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FROM PATIENT TO PERSON

A PATIENTS' FORUM

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Nursing
Development
Units

FROM PATIENT TO PERSON

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MARION CLARKE

BARBARA SHEPPARD

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The King's Fund Centre is a service development agency which promotes improvements in health and social care. We do this by working with people in health and social services, in voluntary agencies, and with the users of these services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences, information services and publications. Our aim is to ensure that good developments in health and social care are widely taken up. The King's Fund Centre is part of the King's Fund.

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MARION CLARKE
Primary Nurse

BARBARA SHEPPARD
Researcher Co-ordinator

Brighton Nursing Development Unit

Brighton Nursing Development Unit
Homeward Rehabilitation Unit
Brighton General Hospital
Elm Grove
Brighton
BN2 3EW
0273 696011

Consulting patients

In recent years, few people can have failed to notice the gradual shift from judging quality issues by such methods as counting through-put to greater emphasis on finding out what patients actually think about their hospital experiences[1-4]. This increasing focus on the customer as arbiter has been given an even higher profile recently with the appearance of the Patients' Charter.

At the beginning, we saw our patients' forum on Homeward as part of this move. It was an interesting and enjoyable way of consulting our patients as consumers and improving the unit at the same time. However, as it continued, we came to recognise that, for our patients, it was equally important as a dynamic and empowering part of their rehabilitation.

Different styles of participation

Homeward is a rehabilitation unit for elderly people. There are four bedrooms each with five beds surrounding a table which is the hub of patients' activities within the room. The Amethyst room is a typical bedroom, with individually chosen curtains, pretty tablecloth and bedspreads all in co-ordinating colours.

A patients' forum has been held in Amethyst every week since January 1992. Between eight and ten patients from different rooms usually come along to each meeting and there are never more than three members of staff. No-one on the ward wears uniform, so staff are unobtrusive. Patients and staff always call each other by their first names. The whole ward has this relaxed and homely atmosphere because we believe that an informal environment encourages the sort of sharing relationships which enable people, ultimately, to take responsibility for their own rehabilitation. This kind of atmosphere has allowed our patients' forum to develop in a particular way. In other settings, different influences will obviously result in different styles of patient participation.

Many of our patients on Homeward have had strokes and may need a lengthy period of rehabilitation to be able to return to independent living. They may have undergone a drastic change in body image and, as a result, often suffer from a severe loss of self esteem.

The quality assurance perspective: permission to be critical

As part of an action research project which will continue throughout the three years of King's Fund Centre support, Barbara Sheppard, the NDU researcher, spent six months interviewing former patients and carers after they had left the unit. In October 1991 she reported her findings back to the nursing team. Marion Clarke, a primary nurse, was particularly keen to hear these. She had been planning to set up some kind of patients' consultation group for a while, and was waiting to hear how past patients had experienced the ward.

One of the research findings made it look as though any efforts to get our patients' real opinions would be doomed. In spite of all our efforts to make the ward as relaxed and informal as possible, many of the former patients had been adamant that they would never have dared to criticise the ward while they were with us. They did see it as much less intimidating than the average hospital ward but they still believed that it was safer 'not to rock the boat'. If this was the case then could we find ways of ensuring that a patients' group would feel confident enough to have honest discussions?

In December 1992, we got together to talk about these problems. In the privacy of their own homes the former patients felt safe and were able to raise several sensitive topics. We decided that, in order to get the discussion going at the crucial first meeting, we would introduce these topics to current patients as issues which had already been identified by previous patients. We hoped that this would encourage patients and show them that it was all right to be critical of the ward and frank about their feelings.

To our delight this worked very well and the first meeting was lively and unrestrained. No such permission to be critical was needed at later sessions. Patients justified their criticisms by explaining that they were not saying these things for themselves but to make things better for the people who would come after them.

Over the next three months we held weekly meetings and patients discussed such things as primary nursing, their own expectations of the unit, the difficulties of rehabilitation, the non-uniform policy and staff identification problems. Patients and staff together rapidly found solutions for many small problems. When changes were made on the ward patients could see that their comments were being acted upon. The meetings themselves were recognised as useful and as resulting in practical benefits. These included such simple but important things as the provision of an air freshener and regular deliveries of favourite daily papers. Meals and quality of the food have been a perpetual source of concern and the problem of the inadequacy of the call-bell system has still to be resolved. We are still thrashing out even thornier questions such as whether alcohol should be on sale to patients on a long-stay rehabilitation ward.

It was beyond the power of the nurses to solve several of the patients' problems and in those cases the relevant manager was invited along to discuss what could be done. For instance, patients protested that the heating system was far too efficient, so much so that they had spent the winter months perspiring profusely. They described long nights spent tossing and turning and days lying listlessly in a state of complete lethargy. They gave the Operations and Maintenance Manager such graphic descriptions of this that he quickly arranged for the heating system to be monitored. New controls have now been installed. As a result, next winter we hope to have fewer drooping patients and much lower fuel bills for the health authority.

After three months, we suddenly realised that, as well as being a great success in quality assurance terms, the forum was also having an extremely positive effect on the patients who took part. They became much livelier and more alert and were mixing far more with other patients. We decided to take a closer look at what was going on during the sessions in terms of rehabilitation.

The rehabilitation perspective

Most patients when they come into hospital undress, send home their clothes and become passive recipients of care. As patients, they expect nurses to make decisions for them. They not only expect nurses to provide them with warmth and comfort but they expect nurses to make judgements about everything to do with them. Each and every person who is admitted into hospital is likely to experience similar feelings of dislocation, passivity, vulnerability and inactivity. They have been removed, often abruptly, from their normal, familiar surroundings and are away from the support of their family and friends. They relinquish their social status. They become an object — a patient.

At the opposite end of the hospital stay, the discharge process may be just as sudden and disorienting. We believe that this need not happen. People should have the benefit of a process of rehabilitation. They should have the time and opportunities to begin to reclaim themselves as people and to start making the therapeutic move from being a passive object to being an active subject, in other words, to change from patient to person. In order to return to the world outside as a person, it is necessary for patients to go through this process. We began to see that taking part in a patients' forum could help it enormously.

From the beginning, we had realised that it was not appropriate for all patients to take part throughout their stay. We had always seen it as most appropriate for those patients who were coming towards the end of their rehabilitation, but we had not quite worked out why. As time went on, we began to recognise that there was in fact an optimum time during each patient's stay on the ward when they became ready, able and willing to participate. Thinking about it, we recognised that this was related to the grieving which our patients experience. After the loss of a body part or a drastic change in body image such as that following a CVA, a period of grieving inevitably occurs. It is only when the final stage of acceptance has been reached that people are able to look outside themselves and take an active interest in what is going on around them.

Jackson[5] described three key activities of rehabilitation as follows:

Re-activation —	the encouragement of patients to be active in their surroundings.
Re-socialisation —	the encouragement of physical and/or verbal contact by patients with peers, families or others.
Re-integration —	the restoration of the patient to society and the regaining of status as a person.

Our patients' forum was successful in every one of Jackson's identified activities. Patients were certainly re-activated by taking part in the weekly discussions. Just getting themselves to the meetings was a major achievement which needed a great deal of mental and physical energy. Few were able to get themselves there independently and had to organise other people to ensure that they were there on time. Once there, they had to summon up their previous powers of concentration and stay alert in order to be able to make their contributions to the discussions.

Power and solidarity

The forum also stimulated patients to be active between meetings. It provided innumerable and, sometimes, contentious subjects for conversations between patients. Some patients went round the ward getting other patients to sign letters to managers about various issues. Other people got information from relatives who had expertise on the areas which were under discussion.

We tape-recorded all the sessions so we had plenty of evidence that, during the meetings, patients were rapidly becoming re-socialised. By listening to successive tapes we could hear how different patients reacted differently to the meetings. Some patients were confident and articulate from the beginning. Others came and said nothing at all for perhaps two or three meetings but after a few weeks they too could be heard holding forth at great length. There was also a great deal of unexpected laughter during the meetings. Patients shared jokes and wry comments about the many difficulties and embarrassments of rehabilitation.

We noticed too that the meetings had a regular pattern. It usually took about ten minutes at the beginning of every meeting for some patients to focus on the topic. So we started to use that time for a review of what had gone on at the previous meeting. After that initial lead-in, conversation usually flowed easily for about half an hour before the patients began to tire and their concentration started to flag. When we realised that this was happening, we set a time limit of about 40—45 minutes for each meeting.

It was noticeable that the patients who came to the forum meetings became far more out-going. Previously, they had stayed within their own rooms but now they began to move around the ward, paying visits and talking to all and sundry *en route*. They struck up friendships with people from other rooms and got themselves to those rooms so that they could have a chat.

They also began to feel a solidarity with other patients in the forum and shared their common experiences of the struggles of rehabilitation. Towards the end of sessions, they often talked over the advances which they and other people had made or about the problems which had cropped up. They were able to reminisce with their contemporaries about a shared past and draw strength from knowing that they had all survived so many other traumatic times.

Our patients gave us a unique insight into what it is like to be an elderly patient. They told us about the ward as only patients can see it. They revealed many small but irritating, inadequate or frustrating things which we could never have known about otherwise. They grew more confident about saying such things and were less and less concerned about toeing the institutional line.

In all hospital settings?

As we have shown, we were prompted to try a patients' forum on Homeward for a number of different reasons. The general background of changing quality assurance activities had identified the importance of knowing how patients see their hospital experience. The research on the ward had reinforced this and it had also suggested some ways in which we could begin to do this on the ward.

A number of factors contributed to the success of the patients' forum on Homeward. These were:

- A ward philosophy which is patient-centred.
- A ward geography which encourages small intimate groups.
- Nursing colleagues who give active support.
- Managerial and administrative staff, including the Unit General Manager, who are not only willing to come to the meetings to discuss patients' problems but will act to resolve them.
- A good quality tape recorder with a boundary microphone which has allowed us to have a complete and accurate recording of every session. This meant that there was no need to take notes and we could concentrate on what was going on in the meetings. The tapes were also available for any patient who had missed a session. They could also act as an introduction to patients who were beginning to think about taking part.
- Someone who was prepared to give up time to prepare for the meetings, to chair the meetings, to clear up afterwards and to carry out all of the follow-up activities. This usually takes about three hours but can take up to five or more hours a week.

There were problem areas such as a level of paranoia on the part of some of the visiting managerial staff when they saw the tape recorder. Many of these people were also, understandably, rather nervous about their very first encounter with real live patients. Later, however, everyone agreed that it had been a novel but enjoyable experience.

The unalterable timetable of other disciplines also caused problems in that this decreed that the meetings had to be held from 4.30 until about 5.30 in the afternoon. At this time of day patients tended to be getting a little weary and they would have preferred morning meetings if that had been possible.

It also proved impossible for us to run the meetings while on duty. This could be a problem for many nurses, as it is unrealistic to expect that they will go on giving their own time indefinitely.

We hope we have shown that a patients' forum can not only act as a sound way of measuring quality but can also embrace many rehabilitation activities by returning power to patients. We would argue that, in varying forms, it could and should take place in all hospital settings. This obviously has financial implications for management. If patients' groups are seen as desirable then they will have to be properly funded and supported. Management must no longer be allowed to see nurses shouldering the burden of unresourced work as evidence of their vocation.

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This series looks at some of the ways nurses in Nursing Development Units (NDUs) have tried to make their nursing more beneficial for patients. The nurses assess to what extent their initiatives really do contribute to patient well-being and what has helped them bring about the changes. Each book will help nurses to introduce new ideas to their work and will suggest ways to evaluate changing practices.

The four NDUs which have contributed to this series have been supported by the King's Fund Centre and the Sainsbury Family Charitable Trusts since 1989 as part of a three-year project. A further 30 new projects have just received funding from the Department of Health and join the growing network of Nursing Development Units.

In this booklet, Marion Clarke, a primary nurse, and Barbara Sheppard, a researcher, describe how they set up a consultative group for patients and the important part the group plays in the rehabilitation process.

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