disability, and 76 of these had read in more than one subject area, only 27 respondents were able to give a reference which included either the author's name or the title of the work.

Eighty respondents had attended an exhibition of physical aids for the disabled. The likelihood of having attended an exhibition increased with nursing grade but no apparent relationship exists between preference for special unit or general ward admission.

NURSES' EXPERIENCE OF DISABLEMENT

Although 52 (23%) of the sample claimed to have had special experience of nursing disabled people, for the majority of them this was experience gained during nurse training either on general medical or surgical wards. Only seven respondents had experience of nursing physically disabled patients in special units as qualified nurses. Special experience in caring for disabled people is not associated with respondents' preferences for admitting disabled patients to general or special wards.

Respondents below the grade of ward sister were given a list of 13 disabling conditions and asked to indicate with which of these they had professional experience.* As may have been expected, a majority of respondents had nursed patients with the more common of the listed conditions. That 19% of the sample had nursed a patient with brittle bone disease and 23% a patient with muscular dystrophy, both relatively rare conditions, could be accounted for by a number of nurses coming into contact with a single patient.

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* The following list of conditions was given:

Amputated limb
Brittle bone disease
Cerebral palsy
Blindness
Chronic bronchitis
Multiple sclerosis
Muscular dystrophy
Osteo-arthritis
Quadriplegia
Paraplegia
Hemiplegia
Parkinson's disease
Rheumatoid arthritis

For the 13 selected disabling conditions there was a general tendency for nurses who had nursing experience of a condition to select that condition as a teaching priority. This tendency was only sufficiently marked to reach statistical significance for multiple sclerosis, hemiplegia, chronic bronchitis and Parkinson's disease (Table 10). The prevalence of a condition is not related to the frequency with which it was considered to be a teaching priority.

Exposure to disability need not be confined to professional contacts. A total of 96 respondents had a non-professional acquaintance with at least one disabled person. Fifty eight of these respondents had seen this person less than one month prior to completing the questionnaire and 76 less than six months prior. In 37 instances, the disabled acquaintance belonged to the respondent's immediate family. No association is apparent between respondents' preferences between special unit or general ward admission for the disabled and the presence, or otherwise, of a disabled acquaintance.

There was a paucity of professional training and experience in physical disability amongst the study sample. Only two respondents had received instruction on the subject and had professional experience in caring for disabled patients. The majority of the sample (129, 68%) had neither received instruction nor had any professional experience with disabled people. None of the variables recorded with a bearing upon nurses' exposure to disability in terms of professional or lay associations with

TABLE 10: Nurses' experience of nursing 13 disabling conditions by felt need for nurse education about each condition (N of nurses = 185)

	Condition	Practical Nursing Experience		No Practical Nursing Experience		Significance Level
		Teaching Priority	Not a Teaching Priority	Teaching Priority	Not a Teaching Priority	
Conditions where more than 50% of respondents were experienced	Multiple Sclerosis	92	55	9	29	$p = <.001$
	Hemiplegia	138	35	5	7	$p = <.005$
	Chronic Bronchitis	83	95	0	7	$p = .01$
	Parkinson's Disease	56	117	0	12	$p = .01$
	Limb Amputation	56	117	3	9	N.S.
	Blindness	50	124	2	9	N.S.
	Osteo Arthritis	13	124	7	41	N.S.
	Paraplegia	25	112	6	42	N.S.
	Rheumatoid Arthritis	63	103	5	14	N.S.
Conditions where less than 50% of respondents were experienced	Brittle Bone Disease	1	35	2	147	N.S.
	Cerebral Palsy	11	79	7	88	N.S.
	Muscular Dystrophy	5	38	12	130	N.S.
	Quadraplegia	5	74	5	92	N.S.

disabled people, professional training in or reading about disability, appear to be related to the nurses' preferences for special units or general wards for the admission of acutely ill disabled patients.

The dominant factor associated with the nurses' preferences for admission of disabled patients to general wards or special units was how much time they felt was available on general wards to talk to patients about their special needs. Respondents who felt that there was usually or always enough time available for talking to patients were more likely to support admission to general wards than were respondents who felt there was rarely or never enough time for talking to patients on general wards ($\text{Chi}^2 = 6.162$, 1 df, $p = < .025$).

In the light of these facts, the preference of the nurses to admit disabled patients to special units could be part of a desire to move a potentially highly dependent patient group from the workload of the general ward. Relevant to this interpretation are the reasons given by 68 respondents in support of admitting disabled patients to special units. These broadly refer to general wards being too busy or too short-staffed to provide optimum care for these patients.

CHAPTER 9

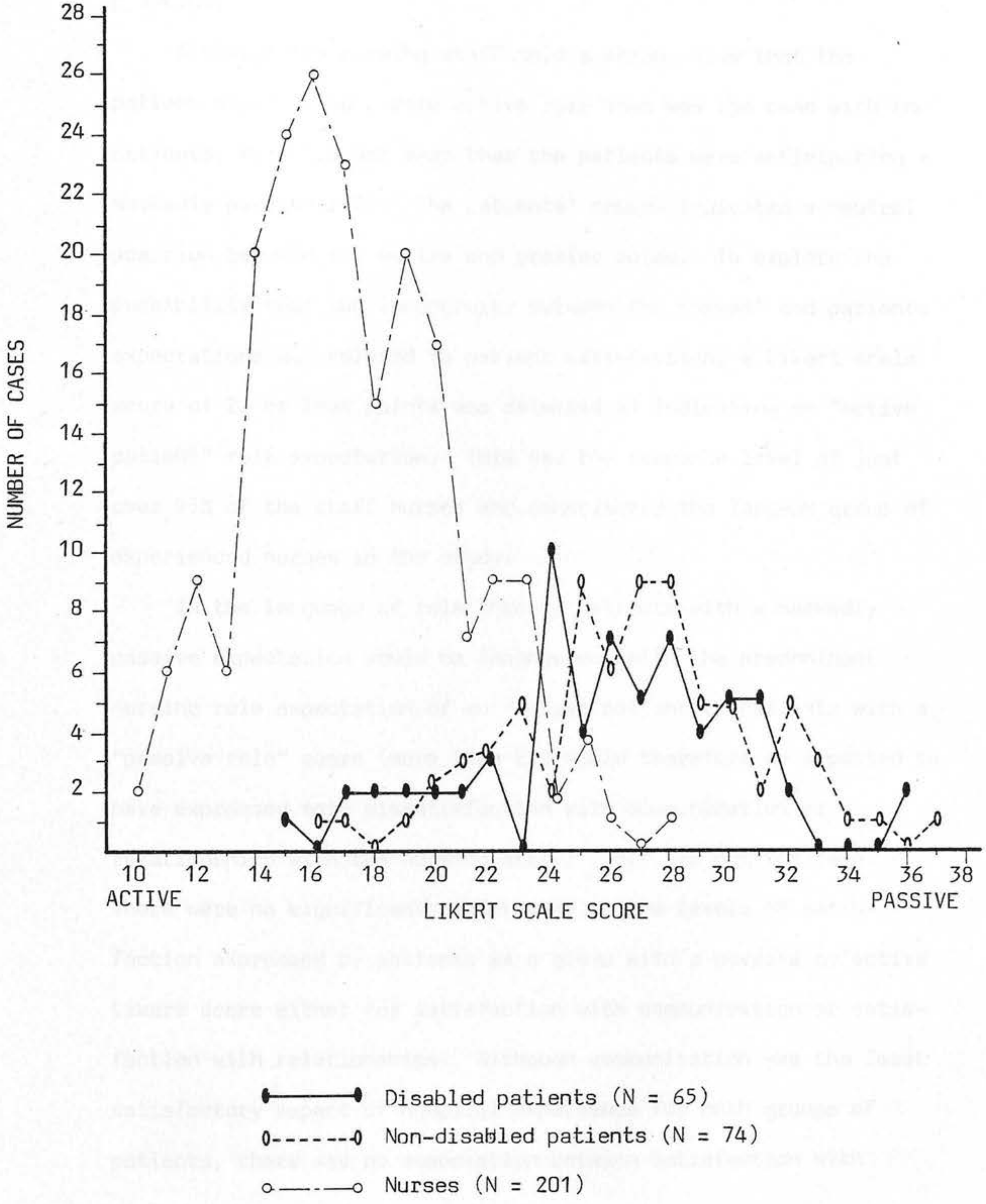
Nurses' and Patients' Views of the Patient Role

Responses to an eight-item, five-point Likert scale were used to assess the patients' and nurses' views of the active/passive dimension of the patient's role. The Likert scale scores provided a maximum possible range of between eight and 40 with a central point of 24. A high score indicates the view that patients should be passive rather than active in the acute care situation. A low score indicates an expectation of high patient activity.

Patients' responses on the scale ranged from a score of 15 to 37, with an overall mean of 26.35 and standard deviation of 4.3. The scores of the patients were approximately normally distributed around the centre of the scale (Figure 13). The scale scores revealed no differences in the level of expectation of an active or passive role between disabled and non-disabled respondents. Both the mean scale scores and their distributions were closely similar.

The nurses' scores revealed a much higher expectation of patient activity than did the scores of the patients themselves with a range from 10 to 28, a mean score of 17.4 and standard deviation of 3.57 (Figure 13). The mean score of nurse respondents was significantly lower than that of the patients (t = 20.96, df = 327, p = <.001). Within the nursing groups who were qualified, or in training, there were no marked differences in this expectation of patient activity (F = .82, df = 182, p = >.05). The mean score of the nursing auxiliaries indicated a less actively orientated expectation of patient role than that of their colleagues (t = 5.79, df = 199, p = <.001). Despite this

FIGURE 13: Likert scale scores, nurses, non-disabled and disabled patients



difference in the expectations of auxiliaries and the other grades of nurse, the mean score of the auxiliaries remained significantly lower than that of the patient groups ($t = 4.69$, $df = 155$, $p = < .001$).

Although the nursing staff held a strong view that the patient should take a more active role than was the case with the patients, this did not mean that the patients were anticipating a markedly passive role. The patients' scores indicated a neutral position between the active and passive poles. To explore the possibility that the incongruity between the nurses' and patients' expectations was related to patient satisfaction, a Likert scale score of 23 or less points was selected as indicating an "active patient" role expectation. This was the response level of just over 95% of the staff nurses who constituted the largest group of experienced nurses in the study.

In the language of role theory, patients with a markedly passive expectation would be incongruent with the predominant nursing role expectation of an "active patient". Patients with a "passive role" score (more than 23) would therefore be expected to have expressed more dissatisfaction with communication or relationships with the nursing staff; this was not the case. There were no significant differences in the levels of satisfaction expressed by patients as a group with a passive or active Likert score either for satisfaction with communication or satisfaction with relationships. Although communication was the least satisfactory aspect of hospital experience for both groups of patients, there was no association between satisfaction with communication and active/passive role orientation for either disabled or non-disabled patients.

In summary, there was no evidence that the "active" role orientated disabled patients expressed either more or less dissatisfaction with information from nurses or their relationships with them than the "passive" role disabled patients. However, an expression of dissatisfaction or satisfaction by patients in a questionnaire-based interview is not the same thing as their being aware or unaware of shortcomings of care in an acute hospital ward. Furthermore, the association between a passive role orientation in patients and their satisfaction with communication and relationship with nurses as predicted from role theory was not found in the present acute hospital care study.

The discrepancy between the nursing staff's and the patients' expectations of activity suggests that there is a considerable gap between the professional aspirations of the skilled nursing staff for "an active patient" and the sharing of this ideal with their patients in practical terms on the acute ward. Other data are available from the patients' questionnaires which could reflect whether or not a respondent tended to adopt a more, or less, active role during his most recent hospital stay. These include responses to questions relating to respondents' wishes to discuss their care and treatment with the doctors and nurses and whether or not they asked the nurses to do things differently for them at any time during their hospital stay.

Patients' preferences for discussing treatment with doctors and nurses were significantly associated with their Likert scale scores. Those patients who preferred discussion with medical and nursing staff were significantly more active (lower mean Likert scale scores) than those who preferred to let the doctors and nurses just get on with the business of care and treatment. On the other hand, no differences are evident on the dimensions of activity-passivity for those respondents who asked nurses to alter the manner in which nursing procedures were carried out and those who made no such request.

CHAPTER 10

Summary and Conclusions

The study began with six research questions. Four of these questions concerned the practical aspects of care provision for disabled people in acute hospital wards, i.e. (1) ward facilities and equipment; (2) nurses' views about care for disabled patients; (3) nursing training; and (4) the effect of changes in care routines upon disabled patients. The other two questions concerned patient satisfaction (5) and patient role perceptions (6). In this concluding chapter the answers to these questions are reviewed and their relationships are examined in the context of role theory. Finally, the study findings are incorporated into a model which both helps to account for the acute care experiences of disabled patients and the nursing problems of providing care. The model is then used as a basis for identifying ways in which improvements might be made in the care of disabled patients in acute care settings.

The findings in relation to each of the six major research questions are summarised below:

1. <u>What facilities are available on acute wards to provide for the needs of disabled patients in terms of physical aids, amenities and manpower?</u>

The equipment and facilities provided by the study wards had variable affects upon the comfort and independence of disabled patients in the activities of daily living. The same equipment, while entirely suitable for one patient, could be quite inappropriate for another patient with a different burden of disablement. The alternative policies of patients being provided with hospital aids or using their own items of equipment in hospital were each shown to hold advantages and disadvantages. Some patients did not bring their own aids to hospital but found alternative equipment to be much superior to their own. Others bitterly regretted not having transferred their aids to hospital as they were obliged to be very dependent on the nurses. Those patients who did bring their own aids to hospital experienced fewer difficulties than those who did not but had little opportunity to sample alternative aids.

The nursing assessment of the ability of patients to continue their self-care activities or of their need for equipment was occasionally ineffective. This was another factor which often led to increased patient dependency upon nurses, as by the case of the nine patients who only required a raised toilet seat in order to use the toilet independently but who, in the absence of this equipment, became entirely and unnecessarily dependent upon the nurses.

As with equipment, the availability and layout of ward facilities had a variable affect upon the dependency of patients on the nurses. For some patients the absence of stairs to W.C.'s and bathrooms meant a higher degree of independence than was attainable in their own homes. Other patients found access to, and use of patient utility areas difficult, if not impossible. The difficulties were not always due to the basic design of patient utility areas, although this was a factor; more often they were brought about by the amount of furniture on the ward and its positioning. The general lack of storage facilities on most of the wards aggravated this problem.

In almost all cases where a patient could not continue a self-care activity because of difficult or blocked access areas, the lack of suitable aids, or poor design of ward fittings, the outcome was an increased dependence upon the assistance of nurses.

2. To what extent are nursing staff trained and experienced in the care of patients with physical disablement?

Very few (5/205) of the nurses included in the study had any formal training in the care of physically disabled patients. More than half the sample (100/190) claimed to have read literature related to disablement but few (27/190) could name either an author or the title of a work they had read. Only seven nurses had experience in caring for disabled patients as qualified nurses in a setting specialising in the care of such patients. Only two (<1%) nurses had both special experience and formal training in the care of disabled patients. However, most of the sample had nursed patients with the more common disabling conditions but this was in the setting of general hospital wards and many nurses saw a need for more education in precisely those disabilities which they had nursed on general wards.

3. To what extent do changes in care routines affect the patient with chronic physical disabilities?

As considered above (see question 1), the effects of change in patterns of care varied from patient to patient. Clearly, a proportion of the disabled patients became dependent upon the nurses for the activities of self-care and most of these individuals would have preferred to have been independent. The assistance available from the nurses was largely considered to be satisfactory by the disabled respondents and most appeared to be content.

The admission to hospital did have long-term affects upon the lives of some patients and in most instances these were beneficial. For example, the exchange of personal equipment for more suitable items following discharge made home living far easier for several patients. However, there were at least two patients who felt that their handicaps had become worse in hospital because of the disruption of their exercise and physiotherapy regimes.

4. What are nurses' views regarding caring for patients with long-term disabilities on acute wards?

The overwhelming majority of nurses (72%) in the study felt that general hospital wards were not the most appropriate location for the care of acutely ill disabled people. Those nurses who held this opinion supported their views mainly in terms of lack of facilities and equipment, inadequately trained staff, and the pressure of time and workload on acute wards.

The nurses who favoured admitting disabled patients to general hospital wards gave as reasons for this view the desirability of integrating disabled people with non-disabled society, the belief that acute care services are best provided on acute wards, and that the education of nurses requires that disabled patients are admitted to acute wards.

Among the different nursing grades, ward sisters most readily accepted disabled people on acute wards, while final year students were the least accepting. The only factor found to be significantly related to choice of location for the care of disabled patients was the nurses' perception of the amount of time available on acute wards. Those nurses who claimed that little or no time was available for talking with patients were more likely to feel acute wards were inappropriate for disabled patients.

5. Are there differences in nurses' and patients' perceptions of the role that the patient should take in care?

The prevailing view of the nurses was that patients should take an active role in their own care. Patients themselves were committed to neither an active nor passively orientated patient role. There was no difference in role perception between disabled and non-disabled patients. Although nurses' and patients' role expectations on the dimension of activity and passivity differed, this apparent incongruence had no demonstrable effect upon patient satisfaction with any aspect of care examined by the study. The extent to which a patient was free to take an active role in an acute ward appeared to be determined by the practical realities of the acute care setting rather than by the patients' or the nurses' underlying conception of role. The theoretical questions related to nurses' and patients' conception of the patient role, and its relevance to patient satisfaction with care are discussed following this summary of the study findings.

6. Do disabled and non-disabled patients experience different levels of satisfaction with care?

The study demonstrates no differences in the levels of satisfaction with care experienced by disabled and non-disabled patients in terms of the six aspects of care explored. A great deal of satisfaction was expressed by both groups of patients and a high degree of goodwill clearly existed towards the hospital and the ward staff. Any differences which did exist between disabled and non-disabled patients related to the reasons for, rather than the level of, dissatisfaction.

The communication of information was shown to be the most crucial factor associated with patient satisfaction. In agreement with findings of other studies, many patients in this study felt let down on this aspect of care, disabled and non-disabled alike (McGhee, 1961; Cartwright, 1964; Carstairs, 1970; Royal Commission on the N.H.S., 1978). A large proportion of patients seemed not to appreciate the nurse's potential role as a communicator of information. The consequent dependence of patients on intermittent contacts with medical staff for information appeared to severely restrict the amount of information the patient received.

NURSES, PATIENTS AND THE PATIENT ROLE

The answers to the questions concerning patients' satisfaction and patient role perceptions identified the problems experienced by disabled and non-disabled patients. The data also enabled a specific theoretical framework to be tested in the context of the practical problems of nurse-patient interaction and the patients' perceptions of their hospital experiences.

Three theoretical propositions for empirical testing were derived from the theory of social roles as it has been previously applied to the roles of patients and disabled persons. These propositions were:

1. Disabled people will view the patient role as more actively orientated relative to non-disabled people and nurses.
2. Where the views of nurses and patients of the patient role are incongruent, patients will be less satisfied with their care in general and particularly with their interactions with nurses and with the communication of information.
3. Incongruent views of the patient's role will occur more frequently between nurses and disabled patients than between nurses and non-disabled patients. Consequently, disabled patients will more frequently experience less satisfaction with their care in general and in particular with their interactions with nurses and with the communication of information, than do non-disabled patients.

None of these three propositions were sustained by evidence from the present study:

1. Disabled and non-disabled patients held similar conceptions of their role in care and neither group viewed the role of patient as so actively orientated as did the nursing staff.
2. The degree of inconsistency between the patients' and nurses' views of the patient role was not related to patient satisfaction with care.
3. Inconsistencies between the patients' and nurses' views of the patient role did not occur more frequently between disabled patients and nurses than between non-disabled patients and nurses. Neither were disabled patients less satisfied

with their hospital care, in all its aspects, than were non-disabled patients.

The taxonomy of disability role types as formulated by Thomas (1966) clearly leads to a conclusion that the role of 'disability co-manager' is primarily an active rather than a passively orientated role, in the context of self-care. While the role of 'disabled patient', in agreement with a majority of the literature on patient roles, is seen by Thomas as essentially passive in orientation. Given that these two roles co-exist for the disabled patient, how does he compromise the demands of each?

Both active and passively orientated patient role behaviours occur in the same patient in response to situational factors, e.g. the ward environment and treatments being received, rather than in response to an underlying role conception held by the patient. It was the constraints of ward design and equipment that rendered some disabled patients dependent upon assistance for the activities of daily life , while the same conditions enabled others to take a more active part in continuing the activities of daily life. Further it was found that when disabled patients felt a modification was required in the way a nursing treatment or procedure was being carried out, it was requested (i.e. active role behaviour) by the patient, and the tendency to make such requests was not associated with role scale scores. This pattern of behaviour was found to apply to both disabled and non-disabled patients. Thus it appears that the labelling of people as "disabled" and "non-disabled" does not coincide with the role of the patient, active or passive.

The implication of this conclusion for Thomas' (1966) typology of roles of the disabled is to emphasise that disabled people adapt, as do all individuals, to situational circumstances which are outwith their control. For the disabled patients in this study adaptation was frequently characterised by an increased dependency upon human assistance, a situation which was brought about through the limitations of ward design, the misuse of ward space, the lack of appropriate aids and equipment, and ineffective nursing assessments. That disabled persons take up distinctive roles, as Thomas' work suggests, would thus seem to be only a partial view.

This is not to say that the underlying conception of an active or passive patient role had no effect whatsoever upon patient role behaviour. Those patients who were found to be at the extremes of the distribution of role scale scores were more likely to ask for information rather than wait to be told if they were at the active end of the scale. The constraints of the acute ward situation, however, seem to be the most important factors in determining patient roles.

The nurses' role scale scores show a strong expectation for patients to take an active role in their care. In relation to the patients' scores the nurses held a markedly higher expectation for patient activity in care, the reverse of the situation hypothesised in the initial theoretical formulation.

This reversal might raise a suspicion that the nurses were merely paying lip service to the ideal of patient activity in care, a theme commonly occurring in the literature related to the nursing process (Kratz, 1979; Marriner, 1983). In view of the practical constraints present on the wards included in the present study an expectation for patients to be highly active may well have been unrealistic and nurses clearly perceived disabled patients as a highly dependent patient group.

Although the nurses' and patients' role expectations on the dimension of activity/passivity differed, this had no demonstrable effect upon patient satisfaction with any aspect of care examined by the study. The communication of information was shown to be the most important single factor related to patient satisfaction, and this association was consistent for both disabled and non-disabled respondents.

In the light of the findings presented here, the role model as it has been applied provides an over-simplified view of the position of the patient and offers little to explain levels of patient satisfaction with their care. The most important factors in determining whether a patient took an active role were clearly linked to the more practical considerations of life on an acute ward. While many disabled patients were undoubtedly placed in a passive/dependent role the mechanisms which brought this about were related to ward design, ward facilities, equipment and the awareness of nurses of the needs and capabilities of the patient.

Although the factors suggested by Freidson (1970) as mechanisms to control patients, i.e. information control and treating patients in a depersonalising manner, may also have operated to bring about patient passivity, these do not operate in isolation.

The study findings have shown, however, that (1) disabled patients do experience a variety of problems when admitted to acute care wards; and (2) the role model offers little help in explaining or providing guidelines to alleviate their difficulties. A model is now developed which attempts to link the various aspects of the study, to explain some of the difficulties encountered by disabled patients and to provide guidance on how some of the problems could be alleviated.

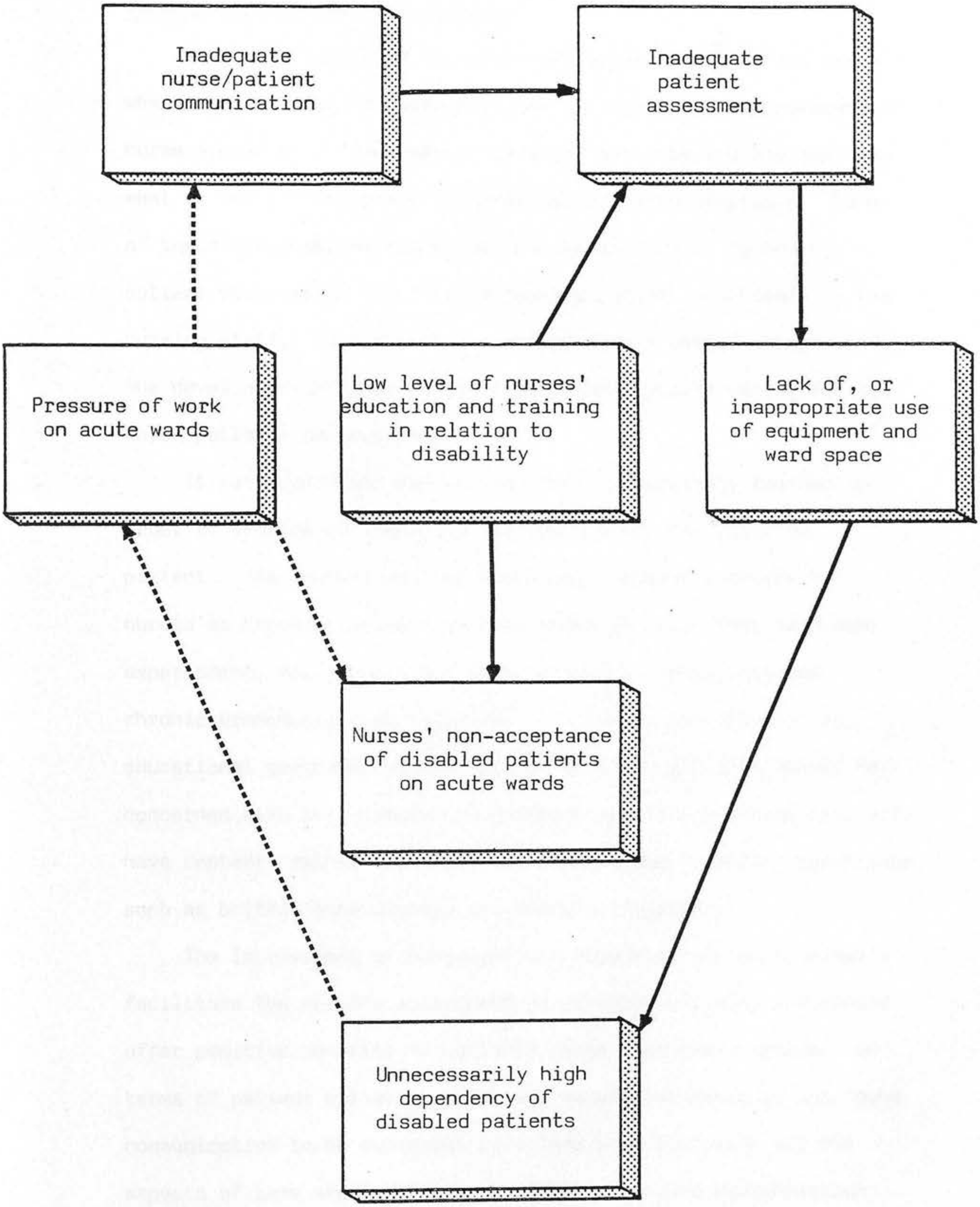
The problems of disabled patients in acute wards arise from a number of different circumstances. In the present study disabled patients were seen by nurses as requiring more nursing time, more specialist knowledge and more facilities than are available on an acute ward. The type of ward design, the availability of aids and equipment, and ward organisation have been shown to have their own effects in making many disabled patients more dependent on the nursing staff, although for some disabled patients ward arrangements were ideally suited for maximising their level of independence. The pressure on the time of the nursing staff in acute wards was shown to be a major factor in the nurses' overwhelming preference that disabled patients should not be nursed in general wards.

Disabled patients did report dissatisfaction with certain aspects of their care but not to a greater extent than non-disabled patients. Levels of satisfaction with communication were shown to be equally important for both groups. If anything, disabled patients were more tolerant and less demanding than non-disabled patients. Tolerance and non-complaint did not signify an uncritical acceptance of a passive and dependent role. The disabled patients in the study were acutely aware of how and in what ways the circumstances of their hospital stay could be modified to enable them to reach a higher level of independence from nursing assistance in their activities of self-care in hospital.

The different elements of these conclusions are related to one another and their interaction helps to explain and point the way to improvement in the care of disabled patients in acute wards. The salient facts are summarised in Figure 14. Most nurses expressed a preference for nursing disabled patients in specialist units, a factor significantly associated with perceived pressure on the time of nurses on acute wards. The low levels of nurse training and experience in caring for disabled people would not only appear to influence their views on appropriate care settings but also to increase the likelihood of ward facilities and equipment being used inappropriately through the medium of inadequate patient assessment; the latter element being further aggravated by the restrictions found to exist in the context of nurse-patient communication.

Together these elements served to create the unnecessarily high degree of dependency which was seen to occur for many disabled patients. The high level of dependency then becomes an input to the system, serving to reinforce the problems of nurse-patient communication and the nurses' lack of acceptance of disabled patients on acute wards by increasing the pressure on the nurses' time. The feedback loop represented in the model is thus completed.

FIGURE 14: Scheme of interrelationships between the major research findings



IMPLICATIONS FOR NURSING

Nurse Education and Communication

The model developed and described above indicates two areas where efforts could be made to break the cycle, the improvement of nurse education in the care of disabled patients and the improvement of the effectiveness of nurse-patient communications. Each of these alternatives holds out the possibility of improving patient assessments and thus decreasing patient dependence on the nursing staff. In turn, this might provide a better situation for the development of more positive attitudes towards caring for disabled patients on acute wards.

It was found that many nurses felt inadequately trained in order to provide optimum care for the acutely ill disabled patient. The conditions that were most frequently chosen by nurses as teaching priorities were those in which they were most experienced, for example multiple sclerosis, hemiplegia and chronic bronchitis (see Table 10). Therefore the focus of an educational programme on the care of disabled patients should be concerned with the disabling conditions with which nurses regularly have contact, rather than with the less common disabling conditions such as brittle bone disease and muscular dystrophy.

The improvement of nurse-patient communication would clearly facilitate the nursing assessment of disabled patients and should offer positive benefits to patients other than the disabled. In terms of patient satisfaction it was shown that patients who found communication to be deficient were less satisfied with all the aspects of care studied than were those who found communication satisfactory. Thus an enhanced system of information transfer between patients and nurses may well raise the general level of satisfaction with care of both disabled and non-disabled patients.

Increasing Nurses' Awareness of the Practical Problems of the Disabled Patient

Guidelines could be developed to encourage nurses' awareness of some of the problems experienced by disabled patients in hospital. These could be directed at matters such as blocking access routes with trolleys when there are patients dependent upon wheelchairs and moving furniture when blind patients are on the ward. While such matters may appear to be relatively trivial, they can greatly add to the burden of being a patient and to the pressure of time on the nursing staff. Guidelines such as these could be presented in the form of a short video film or as a written document.

Patient Education

Many disabled patients included in the study had little idea of what services would be provided for them in hospital, for example those patients who did not think of bringing their personal aids to hospital and those who expected treatments which were not available. Also, some of the disabled people interviewed during the exploratory phase expressed the anxiety that acute hospitals could not accommodate care routines tailored specifically for them. Of the problems experienced by disabled patients, many could have been alleviated by ensuring the patient knew what would be available in hospital and, most importantly, how to communicate his felt need for what was not immediately available.

There is no doubt that the patient's readiness to accept what was provided by the hospital service, and his failure to communicate his special requirements, accounted for some of the problems experienced by disabled patients. However, in every case where a disabled patient requested special consideration in some aspect of care, they were accommodated by the nursing staff. The main purpose of a patient education package would be to stress in general terms the necessity for the patient to communicate his needs to the nursing staff in order to ensure his maximum independence and comfort throughout his hospital stay.

For those patients who were admitted from the hospital waiting list, this information could be provided in the form of written material. In this study, a large proportion of disabled patients (48/75) were admitted as emergency cases which would render the provision of written material inappropriate for the majority. For emergency admissions it would seem, therefore, that responsibility for imparting this information would have to rest in the hands of the domiciliary services, the district nurse or general practitioner; a development which would require close co-operation between hospital and community services.

APPENDIX 1

Interview Schedules and Questionnaires

APPENDIX 1a

Patients' Interview Schedule: Hospital Interview

SECTION "A"

Nursing Research Unit,
Department of Nursing Studies,
University of Edinburgh.

My name is .... and I'm from The Nursing Research Unit at Edinburgh University.

At present the N.R.U., in conjunction with the Scottish Council on Disability, are conducting some enquiries into how well disabled people get along when they're admitted to wards like this one.

[FOR DISABLED RESPONDENTS]:

As part of the study we would like to talk to a few patients who have to limit their activities because of their health, and I wondered if you would be willing to help us with our work.

[FOR NON-DISABLED RESPONDENTS]:

As part of the study we would like to talk to a few patients who are not disabled and normally can do everything for themselves and I wondered if you would be willing to help us with our work.

This would involve asking you a few questions about yourself now and, secondly, some of the people we see we are visiting at home after they are discharged, to talk about how they got on in hospital.

If you are willing to help us I can assure you that everything you say will be treated as confidential and when a report of the study is written no names will be mentioned.

IF PATIENT AGREES TO TAKE PART IN THE STUDY COMPLETE Q1 - Q8.

Q1

Before you were admitted to hospital did you have any difficulty in...

	CODE NUMBER		COL NO
	CODE NUMBER		1 - 3
	MATCH NUMBER		4 - 6
	CLASSIFICATION		7
	MAX DURATION		8 - 11

	Before you were admitted to hospital did you have any difficulty in...		NO DIFFICULTY	DIFFICULTY	For how long have you had difficulty? Yrs	Mths	Can you do it alone even with difficulty? YES	NO	DK	Do you never do item because it is too difficult?		COL NO
1	getting in & out of your chair ?		0					(2) ++++				12
2	getting in & out of bed on your own ?		0				(1) 2	(2) 3 ++	(3) 2	++++ (4) 6		13
3	getting to or using the toilet ?		0				(1) 4	(2) 6 ++++	(3) 5	(4) 5		14
4	having a bath ?	NA (8)	0				(1) 2	(2) 3	(3) 2	(4) 3		15
a	having an all over wash ?	NA (8)	0				(1) 2	(2) 3	(3) 2	(4) 3		16
5	washing your hands & face ?		0				(1) 2	(2) 3 ++	(3) 2	(4) 3		17
6	putting on shoes & socks/tights yourself ?		0				(1) 2	(2) 3 +	(3) 2	(4) 3		18
7	doing up buttons & zips yourself ?		0				(1) 4	(2) 6 +	(3) 5	(4) 6		19
8	dressing, other than buttons & shoes ?		0				(1) 2	(2) 3 +	(3) 2	(4) 3		20
9	feeding yourself ?		0				(1) 4	(2) 6 ++++	(3) 5	(4) 6		21
10	NA MEN combing/brushing your hair ?	NA (8)	0				(1) 2	(2) 3	(3) 2	(4) 3		22
a	NA WOMEN shaving yourself ?	NA (8)	0				(1) 2	(2) 3	(3) 2	(4) 3		23
			TOTALS				☐	☐	☐	☐	☐ TOT NUMERICAL SCORE	
								TOTAL +'S ○				

CLASSIFICATION INSTRUCTIONS CLASS

4 or more +'s 1

If less than 4 +'s count scores (Numbers without brackets)

18 + ... 4
12 - 17 5
6 - 11 6
1 - 5 7
0 8

2. DATE OF BIRTH .... AGE ...... ☐☐ 24-25

3. SEX: Male 1
Female ... 2 ☐ 26

4. WARD NUMBER: ☐☐ 27-28

5. DATE OF ADMISSION: ☐☐ ☐☐ ☐☐ 29-34

6. SOURCE OF ADMISSION: ☐ 35
- Waiting list 1
- Emergency 2
- Referred from OPD 3
- Transferred from other hospital 4
- Other (specify) 5

7. REASON FOR ADMISSION: ☐ 36
- Observations 1
- Investigations 2
- Review 3
- Treatment 4
- Social 5
- Other (specify) 6

8. KARDEX DIAGNOSES:
1. .... ☐☐ 37-38
2. .... ☐☐ 39-40
3. .... ☐☐ 41-42
4. .... ☐☐ 43-44

Date of Interview:

IF RESPONDENT KNOWS DATE OF DISCHARGE ARRANGE APPOINTMENT AND GIVE HIM/HER SLIP.

IF DATE OF DISCHARGE IS NOT KNOWN EXPLAIN THAT INTERVIEWER WILL MAKE CONTACT BY MAIL OR TELEPHONE AFTER HE/SHE GOES HOME.

COMPLETE FOLLOWING: -

NAME:

HOME ADDRESS:

and if different,

ADDRESS TO WHICH GOING ON DISCHARGE:

TEL. NO(S):

APPOINTMENT ARRANGED: DATE
TIME AM/PM

APPOINTMENT NOT ARRANGED:

PREFERRED DAY
PREFERRED TIME AM/PM

TEAR OFF -

NURSING RESEARCH UNIT,
DEPARTMENT OF NURSING STUDIES,
UNIVERSITY OF EDINBURGH,
12, BUCCLEUCH PLACE,
EDINBURGH, EH8 9JT.
Tel. 667 1011 Ext. 6273/6268

.... will visit you at home on .... at .... am/pm. If this time proves to be unsuitable please write to me at the above address, or telephone to arrange another appointment. Thank you.

Ian Atkinson.

Pat Kidd.

APPENDIX 1b

Patients' Interview Schedule:
Home Interview

<u>SECTION "B"</u> CODE NUMBER ○○○

	DAY	MTH	YEAR	
Date of Discharge from Study Ward	☐☐	☐☐	☐☐	45 - 50

1. What is/was your job? (If full-time housewife, ask husband's occupation).

Title:

Description:

SOCIO ECONOMIC CLASS ☐ 51

2. Do you intend to return to work after your convalescence?

Yes 1	☐	52
No........ 2		

If 'No' specify reason

3. Apart from your recent admission had you ever been in hospital before as an adult?

Yes ○ No ○

If NO - insert 00 in boxes and go to next section

If YES - continue.

How many times? ☐☐ 53 - 54

3a. Before this time, how long ago is it since you were in hospital?

6 months ago or less 1	☐	55
More than 6 months to 1 year ago 2		
More than 1 year to 2 years ago 3		
More than 2 years ago 4		
Don't know 5		
N.A. 8		

3b./

3b. Have you ever been in (STUDY HOSPITAL) before?

Yes 1
No 2
N.A. 8

☐ 56

If YES

3c. Have you ever been a patient on Ward (STUDY WARD) before?

Yes 1
No 2
Don't know ... 3
N.A. 8

☐ 57

NON-DISABLED RESPONDENTS OMIT SECTION 'C' AND 'D'
CONTINUE WITH SECTION 'E' PAGE 5

DISABLED RESPONDENTS COMPLETE ALL SECTIONS, SEE
SEPARATE FOLDER FOR SECTION 'C'

CODE NUMBER ☐☐☐

SECTION 'C'

	Do you have any difficulty at all in...	No	Little	Yes		Do you usually have help to do this ?				Do you use any physical aids to help ?				DESCRIBE NATURE OF DIFFICULTY EXPERIENCED & PHYSICAL AIDS USED (CONTINUE ON BLANK PAGE OPPOSITE APPROPRIATE QUESTION SCHEDULE)
						NA	Yes	No		NA	Yes	No		
1	walking ?	1	2	3	7	8	1	2	8	8	1	2	9	
2	getting in & out of bed ?	1	2	3	19	8	1	2	20	8	1	2	21	
3	getting in and out of a chair ?	1	2	3	31	8	1	2	32	8	1	2	33	
4	using the toilet ?	1	2	3	43	8	1	2	44	8	1	2	45	
5	having a bath or shower ?	1	2	3	55	8	1	2	56	8	1	2	57	
6	washing your hands and face ?	1	2	3	67	8	1	2	68	8	1	2	69	
7	getting dressed & undressed ?	1	2	3	79	8	1	2	80	8	1	2	1	
8	eating ?	1	2	3	11	8	1	2	12	8	1	2	13	
9	OTHER (SPECIFY)	1	2	3	23	8	1	2	24	8	1	2	25	

10 IF DIFFICULTY WITH 2 OR MORE OF ABOVE: Which of these gives you most difficulty ? (35) ☐

NA= 0

ITEM NUMBER 1 (Duplicate sheet completed for each A.D.L.)

E How did you manage to walk while you were in hospital ?

With human assistance.............1
With physical aids and
                assistance............2
Didn't do item....................3
Other (specify)..................4
NA................................8

☐ 10

IF '1' CONTINUE WITH QL OR IF NORMALLY USES AIDS CONTINUE WITH QI
IF '2' CONTINUE WITH QG
IF '3' CONTINUE WITH QF

F Why was that ? (PROBE)

END & RETURN TO NEXT ITEM

G Was the equipment you used in hospital...

identical to your own ?...........1
different from your own ?.........2
your own equipment from home ?....3
Other (specify)...................4
NA................................8

☐ 11

IF '2'... In what ways did it differ ?

IF '1','2' OR '4'CONTINUE WITH QH
IF '3' CONTINUE WITH QL

H Was the equipment you used as satisfactory as that which you use at home ?

As satisfactory...................1
Not as satisfactory...............2
NA................................8

☐ 12

Please explain why ?

I Would you have preferred to use your own equipment while you were in hospital ?

Yes...............................1
No................................2
Not bothered......................3
NA................................8

☐ 13

J Why didn't you bring in your own equipment ?

Not in hospital long enough.......1
Didn't think about it.............2
Thought about it but didn't ask...3
Asked but refused permission......4
Unable to transport it............5
Other (specify)...................6
NA................................8

☐ 14

K Were you at all worried about not being able to use your own equipment ?

Yes...............................1
No................................2
NA................................8

☐ 15

IF '1' In what ways ?

L Was there always plenty of staff available to help you to walk when needed ?

Always...........................1
Usually..........................2
Rarely...........................3
Never............................4
NA...............................8

☐ 16

M Would you say the assistance available was generally satisfactory or not ?

Satisfactory.....................1
Not satisfactory.................2
NA...............................8

☐ 17

Please explain ?

N Do you have any other comments you would like to make about doing this activity in hospital ?

☐ 18

RETURN TO ITEM 2

SECTION "D"

1. When you are at home do you have anyone to help you look after yourself, that is either living with you or coming in from outside?

Yes ○ No ○

If NO - go to Q.2.

If YES - Who is that?

PROMPT

Insert '1' in box for helpers available

Insert '2' in box if not available

Relative living with respondent	☐	58
Relative living near respondent	☐	59
Neighbour/s	☐	60
Home Help	☐	61
District Nurse	☐	62
Health Visitor	☐	63
Other (specify)	☐	64

2. When you went into hospital did the way you normally look after yourself change at all?

Yes 1
No 2

☐ 65

If NO - go to next section

If YES - continue.

3. Did it change a lot or only a little?

A lot 1
A little 2
N.A. 8

☐ 66

4./

4. What was it that changed? (specify)

a)

b)

c)

5. Did you find the change/s easy to adapt to?

RECORD FOR EACH SPECIFIED CHANGE

Yes 1
No 2
N.A. 8

67
68
69

In what ways?

a)

b)

c)

6. Was the change/were the changes for the better or worse or did it/they make no difference?

Better 1
Worse 2
No difference 3
N.A. 4

70
71
72

Why do you say that?

SECTION "E"

Now I am going to ask you some questions on how you felt about the services and facilities available while you were in hospital. Firstly, a general question about your overall opinions and then a number of questions on different aspects of your experience as a patient.

1. Could you please indicate a number on the line to show how satisfied you were overall with your stay in hospital ?

HAND CARD TO RESPONDENT)

☐ 73

2. Did you find the general condition of the ward satisfactory or not?

Satisfactory 1
Not satisfactory 2

☐ 74

In what way?

3. On the whole were you able to use the day room if you wanted to?

Yes 0
Sometimes 1
Never ....

If never - why not?

☐ 75
☐ 76

Not available 2
Too busy 3
Too cold 4
Too smoky 5
Couldn't get in 6
Other (specify) 7

4. On the whole were you able to watch TV or listen to the radio if you wanted to?

Yes 1
Sometimes 2
Never ....

If never - why not?

☐ 77
☐ 78

Not available 3
Out of order 4
Couldn't manipulate controls 5
Other (specify) 6

5. On the whole were you able to use a public telephone or not?

Yes 1
Sometimes 2
Never

If Never - why not?

☐ 79
☐ 80

Phone not available 3
Phone out of order 4
Phone always in use 5
Unable to manage 6
Other (specify) 7

CARD NUMBER '2'

6. Did you find the lavatory facilities satisfactory or not?

Satisfactory ○ Not satisfactory ○

If not satisfactory - in what ways?

Satisfactory 1
Access difficult 2
Lack of privacy 3
Too cold 4
Not enough of them 5
Not enough room to manoeuvre equipment ... 6
Other (specify) 7
Not applicable for totally bedfast 8

☐ 1
☐ 2

7. Did you find the bath facilities satisfactory or not?

Satisfactory ○ Not satisfactory ○

If not satisfactory - in what ways?

Satisfactory 1
Access difficult 2
Lack of privacy 3
Too cold 4
Not enough of them 5
Not enough room to manoeuvre equipment ... 6
Other (specify) 7
Not applicable for totally bedfast 8

☐ 3
☐ 4

8. Did you find the facilities for washing yourself satisfactory or not?

Satisfactory ○ Not satisfactory ○

If not satisfactory - in what ways?

Satisfactory 1
Access difficult 2
Lack of privacy 3
Too cold 4
Not enough of them 5
Not enough room to manoeuvre equipment ... 6
Other (specify) 7
Not applicable for totally bedfast 8

☐ 5
☐ 6

9. Were you generally satisfied with the food?

Satisfied 1
Not satisfied 2

In what way?

☐ 7

10. Did you find that the temperature of the ward was generally kept -

at about the right temperature? 1
too warm? 2
too cold? 3
Other (specify) 4

Comment

☐ 8

11. Did you find the hospital bed comfortable or not?

Comfortable 1
Not comfortable 2

In what way?

☐ 9

12. Are there any other comments you would like to make about the ward facilities?

☐ 10

13. Could you indicate a number on the line to show how satisfied you were overall with the facilities available on the ward.

(HAND CARD TO RESPONDENT) ☐ 11

Now I would like to ask you some questions about the daily routine on the ward.

14. After you were admitted who explained the ward routine to you?

Not explained 1
Receptionist 2
Nurse .... 3 ☐ 12
Other patient 4
Other (specify) 5

15. At what time did the day start for patients on the ward you were in?

Do you think this was -

too early? 1
too late? .... 2 ☐ 13
just about right? 3

16. If you wanted to rest during the day-time could you usually manage to do so?

Able to rest ○ Not able to rest ○

If not able to rest - why was that?

Able to rest 1
Could not rest because too noisy 2
Could not rest because too much activity .... 3 ☐ 14
Could not rest for other reasons (specify) 4

17. Were you able to sleep at night without too much difficulty?

Able to sleep 1
Not able to sleep 2

☐ 15

If NO - what caused you difficulty in sleeping?

Specify: -

18. Did you find your time in hospital boring?

Yes 1
No 2

☐ 16

19. Did you find the visiting hours satisfactory or not?

Satisfactory 1
Not satisfactory 2

☐ 17

Why do you say that?

20. Do you think that the ward routine should be improved in any way, other than the things you've already mentioned?

Specify: -

☐ 18

21. Could you indicate a number on the line to show how satisfied you were overall with the ward routine?

(HAND CARD TO RESPONDENT) ☐ 19

Now I am going to ask you some questions about how you got along with people while you were in hospital.

22. When you went into hospital who would you say helped you most to settle down?

No one 1
Sister 2
Other nurses 3
Doctors .... 4 ☐ 20
Receptionist 5
Patients 6
Other (specify) 7

23. Whom did you talk to most while you were in hospital?

Nurses 1
Doctors 2
Domestic staff 3
Patients .... 4 ☐ 21
Visitors 5
Other (specify) 6

24. Many people are apprehensive about what is going to happen to them in hospital. Do you feel that the nurses did all they could to set your mind at rest while you were in hospital?

Yes 1
No 2

What did they do/could have done to set your mind at rest?

Specify:-

☐ 22

25. How about the nurses, did you find them easy to get on with?

(PROBE)

All the nurses easy to get on with 1
Most of the nurses easy to get on with .. 2
A few of the nurses easy to get on with.. 3
None of the nurses easy to get on with .. 4

Why was that? ☐ 23

25a. Did you spend ...

a lot of time 1
a little time 2
Very little time .... 3 ☐ 24

talking to the nurses ?

26. On the whole do you feel you were treated as an individual or as just another case going through the system?

Individual 1
Just another case 2

Comments: ☐ 25

27. Do you have any other comments you would like to make about how you got along with the nursing staff while you were in hospital?

☐ 26

28. Could you indicate a number on the line to show how well you got along with the nursing staff.

(HAND CARD TO RESPONDENT) ☐ 27

Now I am going to ask you about getting answers to your questions when you were a patient.

29. When you are being treated for an illness how far do you like to know the details about your condition and treatment?

Prefers to know all details	1	☐ 28
Prefers to know only some things	2	
Prefers not to know	3	
Other	4	

30. When you were in hospital were you able to find out all you wanted to know about your condition and treatment?

Able to find out	1	☐ 29
Not able to find out	2	

If (1) - go to Q. 31. If (2) - ask Q. 30a.

30a. Were there any particular reasons why you couldn't find out about certain things?

Didn't like to ask	1	☐ 30
Couldn't find anyone who knew	2	
No-one would say	3	
Didn't know who to ask	4	
Don't know	5	
Other (specify)	6	
N.A.	8	

31. Who told you most about your condition and treatment?

No one	1	☐ 31
Sister	2	
Other nurses	3	
Doctor	4	
Other (specify)	5	

31a. How about the nurses, did they tell you very much about your condition and treatment?

Yes	1	☐ 32
No	2	

If No - why do you think that was? (specify)

32. Generally speaking did you have to ask for information or were you told without having to ask?

Asked 1
Told 2
Received no information 3

☐ 33

33. Generally speaking when decisions are being made about yout treatment do you prefer to discuss them or would you rather just leave them to the doctors ?

Prefers to discuss decisions 1
Prefers to leave them to the doctors 2
Doesn't know 3

☐ 34

34. How about your nursing care, do you prefer to discuss this with the nurses or are you happy just letting them get on with it?

Prefers to discuss with nurses 1
Happy to let nurses get on with it 2
Don't know 3

☐ 35

35. When you wanted to tell the nurses anything about your condition, did you find them -

always ready to listen? 1
sometimes ready to listen? 2
rarely ready to listen? 3
never ready to listen? 4

If sometimes, rarely, or never, please give example: 5

☐ 36

36. Do you have any other comments about getting information from or giving information to the nurses?

Yes 1
No 2

If YES - Specify: -

☐ 37

37. Could you indicate a number on the line to show how satisfied you were overall with what the nurses told you about your condition

(HAND CARD TO RESPONDENT) ☐ 38

Now I would like to talk about the way the nurses looked after you while you were in hospital.

38. Would you say that in general the nurses were:

1. Very skilful? 1
2. Fairly skilful?........... 2
3. Not skilful? 3

☐ 39

If (2) or (3) - could you explain how you feel the nurses could have been more skilful?

39. Would you say that in general the nurses were:

1. Very gentle? 1
2. Fairly gentle? 2
3. Not gentle? 3

☐ 40

If (2) or (3) - could you explain how you feel the nurses could have been more gentle?

40. Was there any occasion when you thought that the nurses could have done more for you?

Yes 1
No 2

If YES - what was that?

☐ 40

41. Did you ever feel the need to ask a nurse to do things differently for you?

Yes 1
No .... 2 ☐ 41

If NO - continue with Question 42.

If YES :-

41a. What was that? (Specify)

N.A. .... 8 ☐ 42

41b. Did you ask the nurse?

Yes 1
No 2
N.A. .... 8 ☐ 43

41c. What happened after that? (Specify)

N.A. .... 8 ☐ 44

42. Was there any occasion when you felt that a nurse was particularly understanding?

Yes 1
No .... 2 ☐ 45

If YES - (Specify)

43. Was there any occasion when you felt that a nurse was not understanding?

Yes 1
No .... 2 ☐ 46

If YES - (Specify)

44. Did the nurses always ensure you had privacy when you were being treated or examined?

Yes 1
No .... 2 ☐ 47

If NO - Did that worry you in any way?

45. Could you indicate a number on the line to show how satisfied you were with your nursing treatment.

(HAND CARD TO RESPONDENT) ☐ 48

Now I would like to ask you two or three questions about your discharge from hospital.

46. When you were admitted did you expect being kept in hospital about the length of time you were?

Expected to be in about this length of time .. 1
Expected to be in longer 2
Expected to be out sooner 3
Don't know 4
☐ 49

47. How much notice were you given that you were going to be discharged?

Days ________ Hours ______ DAYS ☐ HOURS ☐☐ 50 - 52

48. Did you find this long enough to make arrangements without too much rush?

Yes 1
No 2
☐ 53

49. Were you discharged to:

Home? 1
Relative's home? 2
Convalescent home? 3
Other (specify) 4
☐ 54

50. After discharge were you told you would be visited by the:

PROMPT

Insert '1' in box for visitors coming,

Insert '2' in box for those who are not.

District Nurse?	☐	55
G.P.?	☐	56
Health Visitor?	☐	57
Social Worker?	☐	58
Home help?	☐	59
Occupational therapist?	☐	60
Physiotherapist?	☐	61
Chiropodist?	☐	62
Other (specify).................	☐	63

If no Community follow-up go to Question 51.

50a. And did your visitor/s come according to plan?

Yes 1
No 2
N.A. 3

☐ 64

50b. If NO - what happened?

N.A. 8

☐ 65

51. Would you like to make any other comments about your discharge arrangements?

Yes 1
No 2

☐ 66

If YES (specify)

52. Could you indicate a number on the line to show how satisfied you were with the arrangements for your discharge.

(HAND CARD TO RESPONDENT)

☐ 67

53. What did you miss most while you were in hospital?

☐ 68

54. What did you like most about hospital?

☐ 69

55. If you had to go back into hospital, and you had a free choice, would you want to go back into the same ward again?

Yes 1
No 2
No preference 3

☐ 70

Why is that?

56. Would you say your stay in hospital was: -

Completely successful? 1
Partially successful? 2
Unsuccessful? 3

☐ 71

What makes you say that?

57. Would you like to make any other comments?

☐ 72

Interviewer Comments

Interviewer	
Length of Interview	
Interview complete	
Interview incomplete	

SECTION "F"

Below are a list of statements, could you please tick a box beside each one to show how much you agree or disagree with it. There are no right or wrong answers, go through the list fairly quicklyand indicate your first reaction to the statement.

		Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	
1.	Nurses should keep a patient's responsibilities away from him.						73
2.	The only people who know what a patient really needs are professional health service staff.						74
3.	Nurses should try to ignore patients' who have a lot to say about their treatment.						75
4.	Once the nursing care of a patient has been decided upon it isn't proper for the patient to question it.						76
5.	If a patient claims to know how to look after himself better than do the nurses then he should be discharged if his condition allows.						77
6.	When a person is sick he is virtually helpless.						78
7.	It is better for evryone concerned if a patient does exactly as he is told by the nurses.						79
8.	A patient who accepts all his treatment without question is a pleasure to have on the ward.						80

CARD No. 3

	DAY	MTH	YEAR	
2nd interview date				1 - 6

APPENDIX 1c

Nurses' Questionnaire

LISBETH HOCKEY, O.B.E., Ph.D.,
Hon. LL.D., F.R.C.N.
Director of Research Unit

Head of Department of Nursing Studies
Professor A.T. Altschul, F.R.C.N.

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Dear

You may be aware that the above research unit in conjunction with the Department of Community medicine, University of Edinburgh and the Scottish Council on Disability is carrying out research into the hospital care of physically disabled people.

As part of the study we are asking nurses who have worked on selected wards at the   to complete a questionnaire, a copy of which is enclosed.

Most of the questions simply involve ticking the appropriate box or boxes but a few do ask for your ideas and opinions. Some questions may not apply to you but these are clearly marked. The information you provide will be treated as confidential and once all the questionnaires have been returned to the research unit the list of code numbers linking individual names will be destroyed, thus all information received will be anonymous.

A stamped addressed envelope is enclosed for the return of your questionnaire once you have completed it. Should you have any queries or would like to know more about the purposes of the work please contact me at the above address.

Thank you for your help.

Yours sincerely,

Ian Atkinson.
Research Associate.

Jan. 81

For office use

CODE No. (1-3) ☐☐☐

(4-7) ☐☐☐☐

1\. What is your present nursing grade ?

(Tick box)

1 ☐ ← Staff nurse
2 ☐ ← Enrolled nurse
3 ☐ ← 1st year student
4 ☐ ← 2nd year student
5 ☐ ← 3rd year student
6 ☐ ← 1st year pupil
7 ☐ ← 2nd year pupil
8 ☐ ← Nursing auxiliary
9 ☐ ← Other, please specify below

(8)

If you are a nurse in training please state which course you are undertaking ?

(9)

2\. Have you ever attended a course of instruction related to the nursing care of physically disabled patients ?

(Tick box)

1 ☐ ← YES If 'YES' continue with question 2A
2 ☐ ← NO If 'NO' continue with question 3

(10)

A/ If you have attended such a course please give (1) the title of the course, (2) a brief description of its content, and (3) the dates of attendance ?

(11)

1) Title..
....

(12)

2) Description of content..............................
....
....
....
....
....

3) Dates, From... To...

(13-14)

3\. In your nursing career have you ever worked in an area which gave you special experience in the nursing of physically disabled people ?

(15)

(Tick box)

1 ☐ ← YES If 'YES' continue with question 3A
2 ☐ ← No If 'NO' continue with question 4

(16)

A/ If you have worked in such an area please give, (1) a brief description of the area, and (2) the dates of this experience ?

1) Description of area.......................................

....

....

(17-18)

2) Dates, From... To...

(19)

4. Have you ever been to an exhibition of physical aids for disabled people?

(Tick box)

1 ☐ ← YES If 'YES' continue with question 4A

2 ☐ ← NO If 'NO' continue with question 5

(20)

A/ If you have been to such an exhibition please indicate when that was by ticking the appropriate box ?

(Tick box)

1 ☐ ← During 1981

2 ☐ ← Between 1977 and 1980 (inclusive)

3 ☐ ← 1976 or before

(21)

5. Many conditions are known to cause long term physical disability, from your experience what would you say are the five most common disabling conditions ?

.... 22

.... 23

.... 24

.... 25

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(26-30)

6. Please state which of the conditions listed above, if any, you think it is important for nurses in a general hospital to be familiar ?

(31-35)

7. Please specify any other disabling conditions about which nurses in a general hospital should have a working knowledge ? If there are no others, just put 'NONE' in the space below.

8. Have you ever read any books, articles or reports on disabling conditions ? (36)

(Tick box)

1 ☐ ← YES If 'YES' continue with question 8A & 8B

2 ☐ ← NO If 'NO' continue with question. 9

A/ If you have read any such literature please tick the box or boxes to show what area or areas were covered by your reading. In the space below each box please state in what ways you found your reading in the area useful or otherwise to your work ? (37)

☐ Community care of disabled people.

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☐ Nursing care of patients with disabling conditions. (38)

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☐ Psychological aspects of disability. (39)

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☐ Causes of disability. (40)

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☐ Other aspects of disability not included above.(Please specify topic.) (41)

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B/ Please give the author and title of one work on disability which you have read and would recommend other nurses to read ? (42)

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....

9 Below is a list of conditions which can cause long term physical disability. By ticking the appropriate boxes please indicate whether or not you have nursed a patient with any one of these conditions within the last three years ?

(Tick boxes)

HAVE NURSED 1	HAVE NOT NURSED 2		
☐	☐	← Amputated limb/s	43
☐	☐	← Brittle bone disease	44
☐	☐	← Cerebral palsy	45
☐	☐	← Blindness	46
☐	☐	← Chronic bronchitis	47
☐	☐	← Multiple sclerosis	48
☐	☐	← Muscular dystrophy	49
☐	☐	← Osteo arthritis	50
☐	☐	← Quadraplegia	51
☐	☐	← Paraplegia	52
☐	☐	← Hemiplegia	53
☐	☐	← Parkinson's disease	54
☐	☐	← Rheumatoid arthritis	55

(56)

10 Below are two statements about the care of disabled patients. Please tick a box next to the statement which is closest to your own viewpoint ?

1) 'As far as possible disabled patients with acute conditions should be nursed in wards with specialist nursing, equipment and facilities' ☐

2) 'As far as possible disabled patients with acute conditions should be nursed in general hospital wards' ☐

A/ In the space below could you please explain your reasons for supporting your chosen view ?

(57)

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11 Do you have any non-professional acquaintance with a disabled person or persons ? (58)

(Tick box)

1 ☐ YES If 'YES' continue with question 11A
2 ☐ NO If 'NO' continue with question 12

A/ In the boxes below please give some further information about the disabled person or persons you know or have known. There are three sets of questions and each relate only to one individual

i Please tick a box to show your relationship to this person ? (59)

1 ☐ Relative in immediate family
2 ☐ Relative outside immediate family
3 ☐ Not a relative

Please tick a box to show how long ago it is since you last saw this person ? (60)

1 ☐ Less than one month ago
2 ☐ One month to six months ago
3 ☐ More than 6 months but less than 1 year ago
4 ☐ One year or more ago

Please describe the nature of his or her disabilities ? (61)

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....
....
....

ii Please tick a box to show your relationship to this person ? (62)

1 ☐ Relative in immediate family
2 ☐ Relative outside immediate family
3 ☐ Not a relative

Please tick a box to show how long ago it is since you last saw this person ? (63)

1 ☐ Less than one month ago
2 ☐ One month to six months ago
3 ☐ More than 6 months but less than1 year ago
4 ☐ One year or more ago

Please describe the nature of his or her disabilities ? (64)

....
....
....
....

iii Please tick a box to show your relationship to this person ? (65)

1 ☐ Relative in immediate family
2 ☐ Relative outside immediate family
3 ☐ Not a relative

Please tick a box to show how long ago it is since you last saw this person ? (66)

1 ☐ Less than one month ago
2 ☐ One month to six months ago
3 ☐ More than six months but less than 1 year ago
4 ☐ One year or more ago

Please describe the nature of his or her disabilities ? (67)

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....

12.- Please describe in the space below any particular qualities you feel it would be desirable for nurses to have to care for disabled patients ? If you feel that no particular qualities are required then just put 'NONE' in the space below. (68)

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....

13. In the hospital wards in which you have worked who usually has had the responsibility of assessing the special nursing needs of patients ? (69-70)

(Tick box/es)

☐ Doctor 71
☐ Sister 72
☐ Staff nurse 73
☐ Enrolled nurse 74
☐ Other grade of nurse, please specify below. 75

(76)

14. Generally speaking, when working on acute medical and surgical wards, do you find enough time is available to talk to patients about their special needs ? (Tick box)

never enough time	rarely enough time	usually enough time	always enough time
1 ☐	2 ☐	3 ☐	4 ☐

15. The following statements about nursing practice may apply to non-disabled as well as disabled patients. Please tick one of the circles beside each statement to show how much you agree or disagree with it.

'A patient who accepts all his treatment without question is a pleasure to have on the ward'	STRONGLY DISAGREE ○	DISAGREE ○	UNCERTAIN ○	AGREE ○	STRONGLY AGREE ○	(77)
'It is better for everyone concerned if a patient does exactly as he is told by the nurses'	STRONGLY AGREE ○	AGREE ○	UNCERTAIN ○	DISAGREE ○	STRONGLY DISAGREE ○	(78)
'When a person is sick he is virtually helpless'	STRONGLY AGREE ○	AGREE ○	UNCERTAIN ○	DISAGREE ○	STRONGLY DISAGREE ○	(79)
'If a patient claims to know how to look after himself better than do the nurses, then he should be discharged if his condition allows'	STRONGLY AGREE ○	AGREE ○	UNCERTAIN ○	DISAGREE ○	STRONGLY DISAGREE ○	(80)
'Once the nursing care of a patient has has been decided upon it isn't proper for the patient to question it'	STRONGLY DISAGREE ○	DISAGREE ○	UNCERTAIN ○	AGREE ○	STRONGLY AGREE ○	(1)
'Nurses should try to ignore patients who have a lot to say about their treatment'	STRONGLY AGREE ○	AGREE ○	UNCERTAIN ○	DISAGREE ○	STRONGLY DISAGREE ○	(2)
'The only people who know what a patient really needs are professional health service staff'	STRONGLY AGREE ○	AGREE ○	UNCERTAIN ○	DISAGREE ○	STRONGLY DISAGREE ○	(3)
'Nurses should keep a patient's responsibilities away from him'	STRONGLY DISAGREE ○	DISAGREE ○	UNCERTAIN ○	AGREE ○	STRONGLY AGREE ○	(4)

16. Please write below any other views you may have, or comments you would like to make about caring for disabled people in hospital ? (5)

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THANK YOU FOR YOUR HELP, PLEASE RETURN THE QUESTIONNAIRE IN THE ENVELOPE PROVIDED.

APPENDIX 1d

Ward Sisters' Interview Schedule

LIST OF QUESTIONS INCLUDED IN WARD SISTERS' INTERVIEW SCHEDULE

SECTION 1: PERSONAL BACKGROUND

1. Have you ever attended a course of instruction related to the nursing care of physically disabled patients?

    1A. If you have attended such a course please give (1) the title of the course; (2) a brief description of its content; and (3) the dates of attendance.

2. In your nursing career have you ever worked in an area which gave you special experience in the nursing of physically disabled people?

    2A. If you have ever worked in such an area please give (1) a brief description of the area; and (2) the dates of this experience.

3. Have you ever been to an exhibition of physical aids for disabled people?

4. Do you have any non-professional acquaintance with a disabled person or persons?

5. What is your relationship to this person?

6. How long ago is it since you last saw this person?

SECTION 2: WARD EQUIPMENT

7. Please indicate which items of equipment on the list are usually held in stock on the ward:

    Wheelchairs
    Walking frames
    Walking sticks
    High chairs
    Non-slip place mats
    Specially adapted eating utensils
    Drinking straws

Hoists.
Adaptable beds
Ripple mattresses
Monkey poles
Pressure pads
Bath seats
Bath boards
Adapted tap handles
Raised lavatory seats

8. Since your appointment to this ward have you ever had to obtain any special equipment for disabled patients in your care?

9. Were you able to get this equipment without difficulty?

10. Looking at the list of equipment again, are there any items which you would encourage patients to bring in to hospital with them?

11. Are there any items of equipment not listed which you would encourage patients to bring in from home?

12. Is there any equipment on the list which you would <u>only</u> recommend the use of hospital stock?

13. Does the storage of equipment on or near the ward cause any special problems?

14. Excluding problems caused by ward design, have you ever experienced any difficulties in using the equipment you have had on the ward?

SECTION 3: WARD DESIGN

13. On the next sheet is a list of rooms which are likely to be used by patients on a hospital ward. Taking each room in turn could you say what features in the design of these areas assist or make more difficult the care of disabled patients?

The features of interest are ease of access for patients, or patients and nurses if assistance is required, access for equipment and room to manoeuvre it once inside the room, the general layout of facilities and ease of use by patients and nurses.

Bathrooms/showers

Lavatories

Day room

Dressing room

Main ward

Side ward

Corridors

16. Do you have any items of fixed equipment in these areas?

SECTION 4: NURSING DISABLED PEOPLE

17. Many conditions are known to cause long-term physical disability; from your experience what would you say are the five most common disabling conditions?

18. Here are two statements about the care of disabled patients. Could you say which statement is closest to your own viewpoint?

    (1) "As far as possible disabled patients with acute conditions should be nursed in wards with specialist nursing, equipment and facilities".

    (2) "As far as possible disabled patients with acute conditions should be nursed in general hospital wards".

19. Could you please explain your reasons for supporting your chosen view?

20. In your experience on this ward has the presence of a disabled patient ever affected the ward in any way, that is in terms of other patients and staff?

SECTION 5

21. Please describe any particular qualities you feel it would be desirable for nurses to have in order to care for disabled?

22. In your ward who usually has the responsibility for assessing the special nursing needs of patients?

23. Generally speaking, do you find there is enough time to talk to patients about their special needs?

24. Are there any other comments you would like to make about caring for disabled people on your ward?

Likert scale (as included in nurses' questionnaires)

APPENDIX 2

Likert Role Scale Construction

The aim of Likert's (1932) method of attitude measurement is to rank people from high to low according to their strength of agreement with one or more statements which express attitudes to the subject of interest. The strength of agreement or disagreement with a statement is assessed on a five-point scale, assumed to be continuous, running through strongly agree, agree, uncertain, disagree and strongly disagree. The variable "strength of agreement" is assumed to be normally distributed. Scores are obtained by allocating the simple weights, 1, 2, 3, 4 and 5, to signify categories of agreement with each statement. The total score of an individual is obtained by summating the scores for all items included in the scale. The statements may reflect relatively favourable or relatively negative attitudes towards a particular object and it is postulated that the level of agreement with a statement will be directly proportional to a person's attitude. Thus a person with a favourable attitude would disagree more strongly with a negative statement than would a person with a neutral attitude, whereas a person who held a negative attitude would be in agreement with the negative statement. The number of statements included in a Likert-type scale is arbitrary but there may be very few (Oppenheim, 1966). The statements included in a scale must all refer to the same attitude object.

Likert scales offer several advantages over other methods of attitude measurement, e.g. Thurstone and Guttman methods, but are subject to certain limitations. A major strength of the Likert method lies in the economy of their construction. As respondents themselves indicate their level of agreement with statements, the procedure of independent judges rating items, as required by both Thurstone and Guttman methods, becomes unnecessary. Likert scales have been found to produce scores which correlate highly with Thurstone scale scores (Schuessler, 1971) and to offer a reliable method for an approximate ordering of groups with regard to a particular attitude (Oppenheim, 1966).

Criticisms of the Likert method are, firstly, that the same score may be obtained by different patterns of response to statements, although such an occurrence would suggest the statements included in the scale do not refer to the same dimension of attitude; and, secondly, that a neutral scale point is difficult to determine, that is locating on the scale where a mildly positive attitude becomes mildly negative.

The Likert scale was used in the present study to assess patients' and nurses' view of the patient's role in care on the dimension of activity and passivity. The scale was constructed using a procedure outlined by Oppenheim (1966) which follows the method propounded by Likert (1932).

A list of 37 statements (Figure 1) which were related to activity/passivity of the patient role were derived from the exploratory interviews. These statements were listed in the form of a questionnaire with a five-point scale ranging from strongly agree to strongly disagree (see above) placed beside each statement. A group of 35 disabled patients, 30 non-disabled patients and 60 nurses of various grades were asked to indicate their level of agreement with each of the statements.

To ensure homogeneity of the final scale, statements were selected from the pool of 37 statements in the following way. Responses were coded for analysis by allocating a low score, i.e. 1, for strong agreement with statements which reflected an active patient role, and a high score, i.e. 5, for strong agreement with statements which reflected a passive patient role. Scores for each of the statements were correlated with the total scores for all 37 statements minus the score of the statement with which the total score was correlated. This procedure was undertaken using the SPSS computer programme, sub-programme Reliability (Hull et al., 1979), using Pearson's correlation coefficient (Yeomans, 1968a). The eight statements which had the highest correlation coefficients, 5.0 or above (Figure 1), were included in the final version of the Likert role scale.

FIGURE 1

	Statement	Corrected item total correlation
1.	It is most important that nurses encourage patients to make decisions for themselves	0.1585
2.	Nursing procedures shouldn't really be changed when a patient asks	0.2496
3.	Generally nurses are able to make a more objective assessment of a patient's needs than the patient himself	0.4600
4.	A nurse should discuss a patient's treatment with the patient	0.4282
5.	If ward rules are broken to please a patient there is a risk that ward discipline will break down	0.4811
6.	Nurses should really ignore patients who have a lot to say about their treatment	0.6003*
7.	A nurse would not be justified in expecting a patient to follow her instructions precisely	0.0964
8.	Nurses should keep strict discipline on the ward	0.3853
9.	Patients need a lot of advice from nurses on how to cope with their illness	-0.1572
10.	Nurses should provide guidance on patients' psychological as well as physical problems	-0.4091
11.	Nurses should keep a patient's responsibilities away from him	0.5646*
12.	The only people who really know what a patient needs are professional health service staff	0.6091*
13.	A most important part of a nurse's work is to let patients help themselves	0.2972
14.	It is quite acceptable for patients to guide nurses in carrying out their duties	0.1498

FIGURE 1 (contd.)

Statement	Corrected item total correlation
15. Nurses almost always have a better understanding of a patient's care requirements than does the patient	0.5275
16. In the treatment setting patients and nurses are equals	0.1016
17. As a rule patients shouldn't be told too much about their treatment	0.3934
18. It is correct for a nurse to reprimand patients who think they know a lot about their treatment	0.4978
19. Once the nursing care of a patient has been decided upon it is improper for a patient to question it	0.5379*
20. Nurses should encourage patients to be as physically independent as possible	0.3819
21. Life is far easier for the nurses when a patient lets the nurses do everything for him	0.3012
22. If a patient claims to know how to look after himself better than do the nurses then he should be discharged if his condition allows	0.5067*
23. A patient who likes to help himself is more often than not a nuisance on a ward	0.3936
24. When a person is sick he is virtually helpless	0.5099*
25. An ill person can only do so much, it's really up to the nurses and doctors to get him better	0.1430
26. It is important that patients know about their treatment in quite a lot of detail	-0.0502
27. It is better for everyone concerned if a patient does as he is told by the nurses	0.6018*

FIGURE 1 (contd.)

	Statement	Corrected item total correlation
28.	A patient should try to do most things for himself	-0.0980
29.	Patients can often teach nurses a lot about nursing care	0.4911
30.	A patient who accepts all his treatment without question is a pleasure to have on the ward	0.6313*
31.	As a rule patients don't want to know anything about their care and treatment	0.4031
32.	A sick person knows better than anyone what will make him comfortable	0.3359
33.	Patients should always ask a nurse's permission before doing anything for themselves	0.3723
34.	When plenty of nursing staff are available they should do everything for the patients	0.3934
35.	Once a patient starts saying how he prefers the nurses to do things he is ready for discharge	0.3902
36.	Generally patients are quite justified in asking the nurses to explain all their treatments and medicines	0.4150
37.	Patients who co-operate with the nurses usually get on better than those who ask questions	0.5545

* Statements included in the final Likert role scale

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