

‘I’ll tell you what suits me best if you don’t mind me saying’: ‘lay participation’ in health-care

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‘I’ll tell you what suits me best if you don’t mind me saying’: ‘lay participation’ in health-care

Increasing ‘lay participation’ in healthcare has become a popular notion in recent years and is generally considered to be a good thing in both nursing and wider policy circles. Yet despite the widespread acceptance of this overall idea, there is a dearth of theorising in this area. This has resulted in a lack of conceptual clarity which has not only hamstrung the development of empirical work in the field, but has also led to a tendency by both nurses and policy-makers to assume that greater ‘lay participation’ in health will lead to a concomitant increase in lay power *vis-à-vis* health professionals. The data presented in this paper indicate that this is, at best, an over-simplistic assumption and, at worst, an erroneous one. Drawing on sociological theories of the division of labour, I suggest that one way in which we might begin to clarify our thinking in this area is by differentiating between the ‘role’ and ‘task’ components of ‘lay participation’. I illustrate my argument with reference to two separate ethnographic studies undertaken between 1994 and 1998 in which participation at the level of the individual was examined.

Key words: care, participation, partnerships, patient, sociology.

Throughout the developed and developing world, increasing ‘lay participation’ in health-care has become a popular idea in recent years, both in nursing and in wider policy circles. The Declaration of Alma-Ata (WHO 1978) states: ‘The people have the right and duty to participate individually and collectively in the planning and implementation of their health-care’. In the UK, for example, public involvement is now encouraged at many different levels of the service system. As well as participation at the level of the individual in the planning and provision of their own care, we now have lay involvement in research and development and in the commissioning of services. In nursing and policy circles alike, increasing the participation of lay people in health-care is generally considered to be a good thing. Yet despite the widespread acceptance of this overall idea there

is a surprising dearth of theorising in this area. The literature contains a bewildering array of terms — ‘patient participation’, ‘user-involvement’, ‘collaborative care’, ‘partnership’, ‘consumerism’ — which are used to mean different things by different people, often for different political purposes. Indeed, the notion of ‘lay participation’ is itself misleading. It implies an inherent contrast between lay users and professional providers, and yet health professionals may themselves be recipients of services. Conversely, health services are also provided by non-professional ‘lay’ staff, such as health-care assistants. This lack of conceptual clarity has not only hamstrung the development of empirical work in the field; it has also led to a tendency by both nurses and policy makers to assume that greater ‘lay participation’ in health will lead to a concomitant increase in the power of the public *vis-à-vis* health professionals. While for some this may be a politically expedient claim, the data presented herein indicate that it is at best, an over-simplistic assumption, and at worse an erroneous one.

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In the absence of a satisfactory alternative, for the purposes of this paper 'lay participation' will be employed as a short-hand to refer to this general area of interest. However, I use it in inverted commas to acknowledge the fact that it is a rather misleading expression and I employ it advisedly. Drawing on sociological theories of the division of labour, I suggest that one way in which we might begin to clarify our thinking is by making an analytic distinction between the 'role' and 'task' components of 'lay participation' (Hughes 1984). I illustrate my argument with reference to two separate ethnographic studies undertaken between 1994 and 1998 in which participation at the level of the individual was examined.

BACKGROUND

Traditionally, what is known as an 'acute-care' philosophy has underpinned the medical-nursing care given in hospitals, reflecting the classic picture of the 'sick role' described by Parsons (1951) of an acutely ill person, temporarily passive and acquiescent, being treated by an active physician and carers (Strauss et al. 1985). While vestiges of this model clearly remain, current thinking about the role of the patient is centred around a model of the lay public as knowledgeable partners in health-care. Efforts are now being made to move towards more participatory models of care based on shared decision-making and greater user control.

This change in thinking has been shaped by a number of considerations. First, the late 1960s and early 1970s saw the emergence of a number of critiques of modern medicine (McKeown 1965) which questioned its achievements, and even went so far as to suggest that it was having a deleterious effect on society (Illich 1976). Second, as a result of public health improvements and medical technologies there has been a shift from acute illness to the dominance of chronic conditions that require continuing management. The long-term nature of chronic diseases make participation particularly appropriate, given that continuing care is needed. Third, there has been long-standing concern about the escalating costs of health-care.

In the UK these trends have influenced contemporary thinking on 'lay participation' in health-care in two important ways. First, efforts have been made to change the nature of the patient-professional relationship by addressing the traditional power imbalance between service users and healthcare professionals. This was manifested in the rise of consumerism within healthcare services that was evident in the Griffiths Report (DHSS 1983). Griffiths criticised the National Health Service for being orientated to the needs of service providers rather than its users. Following the

Griffiths Report the general public was increasingly cast as knowledgeable 'consumers' of health-care rather than its passive recipients. Considerable importance was placed on issues of communication and information-giving. Consonant with the consumerist trend was the introduction of the Patients' Charter, one of a series of citizens charters which aimed to set standards that the general public can expect and demand. Under the current government there has been a change in language — policy-makers have discarded the vocabulary of the market, preferring, instead, to talk in terms of 'partnerships' with 'service users' — but the emphasis on lay involvement in health-care is still very much in evidence. For example, the patient/carer perspective is one of six areas in the New National Performance Framework delineated in the white paper *The new NHS modern and dependable* (Department of Health 1998a) and its Welsh counterpart — *Putting patients first* (NHS Wales 1998) — refers to 'user involvement' in the definition of quality standards and clinical audit. Additionally, as part of its policy research programme, the Department of Health has established a research initiative related to the development of 'partnerships' with patients, carers and the public in healthcare decision making (Department of Health 1998c).

The second way in which 'lay participation' in health-care is changing is in the contemporary emphasis given to self-management and independence and individual responsibility for health and wellness. In the UK, this has been the main focus of recent government policies towards improving the nation's health. The White Paper, *The health of the nation*, states:

The reason is simple. We live in an age where many of the main causes of premature death and unnecessary disease are related to how we live our lives (Department of Health 1992).

Thus, much effort in recent years has gone into health promotion. Under Conservative governance, considerable emphasis was given to individual responsibility for health and the management of chronic conditions. Although this thread is evident in policies formulated by the current Labour administration, the emphasis on individual responsibility has been tempered with a greater recognition of the socio-economic bases of ill health (Department of Health 1998b).

These trends have also found expression within nursing. As Armstrong (1983) has pointed out, until about 20 years ago the caring role of the nurse was restricted primarily to the biological function of the patient. Today, however, nursing has been reconstructed around the centrality of the nurse-patient relationship, which is conceived of as an equal partnership; it is through the establishment of a therapeutic 'healing association' that nurses are said to

promote healing (Salvage 1992). 'Patient participation' is now a central dimension of the professional nursing role. Rather than patients being the passive recipients of nursing interventions, nursing ideology advocates participatory models of practice based on the active involvement of patients. In recent years, emphasis has been given to the importance of good communications (Wilson-Barnett 1984), the involvement of patients in goal setting (Bailey and Clauss 1975) and the planning, delivery (Ross 1987) and evaluation of their care (Hefferin 1979; Hames and Stirling 1987), and nurses' teaching and health promotion role. Contemporary nursing discourse underlines the importance of patients' subjective experience of their illness and its interaction with their daily lives. Nurses are now encouraged to develop close relationships with patients so that they can understand the meaning their illness has for them and to use this knowledge to jointly plan individually tailored plans of care. These 'New Nursing' (Beardshaw and Robinson 1990) ideas are evident in Primary Nursing, models of self-care (Orem 1995), collaborative care (Frances et al. 1992) and family care (Taylor 1989). As well as reflecting the influence of broader societal trends, these developments must also be understood in terms of the occupation's 'professional project' (Larson 1977; Witz 1992) and the desire of the nursing leadership to elevate the status and material rewards of nurses: empowering the client, can only be accomplished if nurses are themselves empowered (Allen 1996).

THEORETICAL FRAMEWORK

There is a wealth of sociological literature which has examined the nature of the relationship between patients and health professionals (although most of this has focused on the medical profession rather than other occupational groups). Located within the 'professions' literature, this body of work has underlined the power imbalance characteristic of professional-client relations. Early sociological studies described these structural inequalities in fairly benign terms. Because the professional-client encounter was founded on an asymmetry of expertise, it was necessary for the client to trust the professional and co-operate with them in order to benefit from their services (Parsons 1951). By the 1960s, however, the study of the professions acquired a more critical edge. Earlier scholars were accused of naively accepting the ideology and rhetoric of the established professions. Writers such as Johnson (1967), Freidson (1970a,b) and Larson (1977) argued that rather than serving disembodied social needs, professions imposed their own definition of needs on clients and were thus a form of social control. Indeed, Freidson (1970a,b) went so far as to claim that

'professional dominance' was the analytic key to the, then present, inadequacies of the health service, in which the doctor was the designated expert and all other opinions (including lay ones) were subordinate. Because the domination of medicine was total, Freidson argued, it not only affected the doctor-patient relationship; it also shaped the nature of the relations between other health professionals and patients. Many of the empirical studies spawned by this more critical body of work focused on issues of information and communication. In particular, attention was directed at the failure of members of the medical profession to provide patients with information about their condition and treatment. Critics argued that the withholding of information was a source of considerable distress to patients, and it was also a further way in which the profession of medicine consolidated its power over patients (Roth 1963; Glaser and Strauss 1965; Davis 1972; Quint 1972; McIntosh 1977). Recent policy developments which have sought to refashion the lay-professional relationship are, in part, a response to sociological critiques of this kind.

Yet while the professional literature is useful in developing our understanding of the client-professional *relationship*, it tells us little about how the *work* involved in the provision of health is accomplished. Furthermore, because its focus has been concerned mainly with medicine as an archetypal profession, it is less useful in the study of real life settings in which health-care is provided by both non- and aspiring professions. This is where sociological theories of the division of labour can aid understanding.

Sociological theories of the division of labour are concerned with the issue of how the activities that need to be done in a given society are divided up. It was the question with which Durkheim (1933) was preoccupied when he wrote *The division of labour*, which was first published in 1893. Writing in this turbulent period, he observed that the mechanisation and concentration of capital forces caused by the agrarian and industrial revolutions of the nineteenth century had brought about 'the extreme division of labour'. By this he was referring to the specialisation of society as a whole and the separation of social life into different activities and institutions. Drawing on Darwinian theories of natural selection, Durkheim argued that the world of work was analogous to an ecological system. External forces may impact upon the system of work and reshape work boundaries. New tasks may enter the system and others may leave or be passed on to other occupational groups or be performed on an unwaged basis.

The work of Hughes (1984) is a good example of the way in which Durkheim's ideas have been developed. As Freidson (1976) has observed, Durkheim paid little attention

to the concrete substance of the division of labour. He was more concerned with its structure and function than its internal dynamics. Hughes, on the other hand, focuses considerable attention on work activity itself. For Hughes, an occupation is comprised of a 'bundle' of tasks. The history of an occupation can be described in terms of changes to these bundles of activity, he claims. Hughes considered the division of labour to be an unsatisfactory concept; for him it emphasised divisions rather than connections. He was more interested in the edges of occupations and their interrelations: it is impossible to describe the work of one person without reference to the work of others, he argued. It was in this context that Hughes drew attention to the importance of the interface between the nurses' work and that of the patient, recognising that the patient was also a participant in the healthcare division of labour.

In drawing sociological attention to the 'work' of the patient Hughes undoubtedly made an important contribution to the field. Although he did not develop this idea to any considerable extent in either his theoretical or his empirical work, others have. Arguably, the most important contribution to the literature in this respect is Strauss et al.'s (1985) study of *The social organization of medical work*. Although the overall focus of the book is on the activities or work that take place in health-care rather than the status of the workers, Strauss et al. (1985) nevertheless devote an entire chapter to the work of patients. The sick work, they argue, but as far as health professionals and their aides are concerned, this is not necessarily conceived of as more than acting properly or decently in accordance with the requirements of their care. Strauss et al. underline the amount of work that people who suffer from chronic conditions do in managing their own illness, and how, often when they come into hospital, they are placed in the ironic situation of delegating responsibility for this to professional staff. They also point out that there are certain things that healthcare staff assume that sentient and ambient patients will do; empirical studies indicate that inappropriate participation in the division of labour frequently leads to judgements by hospital staff which have a strong moral tone (Taylor 1970; Jeffrey 1979; Lorber 1979; Murcott 1981; Kelly and May 1982). As Stacey (1976) and Hughes (1984) have pointed out, although the patient is a worker in the healthcare division of labour, the fact that they are also the work object and service object of others colours the nature of the lay-professional relationship.

Taken together, these theories provide an analytic framework which can be usefully employed in developing our understanding of the lay-professional interface in health-care. On the one hand the literature on professions allows us to

consider the nature of the changing relationship between the general public and health service professionals and their aides, albeit in relation to the archetype of the medical profession. On the other hand, the theories of the division of labour helps us to analyse the ways in which the allocation of work between the lay person and waged health-carers is changing. Interestingly, however, there is relatively little cross-fertilisation between these two areas of the literature. The one notable exception is the work of Hughes (1984), who began to consider the connections between the allocation of work and the nature of the relationships involved. Although he did not pursue his analysis very far, he has left a useful analytic framework to facilitate discussion of this complex area.

Hughes maintained that we should think of the world of work as comprised of two intricately linked elements: roles and tasks. The technical division of labour refers to the allocation of tasks, whereas the moral division of labour refers to one's role — the 'who I am' as opposed to the 'what I do'. If we apply this framework to the current healthcare context we can see that attempts are being made to change 'lay participation' in both these respects. That is, on the one hand efforts are being made to change the nature of the professional-patient relationship and, on the other, the allocation of work tasks is itself being realigned. The 'role' and 'task' elements of 'lay participation' are clearly inter-related, but I suggest that for analytic and practical purposes it is vital to be aware of their differences. It is precisely the failure to keep these two dimensions of public involvement in health-care analytically distinct that has resulted in the kinds of conceptual confusion highlighted earlier and which has led to the rather uncritical assumption that increased participation in the technical division of labour implies parallel changes in the moral division of labour.

METHOD

The data I shall be drawing on in order to illustrate my argument were generated on a urology ward and a vascular ward in two separate ethnographic studies carried out over the last four years. The former was undertaken in a large district general hospital and the latter in a university teaching hospital. Both hospitals were in the UK. The data on the urology ward is derived from doctoral research into the ways in which nurses managed their work boundaries in the course of their everyday practice (Allen 1996). The data from the vascular ward comes from an ongoing programme of work into the ways in which the lay-professional boundary is negotiated in health-care (Allen 2000).

In both settings ethnographic research methods were

utilised: participant observation, informal conversations, semi-structured tape-recorded interviews with staff, and documentary analysis of a range of organisational literature, for example, patient information leaflets, memoranda (anonymised) careplans, and ward philosophies. 'Lay participation' was a largely unanticipated theme in the PhD research and hence the data I will be using from that study is based on my observations and conversations with ward staff. I did not talk to patients about their involvement in care: there was insufficient time and ethical approval had not been obtained. My ongoing work is, however, specifically focused on 'lay participation' — both at the level of the individual and in terms of the involvement of family and significant others — and the views of service users are a crucial component of the data. Ethical approval was elicited from the local research ethics committee and written consent obtained from all patients and their carers directly involved in the research.

In the PhD study, fieldwork was undertaken over a 10-month period on a surgical and a medical ward. Three months were spent on each ward. In the second project, fieldwork was carried out over an eight month period on a surgical and a medical ward. Two months were spent on each ward. Fieldnotes were recorded in a behaviourist and low inference style, that is, they were literal descriptions of field actors' behaviour and talk, rather than my interpretations or glossing of the events observed. My research role was slightly different in the two studies. Although I am a nurse I did not work as such in either of the research sites. The role I negotiated during the doctoral work may best be described as 'researcher as helper', whereas in the study which specifically focused on the lay-professional boundary I negotiated a more active role. An honorary contract was agreed with the Trust which permitted me to assist the nurses in the delivery of care. For the most part, I worked in the capacity of an auxiliary or health-care assistant.

The observational data were supplemented by semi-focused tape-recorded interviews. In the PhD study the interview sample comprised ward nurses ($n = 29$), doctors ($n = 8$), auxiliaries ($n = 5$), healthcare assistants ($n = 3$) and clinical managers ($n = 11$). In the second study, tape-recorded interviews were carried out with auxiliaries ($n = 4$) and qualified staff ($n = 20$) and extended, non-tape-recorded interviews were carried out with a sample of patients ($n = 24$) and carers ($n = 11$) over the course of their hospital stay. As far as possible, these conversations were recorded contemporaneously.

In both studies I employed a broadly interactionist framework. Considered in this way, the allocation of work is not self-evident but has to be actively negotiated within a given context. As Stacey (1976) has argued, 'the health

service is better thought of as a process of continuing interaction between patient and health-care professionals and workers'. Data generation and analysis were undertaken concurrently, with analysis informing subsequent data collection. I adopted an holistic approach to data analysis — data from different sources were compared in order to make judgements as to how each piece should be interpreted. There was then a process of constant cross-checking in which data extracts were related to the emergent overall analysis in order to evaluate its meaning and, on the basis of the analysis of the whole, the meaning of each slice of data would itself be modified. A broad coding frame was developed and modified and refined as the analysis progressed. Folio VIEWS 3.1 was employed to facilitate data management and handling.

RESULTS

For the purposes of this study, data generated on the two surgical wards were analysed, with the aim of using this material to illustrate the importance of the 'role-task' distinction. The urology ward is presented as an example of the way in which patients may increase their participation in the technical division of labour without changing the moral division of labour in any way. The vascular ward is used to illustrate the converse situation: here nurses had developed more egalitarian relations with patients even though the patients participated very little in the healthcare work itself.

The urology ward

When I started the research in the autumn of 1994, I was struck by the extent to which patients were participating in their care compared to my own experiences in clinical practice only six years previously. There were three main areas where shifts in patient participation seemed to have successfully taken place: elimination products work, record keeping and technical tasks. These are not distinct analytic categories; rather there are areas of overlap.

Much of the work undertaken by patients involved the handling of body products. Many patients routinely maintained a record of their fluid balance. This entailed measuring and recording fluid intake and urine output and, in some cases, assessing and recording the colour of their urine. Patients with renal colic filtered their urine for kidney stones.

The second category of work patients had become more involved in was record-keeping. As we have seen, much of patients' elimination products work entailed a record-keeping component but they also undertook record-keeping

of other kinds. For example, they recorded their pain — its location, severity and type and its relationship to other activities of daily living such as eating.

The third category I have identified are technical tasks. Here there were two different modes of participation. First, patients were involved in technical tasks if these were skills that they would require on discharge, for example, how to care for a urethral catheter. Second, those patients whose day-to-day management of chronic disorders entailed technical medical work were encouraged to continue with it if their condition permitted. For example, diabetic patients carried on measuring their blood sugar levels and administering their own insulin.

Although patients were far more actively involved in their care compared to my own experiences in nursing only six years before, the patterns of nurse–patient interaction on the ward suggested that the moral division of labour remained rooted in the traditional asymmetries of client–professional relations. Ward staff did not seem to have moved very far towards establishing partnerships with patients. For example, patient participation in the tasks I have just described seemed to be driven by workload considerations as much as they did the desire to involve patients in their care.

[T]here's no reason at all why they can't measure their own urine. A lot of them are quite happy, they like to do it. Then they go back and they mark it off on their charts and they feel really involved in their care. Well why shouldn't they? It's their body, it's their operation, it's their care. So I quite like it. I like this ward for that. *You don't hear many buzzers going off on this ward ...* [emphasis added]. (staff nurse: interview data)

Furthermore, patient involvement in caring work had become part of the established ward routine, which did not go very far towards supporting patient choice. Indeed, those patients who did not comply were a source of irritation:

Stephanie was complaining about a new lady who was not measuring her urine out as the nurses had instructed her to. She complained that the lady 'kept letting the bed-pans pile up in the toilet'. (fieldnotes)

Current thinking about professional–client relationships emphasises the importance of taking the client's perspective into account and giving patients greater control over the caring process; however, as the following data extract demonstrates, the nurses did not appear to have moved very far in this direction:

On the drugs round one of the patients asked if she could have something for her bowels. Staff nurse said, 'We'll get you something written up'. The patient said, 'I'll tell you what suits me best if you don't mind me saying and that's glycerine suppositories'. Staff nurse said, 'We can't give you anything until the doctor writes it up'. (fieldnotes)

The patient's interactional strategy in this data extract clearly indicates that she believes that in making a suggestion about her medication she is moving into delicate territory, as indicated by her use of the mitigator — 'if you don't mind me saying'. Her suspicions are confirmed when the nurse does not acknowledge the patient's suggestion in any way; she simply asserts the power of the doctor and the hospital rules. Patients' awareness of the sensitivity of nurses' role boundaries was also evident in their routine interactions with staff:

One of the patients asked staff nurse if he was having his 'two special tablets at 10 o'clock'. Staff nurse said, 'What special tablets?'. The patient said, 'I had two tablets this morning and they said I was having some more tonight'. Staff nurse said, 'Oh yes. You're jumping the gun a bit. I'll come back to you with those'. The patient said, 'Sorry nurse — I didn't want to tell you your job or anything'. (fieldnotes)

Another area which has been much emphasised in contemporary ideas about lay participation in health is the importance of information giving. As we have seen, critics of the traditional pattern of professional–client relations have shown that withholding information is a mechanism through which the medical profession controlled patients and bolstered its power. In this setting, although the nurses did volunteer information about patient's treatment, it was also the case that patient enquiries were frequently treated defensively by staff, who appeared to interpret this as implying a lack of trust in their judgements rather than as an expression of the patient's interest in their own condition. As the following extract indicates, enquiries about drugs were a source of tension:

Patients that ask about their drugs they're always seen as trouble-makers. (student: interview data)

In summary, then, although the patients on the urology ward were certainly participating in their own healthcare work to a much greater degree than I had been accustomed to in my own practice, there was little evidence of a partnership between nurses and patients. In Hughes' terms, while they had made shifts in the technical division of labour — by involving patients in new task areas — modification of the moral division of labour by sharing power with patients appeared to have proved more problematic.

The vascular ward

I now wish was to compare caring relationships on the urology ward with those on the vascular ward. Because of their general medical condition the patients on the vascular ward were far less involved in the technical division of

labour than they were on the urology ward, and yet a sense of partnership between nurses and service users was very much in evidence. Collectively, the nurses on the vascular ward seemed to have created what I have called a 'participatory caring context': it was something one felt from spending time there. There were several elements of the nurses' practice that created this feeling of partnership.

First, the nurses demonstrated a respect for the patient's perspective and their knowledge of their condition. For example, in the following extract the nurse and patient engage in a meaningful dialogue in which the nurse provides information and the patient unapologetically asserts his right to control his medication regime.

Staff nurse asks the patient whether he wanted a particular drug and the patient remarked that he'd had it at two and was having them four hourly. Staff nurse looked at the chart and said that the chart indicated that the patient had had the drug at 12 not two. The patient said that this was inaccurate. There then followed a conversation in which the patient asserted that he'd been having these tablets every four hours and staff nurse pointed out that he could have them every hour if he wanted. The patient resolved to wait longer for his tablets — to fit in with the four hourly schedule he had devised for himself. He said that he planned to stick with taking the tablet four hourly for today then 'seeing how we go'; he planned to try to go without the tablets tomorrow. (fieldnotes)

A further aspect of the participatory caring context on the vascular ward was the openness and approachability of staff. Patients frequently and directly asked nurses about aspects of their treatment and nurses responded in a non-defensive manner. There was little evidence of the sorts of tensions I witnessed on the urology ward. Patients and relatives both emphasised how approachable the nursing staff were:

You can ask them anything at all here. (patient: fieldnotes)

When you ask it's never too much trouble to take time to explain it. (relative: interview data)

The nursing staff were themselves conscious of the open atmosphere they had created on the ward:

I just think that everyone is relaxed and patients are allowed to ask questions. (staff nurse: interview data)

I think we feel less intimidated. If there are things to say then we will tell people — you know. We don't hold on to information so much like a lot of people do. (staff nurse: interview data)

Another component of this participatory caring context was nurses' flexible working practices. The ward nurses' focus was on the needs of individual patients — and although they were conscious of the constraints of the ward routine — they made an effort to accommodate individual patient preferences.

[W]e are different because we're not very fussy sort of in the way we don't make beds at a strict time, we don't get them all out of bed. [W]e've altered our style so much that people think we're messy and sloppy but then we will let patients guide their own events. We don't slap them all in the bath ... we do let them decide — I'll say you know 'Well do you want it later or?' (staff nurse: interview data)

Of course accommodating patient choice was not always easy and the patients seemed to be well aware of the constraints within which nurses worked; however, the fact that nurses tried to give people options where they could appeared to mean a lot to patients.

Nurse: Hello my darling how are you?

Patient: OK thanks.

Nurse: When do you want me to do your leg?

Patient: It's up to you. When you've got time.

Nurse: I've always got time for you Larry.

Patient: What I mean is you're the one with things to do not me.

Nurse: I could do it now. Well do you want me to do it now or later?

Patient: Now is OK.

Nurse: Right I'll go and get the stuff now. (fieldnotes)

DISCUSSION AND CONCLUSIONS

In this paper ethnographic data has been employed to explore the ways in which nurses and patients negotiated care on two surgical wards. It has been suggested that, despite the popularity of ideas about patient participation within nursing and wider health policy, our thinking around this subject remains confused. It has been suggested that sociological theories of the professions and the division of labour may provide us with a potentially useful conceptual framework with which to analyse 'lay participation' in health work. Of particular value is Hughes' distinction between the moral division of labour (role relationships) and the technical division of labour (the allocation of tasks) which allows us to traverse the boundary between these two different areas of the literature. I have argued that the failure to distinguish between the role and task elements of lay participation has resulted in an uncritical tendency within nursing and the wider policy context to equate patient participation with their empowerment. As we have seen, the data presented here suggests that this link is by no means automatic. It is possible for patients to participate in healthcare work without being empowered in any real sense (as was the case on the urology ward); conversely, empowerment is possible even if participation in the technical division of labour does not occur (this was clear in the data from the vascular ward).

Clearly 'lay participation' in health-care is far more complex than the two extreme cases discussed here. The wards discussed in this paper were selected for illustrative purposes. Nevertheless, these data do highlight the need for greater clarity, both in our theory and our practice. In both cases staff considered themselves to be 'doing patient participation', but, as we have seen, the form that this took in each case was very different.

Of course many other factors are likely to affect the form 'lay participation' takes in a given context, such as the individual preferences of patients, the stage of their illness/recovery trajectory, age, education, gender, ethnicity and socio-economic status. Furthermore, there may be certain circumstances in which traditional professional-client role relationships are entirely appropriate. The vital thing is that this should be negotiable. Collectively, the nurses on the vascular ward had created a 'participatory caring context', which made patient choice possible. The next stage in this programme of research will be to analyse the reasons why this was achievable on the vascular ward and not on the urology ward.

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