

We listen but do we hear?

The importance of patient stories

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'I did not ask for the stories, but I was given them to tell, to retell and to pass along'
Anon

Patient stories have never formed an integral part of nursing research in their own right (although the patient perspective is now a key focus for the reorganization of the health service). Once collected, stories are usually divided up into 'soundbites', ready for analysis as qualitative data. On rare occasions they may be presented more completely as case studies or accounts, but only extremely rarely as evidence in their own right. Using examples, this article explores the relevance of patient stories and discusses what they can add to nursing research and practice. It also highlights the importance of nurses actively listening to patients in order to improve care.

The examples are drawn from among current or past members of the Leg Club[®], a social model of care delivery for people with lower limb-related problems and leg ulcers. Yet while the stories all relate to treatment in Leg Clubs, they have lessons for all nurses.

In many ways, the patient stories that will be presented in this article are little different from the stories read to children: they also begin with 'once upon a time', are overwhelmingly life affirming in nature and conclude with good prevailing, in the shape of an improved quality of life.

ABSTRACT

Patients' perspectives on their illness and care are increasingly recognized as the focus for the organization of health care, yet patient stories are rarely examined on their own. Mostly, they are dissected for data, and so the impact is lost.

This article presents a number of story tellers, all patients with leg wounds attending a social clinic. Reading their stories helps us understand the experience of being a patient and living with difficult and painful leg wounds. They also show how nurses can play a critical role in optimizing the power of the story in the patient's journey towards physical and psychological healing.

KEY WORDS

Patient stories ♦ Leg ulcer ♦ Holistic care ♦ Leg Club
♦ Empowerment ♦ Quality of life

The key difference is that the stories told in this article are the true lived experiences of wound-care patients.

The importance of stories

Much of human life is recorded and recounted through stories. The story-telling of life, of illness and of dying, is a dynamic process, which no dry nursing textbook can capture.

According to the principles of hermeneutics, in which things acquire meaning by being put into language, the very telling of a story gives it a deeper and clearer meaning for the teller, especially if the telling is assisted by skilled listening. Writing is even more powerful than talking, because the written word stays on the page in the same form, and does not dissipate over time. Written stories create pathways to memories, feelings, and thoughts which we do not always know we have, enabling us to discover, explore, clarify and make connections to our present.

In mental health practice, the diagnostic story continues to be frequently used, despite the introduction of other assessment tools. In telling their story, a patient in mental and/or physical distress provides the health professional with a wealth of evidence which can be used to help the patient on a journey of recovery. Their story is the heart of their human experience and as such should be the primary focus, embracing as it does everything of any significance for that person. Their experience of care and treatment represents a critical chapter in their unique patient story.

Fairbairn and Carson (2002) describe how, to date, story-telling and narrative have not been considered 'academic', and are therefore more often viewed by nurse researchers as a way of gathering data to be manipulated in various ways, cut up and placed into categories, themes and sub-themes for analysis. Where patient stories do feature in nursing research they are often labelled as 'case studies' or 'accounts' (Tilley, 1995).

Researchers rarely consider patients' stories in their entirety. Barker and Buchanan-Barker (2004) claim:

'we long since came to the conclusion that the various labels, classifications, categories and definitions which health professionals conjure with obscure rather than illuminate the patient's story'.

Tilley (1995) claims that:

'to treat stories in this way is to fail to respect the tellers of these stories. It is to make the assumption that our interpretation of the patient's experience is more valid than their telling of it.'

Fairbairn (2000) advocates that story-telling in nurse research should be used less as a method of data collection and more as a way of listening to and learning from the patient. Unfortunately many of the patient stories which form the basis for nurse research are used not to facilitate an increased understanding of the patient's experiences but rather for 'ideas, theories, questions and suggestions which help nurses identify how best they can help the patients be cared for and treated' (Fairbairn and Carson, 2002), the focus being on enhancing the development of nursing practice.

Nursing research can learn from the many great social anthropologists who relied solely on individuals' stories to develop their ethnographic theories of how people live their lives and, more importantly, give them meaning. Ethnography is a way of collecting, describing and analysing the ways in which people categorize the meaning of their world. It aims to learn what knowledge people use to interpret their unique experiences and mould their behaviour within the context of the culturally constituted environment (Morse, 1991). It was social anthropologists that first identified that the meaning of our lives is inseparable from the stories we tell. Patients organize their experiences and even their memories primarily in the form of self-narratives—personal and family stories, myths about circumstances, reasons for doing or not doing something—in order to gain some sense of order, continuity and meaning in their lives.

The first story

The first patient story to be presented here was obtained during an ethnographic study (Lindsay, 1996) and was told by Julie, one of the first patients to attend the original Leg Club, which opened in a Suffolk village in 1995.

Julie had lived with bilateral leg ulcers following the birth of her third child. For over 30 years her leg ulcers had controlled her life, despite weekly community nursing input. Julie self-treated and was subsequently treated for repeated infections and labelled as non-compliant by staff at the GP surgery. When informed that the community nursing service was introducing a social clinic, she reluctantly agreed to attend.

'I found the environment relaxing, and enjoyed meeting other people, many of whom seemed to have worse leg problems than me. It helped turn what was a worrying medical problem into a pleasant afternoon. The general atmosphere made you want to attend, it has more of social atmosphere than a medical treatment centre, it was like meeting old friends each week.'

I had had my ulcers for some considerable time without any improvement but all that changed very quickly. I learnt there were different types of ulcers, all needing different treatments. The doctors had tried one thing

after another but they did not work. Here I find the staff take a lot of care and patience to get my treatment under control and I am very pleased with that.

I have seen other people's leg problems and I have seen how they have improved like mine. Since I have been attending the club most of my ulcers have healed. I am hopeful that I shall be able to get about more and be relieved of the discomfort and disability; now I have a future.

I enjoy meeting with other patients who have become old friends, it does me a lot of good meeting with other people, it stops me from feeling miserable, stuck at home on my own. The club has brought me into contact with other people with leg ulcers and given me the opportunity to talk to them. We are all on a par as we all know what agony we go through. I keep a check on how they are getting on. It helps to be able to compare how you are feeling with the feeling of others. I find it therapeutic to talk and be with others with a similar disability'.

Julie went on to heal completely and despite her personal journey of self-treatment, non-concordance, pain and low self-esteem, she became an invaluable part of the Leg Club team as the first patient educator, offering support to fellow patients.

Julie states that being with and interacting with others sharing the same or a similar condition helped her overcome her own feelings of despair, discomfort and social isolation. Belief in the clinical and social benefits of the Leg Club and her consequent motivation to attend resulted in a positive attitude and improved health. This appeared to be strongly related to the support and bonding of friendship that developed during her attendance at the club. She claimed that the attending the Leg Club had given her confidence and control in the management of her care, empowering her to participate fully in its delivery.

The footballer's story

James was a young, professional man with a passion for football.

'The last few years of my grandfather's life were ruined by leg ulcers which rendered him immobile, in pain, malodorous and unhappy.'

I first remember being aware that I had protruding veins in my lower legs during a holiday to Greece when I was about 16 years old. I went with a group of mates and the whole holiday was spent on the beach wearing shorts and sandals trying to pull girls. I remember being conscious of my legs and trying to walk at the back of the group whenever there were girls about so the legs would not be seen. The last time I was really conscious of my legs was my last beach holiday a few years ago, again I was with friends but this time there was female interest to raise my anxiety levels. Since then I have avoided beach holidays because I know how self-conscious I will feel.

The only other time I am forced to expose my legs is when I play sport. I took to wearing tracksuit bottoms for the gym and to play squash, and when playing football I pull my socks up to cover my legs. Back in the changing room I am conscious of my legs but I can override it because it is an all-male environment. The only time a bloke has commented on my veins was after a football game. He pointed at the vein bulging from the inside of my thigh and said “ugggghhh, look at that vein”. I remember doing my best to brush it aside by saying something along the lines that it always happened after I played sport.

When trousers are just not practical or possible, for example if it is just too hot or I go swimming, I have to do what I can to cover up by investing in long shorts, sitting and lying in positions calculated to hide the worst part of my legs.

In private my girlfriend obviously sees my legs. She says she doesn't really notice veins and doesn't care at all. This has not been the case with other female friends, where I have felt they found my varicosity pretty unpleasant.

After talking to a male friend who had had an operation to strip the veins from his leg I was encouraged to approach my GP. This I did 3 years ago. He examined my veins and told me there was nothing that could be done and ruled out any possibility of an operation. I was bitterly disappointed and reconciled to just live with the varicosity.

Then by chance I encountered the Leg Club. My legs were examined, I was booked in for a Doppler, and given details of compression hosiery, which I was assured would help. Armed with this valuable information and advice I went back to the GP to demand an operation. I saw a different GP this time. Initially he appeared indifferent to my problem until I explained the advice and information I had been given. He referred me to a consultant and now nearly a year later I am booked in for an operation in March 2006. I cannot say I am looking forward to it but I am massively looking forward to the results. The thought of being able to run around in my shorts on the beach without any anxieties about my appearance is great. I am booking myself a beach holiday this summer to celebrate'.

James's improved knowledge and understanding of his leg problem, and subsequent increased self-esteem, were gained through using the collective educational and clinical expertise of the Leg Club staff.

The patient educator's story

Elaine was a founding member of her local Leg Club when it started. She had been attending the doctor's surgery to have her painful leg ulcer dressed by the practice nurse following discharge from hospital following surgery.

'The doctor suggested I went to the Leg Club which was going to be held at the local community centre

every Tuesday afternoon. I went along and met the sister in charge. I liked her, and got on very well with her and the other nurses. They treated me very well. Sister asked me if I would like to help with the social side of things, making tea and talking to the other patients.

Although my leg ulcer is now healed I still attend the Leg Club. My job is to talk to the patients. I know what my nerves were like—nobody knows what having a leg ulcer is like until they experience it. It is nice to talk to people who are attending for the first time, help calm their nerves, tell them what happens and give them a cup of tea. I know most of the patients very well. I see how they are coping with their leg ulceration, it's a new experience for them, both the young and the elderly like me.

I get lots out of my job as patient educator: it gets me out of the house, meeting different kinds of people, helping them cope.'

Elaine's story demonstrates genuine life enhancement through talking and sharing, which highlights psychosocial factors of care and patient education as being paramount.

John also stressed the value of the social interaction with staff and other patients that the Leg Club affords.

'My GP referred me to the Leg Club in 2002 and since then I have attended on a regular basis. I am able to meet, in a very relaxed and friendly environment, with other people with similar leg problems to me. We share our experiences and offer our views on each other's treatments, whilst enjoying a cup of tea and refreshments provided by the members'.

Stories and social science

Social science is concerned with the meaning and behaviours that organize our experience of illness (Radley, 1994). Phenomenology, a philosophical approach used in social science research, values the importance of the person's lived and subjective experience above any interpretation, pre-judgement or preconceived theories or ideas (Morse, 1991). Meanings are socially constructed through on-going relations between people. The main purpose of phenomenology is to describe the lived experience of individuals, but in such a way that it is true to the lives of the people described. Phenomenology fits particularly closely to the person-centred, humanistic, holistic approach to health care, which forms the basis of, and informs the nurse-patient relationship.

The establishment of the therapeutic relationship between nurse and patient is well documented (Hawkins, 2003; Foster and Hawkins, 2005). The nurse is encouraged to develop a relationship with the patient characterized by respect and empathy, and once the patient is able to perceive and appreciate these qualities the relationship is established. Only then will the patient feel safe enough to begin to disclose aspects of themselves and how they experience their life. This is achieved by attempting to make sense of the way ideas interact with bodily feelings to constitute the raw experience of life. It is these life experiences

that combine to form the patient's narrative, and which a phenomenological approach should seek to capture.

How, when and whether the patient shares his or her narrative or story will depend on whether he or she feels engaged in the relationship with the nurse, and is wholly dependent on the story-hearer's responses. By actively listening, nurses play a critical role in optimising the power of the story in the patient's journey towards empowerment and self-healing (Barker and Buchanan-Barker, 2004). Virginia Henderson's work in the 1970s suggests that the nurse who values nursing and its personal, individualized care gives holistic rather than disease-centred care, treating the whole person, not just the disease.

The secretary's story

Marion's story is particularly moving, and graphically illustrates the value of holistic, personalized care and the opportunity to share. It was August 2004 when she was diagnosed with a leg ulcer:

'I was in a lot of pain and was very frightened. I was frightened because the only person I had known with leg ulcers was my mother, who had had them for more than 10 years without them successfully healing. I was visiting my practice nurse twice a week for dressing changes and my general practitioner for pain relief and sick notes, and feeling very sorry for myself. All the time my ulcer was getting larger and more painful. Although the practice nurses were kind they seemed to have very little understanding of the impact my leg ulcer was having on my life. They tried so many different types of dressing, none of which seemed to suit my wound and I seemed to get conflicting advice. No one explained anything to me or seemed to understand how I was feeling. In the end the nurses were at a loss as to what to try next, and while all this was going on my ulcer was still growing and I was going mad with pain, and started to feel depressed.'

She then saw an advertisement in a local paper for the Evesham Leg Club being held in a local church hall.

'I mentioned it to the practice nurse and she suggested I went along. So on 1st November last year I went along, very sceptical at first. I really could not see how going to a church hall to have my leg dressed was going to make any difference, but boy was I wrong. The first person I met was the leader of the club. She made me feel very welcome, she was so positive, listened to me and reassured me that she would get my ulcer healed. All the nurses were so friendly and knowledgeable, they did not mind if I laughed or cried, they always managed to put a smile on my face. Every month my wound was measured and photographed so that I had a true record of how my ulcer was progressing—at its worst it measured 5.5cm x 3.5cm. The whole atmosphere at the club was upbeat and positive, all the members had a cup of tea and a good laugh or moan...we no longer felt alone. Those to benefit the most were elderly and housebound who no longer had to suffer alone.'

I am no longer depressed, my ulcer has healed, and I will be returning to work next month [October 2005]. I feel as though I have been given my life back and an added bonus is that with the support of the staff and club members I have given up smoking after 30 years. I am now secretary of the Friends of Evesham Leg Club.'

We do not need to analyse Marion's story, but rather to reflect on, and identify in its telling, the health benefits of sharing and interacting, which go far beyond the healing of a leg ulcer. The story illustrates a move from ignorance and a depressive state to one of health and wellness, and from confusion to clarity. Marion benefited from appropriate, accurate, evidence-based information and education on the management of her leg ulcer. Psychological and social support from her interactions with staff and fellow patients not only empowered her through the treatment of her leg ulcer but also encouraged her to stop smoking. The story demonstrates that the patient does not stand alone, but rather is part of a web of influences that includes the nurses and other patients—a union of the professional and non-professional within which meaning-making flows back and forth.

That our patients are intimately involved in the construction of their stories, trying to make sense of what is happening to them, what it means to them, what part they may or may not have played in generating such experiences, illustrates precisely why we, as nurses, should hear their stories, without analysis, and learn directly from their telling.

Similarly, practitioners only truly know the patient is making progress or getting better when they are able to shape their own story of what has been said, noticed, observed, felt, and evidenced throughout their health journey. How listeners position themselves in relation to stories is crucial: one needs to help patients elaborate their stories, to hear them out fully, and help them hear each other. As the story-teller engages with the story-hearer, a co-created story emerges, one which belongs to neither alone, but to both as a shared experience (Barker, 2002). This offers an additional, and perhaps a more profound, dimension to phenomenological principles within a research context.

The Leg Club

The Leg Club model was developed to address the limitations of existing mechanisms, such as home visits and leg ulcer clinics, in meeting patients' needs. It provides a framework in which, in a departure from the traditional nurse dominant/patient passive relationship, patients are educated and empowered to take ownership of their care and make informed decisions regarding treatment. Through a unique partnership between nurses, patients (members) and the local community, care is provided in a social, non-medical setting. Patients with leg ulcers and other problems are de-stigmatized and social integration, empathy, peer example, peer support, health education and

KEY POINTS

- ◆ Patient stories may prove to be the most valuable, yet to date neglected, form of nurse research evidence.
- ◆ The very telling of a patient story gives it a deeper and clearer meaning for the story-teller.
- ◆ The choice of what to tell and what to omit lies entirely with the patient. Patient stories are always memorable and grounded in personal experience.
- ◆ Nurses play a crucial role in optimizing the power of the patient story.
- ◆ How, when and whether a patient shares his or her story is wholly dependent on the story-hearer's responses. Nurses need to cultivate the skill of active listening.

promotion can flourish. An integrated 'well-leg' regime promotes positive role models for members and delivers continuity of care that extends beyond healing. It is an environment that promotes social interaction, opportunistic attendance, peer support and participation and patient empowerment. Patients are empowered to take ownership of their treatment and through the development of positive health beliefs and informed behaviour, are facilitated to change their way of life.

Participation in the Leg Club encourages patients to be better informed about and actively involved in their care, and to share with one another and the staff caring for them, through narratives, their experiences of living with a leg ulcer. Time spent at the club can be stretched to include developing friendships, involvement in fundraising activities or just sitting in the company of others, benefiting from social interaction while enjoying refreshments

Stories can only be told when people have time to talk and listeners have sufficient time to hear; the richer the narrative, the more time is needed. One of the advantages of the Leg Club as a model of clinical care is the opportunities it gives both patients and staff to develop and respond to complex narratives, many times delivered in relatively short instalments, but over a sustained period of time.

All the stories have illustrated the strong allegiance felt by patients/members to their individual Leg Clubs, and the importance to them of not just the physical care but the psychosocial support which comes from both staff and fellow patients. Radley (1994) claims the relationships in which we live, and the groups to which we belong, have a demonstrable bearing on the maintenance of good health. To dissect and analyse the stories may well be to lose the strong sense of companionship which is the very essence of their stories.

Conclusion

The purpose of research in nursing is to ask questions, the answers to which refine existing knowledge or add to our existing body of knowledge. Patient stories and narratives add a further, profound dimension to that knowledge.

Patient stories and narratives are about individuals, about

how they think and feel, rather than about what they do or have done to them. The choice of what to tell and what to omit lies entirely with the patient. They are memorable, grounded in personal experience and force reflection on practice by the professionals caring for the story-teller. They provide us with new and important information, and encourage holism and a move to a more therapeutic approach to care.

Julie, Elaine, John and Marion all advocated that being with and interacting with others sharing the same or a similar condition helped them overcome their own feelings of distress, uncertainty, and social isolation. Belief in the clinical and social benefits of the Leg Club provided the motivation to attend, which is clearly related in a large part to the support and friendship that develop between the members, and which resulted over time, in all cases, in a more positive attitude towards health care.

Plummer (1995) claims there is a fundamental shift in story telling: the personal becomes public, then collective and finally political. Although every story is a unique one, there is a generic pattern that emerges; they are held together by certain, common experiences. The cement, which holds these stories together is membership of the Leg Club. To fully understand the treatment options, to be involved in the treatment discussion and decisions, to be treated collectively, observing and sharing with each other and the staff involved in their treatments, their unique patient stories. The unique physical and social environment of the Leg Club facilitates the sharing of lived experiences and the telling of patient narratives. It is through this process of sharing and telling that the patient stories provide robust evidence of good practice, on-going health promotion and qualitative nursing research

As nurses we need to recognize that every patient in our care has a story to tell—the fact that we may not hear their stories is due only to our extremely poor hearing skills.

BJCN

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- Barker P (2002) The philosophy of empowerment. *Mental Health Nursing* 20(9): 8–12
- Barker P, Buchanan-Barker P (2004) Beyond empowerment: revering the story teller. *Mental Health Practice* 7(5): 18–20
- Fairbairn G (2000) Developing academic storytelling. *Education Today* 50(2): 32–8
- Fairbairn G, Carson A (2002) Writing about nursing research: a storytelling approach. *Nurse Res* 10(1): 7–14
- Foster T, Hawkins J (2005) The therapeutic relationship: dead or merely impeded by technology? *Br J Nurs* 13(13): 698–702
- Hawkins J (2003) From task to talking in wound care. *Nurs Stand* 17(31): 63–6
- Lindsay E (1996) What are patient's views of leg ulcer management in a social community clinic? BSc dissertation, University of Suffolk
- Morse JM (1991) *Qualitative Nursing Research: A Contemporary Dialogue*. Sage, London
- Plummer K (1995) *Telling Sexual Stories: Power, Change And Social Worlds*. Routledge, London
- Radley A (1994) *Making Sense of Illness*. Sage, London
- Tilley S (1995) Accounts, accounting and accountability in psychiatric nursing. In: Watson R, ed. *Accountability In Nursing Practice*. Chapman Hall, London