Disability and Rehabilitation
An international, multidisciplinary journal

http://informahealthcare.com/dre
ISSN 0963-8288 print/ISSN 1464-5165 online

Disabil Rehabil, 2014; 36(19): 1600–1607

DOI: 10.3109/09638288.2013.859748

informa
healthcare

RESEARCH PAPER

Exploring the experience of psychological morbidity and service access in community dwelling stroke survivors: a follow-up study

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Abstract

Purpose: Post-stroke depression occurs in one-third of stroke survivors with a similar risk of development across short, intermediate and long-term recovery stages. Knowledge of factors influencing psychological morbidity beyond the first year post-stroke can inform long-term interventions and improve community service access for stroke survivors. This paper aimed to identify the physical and psycho-social functioning status of stroke survivors beyond 12 months post-stroke. Qualitative processes explored the longer term experiences of psychological morbidity and service access needs. *Method*: A cross-sectional follow-up of participants from a prospective cohort study. In that study, patients and were followed for 12 months post-stroke. In this study, participants from that cohort study were interviewed up to five years post-stroke. Data generation and analysis were concurrent and were analysed thematically, employing a process of constant comparison. *Results*: Our sample included 14 participants, aged 58–89 years at an average of three years post-stroke (range 18 months to five years). Our qualitative key themes emerged as follows: physical impacts on post-stroke psychological morbidity, the experience of psychological distress, factors attenuating distress and service delivery implications. *Conclusions*: The experience of psychological morbidity persists beyond 12 months post-stroke, having a profound impact on community access, and social participation. Clinical implications are a need for long-term psychological monitoring post-stroke and for ongoing rehabilitation that addresses disability, community participation and social support.

Keywords

Outcomes, post-stroke depression, qualitative, rehabilitation, stroke

History

Received 8 May 2013
Revised 9 October 2013
Accepted 23 October 2013

➤ Implications for Rehabilitation

- Psychological distress post-stroke is complex and persists over time, thus requiring longer term monitoring beyond the first 12 months of stroke onset.
- Longer term access to allied health can play a significant role in providing interventions that address distress and maintain community participation.
- If patients meet threshold scores at any time, then GPs should consider initiating appropriate treatment, including pharmacotherapy, referral to psychotherapy and referral to community stroke rehabilitation.

Introduction

Post-stroke depression (PSD) is the most common neuropsychiatric condition in stroke survivors [1], and a recent systematic review of observational studies indicated that one-third of stroke survivors will experience PSD at some stage [2]. The extent of PSD is a clinical concern and has been shown to have an adverse impact on rehabilitation gains and function and social outcomes [3–10]. In order to identify and treat psychological morbidity post-stroke, stroke management guidelines emphasise the importance of early detection and management of mood disorders [11,12].

Anxiety frequently occurs after stroke and prevalence ranges between 20% and 25% [13]. However, psychological morbidity following stroke is a broader construct than PSD and anxiety and includes sub-syndromal mood disturbance (such as mood disorders, which do not fit the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) classification of major depression) and other psychological morbidities experienced in the post-stroke period [5].

Early targeted therapy to treat and prevent psychological morbidity post-stroke is facilitated by knowledge of the prevalence of, and qualitative experience of, psychological morbidity over time. Quantitative studies up to 12 months post-stroke have found the prevalence of depression to remain as high as 45% [14,15], while studies beyond 12 months (and up to 3 years) found the prevalence of depression to remain at 30% [16,17].

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Compared to the extensive quantitative literature concerning psychological morbidity post-stroke, there is much less evidence from a qualitative perspective. However, a systematic review of qualitative studies of the general experience post-stroke identified the experience of stroke as being influenced by the extent of disruption to life and role loss, needs of patients and their families, and priorities for, and barriers to, care [18].

Longitudinal research can assist in understanding the complexity of the post-stroke experience of functioning, psychological morbidity and service access [19,20]. As part of a broader research program, we have completed a follow-up study of a larger longitudinal mixed-methods study exploring psychological morbidity post-stroke. The first arm of the study was a twelve-month longitudinal qualitative exploration of psychological morbidity post-stroke, which identified four different trajectories of psychological morbidity post-stroke: resilience; ongoing crisis, emergent mood disturbance and recovery from mood disturbance [20]. The quantitative arm identified that anxiety is more common than depression immediately post-stroke. However, anxiety attenuates while the burden of depression persists over 12 months [20]. We were interested in exploring the longer term functional status and psychological experiences of this cohort, who were now up to five years post-stroke following completion of the larger study, in order to identify their potential ongoing healthcare needs. The aim of this paper is to present results of a follow-up interview exploring the longer term physical and psycho-social functioning status post-stroke. Qualitative processes explored experiences of psychological morbidity and service access needs.

Method

Study design

This was a follow-up of participants involved in the larger, mixed methods, 12-month longitudinal study ($n = 134$) [20]. We used both quantitative questionnaires and qualitative interviews to explore the research questions [21]. Qualitative methods are appropriate for answering research questions about experiences and provide contextual influences [21]. This study used an inductive thematic qualitative approach with semi-structured interviews, and constant comparison drawn from the grounded theory tradition [21,22].

Ethical approval for this project was obtained from Hunter New England Health Research Committee (No. 07/04/18/5.02) and the University of Newcastle Human Ethics Research Committee (No. H- 2008-0273).

Recruitment

Participants were recruited from the larger prospective study of stroke survivors from Newcastle and surrounds in NSW, Australia [20]. Inclusion criteria were as follows: hospital admission and history and examination consistent with stroke as determined by a stroke physician. Participants were excluded if they had significant language or cognitive impairment (Mini-Mental State Examination Score ≤ 24) [22]. Consenting participants were interviewed at baseline (as near as practical to stroke onset), 3, 6, 9 and 12 months (between January 2008 and July 2011). This follow-up study explored patients in the larger study outlined above and involved supplementary cross-sectional single interviews conducted in March 2012.

To obtain an in-depth understanding of the long-term experience of psychological morbidity following stroke, we aimed to invite all the participants completing the larger study to undertake a follow-up interview. Fifty-four people were unable to be located, had moved to a residential care facility or were deceased. As a result, all remaining potential participants ($n = 80$) were sent an information letter and written consent form inviting them to participate in an interview. Participants were contacted by telephone to organise the interviews at a location convenient to them.

Data generation

Supporting quantitative measures

Assessment of physical and psycho-social functioning was undertaken using a range of validated measures and used to contextualise qualitative findings. Psychological morbidity was assessed using the Hospital Anxiety and Depression Scale (HADS) [23–26]. A total HADS score is an acceptable measure of psychological distress (≥ 13 equals high level distress, while < 13 equals low level of distress) [24,27]. Disability was assessed using the Modified Rankin Scale (MRS), which has been widely used internationally to assess disability after stroke [28,29]. Quality of life was assessed using the Assessment Quality of Life (AQOL) [26]. The AQOL has been validated as a useful instrument for assessing health related quality of life in an Australian stroke population [30]. The Adelaide Activities Profile (AAP) [31] has been validated in elderly neurological populations to measure community participation and lifestyle activities.

Qualitative data

Semi-structured individual interviews were conducted and recorded with the participants' permission and transcribed verbatim, with identifying data removed. An interview schedule of questions was formulated to guide the interview (Table 1). Interviews began by asking participants to share the ''story'' of their stroke onset as a means to develop rapport, and subsequent questions explored their experiences of emotional distress and service access post-stroke. Emerging themes were able to inform continuing data collection during interviews, resulting in the question schedule evolving in an iterative manner between interviews [32].

Table 1. Interview schedule example.

Building rapport	When was your stroke? (Where? Length of stay?)
Prompts	How did the stroke affect you?
	How do you find being at home with these symptoms?
	Were there any major adjustments?
Question one: (psychological distress)	How has your mood been since the stroke?
Prompts	Do you feel your back to yourself since the stroke?
	Have you ever have any up or down times?
	Do you ever feel lonely, depressed, anxious or fearful?
	Have you ever had any times where you have been distressed or down in the dumps?
	(Recently? Stroke related?)
	What helps you through the tough times?
Question two: (service access)	Are there any services you would have found helpful following you stroke that you did not receive?
Prompts	Is there anything you feel you still need or want from the health service?

Data analysis

Quantitative

Quantitative data analysis was performed using STATA 11.0 (Stata Corporation, College Station, TX). Differences in demographic variables, and scores on AQOL, HADS and AAP between participants and non-participants in this study (of those invited to participate) were analysed using Mann–Whitney for the continuous variable (age) and chi-squared tests for the categorical variables. For comparison of responders with non-responders, we compared 12-month interview data on physical and psycho-social functioning collected in the larger study. The level of significance was set at 0.05.

Qualitative

Qualitative data analysis was conducted by the first and second author researchers. Both researchers were occupational therapists, with one located within a research setting and one located within a university setting. The inductive analysis process included the three types of constant comparative method [21,22]. This involved the following: (1) identifying units of meaning using a process of reading the transcripts line-by-line; (2) grouping units into categories whereby each category was labelled and given a four-letter code to assist with retrieval between the data (for example role loss was labelled as RLOS), irrespective of the research question; and (3) examining relationships between codes in the context of the research question in order to form themes. This form of coding is effective as it allows for retrieval of data between transcripts and providing scope to cross-check the appropriateness of codes. Final integration of themes was conducted within and between each individual transcript. Consistency of findings was upheld through discussion of interpretations between researchers to confirm codes and categories. Any differences in researcher perspective were resolved by negotiation and, if necessary, regrouped and recoded until consensus was reached. New codes were then fed back into the analysis to cross-check codes and themes and develop an overall interpretation of the data. Lincoln and Guba's work (1985) [33] guided the analysis process to ensure rigor, through the strategies of credibility, transferability, reliability and conformability. Rigor was established by methods of peer review and peer debriefing with a co-researcher. Both during and after each interview, the researchers' recorded reflective notes about the content and process of the interview, in order to ensure investigator reflexivity.

Results

Demographic characteristics of respondents (response rate: 15.55%) are outlined in Table 2. The majority of participants were male (57.14%) with a mean age of 73.43 (age range 58–89) years. Ten of the 14 participants were married (71.12%). Participants were an average of three years post-stroke (range 18 months to five years). Using the MRS [28,29], all but one participant were classified as independent (MRS ≤ 2) at the time of the follow-up. There were no significant differences in the age, gender and living situation, country of birth or marital status of the 14 responders compared to non-responders (Table 3). The mental health (HADS) of responders was better than that of non-responders. Median responder HADS scores were lower than the scores of 8–10 recommended to identify mild cases [34] of psychological morbidity. The median score of non-respondents at their 12-month time-point was above this cut-off. There was a non-significant trend for health-related quality of life (HRQoL) to be poorer in participants than non-participants as lower scores on the AQoL reflect lower HRQoL (Table 3).

Qualitative interviews ranged from 30 to 90 min, and four key themes emerged from the data: the physical impacts on post-stroke psychological morbidity, the experience of psychological distress, factors attenuating psychological distress and service delivery implications.

Table 2. Participant demographics.

Participant no.	Gender	Age range	Marital status	Years since most recent stroke	MRS[a]
1	Male	70–75	Married	2.5	2 (I)
2	Female	75–80	Widowed	3	0 (I)
3	Male	75–80	Married	3	1 (I)
4	Male	75–80	Married	2.5	2 (I)
5	Female	85–90	Widowed	4	2 (I)
6	Male	75–80	Married	4	2 (I)
7	Male	70–75	Divorced	2.5	1 (I)
8	Female	70–75	Married	5	1 (I)
9	Male	70–75	Married	3	1 (I)
10	Female	60–65	Married	1.5	3 (D)
11	Male	65–70	Married	3	1 (I)
12	Male	65–70	Married	2	0 (I)
13	Female	80–85	Widowed	4	2 (I)
14	Female	55–60	Married	2	2 (I)

[a] Modified Rankin Scale [28] categorization as follows:
I = independent' (MRS ≤ 2).
D = dependent' (MRS ≥ 3 and ≤ 5).

Table 3. Demographics and outcomes of responders and non-responders.

Variable	Class	Respondents	Non-respondents	*p* Value
Age (years)	*n*	14	66	0.0860
	Mean (SD)	69.7 (8.55)	74.8 (12.78)	
	Median (min, max)	69 (53, 86)	78.5 (37, 96)	
Gender	Male	8	29	0.368
	Female	6	37	
Live alone	No	10	37	0.289
	Yes	4	29	
Born in Australia	No	3	5	0.117
	Yes	11	61	
Marital status	Not married	0	14	0.410
	Married	10	28	
	Widowed	3	24	
Distress at 12 months (HADS)	Mean	5.6	10.0	0.0051
	Median	4	9.5	
HRQoL at 12 months (AQoL)	Mean	23	26.6	0.054
	Median	22	26	
Participation at 12 months (AAP)	Mean	30.1	22.8	0.11
	Median	29.5	23	

Physical impacts on post-stroke psychological morbidity

The onset of stroke and experience of ongoing residual symptoms was an individual experience for participants. However, the ongoing adjustment to stroke was a core experience being closely linked to the experience of stroke symptoms, co morbidities, the ageing experience and fluctuating role loss. The most commonly reported ongoing residual symptom, expressed beyond the first 12 months post-stroke, related to cognitive changes, in particular memory loss and was a source of worry for many participants.

> The only worry I've got is my memory. Because I've always had such a good memory and all of a sudden as I said it's affected it and its slowly getting worse. (Participant 4, male)

Participants reported that they had become increasingly inactive over time because of physical limitations post-stroke. As a result, they had ceased participation in one or more valued roles that were manageable before stroke. Role loss was reported in all activities including: activities of daily living, sport, leisure and social outings. However, the roles most focussed on when describing loss were leisure (such as gardening, cooking, playing music, reading, participating in sports including lawn bowls and golf) and social outings.

> I'd love to play golf, walk the golf course, but I just can' do it . . . I haven't got the strength in my legs to do it anymore. (Participant 4, male)

Participants also remarked on the impact of post-stroke fatigue over time. The experience of fatigue had a debilitating affect that was unpredictable and impacted on ability to participate in valued roles. For example, one participant commented on her frustration when she continually fell asleep in the company of her daughter.

> My body. . ..well I just fall asleep. ''My god, wake up'', I tell myself. Just, my body just goes, that's it. (Participant 1, female)

As participants adjusted to living with residual deficits following their stroke, they reflected that day-to-day functioning was influenced by other factors including co morbidities such as hearing loss, arthritis, orthopaedic conditions, cardiovascular disease and living with pre-existing injury. Indeed, these experiences of ongoing health issues further impacted on role loss and reduced participation in social outings. For example, many participants identified that hearing loss was a barrier to going out and socialising.

> When you can't hear people, you can't [go to functions]. I used to love to go to parties you know, and enjoy. That's all finished you know. (Participant 3, male)

Moreover, most participants reported the common experience of being *''slowed down'' (Participant 3, male)*, which they attributed to *''getting old'' (Participant 10, female).* It was apparent that most participants were resigned to the experience of being less active to which they attributed to the ageing process.

> It's because I'm getting older . . .. old body's not as tolerant as it used to be. (Participant 14, female)
>
> I never used to think of getting old, never, and now I do. (Participant 10, female)

The experience of psychological distress

Psychological distress was reported by all participants and was described as being experienced on a continuum from greater to lesser symptoms. For many participants, the acute phase of stroke recovery was characterised by feelings of shock.

> I was a bit shocked really because . . . suddenly I couldn't do it [daily tasks]. Yeah so I am still that way now. (Participant 9, male)

Participants relayed that psychological emotional challenges were most commonly encountered following discharge from hospital and when the reality of role limitations due to stroke were confirmed. For example, one participant stated:

> There's nothing I can do. . . . that gets me down at times. (Participant 3, male)

Following the initial shock of having a stroke and being discharged home, participants reported that ongoing psychological challenges were attributed to making adjustments and other life stressors such as financial difficulties or family discontent. At the time of the follow-up interview, participants reported their mood and level of psychological distress continued fluctuate from experiencing *higher levels of distress* to *''coasting along'' (Participant 12, male)*. One participant indicated that while their experience of ''depression'' (*Participant 10, female*) was no longer as acutely experienced, they still reported ongoing struggles.

> I went through depression. I still have my little spats. I have what I call my dark days. (Participant 10, f male)
>
> Well at first, at first it got to me. Coz I was always the stronger one [in our relationship]. But now, I've, I just got to let it happen because I can't do anything else anyway. (Participant 5, male)

Fluctuations in psychological distress were closely linked to the ongoing experience of stroke symptoms and subsequent role loss. As a result, participants experienced an array of emotions such as regret, guilt, frustration, dependency and loneliness, which were still evident beyond the first year after stroke.

> It's the guilt that I am not busy like I was before. (Participant 14, female) .

One participant felt her family did not understand the extent of the impact that having had a stroke had on her ability to undertake her previous role as a mother and care-provided. Indeed, this participant felt there was pressure to perform to the same capacity as prior to stroke.

> I sort of got the feeling that they felt 'ok mum your over this now, come on everything is back to normal, come on, get back into it.' And even to this day I still have days where I think they've got no idea what I went through. (Participant 14, female)

Indeed, ongoing functional limitations were closely linked to the need to rely on other people to assist in maintaining involvement in valued pre-stroke life roles. In several cases, there was an emerging pattern where participants were less inclined to undertake, or withdrew from, previously valued roles due to *''having to rely on somebody'' (Participant 10, female).* Alternatively, participants were worried by their inability to perform tasks to the same standard as pre-stroke. Indeed, one participant indicated they were *''frightened of messing things up you know, or saying the wrong things'' (Participant 9, male).* Another participants stated his current ability to play music was *''disgusting'' (Participant 3, male)* in comparison to pre-stroke.

Feelings of regret were commonly experienced by participants and were associated with feeling guilty about being dependent on others and ''having to rely on somebody and I didn't have to before'' (*Participant 10, female).* As a result, many participants were aware of the increased burden on their spouse or family to attend to their reduced abilities and care for them following stroke:

> I realise since we've had this problem [stroke] she [spouse] has taken over the headship of the house because I couldn't . . . she just suggests things which I appreciate. (Participant 9, male)

Overall, the experience of altered participation or role loss in participants highlighted feelings of increased social isolation and loneliness over time which compounded feelings of psychological distress.

> I am basically like a cabbage sitting in a corner and that does annoy me. (Participant 9, male)

Factors that attenuated psychological distress

At the time of the follow-up interview, most participants acknowledged that they had accepted the changes to lifestyle following stroke. Participant's acceptance of life style changes due to stroke was facilitated by the time that had passed since stroke onset and return home from hospital and resulted in attenuation of psychological distress.

> Well at first, at first it got to me . . .But now, I've, I just let it happen coz I can't do anything else anyway. (Participant 8, female)

Participants' adaptation to their post-stroke life, and their consequent adaptation, was mostly non-passive. Though the passage of time might be beneficial, participants also developed strategies to maintain or improve emotional wellbeing. Indeed, participants endeavoured to manage the problem of fluctuating distress over time. A number of strategies were identified by participants as having an impact on better mood: internal locus of control, reflexivity, positive perspective, motivation and social support.

Some participants demonstrated a strong internal locus of control, that is, the belief that outcomes resulted primarily from their own behaviour, having a desire: *''to beat this'' (Participant 1, male).* These participants were less reliant on external sources for motivation (such as therapists and family) towards ongoing recovery and focussed on active behaviours such as *''learning to do it again'' (Participant 5, female).*

Improved emotional wellbeing over time was facilitated by reflexivity including insight into own recovery and *''improving step by step'' (Participant 2, female).* Participants who were able to compare their experiences of stroke recovery and quality of life to other stroke survivors, tended to have fewer fluctuations in their psychological morbidity.

> When I compare myself, I'm still lucky. (Participant 3, male)
>
> Well I think how lucky I am from that stroke . . . [some have] gone into care now because [of] . . . a slight stroke. So you have a lot to be grateful for, don't knock it! (Participant 5, female)

Maintaining a positive perspective was facilitated by factors such a pre-morbid personality, acceptance, and being less inclined to *''worry about things you can't do, you can't help it, that's it!'' (Participant 6, male).* The modulating factor of faith was characterised by a significant sense of acceptance to changes of routine and role loss since stroke and that *''everything's for a reason. . . and you can sit down and smell the roses more'' (Participant 8, female).*

> as long as we stay in the truth . . . then nothing else worries me, nothing else concerns me. (Participant 9, male)

Only one participant reported having been prescribed anti-depressant medication and having being referred to see a counsellor. For the majority of participants, the support of family and friends and the value of *''companionship'' (Participant 2, female)* was reportedly a key source of ongoing motivation and *''comfort'' (Participant 10, female)*, thus modulating increased psychological distress. Several participants reported supportive friends and family enabled them to resume previously valued activities such as golf or continuing to participate in family roles.

> I used to just walk around with her. Pushing the [golf trolley], as long as I had something to hang onto I was alright. (Participant 8, female)

In many instances, participants were dependent on the emotional and practical support of spouses, which improved psychological wellbeing.

> I've got a wife that I respect more now than I ever did. She's helped me through all of it, and um yeah, I've coped pretty well I think with her help. I've got through it, when I've got frustrated she usually says 'down tiger' and keeps me quiet so (laughs). (Participant 4, male)

Ongoing access to rehabilitation services and support groups, such as stroke recovery groups, appeared to be linked to improved emotional wellbeing over time. Stroke rehabilitation groups promoting ongoing exercise and recovery by *''getting in the group in the gym . . . we talk and we did exercise and all that . . . I went twice a week . . . ah for 3 months'' (Participant 4, female)* assisted stroke survivors to gain confidence in their capabilities, which in turn boosted feelings of confidence.

> [attending the stroke group] gives you confidence, it helps you in that sort of stuff. Plus the friendship and everything like that there is no difficulties there because you know they might be just as bad as I am if not worst. (Participant 1, male)

Overall, most participants expressed feelings of coming to terms with their experience with lifestyle adjustment due to stoke symptoms and associated role changes. However, this was underpinned by expression of feelings of resignation regarding the experience of stroke with some participants expressing feelings of having to *''cop it sweet'' (Participant 1, male)* and *''just accept it'' (Participant 3, male).*

Service delivery implications

Most participants reflected on their hospital admission experience positively and were *''pleased'' (Participant 4, male)* or had *''no complaints'' (Participant 5, female)* about the formal services received and staff interactions experienced immediately following their stroke.

Following discharge, participant reports revealed a dynamic struggle to manage ongoing symptoms post-stroke, and this was exacerbated by lack of knowledge. Central to this experience were participants' reports concerning an inconsistency in advice and information concerning their recovery. This inconsistency further distressed participants as they negotiated recovery post-stroke. Conflicting reports, usually from the participants General Practitioner (GP), was a source of uncertainty and frustration leading to scepticism about health advice.

> Because when you ask 2 doctors the same question, you get 2 different answers and that can be very frustrating you know, I said ''what the hell? (Participant 3, male)

At the time of follow-up, access to ongoing services and information had been limited. Some participants indicated that they had no outstanding needs and reported *''there is nothing that we really need at the moment'' (Participant 6, male)*. In contrast, other participants reported they were unsure about how to access needed services such as ongoing therapy, home modifications, home care or further information/education.

> There is something I want now and I don't know if I can get it . . . I can't get out of my bath and I need a rail. (Participant 2, female)

Discussion

The main aim of this study was to explore the physical and psycho-social functioning status of stroke survivors beyond 12 months post-stroke and to qualitatively explore the longer term experiences of psychological morbidity and service access needs. Psychiatric diagnoses were not formally made in this study. We were, however, able to identify common expressions of ongoing symptoms of psychological morbidity using our qualitative methodology.

Quantitative data were used to contextualise these findings. While results indicated that mood (as measured by the HADS) in participants in the majority of participants was below threshold scores [34], participants' reports indicated that the experience of psychological distress remained problematic beyond 12 months post-stroke. Central to this ongoing psychological distress was the experience of role loss, social isolation and other life stressors, which were not captured by quantitative measures. Results from this study are consistent with those of the larger study, which showed stroke survivors' psychological morbidity is influenced by stroke and non-stroke-related factors and is experienced along a variety of psychological trajectories [28]. However, the persisting experience of psychological distress beyond 12 months further highlights the need for close longer term monitoring of psychological wellbeing and access to interventions that address modifiable risk factors such as disability and social isolation.

Participants reported of altered function, fatigue, distress, reduced community participation and social isolation suggesting the experience of altered HRQoL. Our results are consistent with previously identified predictors of poor HRQoL post-stroke including the following: medical comorbidities, depression, poor social support and functional status [35,36]. Furthermore, results are also consistent with findings from studies indicating that HRQoL in stroke-survivors in the first years after stroke is worse than HRQoL in the general population, especially for physical factors [37,38]. Similarly, Niemi et al. [39] explored stroke-survivors four years post-stroke and identified that HRQoL in 83% of the patients had not been restored to pre-stroke levels.

However, our findings recognised a number of other modulating factors identified by participants including reflexivity, resilience, maintaining a positive perspective and the benefit of carers in promoting role resumption and motivation contributing to better emotional wellbeing over time. The positive role of family support has been well documented in stroke literature [40,41] with regards to alleviating stress and depression and maintaining health [42]. Furthermore, stroke rehabilitation groups promoting ongoing exercise were highly valued and reinforce the need to explore the benefit of intervention which have proved to be of benefit in non-stroke depressed populations [43].

We identified that few participants or their carers received formal services subsequent to inpatient rehabilitation, and only one had received psychological counselling. At the time of follow-up, access to ongoing services and information had been limited, and some participants were unsure how to access needed services such as home modifications, home care or further information. This research highlights the clear need for increased services to enable stroke survivors to re-enter the health system well beyond their hospital discharge in order to address their changing needs and promote their improved or maintained function in community participation. Patients who do not initially meet threshold scores for depression or anxiety at baseline may still have troubling symptoms or meet criteria for disorder later. If patients meet threshold scores at any time, then GPs should consider initiating appropriate treatment, including pharmacotherapy, referral to psychotherapy and referral to community stroke rehabilitation. As a result, there is a need for adequate education and support for GPs to perform screening, assess psychological morbidity and educate patients on the availability of community resources. Community stroke rehabilitation services that complement the GP role include community-based therapies that address modifiable risk factors for post-stroke psychological morbidity, such as disability and community participation. Multi-disciplinary allied healthcare staff are well positioned to implement simple interventions to promote stroke survivors' mobility, confidence.

Strengths and limitations

A key strength of this unique study was that, though cross sectional in design, it followed on from a larger longitudinal mixed methods study [20]. Furthermore, the quantitative data that we collected on our participants contextualised their qualitative expressions.

We were also able to make demographic, clinical and functional comparisons of our participants and the remaining study population of the study from which they were recruited. It is established that research studies non-responders are more likely to have poorer health status, functional status and self-rated health [44,45] and make more use of healthcare services [46,47]. Despite the relatively small sample size, it is difficult to establish if thematic saturation was achieved during the semi-structured interviews [32]. Though the response rate to invitation to participate precluded formal maximum variation sampling, our sample nevertheless manifested a broad range of demographic, clinical and functional characteristics since participant demographics were not significantly different to non-responders. However, we acknowledge that transferability of findings may be limited since the majority of participants in this study were functionally independent (MRS ≤ 2).

Conclusion

The considerable prevalence of psychological distress in community-dwelling stroke survivors makes accurate assessment and treatment availability key management issues. Our results highlight the importance of social support and community access in managing the emotional wellbeing of stroke survivors. Pursuing increased service access, community participation and ensuring good social support for stroke survivors offers a practical strategy for clinicians.

Acknowledgements

We thank all the participants in the study and staff from the Hunter Stroke Service and the University of Newcastle who also supported the study.

Declaration of interest

The authors declare that there is no conflict of interest.

A. D. was supported by an Honours Support Grant from the National Stroke Foundation.

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