

A qualitative study of the experience of psychological distress post-stroke

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Abstract

There is little qualitative data on the emotional effect of stroke upon which to base hypotheses for psychological interventions. We used Interpretative Phenomenological Analysis of semi-structured interviews with 10 individuals in the clinical range for psychological distress on the Hospital Anxiety and Depression Scale to explore their experiences of psychological distress. Three super-ordinate themes (the fear of stroke, loss of self and sense of isolation and aloneness) emerged. Processes involving a lack of acceptance and self-compassion underlined these themes. Internal isolation was found as a great problem. These themes may indicate targets for directed psychological interventions in people following stroke.

Keywords

anxiety, depression, psychological distress, qualitative, stroke

Introduction

Psychological distress is common post-stroke and has important clinical consequences (Hackett et al., 2005; White et al., 2014). It is common practice to simplify psychological distress as either anxiety or depression but it may be more appropriate to characterise individuals with the broader term of psychological distress to capture the complexity of the phenomenon (Schramke et al., 1998) and the cross over between diagnoses. Psychological distress in this context is defined as the presence of depression, anxiety, post-traumatic stress disorder (PTSD) and/or negative affect (Quale and Schanke, 2010). Stroke survivors with depression are more likely to be hospitalised and are more frequent users of health care services (Kotila et al., 1999). Higher levels of distress are associated with a range of adverse outcomes including greater social impairments (Shimoda

and Robinson, 1998), poorer quality of life (Haley et al., 2006), increased risk of incident stroke (Surtees et al., 2008) and even death (Williams et al., 2004).

The merits and role of psychological interventions post-stroke are poorly understood (Kneebone and Dunmore, 2000; Mitchell et al., 2009). It appears that the understanding of psychological distress from the perspective of the stroke survivor is limited, which has hindered empirical research in developing effective

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interventions. Our study aims to explore by means of qualitative analysis the lived experience of stroke survivors with clinically recognised psychological distress and explore the processes that underlie the experience, to try to inform future theoretical approaches and clinical interventions in the area.

Methods

Interpretative Phenomenological Analysis (IPA) (Smith, 1996) was selected as the method of qualitative investigation as it moves beyond description and thematic analysis, to interpretation of the data. In accordance with recommended methods for IPA (Reid et al., 2005), we identified 10 participants with radiologically and clinically confirmed stroke with onset between 1 month and 1 year prior to data collection. Subjects were identified by medical and nursing staff through the outpatients' clinics of the St James's Hospital Stroke service. Staff were asked to look for patients reporting or showing signs psychological distress following their stroke and were then seen by a clinical psychologist for further evaluation. Subjects with significant language impairment, cognitive impairment and other major co-morbid medical difficulties, or with a past history of psychiatric problems were excluded as these factors would either prevent completion of an interview or may have a confounding effect on psychological distress.

All subjects were 18 years or older as they were recruited through the stroke service of an adult hospital. They were all living at home and were independent for Personal Activities of Daily Living and remained under intermittent medical review by the stroke team during the study. Participants were required to have a clinical level of psychological distress defined as scoring above clinical threshold of 11 on the Hospital Anxiety and Depression Scale (HADS) total scale score (Aben et al., 2002; Sagen et al., 2009).

Data collection consisted of a semi-structured interview, which examined participants' experiences of stroke, a demographic profile and the HADS. The HADS total score has

previously been used as a general measure of psychological distress in stroke patients by other groups (Aben et al., 2002; Sagen et al., 2009). All interviews were recorded using two digital recorders. Interviews lasted between 51 and 112 minutes (mean, 74 minutes).

Data analysis

Recorded interviews were transcribed verbatim and the data were analysed using accepted IPA guidelines (Smith et al., 2009) throughout. Each interview transcript was read numerous times and themes were extracted on a transcript-by-transcript basis. Themes arising from each transcript were collated and subject to a verification process through reviewing the presence of the theme in all other transcripts. We performed an in-depth data analysis to facilitate the identification of a small number of themes as recommended by previous authors (Heffernon and Gil-Rodriguez, 2011). Similarly, we established super-ordinate and sub-ordinate themes through review of the presence of the theme and subjective importance of the theme.

In light of the fact that in IPA, the researcher's interpretation is fundamental to the analysis, we engaged in an in-depth prolonged engagement with the data and emerging themes to establish conformability and credibility of the research and supported this by validation of the themes by a second researcher. In addition, a clinical psychologist and research supervisor also conducted independent checks on the data analysis to ensure credibility as recommended in guidelines for conducting qualitative research (Elliott et al., 1999).

Ethical issues

Ethical approval was obtained from both the University and Hospital Ethics Committees. Informed consent was obtained from each participant. In case the interview process might uncover psychological or medical issues that would require urgent intervention, for example, unreported symptoms or apparent risk of self-harm, facilities were provided to allow urgent review by medical and psychological services within the hospital.

Table 1. Demographic profiles of participants.

Participant	Age (years)	Sex	Living arrangements (alone, with family, or with partner)	No. of stroke events	Time since recent stroke (months)
1	76	Female	Alone	1	9
2	80	Female	Alone	1	3
3	60	Female	with partner	1	1.5
4	76	Female	with family	2	12
5	56	Male	Alone	1	6
6	53	Male	with family	1	2
7	76	Male	Alone	1	2
8	58	Male	with family	1	12
9	78	Male	with wife	1	12
10	73	Male	with wife	2	4

Table 2. Super-ordinate and sub-ordinate themes.

The fear of stroke	The loss of self	Sense of aloneness and isolation
1. 'There's no warning, that's the bit really'. (The terror of the suddenness of stroke)	1. 'I would love just one semblance of myself back again'. (The loss of the pre-stroke self)	1. 'It's lonely very lonely'. (Being alone in the world)
2. 'Watch ye therefore, you know not the day or the hour'. (The terror of the aftermath of stroke)	2. 'It's not enough for me just to be living and surviving'. (The inadequacy of the post-stroke self)	2. 'You are suffering on the inside'. (Feeling alone in the world)

Results

The demographic profiles of the 10 participants are outlined in Table 1. Three super-ordinate themes emerged from the interview data that reflected participants' subjective experiences of stroke, with particular reference to the experience of psychological distress. Interpretation of the results indicated that meta-psychological processes of lack of acceptance and self-compassion underlined these themes. A summary of the emergent super-ordinate and sub-ordinate themes is presented in Table 2.

The fear of stroke

This super-ordinate theme permeates the narratives and refers to the fear elicited by (1) the suddenness of stroke itself and (2) the on-going

fear associated with living with the awareness of mortality in its aftermath. One subject gave a voice to the shared sense of fear, when he described stroke as

'frightening, very frightening, because the word stroke falls into the same category I think as cancer'. (Participant 7)

The distress at the sudden unexpected nature of stroke was revealed through discussion of feeling unprepared and accounts of health vigilance and anxiety.

The unanticipated onset of stroke, denying the individual a period of adjustment, seems fundamental to understanding this fear. Without an opportunity to be prepared physically or psychologically for the onset of stroke, participants described feeling vulnerable, exposed or caught

unaware by stroke. This seemed to enhance the experience of stroke as threatening and terrifying:

‘there’s no warning, that’s the bit really, there’s absolutely no warning. You’re fine one minute, the next minute that’s it, you’re gone’. (Participant 3)

However, understanding the participants’ sense of fear involved expanding the frame of reference from literal fears of reoccurrence to touching on existential concerns elicited by stroke. The stroke event was critical in bringing awareness of mortality to their lives, with the time post-stroke feared as ‘borrowed time’ (Participant 4). All participants talked about the impact of stroke as unleashing ‘the fear of the unknown’ (Participant 1), with an awareness of their own mortality fundamental to their distress:

the bigger side effect of it was upstairs, you know, mentally, mentally, it has affected me a lot ... It’s a lack of confidence, it’s a fear and it’s hard to really admit to the fear, you know, because I was never afraid. (Participant 5)

Overall, participants struggled to show compassion for their feelings of fear, and their perceived inadequacy in not overcoming them.

The loss of self

The second major theme identified represented (1) a lament for the pre-stroke self and (2) a rejection of the post-stroke self. Participants offered a narrative about their past selves, which highlighted the contradiction incumbent in their post-stroke selves. For many, the stroke had taken a core sense of identity from them through the loss of former activities, lifestyles and roles, and they struggled to forge a new sense of identity. Participants were clear in delineating two versions of self: the person pre-stroke and the person post-stroke:

from the minute the stroke till now something’s after switching in my brain and I’m not the same person. (Participant 6)

The loss of a sense of self was compounded by the loss of former life coping strategies.

Indeed, for most participants, the coping styles that they had employed in the past were no longer useful to them and left them feeling vulnerable. They identified that in their former roles as parents, or breadwinners, or caregivers, distressing events were not processed but instead worked through because of the demands of daily life:

I mean I hadn’t ever a history of depression, although I had a lot of things to be depressed about. But I sort of got myself up and got going you know? (Participant 1)

Because of their ages, many of them no longer had the same demands or routines in life that they may have previously used to facilitate distraction from distressing events. For most of the participants, defining recovery from stroke necessitated a complete return to their post-stroke selves. The person post-stroke was rejected and instead there was a desire to ‘*resume where I left off*’ (Participant 10).

Loss of energy and loss of youth were identified as significant obstacles in returning to their pre-stroke selves. Many narratives outlined criticisms and rejections of the post-stroke individual. Underlying the rejection of the post-stroke self was a lack of self-compassion. In particular, many accounts showed a lack of compassion for the toll the emotional impact of stroke had taken on them:

I feel sad and I have nothing to feel sad for. (Participant 4)

Indeed, self-compassion seemed fundamental in enabling individuals to accept the changes associated with stroke and ultimately their post-stroke selves. This incongruence between their apparent physical health and their psychological well-being was fundamental in understanding their distress:

If I was handicapped here now I’d accept it but I’m not handicapped. I have all my powers, I’ve everything back ... I know in my head I’m not right but physically I’m ok. (Participant 6)

It seems that for many of them, there was a perception that physical ill-health could be

tolerated or accepted following stroke in a way that the psychological difficulties could not be.

Sense of aloneness and isolation

This theme addresses aloneness from two perspectives: (1) an external aloneness associated with a withdrawal from people and activities and (2) an internal aloneness associated with psychological isolation from others. We describe this as aloneness which incorporates both a sense of being set apart from others, and loneliness, the emotional consequence of this.

Most participants identified a sense of external isolation associated with their stage of life, living circumstances and loss of engaging in their previous lifestyle and roles as highlighted in the previous theme. Stroke seemed to be an important catalyst in highlighting a sense of vulnerability, which led to many of them becoming aware of loneliness in their lives. For some individuals, the sense of loneliness could be related to a life stage where their children had grown up and people close to them had died:

I'd a great marriage and a great husband and good family and they never gave me any sort of trouble or anything; just they went away [laughs]. (Participant 1)

For many of them, the psychological distress associated with their stroke was compounded by having to cope with stroke without their previous levels of social support. In this context, discharge from services was heralded not as a marker of progress, but instead as a termination of help available.

All participants described an internal isolation, which entailed feeling psychologically alone in their experience of stroke. Indeed, all narratives identified a sense that other people could not relate to the experience of stroke without having experienced a stroke themselves. Participants seemed unable to communicate to others the psychological impact of stroke for them:

to really understand it, you have to have had a stroke. (Participant 8)

Internal isolation was also associated with a need to protect the self and others from the participants' distressing thoughts and feelings. Participants seemed to desire other people to understand the impact of stroke for them, although they also colluded with other people in not exposing their vulnerabilities. Their investment in hiding their feelings from others meant that for some participants social interactions had become superficial:

Nobody wants to know the gory details of anything, you know, so you just kind of gloss over everything. (Participant 3)

for the people outside, I would put on a different persona, type of thing, you know, like, I would try to be the same as I was before I had the stroke. (Participant 5)

Without a sense of shared experience, participants experienced an internal isolation that was fundamental to their psychological distress. For them, the emotional impact of stroke was lost on other people:

'people don't understand it, how frightened you would be'. (Participant 4)

'You might look at me and say 'But you look alright'. But I amn't alright really'. (Participant 6)

Finding a way to feel connected with others and within their experience was identified as essential in facilitating them to live with stroke. Developing acceptance and self-compassion appeared important in allowing them permission to seek connectedness with others in their experience of stroke.

Discussion

This study explored the subjective psychological stress for individuals with experience of stroke. IPA analysis revealed three themes: the fear of stroke, the loss of self and the sense of

aleness and isolation. Meta psychological processes relating to acceptance and self-compassion underlined the themes, and seemed fundamental to understanding the participants' experiences of psychological distress.

This study thus provides an insight into the association between stroke and psychological distress, providing further clarity as to the experience of psychological distress in stroke survivors. To a degree the study findings substantiate and extend previous findings (e.g. that social isolation is associated with psychological distress) and further outline how the nature of the experience of aleness (internal vs external) may be most critical in determining interventions post-stroke. It is, however, the first study to document a role for self-compassion in the experience of psychological distress post-stroke similar to that outlined in other health conditions (Alaszewski et al., 2004).

Fear associated with the stroke occurrence was fundamental in understanding the participants' psychological distress. The subthemes reflected the different ways stroke elicited fear; namely, through the suddenness of stroke that denies the individual an opportunity to adjust and through the realisation of practical and existential concerns in the aftermath of stroke. Studies have shown evidence that opportunities for patients to adapt to illnesses such as cancer evolve over time, facilitating integration of the illness into the individual's world (Heim et al., 1997). The narratives suggest that the suddenness of stroke may limit opportunities for integration. Research has outlined acceptance of mortality as one of the key processes in adjusting to stroke (Ch'ng et al., 2008). A recent study found that stroke survivors exhibited significant post-traumatic growth following their event and could integrate the event into their identities (Kuenemund et al., 2014). Interestingly, although fears and anxieties pre-dominated the narratives, this did not preclude concurrent experiences of acceptance of stroke at times. Throughout their accounts, there was a nuanced and fluctuating relationship with fear whereby fear is succumbed to, challenged, denied and acknowledged in the struggle to come to accept

stroke. A reciprocal relationship was evident between participants' acceptance of stroke and their ability not to be paralysed by fear, with those describing an acceptance of their condition able to move forward with living.

Many of the narratives indicated that participants were dismissive or critical of their own feelings of fear. The findings draw attention to the potential relationship between self-compassion and acceptance in coping with psychological distress. Although not explicitly linked to the concept of self-compassion, research with stroke populations has found that acceptance of a concept that 'this is good enough' is important in coping psychologically with stroke (Carlsson et al., 2009).

The loss of a sense of self also emerged as important to understanding the participants' psychological distress, with subthemes elaborating on the significance of the loss of the pre-stroke person and the rejection of the post-stroke identity in this distress. The majority of the participants were orientated towards what had been lost to them through their experience of stroke. Models have highlighted how in stroke a focus on what is lost negates opportunities for adjustment (Murray and Harrison, 2004; Taylor et al., 2011). Our study may indicate that the development of a self-compassionate mind-set that acknowledges what is lost and re-orientates compassionately to a present and future self may be helpful in reducing on-going distress and that loss is most detrimental to psychological well-being when self-compassion is absent.

The sense of isolation in our subjects was evident in two perspectives: being alone in the world and feeling alone in the world. Our results suggest that the sense of social isolation is fundamental in understanding psychological distress. All the accounts recorded illustrated an internal isolation in living with stroke, whereby there was a sense of a disconnection from humanity that only other stroke survivors could understand. There was an apparent consensus that in order to understand stroke an individual needs to have experienced it. This finding suggests that it may be beneficial for stroke survivors to interact with others who have also

experienced stroke. Certainly, research has outlined the importance of connectedness in the process of recovery from stroke (Lamb et al., 2008), and outlined the benefits of engaging with stroke groups (Bishop, 2002).

Recommendations

An experience of stroke is associated with psychological distress for many stroke survivors. For those who are clinically distressed, current interventions frequently centre on medication management of psychological distress (Hackett et al., 2005) rather than trying to identify and address the underlying cause. The themes identified in the present study relate to factors which could be susceptible to psychological interventions. The results suggested that a lack of self-compassion underpinned the subjects' experiences of distress and, although our interview group was small, it may be worthwhile examining approaches that focus on the development of self-compassion in addressing psychological distress in stroke populations (Bishop, 2002). The findings in this study also outline internal aloneness as an equally important aspect to social isolation in contributing to the experience of distress. It is possible that group-based therapy may offer opportunities to address the aloneness of the stroke experience while facilitating de-stigmatisation and relatedness to others with similar experiences (Reed et al., 2010). A larger study of stroke survivors would be of benefit to identify the prevalence and relative contributions of the factors and themes identified in this qualitative study.

Conclusion

Psychological distress experienced by people following stroke is complex and multifaceted. The distress is associated with an understandable fear of recurrence of stroke but also with what is a less obvious sense of internal and external isolation following the event combined with a loss of self and lack of self-compassion. All these elements may be susceptible to therapeutic intervention to reduce the distress suffered by stroke survivors.

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