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5 A Narrative of a Woman's Adaptation to the Recovery of Her Husband Following a Stroke

MARY JENKINS, PAULINE IRVING AND DIANE HAZLETT

Introduction

The narrative is a powerful tool in understanding personal experiences, indeed Byatt explains narration is 'as part of human nature as breath and the circulation of the blood' (2000, p.21). At the heart of narrative psychology is the interpretation of an event/events in an attempt to bring meaning to difficult and disordered times. In this work we did not set out to use narrative specifically. On doing a pilot interview in an investigation into the psychosocial adaptation processes of families living with stroke survivors we realized the richness of the material in helping the interviewee to define her lived experience of managing change imposed by her husband's stroke. There is little evidence that carers' needs are fully understood and effectively considered in assisting them to cope with and adapt to their new lifestyle (Burton, 2000) and this is against the NICE guidelines which state that 'Stroke is a family illness' (Royal College of Physicians, 2004).

McAdams (1985) declares "We are tellers of tales" (p.11) and are tellers of tales because we are attempting to make sense of our lives.

In this specific piece of work the narrative is a means of making sense of the disruption of illness in our lives. According to Murray (2003) "It is through narrative that we can bring a sense of order to the seeming disorder in our lives and it is through narrative that we begin to define ourselves ..." (p.111).

This piece of research sets out to establish what happens when a family member survives a stroke. Families per se have seldom been the topic of investigation and we consider this a paradox given the 'National Clinical Guidance's for Stroke' (RCP, 2004) state "Stroke is a family illness" (p.19). We did not set out to use the narrative. The interview consisted of seven questions gleaned from the available literature (which as already noted is scarce) rather than beginning with "I am interested in finding out what happened during the time of coming to terms with your husband's stroke – you

can begin at the time leading up to the stroke”. Yet during the interview the questions were being covered/answered anyway like:

1. We’ll go onto this now because it’s kind of associated, what I’d like to know how was his recovery managed in hospital.
2. O.K. you talked about home – how was his recovery managed when he came home.

In effect it seemed the narrative won out.

Mishler’s (1979) notion of context without meaning has relevance here. He continues in a later publication. “The interviewer’s presence and form of involvement ... is integral to a respondent’s account. It is in this specific sense that the ‘story is a joint production’” (1986, p.82) and that was the felt experience. When the flyer came around for this Memory and Research conference we queried is this where the work should sit – in the narrative.

In narrative analysis, according to Murray (2003) the focus is on getting the main narrative account. As qualitative researchers we are familiar with Huberman and Miles’ (1984) *Reduction Theory*, Glaser and Strauss’ (1967) *Grounded Theory* and the derivatives and to a lesser extent Smith’s (1996) IPA. The challenge here was to work with the narrative and we readily proclaim ourselves novices in the area. At this juncture there is one case narrative to draw from – the pilot study – we are clearly at the very beginning of the work. We decided to use the conference presentation as a learning experience. We are taking Murray (2003) at his word when he says narrative analysis requires that the analyst should play with the narrative account and that’s what we are doing – playing with possibilities. At discussion time we look forward to hearing from the audience whether in their opinion the narrative fits the inquiry or indeed what might be a better fit.

We structure the analysis: - Beginning, Middle and End and present a summary first.

Case Summary

Millie is a 60+ year old married to Harry who was at sea most of their married life. In the latter years of his job she travelled with him. He had retired some few years. They have 2 adult children, a boy and a girl, both of whom are married and have children of their own. They live in the area, though not considered local. She had moved with her husband in the past number of years to a bungalow with large gardens as they both have an interest in the garden and enjoy time in the open air with their dogs. Neither of them had a history of illness. She was vice captain of her golf club and about to take up the chair. He had bought a Range Rover Discovery – a lifetime ambition and was looking

forward to using it to its potential. His stroke happened 'out of the blue' and Millie's adaptation been long and difficult.

Beginning

Throughout her account Millie emphasised the loss of their previous healthy life together and the shock and suddenness of the event and the accompanying fear of uncertainty. She recalled:-

- Millie: It was on a Wednesday morning and it was just about a quarter past eight and Harry was in the bathroom. I heard him coughing and I shouted in 'Harry, are you alright?'
- I: Hmmm!

And later when she had got him to the bedroom awaiting the GP.

- Millie: I was putting his right leg in, got the right leg in and I said Harry would you lift your left leg and he couldn't lift his left leg. I just put the pyjama bottoms on and then she (GP) was here by that time. She examined him and said 'Mrs M I think your husband's had a stroke'.
- I: So when you heard that – he'd had a stroke – can you talk a wee bit about it?
- Millie: Just – a feeling of terrible fright ... the word stroke – wasn't a heart attack – it was a stroke – dreadful, dreadful.
- I: You obviously had some – the word itself created a vision for you.
- Millie: Just afraid and fear completely. He's had a stroke. I can't believe he's had a stroke. I just could not believe it. This handsome healthy person.

[Not only was her husband 'struck down' in a way. The second shock came with the realisation of the stroke's consequences. "Prepare yourself for nursing homes and hospitals because your husband will never walk again". She was told – she went numb].

- Millie: I didn't hear anything after that because my mind just went. I just wanted to get out.
- I: Hmmm!

The middle

In this part of the narrative Millie describes a very different initial experience of hopefulness and it occurs when Harry was transferred to a rehabilitation unit. Her entry into this is worth relating.

Millie: When we came into the ward there was a big nurse and she said “You’re Harry’s wife and we’re just getting him settled. Now you’re very welcome.

I: Yes.

Millie: They got him settled into bed. Do you know they were wonderful!

I: Good.

Millie: ‘Cause they said like he’s here now. You’re here and this is going to be your place. You’re just going to have to come in and help us.

I: Like home.

Millie: It was a blessing the way they made you feel.

Millie emphasised how this feeling of family brought her contentment and a hope that she had not previously experienced. The period of rehabilitation lasted 5 months. He returned home just before Christmas and this is where the middle part of the narrative is split. Here Millie lives with fear again.

I: So then coming home – how did that go?

Millie: Very, very frightening to get him home.

I: Hmm!

Millie: You’re so nervous and you’re just sick with worry because you keep thinking to yourself – what happens if he takes another stroke? What happens to him? Who do I ring or what?

Millie: When the stroke happened there was one time I just felt ... I felt this going on the road to the hospital. All I really wanted to do was crawl under – believe this or believe this not – crawl under the hedge.

I: Hmm!

Millie: Just get out of the car and go under the hedge and stay there.

I: Hmm!

Millie: Just stay there and curl up in a ball and just stay there.

I: Hmm!

Millie: Or, I thought I would love to climb up the tree and stay there.

These two significant events of seeming despair and/or avoidance occurring in the beginning narrative were matched by a third in this middle narrative when she spoke of an earlier fearful time when the stroke happened.

Millie: I was down the fields and I just made my mind up. I just said to the Lord – this is all I did say – I said Jesus, I’m going to leave him at the foot of the cross and I want you to help carry him.

I: Hmm!

Millie: Mind you there’s days I cry, nights I cry and I still cry for the life that has just changed.

This has been a constant – the pain and shock of this life change.

Millie: I'd always wake up and it would hit me. The pain it was awful. You know I'd just say – I can't believe Harry had a stroke. I just can't believe it – where are we going, what am I going to do – that was the terrible part of it. The worst part of it.

The End

Looking at it now Millie is left with sadness, a sadness that pervades her days.

Millie: The whole thing has made me really very sad. Not – I'm not depressed.

I: Hmmm!

Millie: I'm trying not to be depressed. I try not to say like – I'm trapped – we're both trapped, that feeling – I'd feel that in the cold day of night.

I: Do you feel trapped?

Millie: Yeh! I feel like so sad for us. I feel like the thing I miss more than anything in the whole world. I miss getting into bed and curling in behind him ... I have felt that I have lost this person that I would have ran down the street with, our arms round each other and holding onto him in the rain.

This constant fear "*I can't get out of that afraid syndrome*" tempered with the challenge which she meets well makes Millie's account structure stable and regressive in that their lives have changed as a consequence of the stroke – although there are elements of a contrary narrative – the progressive narrative where she hands Harry and herself over to her God and where through his stroke both she and Harry have met profound friendships that are now central to their life achievements, like the man in the shop who comes to visit.

Millie: He calls him his old mate. Now they weren't really old mates.

I: Hmmm!

Millie: This man is just a wonderful guy. Then we have D. & S. Her husband had a stroke ... we go out. We have our own wee bit of crack.

I: Hmmm!

Millie: Like I'd be counselling S. and she'd be counselling me and she'd say some days "Oh! I had an awful weekend". "Oh! I'll say I had a bad weekend too".

Membership of a carer's group supports this new identity. "*D. started a wee carer's group and we went to it yesterday and we're all together 'sort of thing*".

This narrative account has been the first in this research. Our aim is to listen to the narratives not only of the family members of survivors but of survivors themselves, thus building into a wider story of families surviving a stroke and their subsequent re-definition of themselves. We have left the OHP

entitled 'Conclusion and Transition' blank because we value the insights and thoughts of the audience.

What took place here was an energetic discussion on the story, the power of its telling and if in fact the Narrative as used restricted it. In this open forum we were asked questions about the use of IPA general opinion being that this methodology would present findings in a more psychological framework. It was at this point that we shared with the audience that initially the script had been analysed using Smith et al.'s two-margin procedure. The consensus was that this process would elucidate the personal meanings constructed by families experiencing stroke survival. On returning to the work we acknowledge how IPA's case by case procedure affords us as researchers an ability to analyse in detail the participant's story and their sense of what happened. The semi-structured interview also complies with the process. We thanked the audience attending our talk for their engagement with our process and hope to return to present the findings in this format.

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