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JANE HUBERT and SHEILA HOLLINS

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Men with severe learning disabilities and challenging behaviour in long-stay hospital care

Qualitative study

JANE HUBERT and SHEILA HOLLINS

Background Community-based health and social care professionals have little knowledge of the past experiences of people with severe learning disabilities and challenging behaviour who are living in institutions.

Aims To gain a greater understanding of the experiences and needs of men who are living in a locked ward.

Method The study sample consisted of 20 men who were living in a locked ward of a long-stay institution. Qualitative (ethnographic) methods were used, involving participant observation (for around 250 hours) on the ward. All traceable families were interviewed. The analysis used grounded theory, and material was fed back into the resettlement process throughout.

Results The men's lives were emotionally, socially and physically deprived. Their individual, gender and social identities were not recognised, and their general health and mental healthcare needs were inadequately addressed.

Conclusions People who live in long-stay institutions, segregated from society, lose their individual and social identity, which complicates the presentation of mental health and behavioural problems, and raises important adult protection issues.

Declaration of interest None.

Human rights and adult protection issues have a poor record in the history of institutions worldwide. In the UK, people living in National Health Service (NHS) hospitals have been largely excluded from the remit of adult protection concerns (Royal College of Psychiatrists, 2003), although there is a statutory obligation on local authorities to implement adult protection procedures if a vulnerable adult is at risk in the community (Department of Health, 2001a). As a result of physical and social exclusion, people who have spent their lives in institutions have become invisible to the outside world. The remaining long-stay hospitals in England are due to close by April 2006 (Department of Health, 2001b). Some of the most vulnerable individuals are among the last to be resettled. Many of them have multiple or severe disabilities, mental health problems and challenging behaviour (Collins, 1992; Shepherd *et al*, 1996), and when they do move they are often resettled in newly built homes on NHS campuses.

METHOD

The research project (conducted from 1997 to 2000) was an ethnographic study of 20 men living in a large locked ward of a long-stay hospital, before (and for some time after) it was closed as part of the hospital closure programme. All of them had severe learning disabilities and challenging behaviour, and most of them had psychiatric diagnoses and autism. Almost all of the men had been institutionalised since childhood.

The project was set up to complement the quantitative clinical outcome measures, such as the Life Experiences Checklist (Ager, 1998), Adaptive Behavior Scale (Nihira *et al*, 1993) and the Health of the Nation Outcome Scales (Ashok *et al*, 2002) which were being administered by clinical psychologists. Those findings will

not be reported here (further details available from the author upon request).

The fieldwork consisted of an observer (J.H.) spending extended periods of time in the ward. Little was known about the men as individuals, and the aims of this study were to get to know them by sharing their lives, albeit to a limited degree, and to describe them as individuals, as far as possible documenting their lives from their own perspectives, and thereby attempting to retrieve and restore their individual identities. A further objective was to gain an understanding of the ethos and culture of the environment in which they lived, and the nature of the relationships within that environment.

This paper describes the first stage of the research, before the ward closed. The second stage of the project, which followed the men's lives after the closure of the ward, will be discussed in subsequent papers.

Consent issues

The hospital management and the local research ethics committee approved the study (consisting of observation on the ward, access to the men's case records, and family interviews) and its publication. The participants in the study were unable to give informed consent because of the severity of their learning disability. The study could not have been conducted with people with milder learning disabilities because the primary aim was to consider the vulnerability of members of such a severely disabled and excluded group who do not have capacity.

Since the men had been living in institutions since childhood, parental responsibility for them had, with very few exceptions, been handed over many years ago to the ward sister and hospital management. Although 12 families still maintained at least minimal contact with the hospital, few had direct contact with their family member. It was decided not to seek consent from these relatives. None of the men had effective advocates. However, interviews were conducted with 10 relatives, none of whom expressed concerns about the study. The parent representatives on the ward closure project board, to whom the researcher made regular representation, stated explicitly that they appreciated the researcher's understanding and perceptions of their sons, and approved publication of the material (e.g. 'It doesn't matter how

uncomfortable it makes people feel' and 'I want everyone to hear this').

In English law no one else can consent on behalf of an adult without capacity. Although it is now considered good practice to obtain the written consent of the next of kin (Royal College of Psychiatrists, 2001), in 1997 our decision not to do so was consistent both with research practice and with practice within the hospital.

Research process

The study employed ethnographic methods, which consisted mainly of long periods (over 250 hours in total) of participant observation (DeWalt & DeWalt, 2002) of the men at all times of the day and night. The aim was to get to know them, to establish what their relationships were, to determine how they communicated, to absorb the ethos of the ward, and to try to discover – from people who mostly cannot express themselves in speech – what their experiences, hopes and fears might be. The men's medical files, which dated back to their first admission as children, were examined in order to ascertain their recorded histories and the care professionals' perceptions of them over the years. Family members were interviewed wherever possible.

Field notes from the extensive periods spent observing on the ward were written up comprehensively. The material was then analysed using a grounded theory approach (Strauss & Corbin, 1998; Pope *et al*, 2000). The field notes were read and re-read throughout the research process, within the framework of the ideas and concepts that were developed before and during the fieldwork phase. Further concepts and thematic categories evolved during this familiarisation with the material, and relationships between categories were identified. Thus the analysis was firmly grounded in the data.

The project was also reflective, in that what was learned about the men was fed back into the transition process at all stages.

RESULTS

Loss of individual and social identity

As young children, all of the 20 men had lived at home with their families. When their behaviour became too difficult for their parents to manage, or for other family reasons, they were placed in children's

hospitals on a long-term basis (the majority from 4–8 years of age), and they were eventually moved to this locked ward of an adult institution.

Since their early years the men had been continually investigated and assessed by a wide range of professionals. However, the documentation of these quantitative assessments only described certain aspects of the men, such as their challenging behaviour or their intellectual and sensory impairments. Their medical records, which extended back to early childhood, did not describe them as individuals, so that little was known about the men as social beings with their own unique identities.

When the men were admitted to hospital as young children, they were often simply described as youngsters who were difficult to manage, but after 30 or 40 years of institutionalisation many of them now appeared to fulfil the popular stereotype of 'mad' people in institutions. They flung themselves at the floor and walls, banged their heads, roared and screeched, tore their clothes, spread faeces and injured themselves or each other.

Over the years the social invisibility of the men had contributed not only to their desocialisation but also to a degree of dehumanisation. One of the most powerful ways in which this occurred was by representing them as sexually dangerous. Of all the wards in the hospital, this was the least popular one in which to work.

When J.H. entered the ward for the first time, she had no idea what she would find. The following extracts are taken from her field notes and research diary.

When the self-locking door had slammed behind me and I stood in the ward, I was both appalled and terrified. It was a very chastening experience, exposing fears and prejudices which until then I would have furiously denied. The ward consisted of three huge bare rooms, like community halls rather than places in which to live. Some of the 20 men were sitting rocking in padded metal chairs that were bolted to the floor. Others ran round in circles, some shouting or whooping. One sat, naked, roaring loudly. One banged his head repeatedly against the wall. Another leapt and twisted and threw himself at the wall and the floor with great force. A blind man sat and rocked back and forth, screeching. In this tumult of unfamiliar sounds and movements I could see no member of staff. I was paralysed by fear, and that night I wrote in my field notes that 'I thought I was alone in the ward'.

The statement 'I thought I was alone in the ward' revealed my own acquiescence in the concept of the men's social invisibility, for of

course the room was full of people. I was excluding them from my own social world because of the way they looked and moved and sounded, because they were locked in this bare, deprived environment, and because I was terrified.

Gradually these emotions faded. The better I got to know the men in the long periods of the day and night that I spent with them, the more moved I was by their individuality, their desperate desire to communicate, and the extent of their individual physical and emotional suffering.

Because most of the men in the ward were unable to communicate by means of speech, they seemed to be perceived by others as essentially unknowable beyond the superficial sum of their impairments, basic needs and challenging behaviour. There was little acknowledgement of their more individual qualities, and few members of staff had built up meaningful reciprocal relationships with them as individuals. Some staff paid little attention to the men's hygiene and dress, and ignored ways of behaving which ensured that these men would be perceived as 'beyond the pale' in the outside world, perhaps thereby justifying the decision to physically exclude them.

Communication

The long periods of observation on the ward revealed that all of the men, even those without any speech, spent a considerable amount of their time trying to communicate their feelings and needs. There was often little recognition of or response to these attempts to communicate, and thus there was a rejection of the men as interactive, social beings. This was manifested not only in terms of daily non-communication, but also in the lack of acknowledgement of the possible reasons why the men behaved as they did.

One man frequently spread urine and faeces over himself and around the walls and floor. One day when he was doing this – very angry and red-faced, and making obscene gestures as I drew near – I asked him what was the matter. He stopped shouting and making gestures, and asked quietly – 'Where's Daddy?'

Another man spent much of the time throwing himself with great force, shoulder first, at the floor and at the wall. He was immensely strong, and roared loudly, appearing very threatening, and his face was usually bruised and bloody. Then suddenly his behaviour would change. He would stop throwing himself around and would sit down at my feet, take my hand to his head to stroke his hair, and say 'Mummy'.

Loss of family identity

It is significant that these two men, and others in the ward, felt themselves to be sons. However, as part of their loss of social and individual identity, they had gradually lost their familial and kin identity. Except for the few who had a parent or other relative closely involved in their life, they were not perceived as sons, or brothers, or nephews or uncles. Instead, their identities were constructions by others. Their personal histories had been lost over the years, to be replaced by other people's records made for other people's purposes.

When I told Joey that I had visited his family, and explained to him how much his father cared about him, he took a loose strand of my hair and pressed it against first one of his eyelids and then the other. He did this a few times, and then he touched his eyelids again and smiled. I wondered whether talking about his father had conjured up some memory from childhood – perhaps of hair touching his face as he was kissed goodnight.

For many of the men, the vital linking into the fabric of their families was lost, yet there was evidence that the men still felt and craved this link. Despite the extent to which the outside world had been shut off from them, and irrespective of whether their parents still visited them, they continued to be aware of themselves as a member of a family.

Leroy constantly pulled anyone he could towards the locked door of the dormitory area. If he was allowed in he hunted for his best clothes – a shirt and suit – and wanted to be changed into them. He had done this for years, because he used to wear them for his father's visits. In fact his father had retired to the Caribbean without him, many years earlier, but Leroy continued to try to get him back, maintained the link with him, and perhaps tried to will him to come and see him, by trying to dress up for him.

Loss of gender identity

One of the most significant consequences of the physical and social exclusion of these men was their loss of gender identity and roles. For example, one man, David, always tore up his clothes, and would quickly become naked. All attempts to clothe him were futile, and his nudity had become accepted on the ward. In 'normal' society we do not accept nudity in our everyday social environment. The ward may not have appeared to be a very 'normal' environment, but there were 19 other residents and around 40 male and female staff members working on shifts, as well as domestic staff, maintenance men, psychologists, psychiatrists, and

day-centre staff, who were part of this 'social' environment.

Because David was always naked, he was perceived neither as a social adult nor, it could be argued, as an adult man. To all intents and purposes his sexuality was denied and, at a significant level he was de-sexed and de-gendered. This attitude towards David and his nakedness was perhaps surprising, since there was constant vigilance and concern about possible sexual abuse on the ward. Any touching or feeling, or signs of sexual arousal were discouraged, yet among the men there was an individual who was always naked. It seemed to be assumed that because the staff no longer perceived David as a man, that the men he lived with did not do so either.

After visiting his parents, I talked to David about them, and about the house where he had lived as a child. I said that I expected that he missed them. He stopped roaring and looked at me as I spoke, and then suddenly said, out of the blue, 'Bless you'. I had never heard him say anything spontaneously before that was not a one-word demand, and I was completely taken by surprise. No one around us disputed what he had just said. But those two appropriate words, dredged up from somewhere, indicated that he had understood, and emphasised the fact (usually ignored) that he had feelings as well as needs, and that he had memories, too.

David's story was true, to a greater or lesser extent, of all the men in the ward. Their stories show how a group of young children, instead of being helped to develop into men whose adulthood and gender were acknowledged and respected had, over the years, gradually been allowed to turn to ways of behaving that led them further and further into the category of 'other'. There seemed to be little acknowledgement of their individual desires, needs, hopes and fears as adult men, or of the possibility that they might have normal sexual feelings for each other. They were largely perceived as dangerous, or at the very least unpredictable, and in many cases this had been used as the justification for controlling them within a locked environment. Yet at the same time they were denied normal gender roles, and to some extent their sexuality was mocked.

The effects of sensory disabilities

The individual identities of the men were further compromised by frequent lack of attention to the implications of their sensory disabilities. For example, Sam was blind. He sat doing nothing all day,

often sticking his thumb deep into his eye socket. He was not given things to hold and feel, to listen to or to smell, although it was clear that his other senses were very acute. If Sam had not been living in a closed institution, he would have been given the care and services appropriate to someone who was blind. In fact, although he had lost his sight around 20 years previously, he had not yet been registered as a blind person.

Watching Sam, it was quite obvious that he was listening all the time – he responded differently to different movements, voices and footsteps. Touch was extremely important to him, but he encountered very little, because he was inclined to grab hold of people very tightly and scream, so most people avoided getting too close to him. He had almost no contact with other human beings, instead spending long periods of time sitting alone, totally isolated in a roomful of people.

It was clear that he was well aware of his blindness, which had been caused by self-injury. He only had a few words, but at times he would say 'blind, blind, blind', over and over again, becoming increasingly distressed. Sometimes he sat with tears running down his face. Usually no one took any notice. Other men cried, too.

There also appeared to have been lack of attention to some aspects of the men's physical health. The volumes of past medical notes showed that six of the men had cataracts, which were presumably becoming increasingly serious, but they had not been treated, although for one man a decision had been made that surgery would be too difficult. Other men were recorded as having poor eyesight or hearing impairments. There appeared to be no acknowledgement that such impairments might present continual problems for the men, or that these circumstances might provoke them to react in ways that would then be labelled as 'challenging behaviour'.

Emotional needs

Similarly, the emotional well-being of the men went largely unnoticed from day to day, or was responded to with a diagnosis that merited treatment with psychotropic medication. Many of the men appeared depressed and anxious, some even seemed to be scared, and there was a general disregard of individuals' anxieties.

Jed appeared to be obsessed by the possible death of his parents. He repeated his fears over and over again to anyone who would listen. But discussions with him went round in circles, and he became agitated and distressed, so most of the staff tended to ignore and avoid him as much as possible. However, Jed's anxieties were always apparent, and his lack of intellectual

understanding of death and separation, and his unpopularity, were allowed to mask his emotional confusion and fears.

This neglect of the men's conspicuous physical and psychological suffering had, over many years, become an integral part of the ethos of the ward, and to the succession of changing staff over the years this was regarded as simply part and parcel of life on this locked ward. Yet it has long been known that many of the problems experienced by people who have lived in institutions are the result of such factors as early separation from parents, living in emotionally and physically deprived environments, and emotional, physical and sexual abuse. These legacies of the past could have been addressed for many of the men in this study. It is now widely accepted that 'individual and group psychotherapies may be surprisingly effective contributions to working with those who prove highly challenging to the services and to society as a whole' (Royal College of Psychiatrists, 2004: p. 14). However, these men had been offered neither psychotherapy nor counselling, and their fears remained unacknowledged and untreated.

DISCUSSION

Vulnerable adults in closed institutions

Cultural and attitudinal barriers have prevented people with severe learning disabilities, especially those segregated from society, from being perceived as fully human. Many of these individuals have lived unbearably deprived lives, both physically and emotionally, since childhood. The poor conditions in which they have lived and the abuses that have been perpetrated towards them have been condoned, or simply gone unrecognised, for many years. It is often assumed that these issues have been effectively addressed, yet this research suggests that important issues may still remain unresolved.

Despite increasing acknowledgement of the unacceptable conditions in which they have lived, the violation of the individual human and civil rights of men and women such as these has continued (Department of Health, 2000). It is unclear whether this is the result of 'deliberate intent, negligence or ignorance' (Department of Health, 2000: p. 10), but ignorance must surely be a less appropriate excuse than it has been in the past, especially in the context of the United Nations Global Programme on Disability,

CLINICAL IMPLICATIONS

- Clinical records are an inadequate basis for care planning if detailed attention is not given to individual experiences, needs and relationships.
- The iatrogenic damage and deprivation that are experienced in National Health Service long-stay institutions will need to be actively addressed – for example, with individualised attention, and even the establishing of therapeutic relationships – if the lives of these men are to improve.
- Staff in new homes will need to dedicate time to individual residents, to talk and listen to them, and to provide sensory stimulation and activities for them.

LIMITATIONS

- This is only the first stage of a study that is following the lives of residents of a long-stay ward and their resettlement in new 'community' homes.
- No standardised measures of behaviour have been included.
- The study does not consider the perspectives of ward staff.

JANE HUBERT, MA, Dip Anth (Oxon), SHEILA HOLLINS, MB BS, FRCPsych, FRCPCH, Division of Mental Health, St George's, University of London, UK

Correspondence: Jane Hubert, Division of Mental Health, St George's, University of London, Cranmer Terrace, London SW17 0RE, UK. Tel: +44 (0)20 8725 5504; fax: +44 (0)20 8672 1070; e-mail: jhubert@sgul.ac.uk

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which is currently drawing up an international convention on the protection and promotion of the rights and dignity of people with disabilities (United Nations Department of Economic and Social Affairs, Division for Social Policy and Development, 2004, 2005).

Hospital closure

The large residential houses that are currently being built on some NHS campuses, to accommodate many of the individuals who used to live in the hospitals, already house around 3000 people (Emerson, 2003). Recent evidence suggests that an institutional culture frequently continues in such homes, and also that they are often of significantly poorer quality than community-based homes (Emerson *et al.*, 2000; Owen, 2004).

Given that many years of Government policy and adult protection guidelines failed to have a significant impact on the old order within NHS long-stay hospitals, it is vital that, with the closure of these

hospitals, this situation is not permitted to continue either in the new NHS campus homes or in residential homes in the community.

Moving on

The men described in this research project are among the most vulnerable in our society, and are thus at the greatest risk of abuse. Many other men and women similar to the individuals described here will also have moved into NHS campus homes or homes in the community as a result of hospital closure programmes. Their new carers and health teams will generally have no idea of the nature of their previous life. Identifying the failings of past models of care (as this paper does) and establishing the enduring effects on individuals will be vital if better futures are to be created for the vulnerable people in our care.

Taking responsibility

Both the hospital management and the commissioners have agreed with us that

the public interest would be best served by the publishing of our findings, even though public reaction is unpredictable. Will readers recognise a wider societal responsibility for the inadequate resources available to care for such needy and vulnerable people who lack a voice to speak for themselves?

It has not been our intention to criticise the care staff working in the institution. In general, they should not be blamed for institutional failings. However, it is crucial that further studies are undertaken to try to understand the feelings and perceptions of staff who, until now, have worked in the context of long-established institutions. It may then be possible to find effective ways to provide more appropriate training and support, so that institutional practices are not carried forward into the new homes and futures of these very vulnerable men and women. New community homes should be accountable to the public, and must support lay involvement and advocacy so that the people in their care remain visible to the outside world.

Future lives

The ward described in this paper was closed 5 years ago, and the 20 residents now have the chance of a different life. However, a huge change in attitudes both within the community and among care staff, managers and even families will be needed to restore the social and individual identities of these men.

The men described here were once children. If it is hard to restore their social

and individual identities, and to radically improve their mental and emotional health at this stage in their lives, the least we can do is to ensure that the same thing does not happen to children with similar disabilities today. We must ensure that they are given the support and encouragement necessary to enable them to retain their individual, social and gender identities, and to develop as socially included and emotionally healthy men and women.

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