

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

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Abstract

Background/Aims: limited research exists which considers master plots expressed by individuals with Stroke. The literature so far has focused on identified pre-established illness narrative types and further research needs address different master plots.

Methods: A narrative method was selected and a purposive sample of individuals with Stroke identified. A single online semi-structured interview was undertaken. A categorical-form analysis was undertaken.

Results: Six individuals with a Stroke present a specific narrative master plot named overcoming the monster. The results explore this narrative master plot. The 'monster' was represented in several ways in the current manuscript this included; 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 of health care.

Conclusions: Health care professionals need to understand the importance of understanding the master plot overcoming the monster. This research supports the need for health care professionals to recognise and support narratives by listening in a non-directive way.

What this paper adds:

- This paper identifies the importance of listening to, and understanding critical moments during rehabilitation which can be revealed within stories. It identifies the importance of understanding the story and the impact on the individual's mental health and internal feelings.
- This paper identified the importance of recognising the importance of providing an opportunity to identifying what a monster is, without these poorer interactions may be undertaken which can create another 'monster' that needs to be overcome.
- This research identifies the importance of being attentive to descriptions of events including metaphors, that can reveal experiences. This may be best achieved through non-judgemental and non-directive communication.

Reflective Questions

- Are you aware of what may need to be overcome?
- Can you consider how you may help patients have access to different types of stories 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 biographical history (Boylstein et al. 2007). Current guidelines (Mountain et al. 2020) for best practice illustrate the importance of covering many areas; in the desire to achieve best practice and cover all recommendations, physiotherapists could miss the value of the person's story. Personal accounts of illnesses are important to create social awareness, to reduce stigma towards the illness and influence research and policies (Boylstein et al. 2007). 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 narratives as it will allow a greater access to patients (Pluta et al. 2014), it will also challenge current 'therapeutic employment', which is the creation of stories through interactions, helping consider what is said (or not said) and how they act or what they conceal during an interaction (Mattingly 1998).

Narratives are often identifiable by genres or master plots. Frank (1995) describes this as the "*most general storyline that can be recognised underlying the plot*" (p.75). The most cited illness narrative master plots are often from this work including the quest, chaos and restitution narratives e.g., (Egberg et al. 2021; France et al. 2013). In chronic neurological illnesses including stroke other master plots have been named, for instance Soundy et al. (2013) identifies 13 master plots. Other master plots found in history and culture are often portrayed in film (Booker 2007) give an illustration the most common stories available to people, although, to the best of the authors knowledge they have not yet been considered against illness narrative master plots. One of these types which may be particularly

prevalence in stroke is named 'overcoming the monster'. Booker (2007) states that this story 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.

This 'overcoming the monster' master plot is important because narrative based studies in stroke have identified elements of it. 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). Further to this, the idea of recovery being a war and qualities of a person being a fighter are ever-present in stroke (Boylstein et al. 2007). HCPs need to be aware of such metaphors and how this links to this narrative master plot and patient would likely benefit from sharing stories that illustrate this. It is important to recognise that the 'monster' can be represented in different and unique ways for instance this could include the interpersonal challenges, cognitive, physical or emotional functioning (Pluta et al. 2014). The monster could be identified as symptoms of the stroke directly or experiences associated with having a stroke such as depression due to its high prevalence following a stroke (Wood et al. 2010), isolation (Salter et al. 2008), it could also include an individual social identity which is often associated with successful living post stroke (Hinckley 2006).

Research is needed that can consider what people use in their stories to illustrate the 'monster' and identify how they overcome that monster so that greater support for the aspects of dealing with the monster is possible. Research is also needed that examines the factors which may influence it, for instance adaptation is influenced by the ability to;

reappraise one's situation, make personal choices and accept what happened, the ability to use support networks and learning from others (Woodman et al. 2014). Alternatively, the ability to access such a story may be influenced by empowering interactions with others or disabling experiences of isolation (Luker et al. 2015). It is acknowledged that stroke narratives can vary because of personality, culture and psychological adaptation (Hinckley, 2006). However, gaining an insight to individual stories will be an important start to this research. This may be best achieved through a small sample of individuals that can look back on their own journey to narrate greater details of their experiences.

The aim of this study was to identify stories that illustrated the master plot of overcoming the monster and help individuals with Stroke and HCPs understand it and use it to help others.

Materials and Methods

Design

A narrative methodology was assumed situated within a 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 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 a local community 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).

Eligibility

Participants were included if;(a) Adults who were 18 years of age and over, (b) They were at least 2 years post stroke, (c) any type of stroke was included, (d) individuals had to be able to comprehend and answer questions and communicate through skype or zoom, (e) were able to provide informed consent. Participants were excluded if a translator was required.

Ethical approval

Ethical approval was obtained from the University of XXXXXX (ERN number: 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.

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. Four stages of analysis were undertaken; (1) Open 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, (2) A defensible case was made for the identification of master plots by the first author to the supervising author using mind mapping and tables to represent comments. (3) The selection of overcoming the monster plot was made. Identification of the elements of the story was undertaken by answering each of the following questions for the participants who presented it: (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? (4)

Finally, a description of the master plot from each participant who presented (See supplementary file) and summary of the plot given in tables (see below).

Trustworthiness in the narrative

We used a framework by Andrews (2020) to ensure quality with a focus on the story and ability to provide a plot summary for each individual that include a temporal framing, with critical moments identified.

Results

Demographics

Six participants (59±14 years; 2 male and 4 female) were selected as the master plot identified was associated with overcoming the monster. 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.

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. P3 realised he would not be back to 'normal' in 3-6 months.

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 not being able to have a carer and being dependent on others (P6).

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 and negative impact on dignity (P1). It was expressed as the difficulty faced when seeking support and care from

services and not receiving any (P2), and the doubt suggested by HCPs at what his own rehabilitation activities involved.

How was it overcome and consequences

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. Achievements represented one outcome and the other was the influence and impact on peers and others.

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). 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 them against the monster, that included being determined or bloody minded (P3), determined to prove everyone wrong (P5), motivated not to let someone else down (P7).

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. For P1 It was important to start

with early goals which were a struggle to achieve for P1, the achievements then lead to bigger and impressive goals.

Goals and achievements (consequence)

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 with being able to independently go to the toilet, they existed at his home with goals to ride miles on his recumbent exercise bike (e.g., from his home to Paris) and goals of sharing his experience of health care as part of training for health care professionals.

Having an impact on others (consequence)

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.

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 and P5 was able to help peers in a way she considered that HCPs which is (identifying a key limitation in the service provision).

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. P3 identified realising that going back to normal wasn't possible but realising that mobility could change. P5 identified early after discharge a need to leave her old life behind and begin a new one, so there was no looking back.

Discussion

To the best of the authors knowledge, this is the first study to consider the importance of the master plot overcoming the monster. The monster was represented as mental health difficulties, as the effects of poor experiences to care, and from the loss of a sense of self. 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 influence and support from others is critical, although a number identified the internal strength to change. 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. These aspects are central to the emplotment of the narrative (Mattingly 1998). HCPs need to be mindful of the medical voice that can result from training and influences how they respond to narrative types (Soundy et al. 2010). HCPs must also acknowledge and be prepared for simultaneous stories to be told by patient (Egberg 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 could be central to aiding this process e.g., (Soundy et al. 2021). Also 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 recent 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 employment (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

Further research is needed that can consider health care professionals responses to this narrative master plot. 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 (Egberg et al. 2021).

Conclusions

Health care professionals need to understand the importance of developing the overcoming the monster narrative master plot and understand what factors influence it. This article supports past evidence around the importance of listening to stories in a non-directive way.

Ethical Approval: The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Institutional Review Board (or Ethics Committee) of University of XXXXX (ERN number: 17-0149).

Funding: The first author has received support for undertaking a PhD by the Saudi Arabia Government.

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