

Narrative Methodology: Standing Up in Multiple Sclerosis (SUMS)

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‘Stories are as ubiquitous as water or air, and as essential. There is not a single person who is not touched by the silent presence of stories.’ (Okri 1997: pp109)

We live storied lives. Nursing and medicine traditionally use oral stories to share information about the people they are caring for. Narrative has developed as a form of research that sits alongside qualitative and quantitative methods and as such uses different methodologies and analysis (Holloway and Freshwater 2007). This methodology has been used to research clinical practice (Jarrett 2015, Fordham 2015, Graham 2017), using guided reflection as a process of self-inquiry and transformation (Johns 2009). It has two defining characteristics; the text is left whole rather than themes elicited. This preserves the context and allows a holistic reading of the situation. Secondly outcomes are not generalizable. Narrative aims to ‘show’ meaning rather than to ‘tell’ or list recommendations. Reading of the text is an active process where resonance is sought between the meaning of the text and those who are reading it, encouraging them, to reflect and ultimately consider if they need or want to change their own behaviour. Resonance can be described as, a striking, moving experience that is deeply apprehended, the ‘felt effect’ by a reader when reading a text or ‘the sudden perception or intuitive grasp of the life meaning of something’ (van Manen, 1997, p364).

In the SUMS study we used different approaches to appreciate the impact of using a standing frame for people with MS. This resulted in a randomised controlled trial, a thematic analysis, the production of films and a narrative. This methodology was used to develop the narrative through exploring the lived experience of using a standing frame as part of a home based self-management programme for 10 people with multiple sclerosis and 10 carers. They were asked to record on a portable audio digital recorder how they were feeling each time they stood in the frame. The aim was to capture the immediacy of the moment rather than asking them to recollect these feelings later in an interview.

There can be concern that individuals in narrative texts maybe identifiable. The aim is to write a fictionalised narrative, yet the insights, the meaning is left intact.

'Real stories are about actual people. True stories reflect real life situations that people encounter' (Fairbairn, 2002, p23)

In the words of Fairbairn (2002) narrative aims to create true as opposed to real stories. Consent was obtained from the participants as described in the study protocol (Freeman et al 2016) and all the narrative characters were given pseudonyms.

To analyse the transcripts a method was developed to construct a narrative that plotted the experience of individuals over the duration of the study (see below). The narrative was made publicly available on the SUMS website

(<https://www.plymouth.ac.uk/research/sums>) so as it was available to people with MS, their carers and professionals. The idea of resonance pertains to all of these individuals who may read the SUMS narrative, it provides a way of accessing the standing experience of others that may inform their knowledge, understanding and use of a standing frame.

The influence of the researchers' background and role as MS specialists

Constructing the narrative was undertaken by the primary author (LJ), a specialist MS nurse, after reading and re-reading the texts. It was reviewed for coherence and relevance by members of the research team (JF, WH, RD), who are all MS Specialist Physiotherapists. The reading of the texts was influenced by their knowledge and experience of MS and their roles as MS specialists. In particular how MS symptoms can impact on a person's daily life and function stood out in the stories and were highlighted in the narrative.

Constructing the narrative

The aim of the narrative is to show participants perceptions of using the standing frame over the nine months. Several processes were enacted to preserve the integrity of the data. The primary author (LJ) used the following systematic process to construct the narrative:

- The transcripts were read 4-5 times in one sitting to get a sense of the overall flow of the stories.
- With each individual transcript the essence of their story was crafted, using their words and maintaining the flow of their dialogue (Bohm 2000), but removing text if it did not add to the story.
- Each individual story was then grouped into months (month 1 – month 9), the length of the study.
- These stories were organised into two amalgamated files one for participants and one for carers using the months as an organising structure.
- This resulted in:
 - Seven participant transcripts + letter
 - 37 pages 17171 words
 - Five carer transcripts + email
 - 4 pages 1636 words
- These were then printed to enable the author to read and dwell with the texts.
- Gender of either the stander or carer did not create different perspectives in the texts. Choosing a male/ husband as the stander and a female /wife as carer was considered acceptable as this had been the predominant partnership in the texts, without feeling that the texts would be compromised.
- Pseudonyms were used for each character. The person standing (Bob) was chosen as the main story teller, intercepting his words with those from the carer his wife (Pam).
- One story was very distinct from the others. It was not used as a main thread through the narrative as it would have been too strong and dominant and it would not have been possible to weave in aspects from the other participant voices. However, so as not to lose pertinent elements of his successful journey, elements were included as a friend (Dan) of the main story participant (Bob).
- The stories were then melded and synthesised for each month into a narrative that stretched over the nine months
- One late script (01068) was read and suitable threads moved to relevant months in the emerging narrative.
- The narrative was edited five times

- It was then shared with three other researchers JF, WH, RD who checked it for coherence and resonance.
- The final narrative was published on the SUMS website.

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