Trends in community care and patient participation: implications for the roles of informal carers and community nurses in the United Kingdom

Susan Kirk MSc BNurs RGN RM HVCert DNCert
Research Associate

and Caroline Glendinning MPhil BA(Hons)
Senior Research Fellow, National Primary Care Research and Development Centre, The University of Manchester, Manchester, England

Accepted for publication 6 August 1997

KIRK S. & GLENDINNING C. (1998) *Journal of Advanced Nursing* 28(2), 370–381
Trends in community care and patient participation: implications for the roles of informal carers and community nurses in the United Kingdom

This paper argues that the interfaces between formal and informal care-giving are changing as a result of two current trends; the increased scope of home-based nursing care and the emphasis on participation both within nursing and in the wider health and social care arenas. These various changes are explored in relation to the provision of intensive and complex nursing care in the home. It will be argued that the changing interfaces between formal and informal care have important implications for the respective roles of nurses and informal carers which hitherto have been relatively overlooked. These implications urgently need addressing in research, policy and public debate if professional nurses are to provide appropriate help and support to informal carers.

Keywords: community nursing, informal care, participation, community care, primary health care

INTRODUCTION

This paper focuses on the shifting boundaries between formal and informal care in relation to two recent and important trends and discusses some of the consequences of these changes for both formal and informal caregivers. It argues that the boundaries between informal care and community nursing are increasingly being shaped by two key policy trends: the move from institutional to home-based care; and the growing emphasis on patient participation within health care in general and nursing in particular.

The paper illustrates these shifting boundaries with reference to the provision of complex and intensive nursing care

in the home setting and the potential implications for nurses and informal carers, particularly in relation to the performance of clinical nursing procedures. The focus of the paper is on care in the home for people with acute and chronic physical health problems, therefore its conclusions will be particularly relevant to community nurses. However, the conclusions may also be salient for other groups of nurses who work closely with informal carers.

The paper will first discuss trends towards providing more care in community and primary health care settings, with a particular focus on the provision of what is termed 'hospital level care' in the home. This will be followed by a discussion of the concept of patient participation and its somewhat problematic relevance to informal caregivers. There is very little research focusing on the involvement of informal carers in carrying out clinical nursing procedures and consequently the paper will draw on research

Correspondence: Susan Kirk, Research Associate, National Primary Care Research and Development Centre, The University of Manchester, The Williamson Building, Oxford Road, Manchester M13 9PL, England.

exploring parental participation in care. Although, as will be discussed later, conceptualizing parents as informal carers is problematic, they are nevertheless substituting for nurses (or indeed the patient her/himself) in the care they provide and hence this body of literature is of theoretical importance. Finally, the implications of the provision of hospital-level care in the community and informal carer participation for both informal carers and community nurses will be discussed.

Informal care is a term embracing a range of activities and relationships which has been defined as care which

... normally takes place in the context of family or marital relationships and is provided on an unpaid basis that draws on feelings of love, obligation and duty.

(Twigg 1992 p. 2)

This definition emphasizes three key aspects of informal caring. First that it normally occurs within the context of the family, and data from the General Household Survey suggests that apart from spouse caregiving relationships, it is mainly female relatives who take on the most arduous tasks of caring (i.e. aspects of physical and personal care) (Phillips & Bernard 1995). Second, that it is provided on an unpaid basis, and third that it is based upon feelings such as obligation and love (Graham 1983, Ungerson 1987, 1990). Informal carers potentially can have contact with a range of nurses working in community settings such as district nurses, health visitors, practice nurses, community psychiatric nurses and specialist nurses.

THE FOCUS ON THE COMMUNITY AND PRIMARY HEALTH CARE SECTOR AS THE ARENA FOR CARE

Health and social care policy in the United Kingdom (UK) is placing an increasing emphasis on the community as the arena for care which has implications for both service providers such as nurses and for informal carers. The policy of 'community care' has long shaped services for people with mental illness, learning disability, physical disability and the physical and mental frailty associated with old age. However, the exact meaning of the term has varied. During the 1970s and 1980s, concerns over the costs and the quality of institutional care meant that community care policies focused on the resettlement of people with learning disability and mental illness from long-term hospital care. During the 1990s, 'community care' came to describe a policy shift designed to cap public expenditure on private residential care for older people (Lewis & Glennerster 1996). The success of this latter policy in encouraging the development of domiciliary-based care services as alternatives to residential provision is still far from clear (Wistow 1995).

Parallel changes from institutional to community-based care within the National Health Service (NHS) are some-

what easier to document. There has been a focus on primary health care dating back to the 1978 (World Health Organization/United Nations Children's Fund) Alma Ata declaration, which exhorted governments to place primary care at the centre of health care systems (Coulter 1996). Health policies in the UK have placed an increasing emphasis on the primary health care arena (Department of Health and Social Security 1986a, 1986b, Department of Health 1989a, 1993) which has now culminated in a strategic shift towards this sector (National Health Service Management Executive 1995, 1996a). These changes have also been driven by concerns over the increasing cost of health care, by demographic trends, by changing patterns of illness (Hughes & Gordon 1994) and by developments in medical technology such as non-invasive investigative surgery.

At any one time the boundaries between hospital and community-based services for acute health care are a complex product of current health care policies and historical custom and practice in hospital admission and discharge procedures (Marks 1991). Indeed, it was not until the early 20th century that the acute hospitals dominated health care; until this time hospitals were only used to care for the poor, the wealthy being cared for in their own homes. More recently, changes in the balance of health services have extended community-based care to growing numbers of people with short-term and acute health problems. Services traditionally provided in hospitals, such as diagnostic services, minor surgery and specialist outpatient clinics are increasingly relocated into the primary health care setting. Pressures to increase efficiency in the secondary sector have led to an increase in day surgery and reductions in average lengths of stay in hospital. As a consequence, between 1982 and 1993, the number of hospital beds fell by a quarter; average lengths of stay fell by a third and day case admissions rose by over 200% (quoted in Wistow 1995). It has even been predicted that in the 21st century district general hospitals will disappear, being replaced by a combination of home care, small community hospitals and small highly specialized units (Warner & Riley 1994).

One consequence of this shifting boundary between secondary and primary health care is the relocation of intensive and complex nursing care from hospital to domiciliary settings (Marks 1991). This relocation shifts the burden of care to informal carers (Stocking 1992, Neuberger 1992, O' Cathain 1994, Gregor 1997). Also, potentially, it blurs the boundaries between informal and formal care when informal and family carers are involved in providing an intensive and complex level of care.

The provision of hospital level care in the home

Hospital care at home has been defined as that which brings:

a level of hospital care to the home, supplying medical, nursing

- Demographic changes (i.e. increasing numbers of elderly and very elderly people, increasing numbers of people with a chronic illness).
- Escalating health care costs (particularly in the hospital sector) and the search for cost-effective alternatives to hospitalization.
- A desire to minimize or prevent problems associated with hospitalization. Specifically hospital acquired infections and the psychological trauma of a hospital stay (generally accepted as particularly traumatic for children and elderly people); an awareness that most people prefer to be cared for in their own home where they can exert more control over their lives.
- Potential for more rapid rehabilitation for some conditions in the home (for example, stroke).
- Unsuitability of acute hospitals for certain kinds of care (for example, terminal care).
- Better understanding of the possibilities of early discharge combined with intensive nursing care at home.
- Decreased emphasis on institutional care in all sectors.
- Improved standards in the home (for example, telephones, refrigeration, electricity).
- Technological developments: availability of equipment suitable for home care.
- Recognition of the importance of providing consumer choice.

(Marks 1991, Stocking 1992, Costain and Warner 1992, Haggard & Bosma 1996)

Figure 1 The reasons for the growth of hospital care at home.

and rehabilitative services as well as social support and equipment.

(Marks 1991 p. 7)

Such care is growing, not just in the UK but internationally, as a result of a number of factors presented in Figure 1.

'Hospital care at home' is a term used to describe the relocation of a range of traditional hospital services into the home. It is distinct from the social and rehabilitative care denoted by the term 'community care', as its key feature is nursing care of a frequency or technical complexity traditionally associated with the acute hospital (Marks 1991). People requiring such levels of care are not a homogenous group. They are likely to have a variety of chronic and acute medical conditions to range in age from the newborn to the very elderly and may need this level of nursing care on a short-term or long-term basis. Marks (1991, 1992) has identified five different types of hospital-level care at home, all of which involve the provision of intensive nursing care on either a short-term or long-term basis:

- 1 Services aimed at preventing hospital admission by providing alternative services in the home (for example, for people suffering a stroke or myocardial infarction).
- 2 Services facilitating early discharge from hospital, through the provision of appropriate nursing care in the home (for example, for people with a hip fracture).

- 3 Terminal care services (the most established form of intensive nursing care in the home)
- 4 Home-based services for people needing high-technology care (for example, people requiring mechanical ventilation, haemodialysis, parenteral nutrition, intravenous therapies)
- 5 Services for people with complex and ongoing health problems who periodically require acute treatment (for example, for cystic fibrosis or acquired immune deficiency syndrome (AIDS)-related illnesses) to prevent or reduce hospitalisation.

The UK has had an advantage over many countries in relation to the provision of hospital level care at home, in that it has long-established community-based health and social services. However, hospitals, charities and commercial companies have also developed community services to support patients with specialist and 'high tech' needs (Hunt 1995, Conway 1996, Rudkin 1996). At present there appears to be no clear consensus on the advantages and disadvantages of the various different models of organizing services (Marks 1991, Goodwin 1992). The need for evaluation is evident.

The first two types of care identified above, are those often associated with 'hospital-at-home' or 'rapid response' nursing schemes, which have been developed in some areas of the UK (Mowat & Morgan 1982, Roberts 1992, Hackman 1993, Haggard & Bosma 1996, Brooks 1996). These services are specifically established to provide intensive levels of nursing and rehabilitative care on a relatively short-term basis (for example 12 days) in an attempt to either prevent hospitalization or reduce length of stay. They are often managed by generic district nurses who have acquired additional skills in caring for the group of people targeted by the scheme. Generic support worker posts are also often established to provide elements of health and social care; combining the roles of nursing auxiliary, physiotherapy aide and home help in a single post. However, descriptions of 'hospital at home' schemes provide little insight into either patients' or carers' experiences or roles, though both are generally said to be satisfied with the provision of such care in the home (Mowat & Morgan 1982, Roberts 1992, O'Cathain 1994, Haggard & Bosma 1996).

Hospital level care in the home is also delivered outside so called 'hospital at home' schemes. The other types of hospital level care identified by Marks (1991, 1992) involve the delivery of specialized care on a more long-term basis, often by specialist nurses who may work in both hospital and community settings (Rudkin 1996). It is clear from descriptions of community children's nursing services that their role also encompasses the delivery of hospital level care in the home (Tatman *et al.* 1992). In situations where hospital level care at home focuses on individuals with long-term needs, it is more likely that the

chronically-ill person and/or informal carers become involved in performing clinical procedures such as intravenous injections (David 1989, Friend 1992, Bramwell *et al.* 1995, Conway 1996). To date there has been a lack of research focusing on the impact of providing such 'high tech' home care on informal carers both in the UK and North America (Thomas, *et al.* 1992, Sevick *et al.* 1994, Smith *et al.* 1994).

This trend towards developing community and primary health care is likely to mean that not only will more people receive care from this sector of the health service but more highly dependent, physically ill people with intensive and complex needs will be cared for at home (Costain & Warner 1992). This will have clear implications for both informal carers and community nurses.

PARTICIPATION IN CARE: FROM PATIENTHOOD TO PARTNERSHIP

A second key factor shaping the roles of both community nurses and family carers is the recurrent theme of 'participation' both in the theoretical conceptualization of professional nursing practice and in policy documents. Figure 2 describes the various factors and pressures which have contributed to the emerging importance of this concept. Patient participation is a widely accepted principle underpinning contemporary nursing practice and is endorsed in the Department of Health's Strategy for Nursing (Department of Health 1989b). An important consequence of this principle is a narrowing of the gap in

knowledge and competency between nurse and patient and the consequent transfer of some power or control from the nurse to the patient (Cahill 1996).

Patient participation has been extensively reviewed and analysed by a number of nursing writers (Brearley 1990, Ashworth *et al.* 1992, Cahill 1996). It has also been considered from the perspectives of mental health nursing (Glenister 1994), health visiting (Billingham 1993, Kendall 1993) and, in particular, children's nursing (Coyne 1996), where it is hailed as the pivotal concept underlying practice. These writers have highlighted the unclear and ambiguous nature of the concept, noting that it is frequently used interchangeably with terms such as 'involvement', 'collaboration', and 'partnership'. It is also apparent that there is a lack of consensus within nursing on how far patient participation should extend and how it should be implemented (Jewell 1994, Cahill 1996). Indeed, whether nurses are actually committed to the concept in practice has been called into question (Kendall 1993, Meyer 1993).

A frequently quoted definition of participation illustrates the multi-dimensional nature of the concept:

Participation means getting involved or being allowed to become involved in a decision making process or the delivery of a service or the evaluation of a service, or even simply to become one of a number of people consulted on an issue.

(Brownlea 1987 p. 605)

'Patient participation' can occur in a number of contexts, to different degrees and may involve different participants (Cahill 1996). The context may be the maintenance and promotion of health, the detection of illness, the provision of treatment and care during periods of illness or adaptation to a continuing disability. Participation can range from involvement in decision making to the performance of clinical procedures (Jewell 1994, Saunders 1995). Participation in care is considered to be particularly important for people with chronic illnesses because, by its very nature, chronic illness often requires extended and even life-long treatment. Encouraging self-care reflects not only a desire to give patients control over their condition and promote independence, but also the need to contain the costs associated with the provision of professional care (Brearley 1990; Coates & Boore 1995). Participation may therefore extend beyond patients being involved in making decisions about the treatment and management of their condition, to them actually performing procedures which have traditionally been regarded as the province of nurses or doctors.

Although, within nursing the focus has largely been on the individual patient, participation in health care may also involve informal carers, parents and even the wider community. The paper will now turn to explore the former, informal care, and the interface between nurses and informal carers.

Factors within the discipline of nursing

- The nursing process and the focus on individualised care.
- Nursing theory and models (for example, Orem 1985).
- The philosophy of primary nursing.

External factors

- The consumer movement and increased public knowledge about health care and rights to information and participation.
- Current health policy (e.g. Patient's Charter (Department of Health 1992), Patient Partnership Strategy (National Health Service Executive 1996b)).
- Public's changing perceptions of health professionals: desire for self-determination and a growing mistrust of professionals.
- Demographic and epidemiological factors: the increase in chronic illness in which self-management plays an important role.
- Economic factors: recognition of potential cost-savings of self-care.
- International aspects: Alma Ata 1978 had declared that patients had a right to participate.
- Philosophical/ethical perspectives: beliefs about individual choice, responsibility and autonomy.
- Psychological perspectives: suggestions that participation might improve clinical outcomes.

(Brearley 1990, Avis 1994, Jewell 1994, Cahill 1996)

Figure 2 Factors in the development of participation in care.

INFORMAL CARE AND THE ROLE OF CARERS

Over the past 15 years, considerable research attention has focused on the experiences of informal and family carers. Early research in this area was fuelled by feminist concerns about the role of women as informal carers (Finch & Groves, 1983). This research drew attention to the scale of care-giving within the family and recast as problematic the hitherto unquestioned assumption that care-giving was a taken-for-granted and indeed 'natural' element of women's role. A second theme of research on informal care has been the documentation of costs, constraints and restrictions which informal carers often experience within the private, domestic domain within which they work (Nissel & Bonnerjea 1983, Baldwin 1985, Ungerson 1987, Hicks 1988, Parker 1990, Glendinning 1992). A third major stream of research on informal care has located it within the broader context of 'community care' policies, and evaluated the impact of policies, services and professional interventions designed to support informal caregiving (Davies & Challis 1986, McLaughlin 1991, Twigg & Atkin 1994).

The growing visibility of informal carers was formally acknowledged through the inclusion, for the first time, of a series of questions on informal care in the 1985 General Household Survey (subsequently repeated in an abbreviated form in 1990) (Green 1988). Informal care is now a major subject of discussion, particularly in the social care field and carers have been recognised as central to the achievement of the government's care in the community policy (Department of Health 1989c; The Carer's (Recognition and Services) Act 1995 (DH, 1996a)) with their involvement in the development of community care plans and in the care management process explicitly prescribed. Meanwhile, research on informal care-giving has become increasingly reshaped by a complementary awareness of the experiences and concerns of disabled and elderly people themselves (Keith 1992, Morris 1993, Parker & Baldwin 1992).

These developments have taken place against the background of a marked shift in the nature of 'community care' policies. These originally assumed a significant role for public services in supporting seriously ill and disabled people outside large institutions. However, by the early 1980s, the emphasis had shifted to an increasingly explicit focus on care *by* the community (Parker 1990, Phillips & Bernard, 1995). Moreover, within 'the community' the responsibility for providing more intensive personal and intimate care is likely to fall upon close family members in general and on one family member in particular (Nolan & Grant 1989, Qureshi & Walker 1989). This work includes tasks such as supervision and surveillance in order to avoid danger and help with activities of daily living such as toileting, bathing, preparing food, giving medications,

getting up and getting to bed (Green 1988, Atkinson 1992, Parker & Lawton 1994, Twigg & Atkin 1994, Challis *et al.* 1995, Goldstein & Rivers 1996).

In contrast to the social and community care literature, research on informal care from a nursing perspective appears to have been slow to develop (Atkinson, 1992). As well as carrying out less skilled personal care tasks which have long formed part of home nursing activities, informal carers may also find themselves engaged in more complex activities, such as giving injections and changing dressings (Atkinson 1992, Twigg & Atkin 1994). Little is known about either the role of relatives in performing clinical nursing procedures, or of their experiences or perceptions of such activities. However, as Arras and Dubler (1994) have noted, carers undertaking such tasks are learning skills which were formally considered the province of trained professionals, but unlike professionals they are performing what may sometimes be painful procedures on people they may care for and love.

Parents as informal carers

Due to a lack of nursing research on informal carer participation, this paper draws on the parental participation literature on the basis that both there are similarities between the two groups in that they act as proxies for the 'patient'. However, conceptualizing the parents of seriously ill or severely disabled children as informal carers is problematic. All young children need very considerable amounts of personal care and supervision and Twigg's definition of caring cited earlier in the paper could equally apply to the role parents fulfil. Indeed, Ungerson (1990) comments that in Scandinavia 'informal caring' does encompass the care of healthy children. In the UK, however, Beresford (1994) notes when the child is healthy these activities are generally known as parenting rather than caring. The distinction between caring and parenting appears to relate to a notion of going beyond what might be considered usual for a child of a certain age:

What is different about disabled children is that they have these needs for much longer than non-disabled children.

(Beresford 1995 p. 9)

In policy terms, the parents of disabled children are clearly recognized as informal carers in terms of The Carers (Recognition and Services) Act 1995 (Department of Health 1996a) acknowledging that their parenting role extends beyond what might be considered 'the norm'. While this suggests that it might be straightforward to consider this group of parents as informal carers, there is evidence that the parents of disabled children view themselves first and foremost as parents and not as informal carers (Beresford 1994). This problematic nature of 'informal care' in relation to the care of seriously ill or disabled children is reflected in the ambiguous and confused relationships

parents report they experience with professionals (Ungerson 1990, Baldwin & Carlisle 1994).

While the nursing literature on parental participation does not explicitly conceptualize parents as informal carers, it does implicitly assume an extension of the parenting role. It certainly appears to be in relation to the care of sick children that responsibility has shifted particularly dramatically from professionals to the family (Coyne 1996). Here, lay participation in health care has extended the furthest in terms of informal carers (i.e. parents) performing clinical nursing procedures. Parental involvement in the medical and nursing care of children may therefore offer particularly valuable insights into the changing interfaces between professional and lay care.

Originally promoted as a means of reducing the adverse effects of hospitalization on seriously ill children, parental participation in the care of hospitalized children has gradually evolved from the provision of care associated with normal childcare (for example, bathing) to the performance of nursing procedures such as measuring vital signs, administering drugs, caring for central venous lines and giving intra-venous antibiotics (Pike 1989, Evans 1994, Casey 1995). There is some evidence to suggest that in the UK parents are now also increasingly providing highly technical care in the home (McAffrey 1992, Gartland 1993, Beresford 1995). However, while it has been demonstrated that parents are able to perform these clinical procedures, their perceptions and experiences of providing such care, particularly in the home, have not been fully explored (Evans 1994, Coyne 1995).

While the literature on parent participation demonstrates that it is possible for lay carers to both learn and safely perform clinical nursing procedures, the fact that this is happening within the context of the parent-child relationship is less commonly acknowledged. Transferring responsibility to parents for such care may perhaps be considered to be less problematic because it is seen as an extension of their natural parenting role and because there are strong cultural expectations that parents will care for their child whatever the circumstances. This is in contrast to the far more problematic nature of intimate care-giving between adults, particularly when they are of a different gender or generation (Ungerson 1983). Informal carers are not a homogenous group; moreover the type of relationship between the person giving and the person receiving care has an important effect on how care-giving is experienced (Atkin 1992) and upon the extent to which carers actually wish to become involved in some aspects of personal and nursing care.

Informal care and nursing

If informal care extends increasingly into areas traditionally considered to be the province of formal carers how will carers be supported by community nurses? The avail-

able evidence suggests that, while community nurses potentially could make a significant contribution to supporting informal carers, very few carers have contact with them unless some event such as a medical crisis occurs (Green 1988, Atkinson 1992, Twigg 1992, Atkin & Twigg 1993).

This relatively episodic contact reflects a number of factors. First, community nursing services depend substantially on referrals from general practitioners (GPs) or hospitals. Community nursing staff are therefore heavily reliant on other professionals and organizations to identify possible needs for their involvement. Moreover, community nurses face a difficult dilemma as they may recognize that their role could potentially extend to the support of informal carers, but in practice workload pressures force them to ration their services, leading to informal carers only becoming a priority when a medical problem arises (Twigg & Atkin 1994). Health visitors, who potentially could play a more proactive role in identifying and responding to the needs of informal carers, have traditionally focused upon families with young children. A further explanation suggested for community nurses' relative lack of involvement in the on-going support of informal carers is that, in spite of claims of a holistic philosophy underpinning care, the reality is that community nursing services remain task orientated and give priority to the instrumental rather than the affective dimensions of care (Twigg 1992).

Where informal carers have had contact with community nurses, they report that their needs are given low priority. Nursing interventions instead focus almost exclusively on the sick or disabled person (Nolan & Grant 1989, Atkin & Twigg 1993). In the hospital setting there is also evidence to suggest that nurses do not form participatory relationships with the relatives of adult patients (Batehup 1989, Brooking 1989, Meyer 1993, Laitinen 1992). One explanation for this lack of attention to the needs of informal carers may be the centrality of the nurse-patient relationship in the nurse's construction of nursing.

It is apparent that there is a lack of nursing research on the participation of relatives or informal carers in care, particularly in a community context. Hence discussion of the implications for informal carers and community nurses draws on other bodies of literature, namely social care perspectives of informal care, patient and parent participation and the developing body of literature on the provision of hospital level care in the home.

IMPLICATIONS FOR CARERS: EMPOWERMENT OR EXPLOITATION?

The costs of caring

The social, psychological and financial costs of caring are well documented (Glendinning 1992, Parker 1993). There

is therefore a need to consider to what extent the provision of hospital level care and the extension of informal caregiving into areas traditionally regarded as professional nursing care creates additional costs and pressures for informal carers. As yet we know little of the social, psychological and financial implications of hospital level care in the home for either patients or carers (Marks 1991). Concerns have been raised in the United States of America (USA) about the ethics of this type of care and its impact on carers and the home environment (Arras & Dubler 1994). While participation in decision-making may well have the potential to empower carers, the same cannot be assumed to be true of participation in actual care giving. At the same time, disability research in the UK has warned against highlighting the needs of informal carers at the expense of the sick or disabled person needing care. There is therefore a double risk of exploiting both informal carers and, through their enforced dependency on a close family member, sick or disabled people needing care, unless formal services can appropriately address the needs of both parties.

Preference and choice

The wishes, choices and preferences of both carers and sick or disabled people needing hospital-level nursing care in the home need to be assessed when considering the extent of carers' participation in providing that care (Stocking 1992, Neuberger 1992). Carers need to be willing and able to take on additional responsibilities, without disproportionate or unwanted costs (whether physical, social, emotional or material). An essential prerequisite is therefore the provision of the fullest possible information to potential informal carers on which they can base decisions about how far to become involved in providing hospital-level care at home. This information should include details of the length of time for which their involvement is likely to be needed, and of the support they can expect to receive from statutory services. Time for potential carers to consider the implications for their work, family life and other important commitments will also be needed. Where informal carers do wish to be involved in providing nursing care, individualized assessment and regular reassessment of the level of participation is important, as both may vary from person to person and over time (Coyne 1995).

It has been suggested that informal carers are often unable to exercise real choice over entering into an intensive caregiving relationship, as they are rarely offered an acceptable alternative (Manthorpe 1994). If community nurses are not able — either because of resource constraints or lack of expertise — to provide the level of care required, will informal carers have a real choice over participation if they wish a seriously ill relative to be discharged to or remain in the home environment? The

indications are that the opportunity to choose whether and how far to participate in intensive home care-giving may be outside the control of the informal carer. The transfer of power and the extent of participation appears to be largely controlled by the nurse who will determine whether relationships are based upon partnership and collaboration (Brown & Ritchie 1990, Callery & Smith 1991, Knight 1995). This suggests that nurses need to have a positive attitude towards participation if it is to form the basis of the relationship between nurse and informal carer. The available evidence suggests that such an attitude is influenced by the position, education and inter-personal style of the individual nurse (Ireland 1993, Coyne 1995, Laitinen & Isola 1996).

However, there is an equal danger that nurses can be over-enthusiastic in their adoption of a participative approach to care. Nurses are reported to assume all too frequently that parents want to participate in their child's nursing care (Dearmun 1992, While 1992). It has even been suggested that both patients and parents can feel pressurized by nurses into participation in the hospital context (Waterworth & Luker 1990, Darbyshire 1992). Twigg and Atkin (1994) found that informal carers could also experience pressure from community nurses to perform nursing procedures such as injections. The potential implications for informal carers would appear to be that in the absence of an assessment of their needs and desires they could either not be given the opportunity to consider participating in nursing care or they could be coerced into participation.

Education for carers

It is apparent that the educational and information needs of carers have been largely ignored in the past (Nolan & Grant 1989, Atkinson 1992). In Atkinson's study very few informal carers had received any instruction in relation to caring activities they performed such as bathing, lifting, bowel/bladder management and wound dressing. This emphasizes that the education and information needs of all informal carers should be assessed and appropriate teaching and information provided if they are to provide safe and effective care. This is particularly the case for those informal carers involved in providing care of an intensive and complex nature. Clearly, both generic and specialist community nurses could play a major role in this area.

IMPLICATIONS FOR NURSING: THREAT OR OPPORTUNITY?

Changing relationships

Participation in care necessarily involves changes in relationships between nurses and lay people, whether they are patients involved in self-care or carers. This in turn

means a shift in the attitude and style of nurses, from a compliance approach to one of empowerment and partnership (Coates & Boore 1995). Relationships based on partnership would be characterized by role negotiation with both parties recognizing and valuing one another's contribution and knowledge, by joint care planning, and by collaboration in both goal setting and in the evaluation of care (Brearley 1990, Ashworth *et al.* 1992, Darbyshire & Morrison 1995). Such relationships have been advocated between nurses and informal carers with the latter being viewed as adopting a co-worker role (Nolan and Grant, 1989; Nolan *et al.* 1995). However, at the same time a relationship based on partnership also needs to be forged with the sick or disabled person receiving care, who should not be excluded and disempowered by the community nurse forming a partnership relationship with their carer.

The development of participation in care and relationships built on a philosophy of partnership is largely at the discretion of the nurse, as the party holding the greater power in professional-lay relationships. However, the organizational and professional structures within which nurses practise also need to facilitate participation. It has been suggested that nurses themselves need to be empowered to develop participatory relationships, the implication being that they need to be autonomous practitioners (Trnobranski 1994, Darbyshire & Morrison 1995, Rodwell 1996, Cahill 1996). Yet a perceived lack of autonomy in relation to doctors can inhibit the introduction of a participative approach to care among nursing professionals (Meyer 1993). Nurses working in community settings may experience similar constraints to implementing a participative approach, particularly with their increasingly close attachment to GPs. Indeed, the sense of autonomy felt by community nursing staff may have been further undermined following the NHS reforms and the extension of GP fundholding to community nursing services; district nurses are reported to feel that their priorities and professional practice are increasingly being determined by the requirements of the GP purchasers of their services (Hiscock & Pearson 1996). It remains to be seen whether the future development of new organizational models in primary health care (Department of Health 1996b) will promote the autonomy of community nurses.

Role change

Both the provision of more intensive and high technology nursing care in the home and the involvement of informal carers in providing that care demand changes in the attitudes and roles of community-based nurses. Lay participation in caregiving may be perceived by nurses as threatening, particularly when this extends into activities traditionally associated with professional nursing. Indeed the greater involvement of lay caregivers may ultimately

lead to a reduction in salaried nursing posts (and hence considerable financial savings) (McKeever 1994).

More fundamentally, the participation of informal carers in traditional nursing activities challenges the power and authority which nurses derive from their professional knowledge and skills; which in turn can lead to concerns about deprofessionalization and role erosion (Brearley 1990, Brown & Ritchie 1990, Saunders 1995, Cahill 1996). Such anxieties reflect wider and long-term professional concerns over unqualified health and social care staff extending their role into the sphere of professional nursing practice, in both community and hospital contexts (Waters 1996).

However, if patients and informal carers are to become more involved in performing clinical nursing procedures on a day to day basis, then the role of nurses will also need to adapt in order to complement and support lay caregiving. If nurses will be providing less direct 'hands on' care then other skills will become more important — patient/carers education, service co-ordination, the provision of emotional support, and being a resource for patients and carers (Kitson 1987, Nolan & Grant 1989, Atkinson 1992, Stocking 1992, Atkin & Twigg 1993, Bibings 1994). Such a reorientation is not new. Macmillan nurses for example, act as an expert resource to patients and families as well as to other nurses. Rather than being a threat, the increased participation of informal carers can therefore offer opportunities for role enhancement and the development of other interpersonal skills. Moreover, many 'hospital at home' schemes are currently managed by nurses, with district nurses controlling admission and discharge. There is evidence that involvement in such schemes can increase job satisfaction for district nurses (Brooks 1996).

Education of nurses

The initial and continuing education of nurses will need to place greater emphasis on developing the skills required for a more egalitarian, partnership approach to patients (Ireland 1993, Saunders 1995). Increasing awareness of the needs of carers will also need to be high on the education agenda (Nolan & Grant 1989). In addition, trends towards the delivery of more intensive and high technology nursing care in the home means that community nurses will also need to develop their clinical skills, whether or not they are providing the care directly (Roberts 1992, Corbett *et al.* 1993).

CONCLUSIONS

Substitution of professional by lay care is not new and has been developing both in the care of people with a chronic illness and in the care of sick children in hospital for a number of years. Increasingly, developments in technol-

ogy, together with trends in health and social care policies, are enabling hospital-level nursing care to be carried out in home settings. One consequence of this is that informal carers and community nurses are providing the care formerly provided by hospital staff. As Marks (1992) has noted, the provision of this form of intensive nursing care in the home challenges current boundaries, not only between the roles of hospital and community nurses but also between nurses and informal carers.

Changes at the interface between informal care and formal care challenge traditional notions of how the boundary between the two is drawn and inevitably have an impact upon how nursing itself is defined. Concurrently community nurses are having to respond to role changes at many other interfaces, such as those with general practitioners, specialist nurses, health care assistants and social care workers. At present the degree of autonomy which community nurses actually have to shape their role for themselves is unclear (Hiscock & Pearson 1996). What is important is that in these territorial disputes professional interests do not prevail over those of patients and carers. Changes in roles and how boundaries are drawn between professional groups and agencies have to be determined by and respond to patient need.

Compared with the now-extensive literature on the provision of social care by family and other close relatives, research on the experiences of informal carers involved in intensive domiciliary nursing care is relatively sparse. In the case of parents involved in providing very extensive or complex nursing care for seriously ill or disabled children, assumptions about normal parenting responsibilities and obligations may obscure the additional difficulties, stresses and costs imposed upon informal carers. Research is required urgently to explore the areas where informal care, participation and hospital level care intersect and so provide answers to questions such as, what are the consequences, costs and benefits to relatives (and to the people they are caring for) of providing this type of care in the home; how can costs be minimised and benefits maximised; what are informal carers' perceptions of providing clinical nursing care?

There is a risk that in the drive for greater efficiency and cost-containment, the increased involvement of informal carers is not matched by ideological commitments to greater choice, empowerment and the provision of appropriate support. Claims of cost savings through the provision of hospital level care in the home therefore need careful examination to ensure that they are not based upon the simple substitution of professional care for informal family care, with the direct and indirect costs borne by carers unacknowledged and uncalculated (Neuberger 1992).

Above all, debate is now needed on how far it is acceptable and appropriate to extend lay participation into these sometimes highly complex and technical arenas. To what

extent are actual and potential carers offered real choices about their level of involvement and what freedom do they have to refuse if the personal and family costs simply seem too high?

Acknowledgements

The authors would like to thank Kirstein Rummery and Anne Williams for their comments on earlier drafts of this paper. The views expressed in this paper are those of the authors and not those of the Department of Health.

References

- Arras J.D. & Dubler N. (1994) Bringing the hospital home: ethical and social implications of high-tech home care. *Hastings Centre Report*, Special Supplement September/October, S19–S28.
- Ashworth P.D., Longmate M.A. & Morrison P. (1992) Patient participation: its meaning and significance in the context of caring. *Journal of Advanced Nursing* **17**, 1430–1439.
- Atkin K. (1992) Similarities and differences between informal carers. In *Carers: Research and Practice* (Twigg J. ed.), HMSO, London, pp. 30–58.
- Atkin K. & Twigg J. (1993) Nurses' effectiveness in supporting carers. *Nursing Standard* **7**(42), 38–39.
- Atkinson F.I. (1992) Experiences of informal carers providing nursing support for disabled dependants. *Journal of Advanced Nursing* **17**, 835–840.
- Avis M. (1994) Choice cuts: an exploratory study of patients' views about participation in decision-making in a day surgery unit. *International Journal of Nursing Studies* **31**(3), 289–298.
- Baldwin S. (1985) *The Costs of Caring. Families with Disabled Children*. Routledge, London.
- Baldwin S. & Carlisle J. (1994) *Social Support for Disabled Children and their Families*. Social Services Inspectorate, HMSO, London.
- Batehup L. (1989) Relative's participation in the care of the stroke patient in general medical wards. In *Directions in Nursing Research*, (Wilson-Barnett J. & Robinson S. eds., Scutari Press, Harrow Middlesex.
- Beresford B. (1994) *Positively Parents: Caring for a Severely Disabled Child*. HMSO, London.
- Beresford B. (1995) *Expert Opinions*. Joseph Rowntree Foundation, York.
- Bibings A. (1994) One year on: the carers' perspective. *Primary Health Care* **4**(4), 8–10.
- Billingham K. (1993) Partners with the community. *Primary Health Care* **3**(6), 2–3.
- Bramwell E.C., Halpin D., Duncan-Skingle F., Hodson M. & Geddes D. (1995) Home treatment of patients with cystic fibrosis using the 'Intermate': the first years experience. *Journal of Advanced Nursing* **22**, 1063–1067.
- Brearley S. (1990) *Patient Participation: The Literature*. Scutari Press, Harrow.
- Brooking J. (1989) A survey of current practices and opinions concerning patient and family participation in hospital care. In *Directions of Nursing Research* (Wilson-Barnett J. & Robinson S. eds), Scutari Press, Harrow.

- Brooks R. (1996) Your place or mine? *Health Service Journal* **106**(5500), 35.
- Brownlea A. (1987) Participation: myths, realities and prognosis. *Social Science and Medicine* **25**(6), 605–614.
- Brown J. & Ritchie J. (1990) Nurses' perceptions of parents and nurses roles in caring for hospitalised children. *Children's Health Care* **19**(1), 28–36.
- Cahill J. (1996) Patient participation: a concept analysis. *Journal of Advanced Nursing* **24**, 560–571.
- Callery P & Smith L. (1991) A study of role negotiation between nurses and the parents of hospitalised children. *Journal of Advanced Nursing* **16**, 772–781.
- Casey A. (1995) Partnership nursing: influences on involvement of informal carers. *Journal of Advanced Nursing* **22**, 1058–1062.
- Challis D., Darton R., Johnson L., Stone M. & Traske K. (1995) *Care Management and Health Care of Older People*. Ashgate, Aldershot.
- Coates V. & Boore J. (1995) Self-management of chronic illness: implications for nursing. *International Journal of Nursing Studies* **32**(6), 628–640.
- Conway A. (1996) Home intravenous therapy for bronchiectasis patients. *Nursing Times* **92**(45), 34–35.
- Corbett K., Meehan L. & Sackey V. (1993) A strategy to enhance skills: developing intravenous therapy skills for community nurses. *Professional Nurse* **9**(1), 60–63.
- Costain D. & Warner M. (1992) *From Hospital to Home Care: The Potential for Acute Service Provision in the Home*. King's Fund Centre, London.
- Coulter A. (1996) Why should health services be primary care-led? *Journal of Health Services Research and Policy* **1**(2), 122–124.
- Coyne I. (1995) Parental participation in care: a critical review of the literature. *Journal of Advanced Nursing* **21**, 716–722.
- Coyne I. (1996) Parent participation: a concept analysis. *Journal of Advanced Nursing* **23**, 733–740.
- Darbyshire P. (1992) Parenting in public: a study of the experiences of parents who live-in with their hospitalised child and of their relationships with paediatric nurses. Unpublished PhD thesis, University of Edinburgh, Edinburgh.
- Darbyshire P. & Morrison H. (1995) Empowering parents of children with special needs. *Nursing Times* **91**(32): 26–28.
- David T.J. (1989) Intravenous antibiotics at home in children with cystic fibrosis. *Journal of the Royal Society of Medicine* **82**, 130–131.
- Davies B. & Challis C. (1986) *Matching Resources to Needs in Community Care*. Gower, Aldershot.
- Dearmun A. (1992) Perceptions of parental participation. *Paediatric Nursing* **4**(7), 6–9.
- Department of Health and Social Security (1986a) *Neighbourhood Nursing: a focus for care*. Report of the Community Nursing Review Team (Chair: Julia Cumberledge). HMSO, London.
- Department of Health and Social Security (1986b) *Primary Health Care*. HMSO, London.
- Department of Health (1989a) *Working for Patients*. HMSO, London.
- Department of Health (1989b) *A Strategy for Nursing: A Report of the Steering Committee*. Department of Health Nursing Division, London.
- Department of Health (1989c) *Caring for People: Community care in the next decade and beyond*. HMSO, London.
- Department of Health (1992) *The Patient's Charter*. HMSO, London.
- Department of Health (1993) *New World, New Opportunities: Nursing in Primary Health Care*. HMSO, London.
- Department of Health (1996a) *The Carer's (Recognition and Services) Act 1995: Policy Guidance*. HSG (96) 8. Department of Health, London.
- Department of Health (1996b) *Choice and Opportunities*. HMSO, London.
- Evans M. (1994) An investigation into the feasibility of parental participation in the nursing care of their children. *Journal of Advanced Nursing* **20**, 477–482.
- Finch J. & Groves D. (1983) *A Labour of Love: Women, Work and Caring*. Routledge and Kegan Paul, London.
- Friend B. (1992) Self-service. *Nursing Times* **88**(44), 26–28.
- Garland C. (1993) Partners in care. *Nursing Times* **89**(30), 34–36.
- Glenister D. (1994) Patient participation in psychiatric services: a literature review and a proposal for a research strategy. *Journal of Advanced Nursing* **19**, 802–811.
- Glendinning C. (1992) *The Costs of Informal Care: Looking Inside the Household*. London, HMSO.
- Goldstein R. & Rivers P. (1996) The medication role of informal carers. *Health and Social Care in the Community* **4**(3), 150–158.
- Goodwin S. (1992) Short-term care and treatment in the home: nursing perspectives. In *From Hospital to Home Care: The Potential for Acute Service Provision in the Home* (Costain D. & Warner M. eds), King's Fund Centre, London, pp. 30–33.
- Graham H. (1983) Caring: a labour of love. In *A Labour of Love: Women, Work and Caring* (Finch J & Groves D eds), Routledge and Kegan Paul, London, pp. 13–30.
- Green H. (1988) *General Household Survey 1985: Informal Carers*. HMSO, London.
- Gregor F. (1997) From women to women: nurses, informal caregivers and the gender dimension of health care reform in Canada. *Health and Social Care in the Community* **5**(1), 30–36.
- Hackman B. (1993) There's no place like home. *Nursing Times* **89**(37), 28–29.
- Haggard L. & Bosma E. (1996) Hospital care at home. In *Extending Primary Care: Polyclinics, Resource Centres and Hospitals-at-Home* (Gordon P. & Hadley J. eds), Radcliffe Medical Press, Oxford, pp. 79–97.
- Hicks C. (1988) *Who Cares: Looking after People at Home*. Virago, London.
- Hiscock J. & Pearson M. (1996) Professional costs and invisible value in the community nursing market. *Journal of Interprofessional Care* **10**(1), 23–31.
- Hughes J. & Gordon P. (1994) *Hospitals and Primary Care: Breaking the Boundaries*. King's Fund Centre, London.
- Hunt J.A. (1995) The paediatric oncology community nurse specialist: the influence of employment location and funders on model of practice. *Journal of Advanced Nursing* **22**, 126–133.
- Ireland L. (1993) The involvement of parents in self-care practices. In *Advances in Child Health Nursing* (Glasper E.A & Tucker A. eds), Scutari Press, Harrow.
- Jewell S.E. (1994) Patient participation: what does it mean to nurses. *Journal of Advanced Nursing* **19**, 433–438.
- Keith L. (1992) Who cares wins? Women, caring and disability. *Disability, Handicap and Society* **7**(2), 167–175.

- Kendall S. (1993) Do health visitors promote client participation? An analysis of health visitor–client interaction. *Journal of Clinical Nursing* **2**, 103–109.
- Kitson A. (1987) A comparative analysis of lay-caring and professional (nursing) caring relationships. *International Journal of Nursing Studies* **24**(2), 155–165.
- Knight L. (1995) Negotiating care roles. *Nursing Times* **91**(27), 31–33.
- Laitinen P. (1992) Participation of informal caregivers in the hospital care of elderly patients and their evaluation of the care given: pilot study in three different hospitals. *Journal of Advanced Nursing* **17**, 1233–1237.
- Laitinen P. & Isola A. (1996) Promoting participation of informal caregivers in the hospital care of the elderly patient: informal caregivers perceptions *Journal of Advanced Nursing* **23**, 942–947.
- Lewis J. & Glennerster H. (1996) *Implementing the New Community Care*. Open University Press, Milton Keynes.
- McAffrey, M. (1992) High tech care at home. *Carelink*. Winter 2.
- McKeever P. (1994) Between women: nurses and family caregivers. *Canadian Journal of Nursing Research* **26**(4), 15–21.
- McLaughlin E. (1991) *Social Security and Community Care: The Case of the Invalid Care Allowance*. DSS Research Report 4. HMSO, London.
- Manthorpe J. (1994) The family and informal care. In *Implementing Community Care* (Malin N. ed.), Open University Press, Milton Keynes.
- Marks L. (1991) *Home and Hospital Care: Redrawing the Boundaries*. Kings Fund Institute, London.
- Marks L. (1992) Longer-term acute hospital care in the home. In *From Hospital to Home Care: The Potential for Acute Service Provision in the Home* (Costain D. & Warner M. eds), King's Fund Centre, London.
- Meyer J. (1993) Lay participation in care: a challenge for multi-disciplinary teamwork. *Journal of Interprofessional Care* **7**(1), 57–66.
- Morris J. (1993) *Independent Lives; Community Care and Disabled People*. Basingstoke, Macmillan.
- Mowatt I.G. & Morgan R.T. (1982) Peterborough Hospital at Home Scheme. *British Medical Journal* **248**, 641–643.
- Neuberger J. (1992) Patients' perspectives. In *From Hospital to Home Care: the Potential for Acute Service Provision in the Home* (Costain D. & Warner M. eds), King's Fund Centre, London.
- National Health Service Executive (1995) *Developing NHS Purchasing and GP Fundholding: Towards a Primary Care-led NHS*. Department of Health, London.
- National Health Service Executive (1996a) *Primary Care: The Future*. HMSO, London.
- National Health Service Executive (1996b) *Patient Partnership: Building a Collaborative Strategy*. HMSO, London.
- Nissel M. & Bonnerjea L. (1983) *Family Care of the Handicapped Elderly — Who Pays?* Policy Studies Institute, London.
- Nolan M. & Grant G. (1989) Addressing the needs of informal carers: a neglected area of nursing practice. *Journal of Advanced Nursing* **14**, 950–961.
- Nolan M., Keady J. & Grant G. (1995) Developing a typology of family care: implications for nurses and other service providers. *Journal of Advanced Nursing* **21**, 256–265.
- Orem D. (1985) *Nursing: Concepts of Practice*. Macmillan, London.
- O'Cathain A. (1994) Evaluation of a hospital at home scheme for the early discharge of patients with fractured neck of femur. *Journal of Public Health Medicine* **16**(2), 205–210.
- Parker G. (1990) *With Due Care and Attention: A Review of Research on Informal Care*. Family Policy Studies Centre, London.
- Parker G. (1993) *With this Body: Caring and Disability in Marriage*. Open University Press, Milton Keynes.
- Parker G. & Baldwin S. (1992) Confessions of a jobbing researcher. *Disability, Handicap and Society* **7**(2), 197–203.
- Parker G. & Lawton D. (1994) *Different Types of Care, Different Types of Carer: Evidence from the General Household Survey*. HMSO, London.
- Phillips J. & Bernard M. (1995) Perspectives on caring. In *Working Carers* (Phillips J. ed.), Avebury, Aldershot.
- Pike S. (1989) Family participation in the care of central venous lines. *Nursing* **3**(38), 22–25.
- Qureshi H. & Walker A. (1989) *The Caring Relationship*. Macmillan, Basingstoke.
- Roberts P. (1992) *Hip Home*. *Nursing Times* **88**(44), 28–30.
- Rodwell C.M. (1996) An analysis of the concept of empowerment. *Journal of Advanced Nursing* **23**, 305–313.
- Rudkin S. (1996) Home support for patients on long-term oxygen therapy. *Nursing Times* **92**(34), 34–35.
- Saunders P. (1995) Encouraging patients to take part in their own care. *Nursing Times* **91**(9), 42–43.
- Sevick M.A., Sereika S., Mathews J., et al. (1994) Home based ventilator-dependent patients: measurement of the emotional aspects of home caregiving. *Heart and Lung* **23**(4), 269–278.
- Smith C.E., Mayer L., Perkins S., Gerald K. & Pingleton S. (1994) Caregiver learning needs and reactions to managing home mechanical ventilation *Heart and Lung* **23**(2), 157–163.
- Stocking B. (1992) Moving acute health care into the home. In *From Hospital to Home Care: The Potential for Acute Service Provision in the Home* (Costain D. & Warner M. eds), King's Fund Centre, London.
- Tatman M., Woodroffe C., Kelly P. & Harris R. (1992) Paediatric home care in Tower Hamlets: a working partnership with parents. *Quality in Health Care* **1**, 98–103.
- Thomas V.M., Ellison K., Howell E. & Winters K. (1992) Caring for the person receiving ventilatory support at home: care givers needs and involvement. *Heart and Lung* **21**(2), 180–186.
- Trnobranski P.H. (1994) Nurse-patient negotiation: assumption or reality *Journal of Advanced Nursing* **19**, 733–737.
- Twigg J. (1992) *Carers: Research and Practice*. HMSO, London.
- Twigg J. & Atkin K. (1994) *Carers Perceived: Policy and Practice in Informal Care*. Open University Press, Buckingham.
- Ungerson C. (1983) Why do women care? In *A Labour of Love: Women, Work and Caring* (Finch J. & Groves D. eds), Routledge and Kegan Paul, London.
- Ungerson C. (1987) *Policy is Personal: Sex, Gender and Informal Care*. Tavistock, London.
- Ungerson C. (1990) The language of care. In *Gender and Caring: Work and Welfare in Britain and Scandinavia* (Ungerson C, ed.), Harvester Wheatsheaf, Hemel Hempstead.
- Warner M. & Riley C. (1994) *Closer to Home: Healthcare in the 21st Century*. National Association of Health Authorities and Trusts, Birmingham.

- Waters J. (1996) How care in the community has affected older people. *Nursing Times* **92**(4), 29–31.
- Waterworth S. & Luker K. (1990) Reluctant collaborators: do patients want to be involved in decisions concerning care. *Journal of Advanced Nursing* **15**, 971–976.
- While A.E. (1992) Consumer views of health care: a comparison of hospital and home care. *Child: Care, Health and Development* **18**(2), 107–116.
- Wistow G. (1995) Aspirations and realities: community care at the cross-roads. *Health and Social Care in the Community* **3**(4), 227–240.