Trajectories of Psychological Distress After Stroke

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ABSTRACT

PURPOSE There has been little exploration of the distinct trajectories of psychological distress after stroke and the factors that predict recovery from distress. These trajectories may assist primary care physicians by providing insight into disease onset, progression, and resolution and may be a useful way to conceptualize and understand the pattern of psychological morbidity in stroke over time. We undertook a longitudinal qualitative study to explore poststroke psychological trajectories

METHODS The primary data collection method was semistructured interviews with community-dwelling stroke survivors in metropolitan Newcastle, New South Wales, Australia. Our sample included 23 participants (12 men, 10 women; age range 37 to 94 years) discharged from a tertiary referral hospital after a stroke; these participants subsequently participated in a total of 106 interviews over 12 months. Qualitative outcomes were participants' perceptions at baseline, 3, 6, 9, and 12 months. Thematic saturation was achieved.

RESULTS Most participants were male (54%) and had a partial anterior circulation infarction stroke subtype (57%). Four different longitudinal trajectories were identified: resilience (n = 5); ongoing crisis (n = 5), emergent mood disturbance (n = 3), and recovery from mood disturbance (n = 10). Recovery from mood disturbance was facilitated by gains in independence and self-esteem and by having an internal health locus of control.

CONCLUSIONS Stroke survivors experienced a variety of psychological trajectories. Identifying distinct trajectories of psychological morbidity may help primary care physicians develop appropriately timed interventions to promote better mental health. Interventions require implementation over a longer duration than the current outpatient services that, in Australia, are typically provided in the first few months after stroke.

INTRODUCTION

Poststroke depression is the most studied of poststroke psychological sequelae. A recent systematic review reported similar prevalence rates of poststroke depression in the early, medium, and long-term recovery stages; one-third of stroke survivors will experience poststroke depression at some stage after stroke, affecting long-term care management.[1] Moreover, poststroke depression can persist for many years after stroke[2,3] and has been associated with disability,[4-9] increased mortality after stroke,[4,10,11] poorer rehabilitation outcomes, and reduced quality of life.[4,6,7] After discharge from the hospital, management is frequently the responsibility of primary care physicians, who are the key providers of medical information, preventive interventions, and other ongoing care after stroke.[12,13] In addition, 5% to 20% of stroke survivors are not hospitalized and are managed solely on an outpatient basis.[14,15]

Disease trajectories are temporal patterns of symptoms and other components of the disease experience over time and have been particularly

well documented in palliative care and chronic disease.[16-18] Disease trajectories can provide insight into disease onset, progression, and resolution and therefore can assist with the planning and appropriately timed delivery of relevant services.[17,19] Trajectories of depressive symptoms have been documented in such disease groups as cardiac and pulmonary disease and frequently include the onset of depression following diagnosis, recovery from depression, and persisting depression.[20,21]

Psychological morbidity after stroke is a broader construct than poststroke depression; anxiety, subsyndromal mood disturbance, and other psychological morbidities have also been documented in the poststroke period.[4] There are few stroke-specific qualitative studies exploring recovery trajectories,[22-24] and to our knowledge there are no qualitative studies documenting depressive or other psychological symptom trajectories after stroke. This construct is clinically relevant to primary care physicians, as most stroke survivors receive ongoing care in the community after discharge from a secondary or tertiary health care setting.

In this study, we aimed to explore the patterns of psychological morbidity longitudinally after stroke, especially seeking to establish disease trajectories. Although most poststroke research examines poststroke depression, we chose to explore the wider construct of psychological distress (of which mood disturbance was a prominent component).

METHODS

This prospective qualitative study involved individual semistructured interviews with stroke survivors. Participants were identified from a larger, longitudinal quantitative study of 134 stroke survivors that explored psychological morbidity after stroke.[25] Participants in that study were identified from consecutive admissions after stroke onset in 2 tertiary referral hospitals servicing an Australian mixed rural/urban region; they completed (quantitative) structured interviews at baseline, 3, 6, 9, and 12 months. Inclusion criteria were hospital admission and diagnosis of stroke as determined by a neurologist. Participants were excluded if they had major language or cognitive impairment (Mini-Mental State Examination Score of 24 or less).[26]

Demographic data were available from hospital records. Several well-validated quantitative measures were administered during a face-to-face interview before the patient's further participation in the study. Stroke subtype was classified using the Oxfordshire Community Stroke Project classification[27] (OCSP), disability was assessed using the Modified Rankin Score[28] (mRS), and psychological morbidity was measured using the Kessler-10 (K10).[29]

Sampling

Using data from the larger quantitative study, we purposively selected participants for invitation to participate in this qualitative study. Purposive sampling was on the basis of age, sex, stroke topography (anatomical site), and stroke severity to achieve as heterogeneous a sample as possible.[30] All invitees agreed to participate. Sampling continued until thematic saturation (2 coders agreeing that no new themes were emerging) was achieved. Saturation occurred with 23 participants. Approval for this project was obtained from the Hunter New England Research Ethics Committee (approval number 07/04/18/5.02).

Data Collection Methods

Qualitative Interviews

Semistructured interviews were conducted by the primary author (J.H.W.) at baseline, 3, 6, 9, and 12 months. Interviews (n = 106) ranged from 30 to 60 minutes and were recorded with the participants' permission. A topic guide was used during interviews (Table 1); however, discussions were informant led, and emergent themes informed continuing data collection. All interviews were transcribed verbatim with identifying data removed.

Data Analysis

An inductive thematic approach was used. Analysis involved constant comparison, and concurrent data collection and analysis (whereby analysis informed data collection in further interviews). We sequentially examined each transcript both in relation to themes and concepts in the cohort as a whole and in temporal relationship to other interviews with the same participant. As themes emerged, negative or deviant cases were sought. After each set of interviews, 2 qualitative researchers (J.H.W. and P.M.) coded the data independently, with consensus coding to ensure the codes and themes were grounded in the data. Any disagreements in interpretation were resolved by consensus.[30,31] The final application of codes was undertaken with input from all authors. A detailed outline of coding process is shown in Supplemental Appendix 1, available at http://annfammed.org/content/10/5/435/suppl/DC1.

RESULTS

Participant Characteristics

Characteristics of the 23 participants are presented in Table 2. All participants had experienced an ischemic stroke, the majority having experienced a partial anterior circulation infarction. Ages ranged from 37 to 94 years.

Four distinct qualitative trajectories emerged in participants' experiences of poststroke psychological

morbidity and in their adjustment to stroke: resilience (n = 5), ongoing mood disturbance (n = 5), emergent mood disturbance (n = 3), and recovery from mood disturbance (n = 10).

Using the mRS, 5 participants were classified as independent at baseline, and 15 were classified as independent at 12 months poststroke (Table 3). Quantitative mood scores as assessed by the K10 were available at each time point and area also shown in Table 3. For many participants scores on the K10 reflected the journey of mood and emotional disturbance as identified in qualitative interviews, except for participants in the ongoing mood disturbance trajectory, several of whom consistently scored "likely to be well."

Table 1. Example of Topic Guide

Questions	Prompts
Main question	
Can you remember how you felt when you were admitted to hospital with stroke?	Fear?
	What did you think was going on?
	Did you consider you were having a stroke?
	What is a "having a turn?" to you?
	How did it impact on you seeking medical help?
	Did you think it was serious?
What was your biggest hope at that time?	
Relationship changes	
Have you experienced any changes in your relationships with:	Did you still want the same things from people? Did you want more?
Family	Have you maintained the same friends?
Friends	What was your experience with regards to resuming any sexual relationships?
Strangers	
Adjustment	
Would you say you have adjusted to having had a stroke?	How would you describe your quality of life?
	How do you feel on average, eg, happy, sad, adjusted to the stroke, accepted the stroke?
	What is hardest?
	Can you identify anything that would help?
Motivation	What keeps you going?
	What gives you a reason to keep going?
	Independence? Why?
How do you feel about your:	Your current level of social activity?
	Your current ability to look after yourself?
	You current ability to do the things you enjoy?
Anxiety	Does worry affect you?
	How does it impact you?
	Do you think you worry more now?
Mood	How do you feel about the future?
	Have you lost interest in things?
	Does anything cheer you up?
	Are you happy sometimes? When?
Self image	Has your view of yourself changed?
Independence	What gives you feelings of independence?
	What does freedom mean to you?
	How does being more independent make you feel?
What does the future look like for you?	Are there things you would like to do?
	What things, people, activities are important to you?

Resilience Trajectory

Five participants exhibited a stable good mood throughout the course of the poststroke year. Participants has a resilient nature before and after their stroke in response to a range of life experiences as well as the stroke (that is, they had achieved a sense of mastery during a range of previous life challenges).

In the acute phase after stroke, they were less distressed by the unfamiliar surroundings of the hospital environment and were focused on enhancing their recovery.

You know…lot of people don't put themselves out. But I was determined to try and overcome things…" (Participant [P] 2, male, 84 years, baseline interview).

Resilient participants readily embraced the future and adapted to any changes resulting from residual symptoms. Their skills included the ability to adapt to new routines, whether in the hospital or after their discharge home, such as the use of alternative or compensatory approaches.

After a shower I sit down to wipe my feet. I have a little gadget to wipe between my toes—it is the best invention!" (P 6, male, 94 years, 9-month interview).

Adaptability contributed to resilience in further ways. Resilient participants showed an ability to adapt to changed living circumstances. For example, one participant readily accepted moving to more supported care as a result of his need for assistance with daily living tasks: "I'd be quite happy to move here [hostel accommodation]" (P 10, male, 76 years, 6-month interview).

It was common for participants to attribute their resilience to previous life experience, such as war experiences, work history, and difficult up-bringing caused by poverty and alcoholic parents. Furthermore they tended to report being "an optimist rather than a pessimist" (P 10, 6-month interview), "lapsy dazzy [lackadaisical]" (P 2, bseline interview), and less inclined to worry.

Table 2. Participants' Trajectory Status, Demographic Characteristics, and Stroke Subtype Classification at Study Entry

Participant	Trajectory	Sex	Age, y	Marital Status	Country of Origin	Oxfordshire Classification
2	Resilient	M	84	Married	Australia	Lacunar infarct
6	Resilient	M	94	Widowed	Australia	Partial anterior circulation infarction
9	Resilient	M	78	Married	Australia	Posterior circulation infarction
10	Resilient	M	76	Lives with partner	Australia	Partial anterior circulation infarction
19	Resilient	M	56	Single	Australia	Lacunar infarction
1	Ongoing	F	50	Single	Australia	Posterior circulation infarction
5	Ongoing	M	59	Widowed	Australia	Partial anterior circulation infarction
12	Ongoing	F	37	Single	Australia	Partial anterior circulation infarction
17	Ongoing	F	52	Married	Australia	Posterior circulation infarction
20	Ongoing	M	65	Divorced	Australia	Lacunar infarction
7	Emergent	M	65	Married	Australia	Partial anterior circulation infarction
13	Emergent	M	87	Married	Czechoslovakia	Partial anterior circulation infarction
14	Emergent	F	82	Widowed	Germany	Total anterior circulation infarction
3	Recovered	F	69	Married	Australia	Partial anterior circulation infarction
4	Recovered	M	70	Lives with partner	Australia	Partial anterior circulation infarction
8	Recovered	F	62	Married	Australia	Posterior circulation infarction
11	Recovered	F	62	Single	Australia	Partial anterior circulation infarction
15	Recovered	F	93	Widowed	Australia	Posterior circulation infarction
16	Recovered	F	77	Widowed	Australia	Partial anterior circulation infarction
18	Recovered	M	79	Married	Australia	Partial anterior circulation infarction
21	Recovered	F	76	Married	Italy	Partial anterior circulation infarction
22	Recovered	M	72	Married	Austria	Partial anterior circulation infarction
23	Recovered	M	62	Married	Australia	Lacunar infarction

F = female; M = male.

Throughout the first year, resilient stroke participants continued to appreciate being "lucky to be alive" (P 19, male, 56 years, 3-month interview), and this appreciation contributed to developing an altered life perspective and attitude to life.

I think I am pretty lucky, you know…so I am going to sit back and smell the roses, for want of a better word (P 2, male, 84 years, 3-month interview).

Ongoing Mood Disturbance Trajectory

For 5 participants, life was characterized by feelings of ongoing difficulties. For these participants, the experience of stroke was an additional challenge to existing life stress and exacerbated symptoms of mood disturbance.

It is just [there is] something in me that is not there anymore. I don't know what it is…, an emptiness…. I can't put my finger on it.…with losing my wife, the car accident in July, um, and then losing mum and moving, it sort of…my life has been fairly well disrupted." (P 5, male, 59 years, 6-month interview).

Participants frequently felt isolated, and the initial few poststroke months were characterized by feelings of alienation: "I felt like an alien. I felt I was in a 'slow' world after I had the stroke" (P 1, female, 50 years, 3-month interview).

Although many participants in this trajectory scored "likely to be well," using the K10, qualitative reports identified that participants were in fact highly anxious or apprehensive throughout the stages of hospital admission, discharge, and ongoing adaptation to residual poststroke symptoms. One participant went on to experience severe and debilitating depressive symptoms throughout the first poststroke year: "I would like to take a pill and go to sleep, if I could just go to sleep and not wake up. Sleep is a marvelous escape" (P 20, male, 65 years, 9-month interview).

Overall, participants found it hard to judge how to handle their symptoms and ongoing distress. During the first year 4 participants met with a counselor for assistance with the enormity of change to life after stroke. Referrals were instigated by family members or a general practitioner, suggesting that participants waited for cues from others rather than taking responsibility themselves. This finding was consistent with having an external health locus of control, whereby individuals believe that powerful others (such as doctors), fate, or chance primarily determine events. Such individuals may relinquish responsibilities and avoid making decisions. Conversely, individuals with an internal health locus of control believe their own actions can determine their health.

The experience of persisting difficulties in life appeared linked to having an external locus of control whereby participants relinquished responsibilities and tended to avoid making decisions. Several participants intentionally delayed setting goals for up to a year. In some cases this delay caused additional stress, because their lack of direction and self-worth led them to avoid the resumption of prestroke activities.

I gave myself 12 months that I wouldn't do anything, or make any major decisions for 12 months. I had every hope that in 12 months time, I would significantly recover and be able to do things that I couldn't…but now I have to face the fact that is not the case (P 20, 12-month interview).

As these participants began to resume some of their former roles, such as work and valued social activities, there were periods characterized by stability of mood. Improvement in this trajectory, however, was interrupted or transient, and the experience of low mood was often exacerbated by other life stressors and demands.

I am worrying about how I can care for dad, because he has the dementia as well as the Parkinson's now. But worrying about only makes the situation worse, because then you're not going to be well enough to deal with it…. The other thing is, I have never felt this stressed with building a house before…. I am noticing that I am getting more stressed (P 17, female, 52 years, 9-month interview).

Emergent Mood Disturbance

Emergent depression is a trajectory typically depicted in disease trajectory research. In this study, we identified 3 truly emergent cases whereby participants did not experience depressive symptomatology immediately after the stroke (aside from the experience of normal emotional adjustments early after stroke). Instead, they developed depressive symptoms several months after their stroke as other life difficulties emerged, and suddenly life was fraught with difficulty.

….just a build-up of different things you know, yeah, and, ah, you know I just thought I could handle it and control

Table 3. Participants' Trajectory Status, Disability Status, and Quantitative Mood Scores at Study Interview Points

Participant	Trajectory	mRS[a] at Baseline	mRS[a] at 12 Months (unless specified)	K10 at Baselines	K10 at 3 Months	K10 at 6 Months	K10 at 9 Months	K10 at 12 Months
2	Resilient	3 D	0 I	Well	Well	–	Mild	Mild
6	Resilient	4 D	3 D	Well	Well	Well	Well	Well
9	Resilient	4 D	4 D	Well	Well	Well	Well	Well
10	Resilient	1 I	1 I	Well	Well	Well	Well	Well
19	Resilient	3 D	1 I	Well	Well	Well	Well	Well
1	Crisis	4 D	0 I	Well	Well	Well	Well	Well
5	Crisis	1 I	0 I	Moderate	Moderate	–	Moderate	Mild
12	Crisis	4 D	1 I	Well	Well	Well	Well	Well
17	Crisis	3 D	0 I	Well	Well	Well	Well	Well
20	Crisis	4 D	1 I	Well	Moderate	Severe	Severe	Severe
7	Emergent	4 D	0 I	–	Well	Mild	Severe	Moderate
13	Emergent	4 D	3 D	Well	Mild	Mild	–	–
14	Emergent	3 D	5 D	Severe	Severe	–	–	–
3	Recovered	3 D	1 I	Moderate	Severe	–	Mild	Mild
4	Recovered	2 I	0 I	Moderate	Severe	Moderate	Mild	Mild
8	Recovered	2 I	1 I	Well	Well	Well	Well	Well
11	Recovered	4 D	0 I	Well	Well	Well	Well	Well
15	Recovered	4 D	4 D	Moderate	Moderate	Mild	Moderate	Well
16	Recovered	1 I	0 I	Well	Well	Well	Well	Well
18	Recovered	4 D	3 D	Severe	Severe	Severe	Severe	Moderate
21	Recovered	4 D	4 D	Severe	Severe	Severe	Moderate	Well
22	Recovered	3 D	1 I	Well	Well	Well	Well	Well
23	Recovered	4 D	3 D	Severe	Severe	Severe	Mild	Well

D = dependent; I = independent; K10 = Kessler-10; mRS = Modified Rankin Scale.

Notes: mRS categorization as follows: I = independent' (mRS ≤2); D = dependent' (mRS ≥3 and ≤5); K10 scoring[28]: well equates to "likely to be well" = 10-19; mild equates to '"likely to have a mild disorder'' = 20-24; moderate equates to "likely to have a moderate mental disorder" = 25-29; severe equates to "likely to have a severe mental disorder" = 30-50).[28]

it. But no, it just got on top of me (P 7, male, age 65 years, 6-month interview).

Life stressors that precipitated depressive symptoms included comorbidities, social issues, deterioration in health, and increased dependency: "Everything was going fine with my recovery until I slipped and I broke my hip" (P 13, male, 87 years, 6-month interview).

Recovery Trajectory

The final trajectory comprises 10 participants who experienced psychological symptoms in response to the stroke and showed sustained improvements in mood, or restored mood, by the end of the first year. In the initial months low mood was often linked to fear of recurrent stroke.

I am scared of having another stroke…really scared, because I spent a week in the stroke unit and saw other people who were permanently damaged—had to be taken to the toilet and everything. I am frightened of that! (P 8, female, 62 years, 9-month interview).

With time this fear lessened and was associated with improved mood. In fact, the passing of time for participants in this trajectory was closely linked to participants' adaptive behavior, especially regarding their ability to reframe expectations and take a different outlook on life. Most participants referred to the need to "take 1 day at a time" (P 4, male, 79 years, 6-month interview) and to "stop and smell the roses" (P 18, male, 79 years, 3-month interview).

Participants in this trajectory showed increased self-efficacy during the poststroke year as they shifted from having an external to an internal health locus of control.

I have stopped being the patient…stopped monitoring every tweak. I just think it is one of those things. It happened, get over it…get on with your life (P 11, female, 62 years, 9-month interview).

Participants took the initiative for adapting to their circumstance and modifying prestroke tasks that contributed to having a feeling of control over their circumstance. For many, this transition was closely aligned with increasing independence or a gradual resumption of the demands of normal life and previously valued life roles: "Independence…it means doing what I want and not having to bother anybody else really. You know…just living like I was before" (P 16, female, 77 years, 6-month interview). "The turning point has been going back to the work. It feels like a new lease on life a bit…doing what I love" (P 18, 9-month interview).

Independence, participation, and self-efficacy were all related to rehabilitation, often bidirectionally. Most participants in this trajectory reported benefitting from persisting with follow-up rehabilitation after discharge, including outpatient physical therapy, driving assessment, and dietary advice.

A couple of times it would have been just as nice to bury my head and sleep the afternoon away, but the therapist was coming and I thought, …that is not in the spirit of what I agreed to do, but it also gave me a focus (P 11, 9-month interview).

I didn't realize I was improving [until my next appointment]…it gives you a little bit of hope and you have got to have something to wish for (P 18, 12-month interview).

DISCUSSION

The main aim of this study was to explore the longitudinal experience of mood and other psychological changes in community-dwelling stroke survivors over time. Psychiatric diagnoses were not formally made in this study. We were, however, able to identify common expressions of symptoms of psychological morbidity through psychologically focused analysis of transcripts at each time point. Although participants did not often label their experiences as depression, their descriptions are consistent with a spectrum of mood disorders.[32] Four distinct trajectories of the experience of psychological morbidity were identified—resilience, ongoing mood disturbance, emergent mood disturbance, and recovered—and were influenced by stroke- and non-stroke-related factors.

Clinical Relevance of Our Findings

The resilience trajectory was closely linked with previous life experience in overcoming adversity, the use of established coping strategies, and optimism. In the clinical setting, poststroke adjustment may be facilitated by identifying and encouraging resilience traits.

Ongoing mood disturbance was linked to current life stressors and a previous history of depression. These factors might identify patients at risk of ongoing distress in clinical settings and enable therapeutic intervention. Our results are consistent with previous research highlighting the link between the impact of life stress, previous depressive episodes, and poststroke depression.[33]

Emergent mood disturbance is, by definition, not identifiable at stroke onset. In emergent cases the primary care physician may be the clinician best positioned to identify depression and initiate appropriate treatment. Case finding in this situation will be informed by targeted assessment in poststroke patients who experience social stressors or intercurrent health problems.

Many participants showed improvements in mood with time. Overcoming fear, maximizing self-efficacy,

having an internal locus of control,[34,35] and facilitating independence were associated with this trajectory, which is consistent with previous findings.[36,37] Recovered participants in our study were also more likely to attend follow-up services, providing encouragement and continued goal setting. This finding highlights the importance of follow-up therapy beyond the first few months after the stroke.

An essential component of stroke service delivery should be the ongoing monitoring and assessment of psychological status, including mood. In Australia, intensive community-based rehabilitation is typically provided in the first few months after stroke. This study suggests that longer-term surveillance and interventions may be necessary to facilitate recovery from and to prevent poststroke depression. Longer-term, less-intensive, community-based services that include mood screening may be beneficial but require further research.

Depression is often undetected in primary care and hospital settings,[38] and it is likely that other psychological distress is similarly underdetected. Although screening is often advocated, there is conflicting evidence regarding the benefit of screening and case finding for depression.[39] The K10 is frequently used in Australian general practice as an assessment and monitoring instrument in patients with mental illness.[40] The congruence of K10 scores and qualitative findings in our study are of potential clinical importance. Such was not the case, however, for participants in the ongoing mood disturbance trajectory who consistently scored "likely to be well." Possible reasons for the incongruity can by hypothesized, such as the manifestation of personality traits, which were not explored in this study. Also, subsyndromal distress identified by our in-depth interviewing may not have been elicited by the K10 (though such distress was real and a source of suffering for participants). An implication is that overreliance on generic screening measures may result in underrecognition of distress in poststroke patients. Clinical assessment is required as well, and the primary care physician is ideally placed and has the appropriate skills to make such assessments.

Strengths and Limitations

The strength of this study lies in the longitudinal, qualitative methods and tracking changes over time. Our trajectories are congruent with trajectories found in other chronic disease groups.[20,21] Serial interview studies remain underused in medicine despite the benefit in exploring the complex and dynamic effects of disease that may in turn inform health care.[19]

A limitation to the study is our exclusion criteria of poststroke cognitive or language impairment. Psycho-

logical morbidity and trajectories may be different in these groups.

Illness trajectories after stroke are a useful way to conceptualize and understand the pattern of psychological morbidity in stroke over time. Further explorations of the clinical implications of trajectories of psychological morbidity after stroke are indicated. Our results suggest that although screening for depression and other psychological morbidity may be valuable after a stroke, other clinical cues, such as reports of life-stress and impaired self-esteem, may increase sensitivity of detection.

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