



# Identity and sense of self: the significance of personhood in rehabilitation

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## Abstract

Recovery from conditions leading to illness/disability is often defined in terms of physical improvement; however, people themselves describe their own recovery as more than this alone: it is a returning to the life they led before their illness. These two approaches highlight a potential mismatch between the way we as health care professionals perceive our world (the observable) and the way the people we are caring for perceive their world (often hidden from us). In this presentation I will explore how we can access the subjective world of those who use our services by exploring the role of life narratives within rehabilitation. I will share ideas from research linked to life changes, sense of self, and agency which we can use to inform our practice and support people in their recovery and rehabilitation.

## The importance of 'invisible' work in rehabilitation

Thank you very much for inviting me to speak at this prestigious conference. In the presentation today I am going to chart my journey through quantitative and qualitative research which has led me into many interesting areas and brought me here today. I will be presenting my own work and that of others who have influenced me on the way – including other researchers and also people following stroke. Although I have focused on stroke in this presentation, I feel many of the issues raised will have relevance for nurses working alongside any person who has an acquired physical disability. I have focused on a hospital setting as this is based on my own experience; however, as mentioned before, I feel the issues will have wider relevance. The focus for my presentation is the importance of the 'invisible' work we do and how we can acknowledge and develop this work in our practice.

## Individual responses and self-concept

I became interested in this area while I was working as an occupational therapist on a stroke ward. I was interested in people's responses to having had their stroke. Some people appeared to be very stoic and just seemed to 'get on with it' whereas others, who in comparison were less physically disabled, appeared to be completely overwhelmed by their situation. I was interested to learn why this may be. I attended a seminar given by Dr Andy Tyerman, who was a clinical psychologist working with people following traumatic brain injury. He spoke about the self-concept, which can be seen as a dynamic collection of self-representations, which are formed through personal experiences, and interpretation of the environment<sup>1</sup>. These can define and determine how people view themselves in relation to the world<sup>2,3</sup>. I carried out a research study looking at the self-concept changes of people following a stroke<sup>4</sup>. There were 26



participants (16 men), mean age 72 years (range 50–83 years), who had had a first stroke and had left hospital over the previous two years. The mean time since stroke was 13 months (4–26 months). We found that people following stroke did describe a change in self-concept ( $Z = -3.58$ ;  $p = 0.000$ ) compared to a group of gender and aged matched controls who did not show any changes.

I repeated this assessment in a prospective study<sup>5</sup>, seeing people following a stroke in hospital, at six months and at one year, and found that people reported changes in self-concept at all of these time points. As part of the research I also assessed mood, using the Hospital Anxiety and Depression Scale<sup>6</sup>; motor ability, using the Rivermead Motor Assessment<sup>7</sup> and self-care using the Nottingham 10 point ADL scale<sup>8</sup>. I found that there was a very weak correlation between mood and either physical disability or self-care skills even up to one year post-stroke; supporting my experience while I was a clinician. However, I found that there was a very strong correlation between the degree to which somebody had felt they had changed as people and their level of depression

( $r = 0.80$ ;  $p = 0.000$ ) and anxiety ( $r = 0.64$ ;  $p = 0.000$ ) even at one year<sup>5</sup>. This is only an association and so it was not possible to state cause and effect, but something about sense of self was important in understanding mood and psychological response following a stroke.

### Subjective realities

As part of my development while I was undertaking my PhD, I needed to explore and grapple with the nature of reality. I had always assumed that there was one reality – the one I was experiencing and took for granted. However, I began to understand that each person had their own subjective reality and that understanding this reality was going to be important. I began to question the assumption of an 'objective' reality which could be measured and tested. For me, this approach worked for the material and often visible aspects of the world, for example bodies or 'objects' such as measuring range of movement of the knee, or looking at the response of somebody's body to their medication. As Howard<sup>9</sup> highlighted, chemicals are not going to react differently in an experiment because they

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are being studied. However, often in rehabilitation research and always in clinical practice we are humans studying and working alongside humans. We have our own subjective realities, which will impact on how we experience and view the world<sup>10,11</sup>. These subjective realities are influenced through our social interactions and through the language we use<sup>12</sup>. There are many concepts in the world, which are often treated as if they are material objects such as 'stress', and 'disability' – it is useful to see that they are created through language in the social 'world' which is invisible and not fixed as a material object would be. The meanings of these concepts changes through time and in different contexts, creating the milieu of the social world which is constantly created and recreated. For example, in a simple, one-to-one interaction between a nurse and a patient, each brings their own social reality to bear on that moment. The patient will bring meanings related

“*However, often in rehabilitation research and always in clinical practice we are humans studying and working alongside humans*”

to their current life, ideas about disability, family meanings and meanings related to being in hospital. The nurse will bring his/her own personal meanings, professional meanings and meanings about that particular work environment. All of these meanings will influence the behaviour of the patient and nurse. What on the surface looks like a simple, one-to-one interaction has many layers of complexity affecting the outcome of an intervention.

### Life narratives and rehabilitation

Because I was interested in self and identity, I chose to explore one aspect of this invisible social reality – life narratives. Gergen and Gergen<sup>13</sup> describe these as stories we tell about ourselves to ourselves and other people. Sarbin<sup>14</sup> describes how these create a link between who we were (thoughts about our past, our memories), who we are now in the present moment and who we feel we are going to be in the future (future plans).

These create a sense of coherence, predictability and security in what is in reality an unpredictable world<sup>14</sup>. Bury<sup>15</sup>, who is a medical sociologist, carried out a study with people following a diagnosis of rheumatoid arthritis and found that even though they had not yet been affected by their physical condition, people felt that the diagnosis had separated the person who they were in the past, from who they expected to be in the future. They had lost that sense of continuity and security; he called this biographical disruption<sup>15</sup>. Following my own studies<sup>5,16</sup>, where people following a stroke described a sudden life change, and entering a new reality with different physical and social rules unlike any they had encountered before, I created a visual model called the Life Thread Model<sup>17</sup>, which captures this process. Life narratives are represented by threads, which become frayed and rejoined during the process of injury and rehabilitation

The sense of being in a new reality has been described well by Anna McKenzie<sup>18</sup>, who was a professional counsellor in a social services setting. She had worked with many people who had an acquired injury and was considered to be an expert in the field. Following a car crash she said:

*I had entered the strange and new experience which I now know as 'disability country.' Of course it is not a different country but it often felt like it – with different names, expectations, conventions and possibilities<sup>18</sup>.*

This sense of a new reality or new rules is compounded by entering a ward environment, as Cant said about entering a ward following his stroke, "... you actively seek clues as to what is appropriate behaviour, how to respond to situations, what is expected of you, what is right"<sup>19</sup>. Patients look to staff and other patients to make sense of their situation and create meanings linked to their stroke and future.

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However, it would seem that we do not always support patients in seeing an active, meaningful future for themselves. We may be dominated by the 'visible' ward culture (such as routines and processes) which can lead to passivity in patients, as we fit them into a unified system rather than focusing on the individual invisible social reality and lives of the people in the ward. This can lead to a loss of confidence. As Cant said:

*I had not been conscious of losing it [confidence], but in the period since my stroke it 'leaked away'. I had become very well adapted to living in an institutional environment and had not experienced many of those small day-to-day cues that keep you informed that you are an okay 'normal' person. Now my unconscious was dominated by a 'disability outlook' and a fear of failure in the 'real' world. This was nobody's fault. Merely an inevitable consequence of institutionalisation<sup>19</sup>.*

This highlights an important role for the nurse, working not only to physically support and care for the person (visible work) but also sharing their journey and helping to create progressive

future life narratives (invisible work). Kearney<sup>20</sup> highlighted that following a stroke people move between loss and grief, looking back, and looking forward to reconfiguring positive new life narratives which incorporate the stroke but are not dominated by it. This is a long-term process that can last for many years but the foundations of this process start in hospital.

As we have seen from the self-concept studies, people's sense of self is particularly fluid after their stroke. People are facing many changes and they are looking to others to help create new meanings in a confusing world as their old assumptions about their bodies, and aspects such as people's reactions in social settings no longer hold true<sup>16</sup>. Meanings are created through narratives and any narratives, such as life narratives, are created between at least two people, the narrator and the audience. They are created and recreated through everyday social interaction. Through narrative-sharing, a person's sense of self can be enhanced through a) hearing and validating their experience and b) allowing a person to reflect on and re-evaluate life possibilities and c) practise new narrative positions or stances. Using a life



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narrative approach, the role of the nurse would be to help the person connect who they were in the past to who they want to be in the future. They may do this in ways that are familiar to them, for example, supporting the person to improve physically so that they can return to their usual activities, or supporting the person to achieve their goals in alternative ways by using adaptations or equipment. Nurses may also support people to maintain past narratives into the future by talking about them; they may create entirely new positive narratives about the future; or help the person tie off past narratives in a way that feels comfortable for them. But how is this accomplished in practice?

### Use of life narratives in practice

During my research, I saw people for an hour three times over a year. During the interviews I asked people to talk about their lives and I interrupted as little as possible in order to get a sense of their lives narratives with as little input from me as possible. When I was analysing a person's life narratives, I was struck by how the same narrative threads came through in each of the three interviews. They were almost like fingerprints; each person had their own specific threads. A nurse using a narrative approach would firstly discover what a person's life threads were. They would do this during caring procedures by asking the person about their past life, what they wanted to achieve in the future and with their permission share this information with others. These narratives would then be built on in rehabilitation sessions. A colleague worked with a man with Parkinson's disease, who was finding it difficult to practise his walking exercises. He found out that the man, in his younger days, used to be an athlete and a runner. He incorporated terms the man had used about training and running into his current exercise routine and reframed the activity in a way which was acceptable for the man and also contributed to his identity as a runner.

Using a life narrative approach, a nurse would see each interaction as an opportunity to create joint narratives recognising that they, as a nurse, brought the expertise in terms of physical recovery and nursing care and that the person brought the expertise of knowing what worked best for them and what issues they were facing at the time. The nurse would always ask people how they were feeling and thinking about the situation. Another colleague

of mine was having great difficulty in helping a person stand from the side of their bed for the first time following their stroke; the person kept panicking and fighting the nursing staff. My friend went back the next day and tried again. Throughout she asked the person what was happening for them. He described how the floor was moving up and down, how he kept feeling dizzy and that he felt completely out of control. Together they agreed that he would say how far he sat up and when he felt ready to stand. He took control of the situation, was much more successful and soon learnt to stand independently

Again, using a life narrative approach a nurse would tolerate what could be perceived as unrealistic expectations. People living with an acquired disability have highlighted that health professionals have a tendency to have low expectations of them<sup>21</sup>. This is probably because our usual focus is the body (visible) and as this has been damaged /affected we feel that a person's life will become more limited. Doolittle<sup>22</sup> highlighted that although bodily improvement was important to people following stroke they saw recovery as getting back to their lives. This can be achieved through transformative learning<sup>23</sup> and redefining disability<sup>24</sup> where the meaning (or narrative) is changed despite continuing physical disabilities. People do not need to be limited by their physical disability. Using a life narrative approach, a nurse would not feel totally responsible for the person; they would feel comfortable in sharing responsibility with the person and finally handing it over to them; so challenging the passivity and loss of confidence described by Cant<sup>19</sup>. This would take a large shift in attitudes within rehabilitation and nursing culture so that risk to loss of self could be balanced against physical risk. In the UK, Fiona Jones has developed a very interesting self-management programme following stroke where people take control of their own rehabilitation with the support of therapists<sup>25</sup>. It is called Bridges (<http://www.bridges-stroke.org.uk/>) and consists of workshops for staff development and a self-management workbook. The workbook is used by the person following a stroke and is based on the stories and strategies from other people following a stroke, with a diary section to record personal targets and successes. It has been shown that this approach increases agency and self-efficacy and that people are much more active in their own rehabilitation<sup>25</sup>.



Using a life narrative approach, a nurse would feel able to balance hearing alongside doing. From the research I have carried out<sup>5</sup>, one of the key messages that has come out is that people want to be heard. I have a sense that sometimes we avoid hearing about people's experiences and life problems because we do not feel that we can do anything about it for them. A strong message that has come out for me is that people do not always want us to 'solve the problem'; being heard, sharing experiences and receiving validation is just as important. Again this 'invisible' work would challenge the traditional culture of a ward where staff are expected to be busy doing 'visible' tasks.

## Family members

Throughout this presentation I have been focusing on the person that has had the stroke. I have not had time to cover it here, but I would also like to highlight that family members, especially spouses, go through exactly the same sense of disruption of their life narratives<sup>26</sup>. They face many life changes, taking on responsibility for their partner's household work, health and safety, rehabilitation and short- and long-term life goals. If we took a life narrative approach to rehabilitation they would be receiving as much support as the person who experienced the bodily manifestations of the stroke. This would mean that they could create many positive progressive life narratives incorporating the stroke, not just one life narrative – that of being a carer.

I feel that there are many benefits of using a life narrative approach – not only for the person receiving care but also for those providing it. A key aspect is that it provides the nurse with more variety; a person is not just 'another stroke' with the same approach for all, which could become mundane and routine. Also, responsibility for rehabilitation is shared, allowing more flexibility in what is included in a person's programme. When using this approach, nurses are providing support for psychological as well as physical rehabilitation throughout everyday interactions, addressing a perceived lack in this area<sup>27</sup>. Finally, rehabilitation can become more adventurous as possibilities for the future are not limited by physical disability but can be explored through narrative imagination.

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