A qualitative study of illness narratives

Alawafi, Rana; Rosewilliam, Sheeba; Soundy, Andrew

DOI:
10.12968/ijtr.2021.0131

License:
Other (please specify with Rights Statement)

Document Version
Peer reviewed version

Citation for published version (Harvard):
Alawafi, R, Rosewilliam, S & Soundy, A 2022, 'A qualitative study of illness narratives: 'overcoming the monster' master plot for patients with stroke', *International Journal of Therapy and Rehabilitation*, vol. 29, no. 9, pp. 1-12. https://doi.org/10.12968/ijtr.2021.0131

Title: A Qualitative Study of Illness Narratives that Demonstrate the Master Plot of Overcoming the Monster and Support Stroke Survivors in Utilising it

Authors: Rana Alawafi[1,2*], Sheeba Rosewilliam[1], Andrew Soundy[1*],

*Corresponding authors

[1]School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham, Birmingham B15 2TT, UK;
[2]College of Health and Rehabilitation Sciences, Princess Nourah Bint Abdulrahman University, King Khalid International Airport, Riyadh 13412, Saudi Arabia

Emails: rxa905@student.bham.ac.uk, a.a.soundy@bham.ac.uk, s.b.rosewilliam@bham.ac.uk

Abstract

Background/Aims: Research is needed that considers illness narrative master plots expressed by individuals who have had a stroke. The literature so far has focused on identified pre-established illness narrative master plots. Further research needs to identify if other master plots exist and consider the implication of such plots.

Methods: A narrative methodology was undertaken situated within a social constructivist world view. A purposive sample of individuals with stroke undertook a single online semi-structured interview. A categorical-form narrative analysis was undertaken in 5 stages.

Results: A total of 8 individuals were interviewed. Following analysis 6 individuals' narratives were identified as representing elements of the master plot called overcoming the monster. The results explore this narrative master plot. The 'monster' was represented in several ways in the current manuscript this including; a mental health problem or an expression relating to internal feelings, a sense of being isolated from others, a threat to the individuals independence, and a negative interaction or experience related to healthcare.

Conclusions: Health care professionals need to understand the importance of this master plot. Implications from these findings are provided.

What this paper adds:

- Overcoming the monster appears to be an important narrative master plot. The monster within experiences of stroke could fall within specific categories such as a feeling isolation, a mental health problem, or a threat to independence. Being able to share this master plot appear important. Healthcare professionals (HCPs) need to consider how patients are able to overcome their identified monster.
- HCPs need to understand that the narrative may be hidden or could be missed or denied during interaction. Opportunity should be given to listen to master plots even if the plot appears unrealistic or that don't fit with the aims of therapy.
- This research identifies the importance of being attentive to descriptions of events including metaphors, that can reveal experiences. Strategies that non-judgemental and non-directive may be placed to understand difficulties whereas motivational strategies may also be needed.

Reflective Questions

- Are you aware of what may represent a monster for the individual you are treating and what may need to be overcome?
- Can you consider how you may help patients have access to different types of master plot which could illustrate how they overcame their own challenges?

Key words: Qualitative, Narrative, Stroke, Experiences, Perceptions

Introduction

Health care professionals (HCPs) and patients express the effects of a stroke differently. Most typically HCPs focus on the identification of physiological and neurological effects, whilst patients identify meaning by interpreting the event in relation to their own bio-graphical history (Boylstein et al. 2007). HCPs need to appreciate the personal account of illnesses, as this helps create social awareness, reduce stigma towards the illness being treated and influences research and healthcare policies (Boylstein et al. 2007). This would also likely address some of the psychosocial needs identified by patients and caregivers (Mountain et al. 2020). Telling stories provides the individual with an opportunity to create meaning and (re)establish a sense of social identity (France et al. 2013). HCPs will benefit from understanding patient narratives as listening to narratives enhances their understanding of a patient's psychosocial wellbeing (Pluta et al. 2014).

Illness narratives are often identifiable by a master plot. Master plots represent general storylines that are easily recognisable and frequently expressed by individuals who have a chronic illness (Frank, 1995). Master plots should not be considered a complete reflection of a patient's experience. A patient may express different master plots at the same time and any one master plot may change over time (Soundy et al. 2013). The three most cited illness narrative master plots include the quest master plot (the plot emphases the full benefits of what has happened), the chaos master plot (the plot identifies the hopelessness of what has happened, underlined by loss from the past) and restitution master plot (the plot emphases an expectation of a complete recovery in the future) (Egbert et al. 2021; Frank, 1995; France et al. 2013). However, other master plots have been expressed by individuals who have had a stroke. For instance, Soundy et al. (2013) identified 13 master plots. Further to this, other master plots are found in history and culture are often portrayed in film (Booker 2007).

One master plot that could be frequently expressed by individuals who have had a stroke is named ‘overcoming the monster’. Booker (2007) states that this master plot can be identified when a life is threatened by an all-powerful monster. Once identified, the hero has to fight and defeat the monster. Typically, in past stories the monster is represented by a creature (e.g., a giant). The creature holds power over the hero. The important part of the story is that the monster or evil is killed and the power it holds overthrown.

In stroke the monster could be identified as symptoms of the stroke directly or experiences associated with having a stroke. This could include depression due to its high prevalence following a stroke (Wood et al. 2010), experiences of isolation (Luker et al., 2015; Salter et al. 2008), or changes to the individual’s social identity (Hinckley 2006). Interestingly, these examples are associated with factors that remove hope (Soundy et al., 2014). This is important, because hope is uniquely expressed in each master plot (Soundy et al., 2013). Thus, challenging, preventing or changing an individual’s illness master plot will likely influence their psychological wellbeing (Soundy et al., 2014).

HCPs need to be aware of how to manage master plots within patient-therapist interactions. This will help to ensure the hope and wellbeing of a patient is manged (Soundy et al., 2014) and provide the best opportunity to empower the patient (Luker et al., 2015). This is important, for instance, the most common metaphors identified alongside the experience of stroke include the terms journey and battle, such metaphors suggest an experience of social disempowerment (Ferguson et al. 2009). Alternatively, the idea of recovery being a war and qualities of a person being a fighter are ever-present in stroke (Boylstein et al. 2007). These metaphors found within the narrative illustrate a frame of mind or characteristic that may accompany particular master plot.

Further research is needed that identifies if, and why overcoming the monster is an important narrative for people who have had a stroke. Gaining an insight to individual narratives will be best initially achieved through a qualitative study which captures rich detail. Given this, the aim of this study was to identify stories that illustrated the master plot of overcoming the monster and help individuals who have had a Stroke and HCPs to understand the value of them.

Materials and Methods

Design

A narrative methodology was assumed situated within a social constructivist view of the world, with a relativist ontology and a subjectivist epistemology (Labornte and Robertson 1996). This means that reality is viewed as multiple, and knowledge view as being constructed through interactions and then formed on a psychological level. A standardised framework was used to report methods (O'Brien et al. 2014).

Researcher characteristics and reflexivity

The researchers undertaking this research were a white male academic who is 42 years old and a middle eastern female PhD student. People with Stroke were not known to either individual and no information about the researchers was given before the interview.

Context

The setting of the interview was from the supervising researcher's home and delivered across skype in a single time point. This was selected to protect individuals during the COVID-19 outbreak and local restrictions. Prior to the interviews, demographic information was gathered, including gender, age, type of stroke, and time since onset of stroke.

Sampling and Participant

Participants were purposively sampled from a well-known website (not identified to shield individual's identity) that allows advertisement of research projects and advertised at a local community stroke group. Individuals interested emailed the authors to arrange an interview following consent procedures. Sample size was selected on the ability to reveal rich aspects of a singular master plot examined through the experiences of individuals, the need of this research was not to claim statistical generalisability but rather to impact the reader and consider how it may transfer to others stories (Smith 2018). Thus, we did not seek to

establish data saturation of the content, we did however seek to detail examples of the narrative master plot through a specific analytical process (see below).

Eligibility

Participants were included if they were adults who were 18 years of age and over. Individuals were required to be at least 2 years post stroke. Any type of stroke was included in the study if individuals were able to comprehend and answer questions and communicate through skype or zoom. Individuals were required to provide informed consent. Participants were excluded if a translator was required.

Ethical approval

Ethical approval was obtained from the University (Ref: ERN_ 17-0149).

Semi-structured interview guide

A single semi-structured interview was developed and pilot tested. No changes to the guide were made following the pilot interview. The interview schedule had 4 major sections and 29 questions and can be viewed in the Supplementary file. The average interview time taken was 60 minutes. The interviews were audio recorded via zoom. A transcript was automatically generated and scripts were independently checked for accuracy by the lead and supervising authors.

Data analysis

Following the interviews and data collection, individuals were selected to be part of the analysis if their story represented elements of the narrative master plot overcoming the monster. A categorical-form type of narrative analysis (Earthy et al. 2008) was conducted. Five stages of analysis were performed. Stage 1 includedopen coding, during the stage the lead author immersed herself in the text and verbatim recorded to identify codes and comments on relevant excerpts in relation to what master plots could be identified and

why. Stage 2 required the lead author to present a defendable case to the supervising author for each master plots identified. During stage 3 both authors examined the scripts for the most prevalent plot type against those previously identified (Soundy et al., 2013; Booker, 2007). During stage 4 independent agreement was undertaken to evidence the expression of overcoming the monster for each participant. Authors agreed this master plot was clearly identifiable in the majority of the participant interviews (n=6/8, 75%). (5) An examination of that plot was made to further detail and understand it. The following questions were used to aid this process: (a) What was the monster? (b) What needed to be overcome? (c) How was it overcome? (d) What were the consequences and (5) What were the critical moments? During the final stage, the expression of the master plot was agreed and a summary of the master plot for each participant was provided (see below). Figure 1 provides a diagram illustrating the stages of analysis.

Trustworthiness in the narrative

A framework by Andrews (2021) that helps ensure quality was utilised and adhered to as follows: Truthfulness and trustworthiness of the data identifying examples of monsters was judged against known and established experiences from other research (e.g., Luker et al. 2015; Soundy et al., 2014). Critical reflexivity is acknowledging in that the personal interests of the supervising author around narrative master plots may have influenced choices for analysis and limited the focus of the study. The accessibility of the article was enhanced by identifying the types of monsters identified by individuals who have had a stroke. This in turn provided a greater understanding for the role the HCPs have in co-constructing the master plot. The attention to the untold narrative, the awareness of temporal fluidity and multi-layered natured of the stories may be limited due to sampling bias and focus on one master plot.

Results

Demographics

Six participants (59±14 years; 2 male and 4 female) were selected from a total of eight interviews. See Table 1 for a break-down of information.

Findings relating to overcoming the monster master plot

Several key findings were identified across participants which helped explain the master plot. Table 2 provides this information. See the supplementary File for example quotes for each participant.

Identification of the monster and what needed to be overcome

The monster could be identified as the experience of mental health problem or a thought cycle that linked in with a sense of being defeated or crushed and the experience of a different sense of self (P1; P2; P3). For P1 this was overcoming a sense of feeling crushed by the experienced but slowly identifying it was possible to overcome. He states;

> *"my friends and family could see a horrific deterioration in my psychological state, especially when I tried to go back to work. And they were afraid to talk to me about it because they knew how fragile I was. My wife was amazing in that there were times when I was crying my eyes out, saying I just couldn't do it. I couldn't go back to work. And she knew that if I didn't do it that would be the end."*

P3 realised he would not be back to 'normal' in 3-6 months. Both P1 and P7 identified motivation as an aspect of what needed to be overcome. A sense of feeling isolation was another monster (P2; P5:P6). This was created by not being able to identify with others in a similar situation (P5), or feeling and experiencing isolation from others (P6). P6 explains this;

"*What really sticks out in my mind about that period is the healthcare team not realising…there's a person inside the body and the communication to get to know me, if you like, never occurred. That was the negative side."*

The monster could be seen as the threat to being independent (P1; P2: P3:P6). For instance, experiencing a threat to independence and living, and needing to be open to all change that occurs (P6). The ability to work and earn (P1; P3).

Identification of problems with the health care experience that was seen as a monster that needed to be overcome, although recognised importantly as one that didn't have to exist (P5). The monster could be the negative experience of care received, which in turn had a negative impact on dignity (P1). It was expressed as the difficulty faced when seeking support and care from services and not receiving any, and the doubt suggested by HCPs at what his own rehabilitation activities involved (P2).

How was it overcome

Three principle ways the monster was overcome, included the character of the person and identification of a fight, ways of instigating change and improvements and goals and achievements.

The fight and characteristics of the person

The ability to begin overcoming required motivation, so in some cases there was a change from surviving to fighting back and creating a motivation and want to fight (P1; P2). For instance, P2 stated: "*I've had counselling and different things, but they haven't gone really, they haven't really helped. So I'm kind of thinking of ways I can help myself*". Several participants identified with the idea of fighting. This was represented as fighting for independence and taking back control (P1), fighting with social services for extra support for her children (P2), and fighting with and benefiting from treatment (P6).

In addition to this several individuals focused on their characteristics which represented one aspect of how they would overcome the monster, that included being determined or bloody minded (P3), determined to prove everyone wrong (P5), or motivated not to let someone else down (P7). P7 illustrates this clearly;

> "*I read about a man who was, he was some kind of trainer, I suppose in the SAS, talking about the types of people that they liked. And one of the things he had said was determination to do, to achieve, was not enough. It was persistence [that was needed]. Then I have discovered that with persistence…if I don't do my exercises regularly I go backwards. So that has really helped me [knowing] that I have to be always persistent…Because if you think of young children, when they like, I remember my children when they were trying to walk they just persisted and persisted. And they didn't mind falling over because I suppose we all say [to them], "Oh, well done"."*

Ways of instigating change and improvements

Individuals were firstly able to make further improvements by internally viewing life differently e.g., P5 stated a recognition to moving on early after discharge and identifying a new life. P6 identified this by viewing experiences differently, being open to change and embracing uncertainty as an adventure. P3 was able to make improvements by undertaking specific activities, for instance, activities which were not prescribed, part of overcoming the monster for P3 was overcoming the disbelief from the HCPs. He states;

> "*She'd [participants wife] get my right hand, like a train, the wheels going round. And we'd do this. And that got my arm moving. And the one physio, because I had a home care team come in, used to ask me what I was doing, he goes [healt care professional said] it was a pointless movement. But it got my arm going*."

For P1 it was important to start with early goals which were a struggle to achieve, following this the achievements lead to bigger and more impressive goals.

Consequences

Two main consequences were mentioned as a result of overcoming. These included (a) goals and achievements and (b) the influence and impact on peers and others.

Goals and achievements

Identification of goals which were to be achieved and changing these goals as improvements were made was clearly identified by P1 and P5. For instance, for P1 goals began in the hospital. They began with being able to independently go to the toilet and were something which continued from there, as he states

> "*I've achieved every goal that I've set myself, other than doing the physical cycle ride to Paris, which I realised was a non-starter in 2014. So I sort of gave up on that particular one. They started in hospital as the most basic, primitive drives. Being able to take myself to the lavatory by myself was my first goal. I was fed-up of people I didn't know having to support me in that very, very basic human function… My goals change and as you start to appreciate how you've improved or you can improve, you then can change your goals …I think improvement is infinite and that's what we should be doing in terms of giving people hope*'.

Having an impact on others

One of most consistent consequence and identified benefit was influencing others and wanting to help those who had to do through similar experiences (P1; P2; P3; P5). For instance, P5 had undertaken volunteering at a hospital and had become a counsellor to achieve this but now was more involved with research as they stated:

"*I did get involved with the [Major UK Stroke Charity] and as I say, counselling. But I've stopped the counselling now. I've pulled away from the [Major UK Stroke Charity] because I want to move on with my life. I don't want to be kept being pulled back, if you like. So doing research, yes, still keeps me involved, but in a good way*"

Critical moments within the plot

Two general moments were represented across individuals, this included moments when they recognised limited or negative support and moments when change was identified.

Moments of recognising limited or negative support

Several participants identified negative moments of support from HCPs. For instance, P1 identified that false despair could be caused through interactions with HCPs, he felt so strongly about this that he became involved in research to change health care. P2 identified feeling abandoned in hospital by HCPs. P5 highlights a moment of limited support stating;

"*I had my own room in the hospital, which was very nice. It had a complete, one window of glass, it was a very nice room. But I didn't meet any other people, although it was a stroke ward, I didn't meet any others. It would have been nice for staff to talk to me about my experience, or to put me in contact with someone else in a similar situation in hospital, but that didn't happen*."

Moments when change was identified or understanding what was possible

Several, critical moments existed when considering possibilities. This included moment when P1 identified the importance of family at a moment of being fragile, when support

helped change his view. In a similar way P7 had identified that a want and need to change her situation was driven from interacting with her daughter and wanting to change for her daughter's sake. P6 had a similar experience of being dependent on others in hospital. However, P6 had past experience of seeing life differently and was able to use any experience as an adventure, not sure of what would come from it;

> "*P6*; *I'm still coming to terms with it…. But I don't mind that… it's kind of an adventure to me*. Interviewer: *Could you just tell me when you started thinking I can treat it like an adventure."?...* P6: *Well, I have had the advantage of falling over – this is four years before my stroke. I fell over and I smashed my face. I tripped on a paving stone and I lost my sight totally in the eye….And from that time on it gave me the advantage of looking at life as learning new things… I have had lots of things that I call adventures. Meeting people unexpectedly in the street and being taken for coffee and finding out about them has been really fascinating actually"*

P3 realised that going back to normal wasn't possible although mobility could change. P5 identified a need early after discharge to leave her old life behind. This meant looking to the future and not at the changes from the past.

Discussion

To the best of the authors knowledge, this is the first study to consider the importance of the master plot overcoming the monster for people with stroke. The monster was represented in different ways. This included mental health difficulties, poor experiences of healthcare, and losses including a sense of self and independence. Individuals identified a period when overcoming wasn't possible, this may be seen as a time when individual have to survive, as such a time HCPs voices are critical in influencing the wellbeing of the individual who has had a stroke. Overcoming the monster required an ability to see that change needed, to identify a reason to fight for a person like a close other or people that could be helped. Interestingly, the identification of different types of monsters was associated with previously identified factors which remove hope and further the way the monster was overcome was closely aligned to factors which enable hope (Soundy et al., 2014).

HCPs need to be mindful of the medical voice that can result from training and influences how they respond to narrative master plots (Soundy et al. 2010). HCPs must also acknowledge and be prepared for simultaneous stories to be told by patient (Egbert et al. 2021). Responding to a highly recognisable (possibly perceived unrealistic) master plot, like Restitution, in a directive way may create a monster. A first step in interacting with narrative master plot may be to understand what the monster may be for the patient or exploring metaphors which could reveal the narrative and empower the individual (Ferguson et al. 2009). Training around the value supportive non-directive interactions e.g., (Soundy et al. 2021) could be central to aiding this process especially for those who identified the monster associated with isolation feeling isolated and experiencing overwhelming feelings. Alternatively, for individuals lacking motivation it may be important

to develop an autonomy supportive environment e.g., (Souesme and Ferrand, 2019). Further to this, adopting a storytelling approach to therapy may also be importance, since such interventions in stroke are associated with positive psychosocial outcomes such as coping, hope and support (Alawafi et al. 2021). It is possible that particular stories of overcoming the monster are more identifiable and accessible from peers as shown in peer interventions (Salter et al. 2008).

Motivation was gained out of positive and successful experiences and their appeared to be great value in understanding the importance of identifying and focusing on small improvements. This finding can be supported by the significant association between family support with motivation and self-efficacy identified in past research (Kurniawati et al. 2020). Supporting independence could be critical to this narrative and seeking positive improvements however small could lead to gains in self-efficacy and an ability to overcome created. This could reflect the importance of careful attention to narrative emplotment (Tropea 2011).

Understanding that the creation of such a plot can take years is important, so health care professionals and patients may need to wait for other plots to be expressed, the initial plots identified by people like wanting to be restored or having no hope require careful support. Rather than focusing on what is wrong with the plot there may be more value in understanding how to motivate individuals by knowing the strategies that enhance adherence (Oyake et al. 2020).

Clinical implications

Overcoming the monster may represent a master plot that evolves over time and may not initially be seen straight after Stroke. It is possible that clinicians recognise more common plots and may seek to correct them, not understanding what the monster is or that their

interaction could create a monster. Seeking to understanding patient metaphors may be one simple step to identifying a 'monster'. Metaphors may allude to a characteristic which the person has to maintain in order to successfully engage in rehabilitation. For instance, metaphors that represent a battle or fight, could represent the individual's character as a 'fighter'. In order to protect this type of characteristic it may be better to focus on smaller attainments and improvements than to address what may be considered as an unrealistic goal. Further to this, understanding how this type of narrative is accessed and is supported is essential. It may be that this type of narrative is accessed from peers that may illustrate how their own 'monster' was overcome.

One form of monster in the current study was poor interactions with health care professionals. To prevent this training that helps health care professionals understand the psychology of master plots is important and further research needs to consider this. It may be important that health care professionals recognise the importance of individuals with stroke in accessing peer stories and seek to offer a variety of stories in different formats (e.g., groups, tele-based, videos online).

Limitations

The focus of this research may be limited by the focus on one a-priori identified master plot. How dominate the master plot is cannot be established. A process of analysis using independent opening coding was not undertaken and no measures of agreement between authors. The applicability of this work may vary depending on the extent of deficits experienced (e.g., language, perception, or memory) or the side of the brain effected (Egbert et al. 2021). The results do not detail other demographical details e.g., years of education and it is acknowledged that stroke narratives can vary because of personality,

culture and psychological adaptation (Hinckley, 2006). The current work was not able to account for this.

Conclusions

Overcoming the monster represents an important master plot for healthcare professionals to understand. Healthcare professionals may further benefit from understanding the factors that influence it. This article supports past evidence around the importance of listening to stories in a non-directive way. Further research is needed that can consider health care professionals responses to this narrative master plot.

Ethical Approval: The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Ethics Committee of the University of Birmingham (ERN number: 17-0149).
Funding: The first author has received support for undertaking a PhD by the Saudi Arabia Government.

References

Alawafi R, Rosewilliam S, Soundy A. 2021. An integrative review considering the impact of storytelling and sharing interventions in Stroke. Behavioural Science, 11; 88. https://doi.org/10.3390/bs11060088

Andrews A. 2021. Quality indicators in narrative research, Qualitative Research in Psychology, 18:353-368. DOI: 10.1080/14780887.2020.1769241

Booker C. 2004. The seven basic plots: why we tell stories. Bloomsbury, USA.

Boylstein C, Rittman M, Hinojosa R. 2007. Metaphor Shifts in Stroke recovery. Health communication, 21; 279-287. https://doi.org/10.1080/10410230701314945

Earthly S, Cronin A. 2008. Chapter 21 Narrative analysis. In N .Gilbert (Ed). Researching social life, 3rd Edition, London, Sage.

Egbert AR, Pluta A, Poweska J, Lojek E. 2021. In search for the meaning of illness: content of narrative dis-course is related to cognitive deficits in stroke patients. Frontiers in Psychology, 11:548802. https://doi.org/10.3389/fpsyg.2020.548802

Ferguson A, Worral L, Davidson B, Hersh D, Howe T, Sherratt S. 2009. Describing the experience of aphasia rehabilitation through metaphor. Aphasiology, 24; 685-696. https://doi.org/10.1080/02687030903438508

France EF, Hunt K, Dow C, Wyke S. 2013. Do men's and women's account of surviving stroke conform to Frank's narrative genres? Qualitative Health Research, 23; 1649-1659.

Frank A. 1995. The Wounded Story Teller. Chicago University Press. USA.

Hinckley JJ. 2006. Finding messages in bottles: living successfully with stroke and aphasia. Topics in Stroke Rehabilitation, 13; 25-36.

Kurniawati ND, Rihi PD, Wahyuni ED. 2020. Relationship of family and self-efficacy support to the rehabilitation motivation of stroke patients. EurAsian Journal of BioSciences, 14: 2427-2430.

Labonte R, Robertson A. 1996. Delivering the goods, showing our stuff: the case for a constructivist paradigm for health promotion research and practice. Health Education and Behavior, 23; 431-447.

Luker J, Lynch E, Bernhardsson S, Bennett L, Bernhardt J. 2015. Stroke survivors' experiences of physical rehabilitation: a systematic review of qualitative studies. Archives of physical medicine and rehabilitation, 96; 1698-1708.

Mattingly C. 1998. Healing dramas and clinical plots: the narrative structure of experience. Cambridge University Press, Cambridge.

Mountain A, Linday MP, Teasell R, Salbach NM, de Jong A, Foley N et al. (2020). Canadian stroke best practice recommendations: Rehabilitation, recovery and community participation. Part two: transitions and community participation following stroke. International Journal of Stroke, 15; 789-806.

O'Brien BC, Harris I, Beckman T, Reed DA, Cook DA. 2014. Standards for reporting qualitative research: A synthesis of recommendations. Academic Medicine, 89: 1-7.

Oyake K, Suzuki M, Otaka Y, Tanaka S. 2020. Motivational strategies for stroke rehabilitation: A descriptive cross-sectional study. Frontiers in Neurology, 11, 553.

Pluta A, Ulatowska N, Gawron N, Sobanska M, Lojek E. 2014. A thematic framework of illness narrative produced by stroke patients. Disability and Rehabilitation; 37; 1170-1177. https://doi.org/10.3109/09638288.2014.957789

Salter K, Hellings C, Foley N, Teasell R, 2008. The experience of living with stroke: a qualitative meta-synthesis. J. Rehabil. Med. 40, 595–602. http://dx.doi.org/10.2340/16501977-0238.

Smith B. 2018. Generalizability in qualitative research: misunderstandings, opportunities and recommendations for the sport and exercise sciences, Qualitative Research in Sport, Exercise and Health, 10:1, 137-149, DOI: 10.1080/2159676X.2017.1393221

Souesme G, Ferrand, C. 2019. What is an autonomy supportive environment in geriatric care units? Focus group interviews with healthcare professionals. International Journal of Older People Nursing. 14; e12221.

Soundy A, Hemmings L, Gardiner L, Rosewilliam S, Heneghan NR, Cronin, K et al., (2021). E-learning communication skills training for physiotherapy students: A two phased sequential mixed methods study, Patient Education and Counseling, 104; 2045-2053.

Soundy A, Smith B, Cressy F, Webb L. 2010. The experience of spinal cord injury: using Frank's narrative types to enhance physiotherapy undergraduates understanding. Physiotherapy, 96: 52-58.

Soundy A, Smith B, Dawes H, Pall H, Gimbrere K, Ramsay, J. 2013. Patient's expression of hope and illness narratives in three neurological conditions a meta-ethnography. Health Psychology Review, 7:177-201.

Soundy A, Stubbs, B, Freeman P, Coffee C, Roskell C. 2014. Factors influencing patients' hope in stroke and spinal cord injury: A narrative review. International Journal of therapy and Rehabilitation, 21:5.

Tropea S. 2011. 'therapeutic emplotment': a new paradigm to explore the interaction between nurses and patients with a long-term illness. Journal of Advanced Nursing, 68;, 939-947. doi: 10.1111/j.1365-2648.2011.05847.x

Wood JP, Connelly DM, Maly MR. 2010. 'Getting back to real living': a qualitative study of the process of com-munity reintegration after stroke. Clin. Rehabil. 24, 1045–1056. http://dx.doi.org/10.1177/0269215510375901.

Woodmand P, Riazi A, Pereira C, Jones F. 2014. Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors. Disability and Rehabilitation, 36: 2031-2043.

Table 1 A breakdown of participant demographics

Participant ID	Ethnicity and Gender	Age	Time with stroke	Type of stroke
1	White British Male	62 years	15 years	Ischemic
2	Asian British Female	40 years	13 years	Multifocal
3	White British Male	64 years	12 years	Ischemic
5	Asian British Female	63 years	8 years	Ischemic
6	White British Female	80 years	16 years	Ischemic
7	White British Female	46 years	4 years	Ischemic

Table 2 Showing the breakdown of component of the overcoming the monster narrative

Participant	What was the monster?	What needed to be overcome?	How was it overcome?	Consequences	Critical moments
1	1. Threat of the illness on his mental health, ability to work and sense of self 2. The problems and aspects that went wrong in hospital	1. Mobility 2.Psycholgoical state, not believing what was possible. 3. Motivation and overcoming the feeling crushed by the experience but identifying that it was possible to improve your situation.	1. Identify goals and an action which are to be achieved from initial goals like going to the lavatory alone, to influencing research and presenting at conferences. 2. Having and benefiting family support 3. Fighting for independence and taking ground back that represented him	1. Achieve personal goals 2. Influence change and help others.	1. Identifying that hope is needed in some form and there is a danger of false despair, as much as false hope. He did this by focusing on improvement rather than recovery. 2.Identification of the need to change what was wrong with the health care interactions he had. A mission was begun. 3.Having family that support and encourage at a time or feeling fragile
2	1. The internal view of her situation and the mental health experiences that resulted 2. The difficulty and challenge faced when trying to change her situation and obtain support.	1. The isolation and feeling of being abandoned 2. being able to support her children independently	1. Need to 'fight' with social services to get support for her children 2. Sought counselling 3. identified a need to help herself 4.volunteering	1. Being able to help others with a stroke who faced similar difficulties	1. Feeling abandoned in hospital 2. Getting support for children
3	1.The physical effects of the stroke and impacting on the ability to leave hospital and on living post discharge 2.The inability to move 3. The doubt from health care professionals around the benefit of activities selected	1. Move in hospital enough to be discharged 2. That he wouldn't be back to normal in 3-6 months as he had originally thought post stroke 3. Continue to work 4. Mobility and movement against the odds	1.Increasing mobility 2.Identifying who he wanted to be and who he did not want to be 3.Identificaiton of being determined or 'bloody-minded' 4.Undertaking activities which were not prescribed persistently in order to obtain benefit	1.Using his disability to help others by volunteering	1.That going back to normal wasn't going to happen 2. realising that mobility could change

5	1. Within hospital. The need to come to terms with what was happening by herself 2. Being alone and not being able to identify with others in a similar situation	1. Inability to share experience with others within hospital and the feeling of isolation 2. The psychological difficulties as a result of this	1. Identification of what she wanted to do 2. Identification of achievements made that linked to what she wanted to do 3. Determination to prove 'everyone' wrong	1. Want to give something back 2.Becoming a counsellor and volunteer at a hospital 2. Seek to use her own experience to share with and help others move on and see that a 'new' life is possible. Identifying to them that they didn't have to seek to be restored or identify as life as being over. 4. Being able to identify, listen and understand others in order to help them	1.Coming to terms by herself with what has happened and the need to move on soon after discharge 2. Beginning a journey of helping others 3. That health care professionals were not able to do what she could.
6	1.Experience of a threat to independence and living 2. Not having a carer or being dependent on others	1.The isolation and inability to relate or talk to others 2. Identifying the need and negative outcomes of isolation 3.Understanding that uncertainty can be embraced when seen as an adventure	1. By fighting and benefiting from treatment 2.By using experiences to create change	1. Openness to change, knowing change was uncertainty by being willing to be open to embrace it as an adventure.	1.Inability to speak or community, dependent on others in hospital 2.Past experience of benefit finding and seeing the adventure that could be had
7	1.Mental health including depression 2.Lack of motivation and being disheartened	1.Motivation to engage in rehabilitation 2.Movation to want to change	1. Having a significant other encourage her 2.Motivated not to let the other down	1.Finding a way out of a place where mental health problems didn't impact on her and where symptoms were different	1. Experiencing mental health difficulties and a lack of motivation 2. Engagement with her daughter to create change.

Figure 1 A process illustrating how overcoming the monster narrative master plot was identified and analysed