

# Seeing the person behind the patient: enhancing the care of older people using a biographical approach

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## Summary

- Recent policy statements have stressed the need for fundamental changes to the NHS, especially to the hospital care of older people. Person-centred care underpins such changes. If practitioners are to deliver person-centred care, then they need to learn more about the patient as an individual. One way that this might be achieved is through biographical approaches.
- This paper describes the findings of a developmental study undertaken over a 6-month period to investigate the introduction of a biographical approach to care on a unit in a NHS hospital. It concentrates on the views of the practitioners who used the approach.
- The study aimed to explore whether a biographical approach – in the form of storytelling – might be used to encourage person-centred practice.
- Using a practice development approach, the study explored the views of older people, their family carers and practitioners regarding their participation in life story work.
- Initial data were collected by focus groups with staff from a nursing home who regularly used life stories as a basis for care planning. Further data were collected through focus groups, semistructured interviews and observation – undertaken before and after the introduction of life story work – with older people, family carers and practitioners.

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- Findings revealed that life stories helped practitioners to see patients as people, to understand individuals more fully and to form closer relationships with their families. Support workers also said how much they enjoyed using the approach to inform their care.
- Further longitudinal research is required to investigate biographical approaches more fully and to work more closely with practitioners to explore how biographical approaches can be undertaken as part of standard practice and be integrated into the culture and management of care.

*Keywords:* biography, gerontological nursing, life stories, older people, person-centred care.

## Introduction

Although much has been written about person-centred care of older people, commentators have recently questioned whether it actually occurs in everyday practice (Packer, 2000). Reinforcing such contentions, the Standing Nursing and Midwifery Advisory Committee report, *Caring for Older People: a Nursing Priority* [Department of Health (DoH), 2001a] noted major deficits in the standards of nursing care given to older patients in acute hospitals, which resulted in some of their most fundamental needs remaining unmet. Similarly, the Age Concern (1999) report *Turning Your Back On Us* suggested that the quality of care received by older people in hospital is highly variable, and noted that while some wards are excellent, others are deficient in important respects. The main problems identified by older people and their relatives in the above reports included the persistence of negative attitudes towards older people and practitioners failing fully to involve older people in decisions about their care or treatment. This may in part be because of practitioners' limited awareness of the needs of older people (Nolan *et al.*, 2002).

Several recent policy statements, including *The NHS Plan* (DoH, 2000), *The National Service Framework for Older People* (NSF) (DoH, 2001b) and *The Information Strategy for Older People in England* (DoH, 2002), have stressed the need for fundamental changes to the NHS, especially to the hospital care of older people. 'Person-centred care', defined as 'treating older people as individuals and enabling them to make choices about their care' (DoH, 2001b, p. 12) underpins such changes and lies at the heart of the NSF.

Person-centred care necessitates that practitioners learn more about the older person as an individual, together with a better understanding of the patient's personal meanings, experiences and attitudes (Williams & Grant, 1998). It also involves uncovering what makes a particular

individual unique, and what connects them to others (Kitwood, 1997).

In order to deliver person-centred care, practitioners must acquire knowledge about the person which allows them to 'provide care and services that are compatible with the individual's values and which are, as such, highly valued' (Ford & McCormack, 2000, p. 42). This goes beyond caring for people's physical or mental needs, to discover more about the everyday experiences of the older person, their aspirations and concerns, and the relationships that are important to them. In other words, valuing the personhood of the older person requires practitioners to see behind the 'mask' of ageing (Featherstone & Hepworth, 1991), illness or disability. One way that this might be achieved is through the use of biographical approaches.

## Biographical approaches: rationale, benefits and challenges

Biographical approaches provide older people with opportunities, if they so desire, to talk about their life experiences – family, friends, work history, hobbies – often using photographs and personal belongings as triggers to discussion (Elipoulos, 1997). Exploring older people's past and present lives with them, particularly the circumstances which have shaped their experiences, potentially provides greater insights into their needs and aspirations (Johnson, 1976) and may help to challenge ageist stereotypes about later life (Gibson, 1998; Clarke, 2000). Listening to a person's life story is a powerful way of showing that they are valued as an individual (Bartol, 1989) and may also have a cathartic value (Bytheway, 1996; Barnett, 2000; McKee *et al.*, 2002). Their stories may subsequently be recorded formally in a life storybook – either by the patients themselves, their family carers or members of the ward team – thereby assisting practitioners to focus their efforts on the individual's needs in a

manner consistent with their life perspectives (Adams *et al.*, 1988; Gibson, 1994; Gearing & Coleman, 1996).

A biographical approach thus enables practitioners to gain a better understanding of the older person by providing knowledge which may directly influence decisions made about appropriate care. This is supported by Heliker (1999), whose study in a long-term care setting in the US concluded that an approach which encouraged storytelling and listening, resulted in care that accorded with the residents' personal meanings and values and enhanced staff-patient relationship.

Pietrukowicz & Johnson (1991) investigated whether the use of life stories had an effect on the attitudes of nurses' aides in two nursing homes in the US, taking into account individual differences, such as previous work experience and knowledge about ageing. Using an attitude scale, they discovered that staff using life stories described residents as more autonomous and personally acceptable than those who did not (Pietrukowicz & Johnson, 1991). They concluded that life story work is a low-cost intervention which could be incorporated into everyday care activities thereby improving the quality of life of residents, and the self-esteem of health workers (Pietrukowicz & Johnson, 1991). These are not isolated findings. For example, Mills (1997, p. 695) found that undertaking narrative work with people with dementia, reinforced practitioners' attitudes of 'respect, understanding and acceptance'. Similarly, Murphy's (2000) study suggested that the use of life storybooks might have a positive effect on the attitudes of staff towards their clients. Also, Hansebo & Kihlgren (2000), based on a study in three nursing home wards in Sweden, reported that learning more about the patient's lives helped the nursing staff to see the patient as a 'unique' person.

A biographical approach is valued by older people themselves. The older participants in Nolan *et al.*'s (2001a) study indicated that they wanted to have their personal biographies recognized and valued as basis for individualized care. Similarly, McKee *et al.*'s (2002, p.13) evaluation of the impact of reminiscence on the quality of life of older people, concluded that most older people in long-term care enjoyed talking about their lives and that being listened to accorded 'personhood, identity and significance' to the older person.

Relatives also appreciate staff taking an interest in the older person's life and focusing on more than their physical needs (Nagai-Jacobson & Burkhardt, 1996). Conversely, Hertzberg & Ekman (1996), in a study exploring the relationships between staff and relatives of older people who were living in nursing homes, reported

that inadequate knowledge concerning residents' biographies created barriers between relatives and staff.

In a wider context, biographical approaches have been used in order to elicit the views, experiences and preferences of older users regarding service provision and delivery as an aid to assessment and care planning (Johnson *et al.*, 1980; Cornwell & Gearing, 1989; Reed & Payton, 1996; Roe *et al.*, 2001). However, although there have been many advocates of biographical approaches within the nursing literature (Redfern, 1986; Best, 1998; Wells, 1998; Clarke, 2001) and biography is used informally in some settings (Penn, 1994; Schofield, 1994; Broadbent, 1999), particularly in dementia care (Murphy, 1994; Jarvis, 1998; Killick, 2000), few studies have evaluated the impact of biographical approaches on care delivery in a general hospital setting.

There are several possible reasons for this, both pragmatic and ethical. These include, lack of knowledge amongst nurses about using a biographical approach, the amount of time needed to implement it (Adams *et al.*, 1988), problems gaining consent from some older people and the difficulty of co-operation with carers and other practitioners (Roberts, 2002). Moreover, the use of such approaches requires emotional investment, both on the part of the narrator and the listener: to ensure older people feel comfortable talking about their lives, a relationship of confidence and trust needs to be established. This is a two-way process, involving the sharing of experiences and is something that not every practitioner will feel comfortable about (Clarke, 2001). Coleman (1999) also cautions that there is a need for greater awareness of the potentially negative aspects of storytelling on the older person (cf. Hunt *et al.*, 1997). As Coleman (1986), Slater (1995) and McKee *et al.* (2002) amongst others have pointed out, not all older people want to talk about their lives. Although encouraging older people to reflect on the past has been seen as 'a panacea for many things, and a source of happiness and satisfaction' this is not the case for all people (Bornat, 1998, p. 41).

The approach can also be challenging to the listener, especially in knowing how to react when people talk about aspects of their lives that are distressing. This involves making decisions regarding whether to ask certain questions, encourage someone to talk about a particular subject or discourage them from talking about something that is clearly upsetting them (Clarke, 2001). Those promoting a biographical approach contend that if the older person is prepared to talk about a difficult or painful issue, at the very least, they should be listened to (Bornat, 1998; Parr, 1998). Nevertheless, it is clearly important to consider the

purpose of a biographical approach, and its appropriate use, before widespread introduction of such a model. Exploring the potential for its use within a hospital setting was the purpose of the present study.

## The study

### RATIONALE

The study evolved following informal conversations with nurses on a transitional care unit at a NHS hospital (for older people relocating from hospital to continuing care settings in the community), which revealed that, although there was space on the nursing assessment forms for 'biography', staff were unclear as to how or why this should be utilized. Concurrently, staff from a number of the local care homes which received patients from the unit had expressed a desire for more information; not simply in terms of physical needs, but also about their past lives and their everyday wishes, concerns and preferences. As one care worker poignantly said:

You only get to find out about residents' lives  
when you go to their funerals.

The inspiration for the study therefore came from practitioners themselves and their desire to know more about the people for whom they were caring.

### PURPOSE

The main aims were to work alongside older people, their family carers and practitioners in order to explore whether biographical approaches might be used to:

- elicit and understand more about the present needs and concerns of older people;
- encourage person-centred care.

## Methodology

This practice development initiative used a 'collaborative' approach whereby the researchers investigate a specific intervention in the clinical setting (Holter & Schwartz-Barcott, 1993). McCormack *et al.* (1999, p. 256) state that practice development aims to improve 'increased effectiveness in patient-centred care, through the enabling of nurses and health care teams to transform the culture and context of care'.

The focus of the study was on the experiences and views of older people (and, wherever possible, their families) and practitioners working in the field. Practitioners were central to the research process and were involved throughout the planning, delivery and dissemination of the study.

Staff included both Registered Nurses and support/care workers who volunteered to participate in the study. From the outset, it was agreed that support workers would work with the older person and their families in undertaking biographical work, as they spent the most direct time with patients' care-related activities.

### PARTICIPANTS

Prior to the study, approval was granted by the local research ethics committee, all participants were fully informed about the study (verbal and written information was provided) and confidentiality was maintained throughout. Patients and relatives were approached as potential participants in the study by staff on the unit as they could assess the most suitable time to raise the matter, allowing patients (and relatives) to settle down and become familiar with the new environment. Staff excluded patients who were more likely to stay on the unit for a short period of time. Potential participants were informed about the project and an information sheet was provided. Staff returned a few days later to answer patients' and relatives' queries and asked them if they would like to participate in the study. As staff, patients and relatives volunteered to take part in the study, the research group could be said to be one of convenience (Roe *et al.*, 2001).

Bornat *et al.* (1998) point out that relatively little attention has been given to the involvement, perspective and education of staff in the research and evaluation of biographical approaches. With this in mind, care workers from a local nursing home who were already undertaking life story work with residents, collaborated in several informal training sessions about biography for staff on the ward who were interested in participating in the project. The sessions were undertaken in paid time and had been approved by the manager of the nursing home who was highly supportive of the project. The care workers illustrated their experiences of using the approach with practical examples, thereby helping to allay anxieties such as constraints of time and listening to (and acting upon) painful or upsetting memories. Where appropriate, existing research was highlighted to support such views further. Feedback regarding these sessions was positive; involving support workers in the teaching sessions was seen as preferable to members of the research team providing 'textbook' explanations about the use of biography. The care assistants had used the approach in practice and were seen as more 'credible'. A literature file regarding the use of biography was placed on the unit and was made available to staff.

#### DATA COLLECTION

Focus groups were undertaken with hospital staff – who had never used a biographical approach – and nursing home staff – who already undertook life story work – to ascertain staff's perceptions of using biographies. In order to gather information regarding storytelling and using biographical approaches, focus groups were undertaken with staff and semistructured interviews were completed with patients and relatives before the project commenced and after it had ended. A checklist of topics and/or open questions were used to gather data (Nilsson *et al.*, 2001).

Questions asked included: participants' understandings of biographical work, whether they already used the approach in their everyday work, and the advantages and disadvantages of the approach. Older people and their families were asked how they felt about telling their stories and whether they considered that the approach had an impact on their care. Additional stages in the research process included observation of nurse–patient interactions (Adams *et al.*, 1988).

As our purpose was for practitioners to explore for themselves the ways in which biographical work could be undertaken with patients, no formal guidelines (for example, see Birren & Cochran, 2001 and Garland & Garland, 2001) were given to staff regarding undertaking life stories, but colourful folders were provided in which patient's stories, photographs and/or other memorabilia could be placed.

#### DATA ANALYSIS

Focus groups/interviews were transcribed in full and two members of the research team thematically analysed the transcripts for similarities and differences in the data using the constant comparative technique (Glaser & Strauss, 1967; Byrne, 2001). Discussion occurred until consensus was reached.

#### Implementation in the field

Despite initial enthusiasm, the project was slow to start and was hampered by a number of practical constraints, including an increasingly heavy workload, exacerbated by staff sickness. The overall scene was analogous to the picture depicted by Adams *et al.* (1998, p. 30) who describe how the nurses were always 'too busy' to undertake biography work with patients. To move things forward, a staff nurse suggested that it would help if a support worker could devote time to the project, rather

than staff trying to 'battle against the odds' in order to undertake the work alongside their usual activities. Following discussion with ward staff, it was decided to use the remaining monies from the project fund to pay a care worker to give dedicated time to the project. This proved to be the turning point, and in the next few weeks the support worker involved reported how much she was enjoying the work; this led to other support workers asking to be involved.

By the end of the fourth month of the project, eight patients and their families had been recruited and six support workers were actively involved in helping patients to compile their life stories using the folders provided. The contents of each folder differed between individuals, but commonly consisted of written recollections recorded with the aid of the key worker or family members, pieces written by adult children or grandchildren about their relative, and photographs. From the start of the project, it had been agreed that the older person (or in the case of people with dementia, their main family carer) would have ownership of their life storybook and their permission had to be sought to gain access to the material.

#### Findings

Our findings revealed that using a biographical approach encouraged practitioners to:

- see the person behind the patient;
- build and strengthen relationships with patients and their relatives.

However, practitioners also acknowledged that there were limitations and recognized that such approaches were 'not suitable for everybody'.

#### SEEING THE PERSON BEHIND THE PATIENT

Staff already using the approach in the nursing home said that collecting biographical material about people's lives helped them to gain a more dynamic and complete picture of those for whom they were caring, and that knowledge of people's life stories enabled them to find out more about residents' needs and behaviour. Care staff from the nursing home said:

Sometimes I think, 'Oh dear, a grumpy person', but once you get talking to them, you find out why they are grumpy, or why they are frightened.

Also, hearing about a resident's life story helped staff to see the person in the context of their whole life, rather than simply in terms of their medical condition and physical needs:

They become people that have actually lived rather than looking at them in terms of their medical needs.

This possibility had been recognized by support workers from the hospital unit prior to the implementation of the approach:

It gives them their own identity. Sometimes they can be classed as 'the elderly', you know, 'the patients', whereas they are individuals.

They also considered that they currently tried to discover more about people's lives, but in a rather haphazard way. One support worker said that the more structured approach helped her to see the older person in a new way:

Your attitude changes. There was a patient who used to be a buffer lady and when she used foul language if you didn't know her you would think, 'Well she's not very nice'. But once you got to know that's her normal life and when she's f – ing and blinding that's when she's at her best, you don't take it so personally.

Similarly, when asked initially about how they would feel telling their stories, patients and relatives seemed to like the idea. One participant, who said that he had been treated like a number for most of his working life commented:

If the staff knew more, they would see you as a person not a number.

This positive perception was borne out once patients and relatives began to contribute life story material to their life storybooks. Photographs, in particular, seemed to bring the person's biography alive for all concerned and provoked strong memories, which may otherwise have been difficult to appreciate. The daughter of a woman with Alzheimer's disease which had affected her short-term memory said:

I really think this will help Mum, especially if the life story went with her to the nursing home. She enjoys talking to people and looking at photographs of days gone by. I also enjoy it, as there are people on the photos that I do not know and it is nice for Mum to be able to tell me about them. I want to ask her who they are whilst she can still remember.

Staff, too, were enthusiastic about collecting biographical information in a more formal way than they were used to:

It helps you to understand how and why someone is like they are... to understand why people are like they are in mood and temper when you do get to know them better.

The following comment from a support work was typical:

You get a better insight into the patient that you're looking after. It's not just a medical condition: you get an insight into what they used to do years ago.

Several support workers commented that photographs in particular provided a talking point between themselves, the patient and their relatives. Photographs became an enjoyable trigger for discussion for all concerned:

It's like when they brought photos of when they were younger, different cars and bikes they had, it was nice seeing them as younger people. I right enjoyed it me.

Staff also commented that the approach helped to develop a common bond between themselves and the older person, as they shared their experiences and stories:

You're not seeing them any more as a patient – you're seeing the person behind that. And, by them telling you more, it connects with things in your life as well.

#### BUILDING RELATIONSHIPS BETWEEN STAFF AND RELATIVES

Collaborating together in biographical work not only helped to strengthen the relationship between the care worker and the older person, but also between staff and the older person's relatives. A care worker from the nursing home said how helpful a resident's life story had been to his family following his death:

I once did a chap's life story and when he died it was part of his funeral service and his wife – who's still here – she's got it at the side of her bed so she can read it when she wants.

Support workers from the hospital also reported that they felt their relationships with the family had changed as a result of becoming involved in collecting biographical information. One support worker said:

I think in my particular case, talking to my patient, I got to know his relatives a lot, lot more. You know listening to their side of the story, what he couldn't remember himself, what he used to get up to as a lad, what he liked doing and things like that. You got to know him, but you also got to know his relatives. Whereas before you probably wouldn't have got to talk to the relatives.

He went on:

When I went to A's funeral, I took his life storybook to show his daughter and I was quite surprised how many of his relatives wanted a copy straight away because they said it was something that would be nice to look back on, to remember him by. I mean, I'd never known A's relatives before and now I go

drinking with them (laughs). I still keep in contact with them, that's the best bit about it.

Participants' relatives confirmed that they felt similarly, and that they appreciated the time the support workers were spending with them. One patient's daughter, who had written a story for her mother's life storybook about her own childhood said that she had enjoyed sharing memories with her mother, 'I'm so pleased that she still remembers most of the family – we all love her dearly'. The patient's support worker elaborated:

It's a more friendly atmosphere when you can sit down with someone and talk to them, patient and their families. Like I asked C's family, to bring in some photos and we had a laugh and enjoyed it.

#### 'NOT SUITABLE FOR EVERYBODY'

Hospital staff recognized a number of limitations to the widespread use of life stories in everyday practice. Several workers commented that such an approach was 'not suitable for everyone' and, in particular, those individuals who were more reserved, 'If you are a private person, you wouldn't want someone to know all about you'. Another support worker agreed:

It depends on what sort of people they are how much they want you to know really.

Two support workers recalled patients who they had asked to participate in the project but had refused for personal reasons as a result of painful past experiences. They also acknowledged the importance of privacy and confidentiality in relation to the sharing of personal information:

One lady, I was talking to her for about an hour and she suddenly changed her mind, she said she didn't want to do it. She got too upset and said she didn't want to remember what had gone off. and I said we didn't have to put that in her book, but she didn't want people to know about it because of the stigma. They don't mind sharing it with you, but don't want it sharing publicly.

Most support workers considered that it was important to 'get to know the patient' before working more directly with their biography:

You have to make sure that you have known that person for a few weeks before you ask them because they have got to trust you and vice versa.

They've got to get to know you and get to like you and who you are.

The issue of trust was particularly pertinent as the patients on this unit were more likely to undergo a number of assessments in relation to planning for long-term care:

It's like when they are assessed to go into a nursing home, asking all these questions, they are dubious about answering them.

Despite these difficulties, all support workers said that they wanted to continue working with people and their life stories once the project was finished. They acknowledged that having a whole day to spend with a particular patient was highly enjoyable for all concerned:

They enjoyed it. It was a change for them and it was a change for us and we found out loads about each other. We had a right laugh.

One patient, after she had been taken to a café within the hospital to tell her story, said that it was, 'the best time I've had had since 1948!'

#### Discussion

Our findings support much of the existing literature, suggesting that the use of biographical approaches may have a positive effect on the attitudes of staff towards the older people for whom they care, while also enhancing relationships between staff and family carers. In our study, support workers appeared to have taken great pride in their contribution to the biographies and became very involved with the older person and their family when gathering information for the patient's life storybook. Their interactions whilst they were working together, helped patients, their family members and practitioners to develop therapeutic relationships with one another.

Such relationships formed the basis for the caring context on the unit, resulting in an increased awareness amongst practitioners of the positive aspects of working with older people, which simultaneously enabled family members to feel more satisfied about the care their relative received. This is important, as often the views and experiences of the older person, and indeed, their family carers, may be neglected by nurses and others. It is essential, that relatives feel that staff are interested in the details of their loved-one's lives, and our findings indicate that storytelling may be beneficial in promoting positive, holistic relationships between all those involved in the care of the older person.

Ford & McCormack (1999) suggest that one of the core attributes of the gerontological nursing specialist is 'knowing the patient', and using in-depth knowledge of individual and family biographies to work in partnership with the older person and their family. As advocated by Heliker (1999), biographical approaches are one way of helping to create a 'caring community' – an important factor for many older people and their family carers (Davies & Nolan, 2002), as reflected in more recent

arguments promoting the notion of relationship-centred care (Nolan *et al.*, 2002; following Tresolini & The Pew-Fetzer Task Force, 1994).

There are, however, important pragmatic implications to take into consideration, as it was only as a result of having dedicated time to work on the project, that the life story work was implemented. Building a trusting relationship between the narrator and listener, undoubtedly takes time and, as Booth & Booth (1994, p. 417) point out, it is not possible to achieve using 'a hit and run approach'. It will therefore be important to follow the initiative over time, in order to see if the unit continues to use biographies. As the project ended, the ward manager was looking into the possibility of allowing support workers to dedicate time to undertake life story work; she acknowledged how much they had enjoyed participating in the project and that the approach had enhanced the delivery of care.

Further, funded longitudinal action research is required to investigate biographical approaches more fully, and to work more closely with practitioners to explore how biographical approaches can be undertaken as part of standard practice and become part of the culture and management of care in the clinical area. This will require exploring ways in which biographical approaches can be incorporated into the ongoing care needs of the individual, perhaps by integrating the approach into everyday care activities, for example, whilst assisting the patient with activities of daily living as opposed to a more formal activity. This will necessitate further education and skills training as well as organizational commitment. The ways in which biographical approaches can be sustained and developed over time in a variety of care settings is an important area for further research and development.

In addition, staff who participated in the study, frequently told us how much they had enjoyed the work; therefore, subsequent studies might explore further the effects of participation in life story work on the job satisfaction of care workers. For, as McKee *et al.* (2002) state, helping staff to promote person-centred care includes recognition of the importance of their skills – of listening, talking and sharing.

## Conclusion

In conclusion, we argue that our small-scale study has demonstrated that the use of a biographical approach may enhance the personhood of the older person and thus promote person-centred care. In addition, it can strengthen relationships between practitioner and older people and between practitioners and patients' families.

Moreover, staff said that they enjoyed listening to and working with older people and their relatives in undertaking life story work and acknowledged that it helped them to respect and value the patient as a person. This is crucial for, as Nolan *et al.* (2001b, p. 16) contend:

We believe that quality of care is unlikely to be achieved and sustained unless staff enjoy and value their work. Ageist attitudes and the devaluing of work with older people are still all too apparent.

If the aspirations of policy initiatives such as the NSF for Older People (DoH, 2001b) are to be realized, it is therefore essential that the value of such person-centred approaches as biography are recognized and accorded the status they deserve.

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