

BETHANY STROYDE BSc Hons

MULTIDISCIPLINARY PROFESSIONAL PRACTICE AND
UNDERSTANDING OF THE PSYCHOLOGICAL NEEDS OF STROKE
SURVIVORS

Section A: Reported views and clinical practice of healthcare professionals in addressing the
psychological needs of stroke survivors: a review of the literature

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To my family, friends and my partner for their eternal support and belief that I am capable.

Summary of the MRP

Section A

Section A presents a systematic literature review exploring how stroke MDT staff members in stroke settings from a range of countries report their awareness of psychological aspects of stroke and their clinical practice in regards to these. The available literature, of qualitative, quantitative, and mixed method designs, has been narratively synthesised and critiqued in line with the research questions. Clinical and research implications are discussed.

Section B

Section B presents a study exploring in-depth how a sample of MDT stroke staff members in the south of England understand and respond to psychological aspects of stroke. A qualitative design was employed using individual semi-structured interviews and thematic analysis in line with Braun and Clarke (2006) to develop insight into the perspectives of MDT stroke staff members who are expected to deliver psychological care in accordance with national guidelines. The limitations of the study are discussed, along with clinical and research implications.

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Abstract

Section A discusses the background to psychological care in stroke, the related policies, and relevant theories. A systematic literature search was then carried out in five databases (Psychinfo, Web of Science, Wiley, Cochrane Reviews, and Ovid Medline) to explore how multidisciplinary (MDT) staff members in stroke settings from four countries reported their awareness of psychological aspects of stroke and their clinical practice in regards to these. Ten papers were found to meet the inclusion criteria for review. The papers, of qualitative, quantitative, and mixed method designs, were then narratively synthesised and critiqued in line with the research questions. The review noted similar themes across the range of disciplines and across the timeline from 1996 to 2018. There was a range of opinion on how involved staff felt they should be in addressing psychological issues, while acknowledging the prevalence of these, and generally low confidence in being able to do so. Clinical and research implications are discussed, including the need for training, supervision, and consultation, as well as the need for further research into MDT perspectives.

Introduction

Background to the review

Stroke care in the UK

A cerebral vascular accident, commonly known as a stroke, is one of the most disabling conditions in the world and the UK, with around 150,000 people every year suffering from this, for which the aftermath can be chronic disability (Kneebone and Lincoln, 2012). According to the Stroke Association, there are currently around 1.3 million stroke survivors in the UK and almost two thirds leave hospital with disabilities (Stroke Association, 2018). One in five are reported to experience emotionalism (difficulty controlling emotional behaviour) within the first six months of stroke, around a third are reported to experience depression, and over half of stroke survivors are said to experience symptoms of anxiety within ten years of their stroke (Stroke Association, 2018). Cognitive impairments are also common, including memory problems, information processing difficulties, and executive dysfunction, such as difficulty with planning, initiation, and self-monitoring (Stroke Association, 2018). The biggest steps in recovery usually occur within the first few weeks and months after a stroke, therefore time spent in hospital after a stroke is a crucial period.

In recent years, specialist stroke units in hospitals have developed internationally following recognition around the world that stroke care is best delivered by those with particular skills in this area (Indredavik, 2009). A specialist team within stroke care typically includes doctors, nursing staff, physiotherapists, occupational therapists, and speech and language therapists. There is also increasing evidence of the helpfulness of hospital-based rehabilitation for stroke survivors, whereas historically it was thought that there was little to be done for those who survived a stroke (Taylor, McKeivitt and Jones, 2015).

Theoretical understanding of the psychological consequences of a stroke

Not only may stroke survivors have neurological damage to areas of the brain involved in emotional regulation and cognition, but environmental, social, and psychological factors are also key to their clinical presentation after stroke (Coetzer, 2009). As with many other chronic illnesses, experiencing a stroke can include dealing with loss, discontinuation of identity, and difficulty coping with physical, cognitive, and communication disabilities. There are a number of models that may be relevant to this, including the stress-coping model (Lazarus and Folkman, 1984), the common sense model of illness representations (Leventhal, Brissette, & Leventhal, 2003), and the adaptive tasks and coping model (Moos and Holohan, 2007). It is beyond the scope of this review to detail all these models, but the most significant model to date for stroke appears to be the Social Cognitive Transition Model for Stroke [SCoTS] by Taylor, Todman and Broomfield (2011). This model describes a dynamic process incorporating the individual's assumptions about self and the world, their intrapersonal and interpersonal responses, and takes into account stroke-related consequences and disabilities, including cognitive capacity for self-awareness. This model may be helpful in considering the stroke survivor's experience in hospital, by formulating with each aspect of the model and tailoring care in accordance with this.

Psychological provision in stroke care

Guidelines in recent years (Gillham and Clark, 2011; British Psychological Society, 2010) have emphasised the importance of psychological expertise in stroke care given the significance of psychological problems, as described above; however, they also highlight a dearth of qualified psychologists to work in these settings (George, 2013). The fourth annual report of the Sentinel Stroke National Audit Programme (SSNAP), produced by the Royal College of Physicians (2017) stated that there was a "striking inadequacy in psychology services for inpatients with stroke". However, their audit summary provides little in

comparison to other stroke therapies and only discusses screening for mood and cognition, rather than other psychological roles or interventions. This is in spite of the linked National Guidelines for Stroke 5th Edition (Rudd, Bowen, Young, & James, 2017) stating that all stroke services should have psychology (from hyper-acute, to rehabilitation) and that this provision should be comprehensive and offered to all patients regardless of their presentation. They also state that psychology should provide training to all staff on awareness and management of mood and cognition.

There is also a related problem with the development and research evidence around the role of psychologists in stroke care, with a paucity of research into psychological interventions in stroke (Kneebone and Lincoln, 2012). Lincoln, Worthington, and Mannix (2012) conducted a nationwide survey of UK clinical psychologists in stroke settings to investigate what types of psychological interventions were being offered for mood problems. This was carried out due to the lack of data regarding such provision and a need to justify the development of clinical psychology within stroke services (Lincoln et al., 2012). Data were gathered by requesting that clinical psychologists record every stroke patient referred for screening, assessment, and treatment in regard to mood problems, over a three-month period in 2009. They were also asked to give subjective judgements of how effective interventions were.

Results contained data on a total of 140 stroke patients. A total of 89.3% had been screened for mood difficulties, with the majority referred by allied health professionals, nursing staff or doctors, but with 15% having been routine mood assessment. Of these, 56.4% were reported to have mood problems (predominantly depression) and 15.7% to have cognitive problems. Subsequently, the majority were monitored for their mood (47.9%) and given advice (45%). Others (42.1%) received psychological treatment, usually delivered by a clinical psychologist (74.6%) and consisting of cognitive-behavioural therapy most commonly (49.2%), as well as behavioural (40%), systemic therapy (27.1%), psychotherapy (11.9%) or

'other' (33.9%). The psychologists rated 64.4% of treated patients as having had their problem improved or resolved. Lincoln et al. (2012) were unable to conclude from the data gathered if treatment decisions were related to severity of mood problems, or availability of treatment. It is not known how representative this audit was of nationwide clinical psychology practice in stroke care; however, Lincoln et al. (2012) suggested the results indicated that recommendations for provision were not being met in a number of services, despite ability of clinical psychology to address cognitive and emotional problems after stroke. This study, though completed a few years ago and with no subsequent update as yet, gives some insight into psychological interventions provided in the UK for stroke survivors by clinical psychologists.

Clinical psychologists potentially have much to offer in the way of training and consultation skills to other staff (Mowbray, 1989) and therefore this may be where clinical psychologists can effectively use their specialist psychological knowledge and skills. Gillham and Clark (2011) have highlighted the importance of MDT stroke staff having the necessary and sufficient skills and knowledge to provide psychological care. Staff are expected to consider emotional, behavioural, and cognitive sequelae of stroke and to engage in appropriate assessment and treatment of these. Through providing psychological consultation and training to MDT staff, psychologists may consider the zone of proximal development of staff as a way of determining their learning needs and maximising their learning of new skills. The zone of proximal development (Vygotsky, 1978) describes the area between what an individual is capable of doing independently and what they are potentially capable of with enough support from a more knowledgeable peer. By being supported in their workplace through supervision and consultation with psychologists, staff could more effectively develop the necessary skills and knowledge to provide suitable psychological care.

Gillham and Clark (2011) described how staff should be expected to deliver at least level one skills within a stepped care model and up to level two skills where they have the necessary knowledge, training, and skills. According to Kneebone (2016), level one would include empathic listening, normalising, and providing information, and level two provision would include brief interventions such as problem-solving and psychosocial education groups, with supervision from clinical psychologists or neuropsychologists. Where a stroke survivor's psychological difficulties meet the criteria for level three of the stepped care model, such as severe and persistent disorders of mood or cognition, the direct intervention of qualified psychologists would be required (Kneebone, 2016).

Changing roles of healthcare professionals in stroke care

In the past, working with stroke patients has been described as “unwanted” and “dreaded” by healthcare professionals due to the disabling consequences of stroke, a belief that nothing could be done to help recovery, and perception that such work is therefore unrewarding (Hoffman, 1974). It was considered that this fear was largely due to what staff understood to be “doing something” with stroke patients and that perhaps this type of work needed to be redefined and the stroke trajectory reframed (Hoffman, 1974). Becker and Kaufman (1995) noted divergence in how stroke survivors and stroke physicians understood and perceived “illness trajectories” following stroke, whereby patients assumed they could influence their trajectory, while doctors made assumptions based on age and biomedical models. Pound and Ebrahim (1997) later concluded that health professionals were adapting to meet the needs of their patients through having reframed their role with stroke survivors, whereby “doing something” was increasingly seen as facilitating the process of rehabilitation from stroke rather than aiming for complete recovery to pre-stroke levels of health.

Adapting to new expectations and roles within stroke care has continued for MDT members with psychological needs taking a more prominent role for consideration and

research. With increased expectation to understand and deliver psychological care to stroke survivors, it would be timely to explore and review the literature regarding the perspectives of non-psychology stroke MDT members in regard to psychological consequences of stroke and the psychological interventions they may employ in order to meet the psychological needs of their patients. In understanding the skills and practices employed by staff as well as their views on their own knowledge base, psychologists offering consultation to these staff can aim to work within staff members' zone of proximal development.

Aim of the current review

To the author's knowledge, there has been no review to date of the evidence base from the perspective of MDT stroke staff in relation to psychological issues within stroke and how they address these. This review aimed to address the gap in knowledge in this area by exploring and evaluating available evidence regarding awareness and approaches of MDT stroke staff in hospital settings. It also considers potential future areas of research to help further understand the issues.

Method

Research questions

A systematic literature search was conducted to answer the following research questions:

1. What does the literature suggest is stroke MDT staff awareness of emotional and behavioural consequences of stroke?
2. What roles, approaches, or interventions do MDT staff report using to address emotional and behavioural needs of stroke survivors?
3. What are MDT staff views about the help and support they need to address emotional and behavioural issues for stroke survivors?

Search process

A search of literature was conducted in databases Psychinfo, Web of Science, Wiley, Cochrane Reviews, and Ovid Medline to find relevant papers to answer the research questions. The initial search was carried out in November 2015 and a final search in September 2018. Search terms were developed on the basis of previous relevant literature and employed Boolean operators to combine these. The following terms were used:

Table 1: search terms

stroke OR	staff OR	depress* OR
poststroke OR	professional* OR	anxi* OR
cardiovascular accident OR	team OR	cognit* OR
cerebrovascular accident OR	clinician OR	behavio* OR
cerebrovascular disease	occupational OR	affective OR
	physiotherap* OR	emotion* OR
	multidisciplinary OR	emotional adjustment OR
	interdisciplinary OR	mood OR
	nurs* OR	psychological OR
	therapist*	psychosocial OR
		executive dysfunction OR
		distress OR
		mental health

The results of each of these were combined to find studies that addressed all three aspects and a limit was set to papers written in the English language. Due to the paucity of research, there was no date limit set and non-UK based studies were also included.

Eligibility criteria

The search returned a total of 4557 papers. Figure 1 shows the search and selection process. Papers were screened initially by title to establish relevance to the eligibility criteria. If the title seemed relevant or there was uncertainty about this, abstracts were then screened. Empirical papers were sought and not limited by design as a variety of methodologies may address the research questions. The eligibility criteria applied are described below.

Papers were included for review if they:

- 1) Explicitly explored experiences or perspectives of MDT stroke professionals, with regards to psychological issues (emotional, behavioural, cognitive) after stroke
- 2) Were an empirical paper rather than discussion of the issues
- 3) Were available in the English language

Papers were excluded if they:

- 1) Focused only on the stroke survivor, family, or clinical psychologist's perspective
- 2) Focused only on community settings
- 3) Did not explicitly explore psychological issues associated with stroke
- 4) Only described investigations or suggestions into what health professionals could do, rather than what they are already doing
- 5) Reported on joint interventions with clinical psychologists
- 6) Were not an empirical study (e.g. theoretical model or commentary)
- 7) Did not provide substantial information about the study (e.g. conference poster).

Hand-searches of reference sections were carried out and backward and forward citation searches of the included studies were conducted. Duplications were identified and removed. This resulted in ten relevant papers to be reviewed. The selection process is shown in the PRISMA (Moher, Liberati, Tetzlaff, & Altman, 2009) diagram in Figure 1 below.

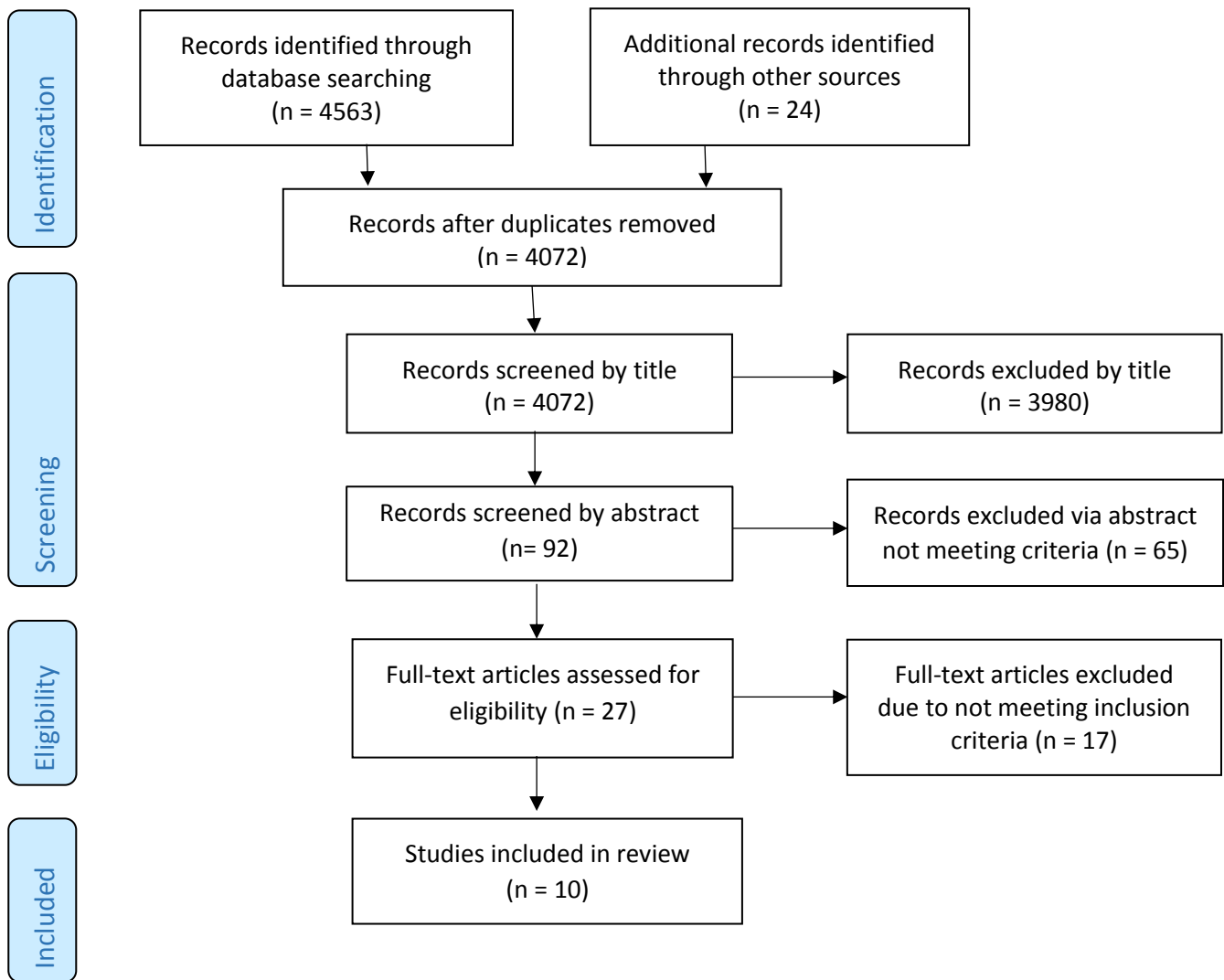


Figure 1: PRISMA selection process diagram

Structure of the Review

This review is a systematic search and review of the relevant literature, as described by Grant & Booth (2009). A critique of the studies will firstly be provided based on the quality of the empirical research and will then consider the included papers in relation to the research questions, providing a synthesis of the findings.

Results

Overview of the studies

Ten papers were included for review. Seven studies were UK-based, one was based in Ireland, one in Australia, and one was USA-based. The total number of participants across the

studies was 1327. The table below shows the breakdown of participants according to discipline, including how many participated in quantitative or qualitative data collection (inclusive of mixed methods studies). As Gurr (2009) did not state which disciplines were included within ‘therapists’ in their study, it was not possible to give an exact number for each type of therapist.

Table 2: Participant disciplines

MDT member	Number of participants	Quantitative	Qualitative
Occupational therapist	>770	>754	>16
Speech and language therapist	>437	>408	>223
Qualified nurse	52	7	52
Physiotherapist	>20	>1	>20
Other	13	6	13
Stroke specialist doctor	12	3	12
Nursing assistant	9	-	9
Dietician	2	-	2

Given the focus of the topic, the reviewed studies all included some kind of questionnaire or interview design with different MDT staff. Half of the papers employed qualitative designs, four included a mixed methods design, and one study employed quantitative design.

The quantitative (or quantitative part of mixed method design) used surveys which resulted in larger numbers of participants; the qualitative studies (or qualitative part of the mixed methods studies) used interviews or focus groups which resulted in richer data, but with fewer participants. Despite the differing types of investigation there was often convergence of themes across studies.

Two of the studies carried out research with a range of stroke MDT staff, while the rest were focused on a particular discipline within a stroke MDT. Four studies surveyed speech and language therapists and two of these were by the same authors and recruited from the same

aphasia specialist interest group (though the authors state it is unknown whether the same participants completed both studies). Two studies focused on nursing staff only. One study focused exclusively on the views of physiotherapists and another on occupational therapists only. Six of the studies discussed stroke survivors in general, while four discussed stroke survivors who have aphasia.

The papers are summarised in Table 3 below.

Table 3: Summary of studies

Study & Location	Participants & Setting	Aim	Design & Methodology	Key findings
Simpson, Ramirez, Branstetter, Reed, & Lines (2018) USA Occupational therapy practitioners' perspectives of mental health practices with clients in stroke rehabilitation.	Total = 764 OT practitioners in USA (754 OTs from 36 states, with experience of working with stroke survivors in neurorehabilitation) (10 OTs in 2 rehabilitation units)	To explore the ways in which OTs address the mental health (MH) needs of clients post-stroke.	Mixed methods – sequential explanatory design. Online 20-item survey, analysed using descriptive statistics. Two focus groups employing semi-structured interview guide, developed following survey results, analysed using content analysis.	Framework developed with 3 categories: <ul style="list-style-type: none"> • <i>Education & preparedness</i> Reported lack of training & knowledge for working with MH issues in stroke. Majority indicated insufficient education on MH in stroke during OT professional training, described education as holistic in philosophy, but not in practice. Taught to value but not directly treat MH needs of stroke survivors, instead refer to psychology/psychiatry. Physical rehabilitation emphasised over MH. • <i>Therapeutic approaches & priorities</i> 92.57% considered MH needs important part of treatment. 56.64% satisfied with their provision of MH care. Variety or approaches identified: 74.40% reported typically initiating conversation on MH with patients; 88.46% regularly ask how they feel; 61.27% ask directly about sadness or anxiety; 86.87% encourage patients to talk about issues; 64.19% educate on post-stroke MH; 55.96% educate on symptoms of depression & anxiety; 86.20% regularly find ways to show they care about patient's MH, e.g. compassion & empathy. Attempts made to integrate MH care into all activities & some believed optimal physical results impossible without addressing psychosocial issues. Some consult with other disciplines to ensure best care. Some emphasised therapeutic relationship & interpersonal skills & use of self therapeutically to encourage clients to be open about concerns & to show investment in them. MH considered essential to reintegration following discharge from hospital & key time to address MH needs. Barriers identified as preventing OTs from meeting MH needs: prioritising physical/motor recovery; time & productivity constraints; insurance limitations; limited resources; patient reticence; lack of OT knowledge & experience. • <i>Recommendations for practice</i> 28.28% OTs suggested greater focus on MH in stroke in professional training; 27.5% for greater availability & access to continuing education; 26.10% for on-the-job training. Range of opportunities to expand knowledge desired by OTs. OTs felt they needed to more clearly articulate their roles in stroke settings & their ability to address MH

needs. Others felt OTs needed more education in order to fully value their role in addressing MH needs of stroke patients.

<p>Northcott, Simpson, Moss, Ahmed & Hilari (2017) UK How do speech-and-language therapists address the psychosocial wellbeing of people with aphasia? Results of a UK online survey.</p>	<p>124 speech and language therapists (SLTs) working with people who have aphasia</p>	<p>To explore UK speech and language therapists' clinical practice in addressing the psychological needs of people with aphasia, including their experiences of working with mental health professionals.</p>	<p>Mixed methods – convergent design 22-item online survey containing Likert scales and free text responses Descriptive statistics and qualitative content analysis (Graneheim & Lundman, 2004)</p>	<ul style="list-style-type: none"> • ~50% believed 70-100% of people with aphasia experience psychological difficulties, 93% agreed addressing psychological wellbeing part of their role – through supportive listening (100%), holistic collaborative goalsetting (87%), 42% felt confident about addressing psychological needs of patients. • 67% had some training in counselling, 45% in solution-focused brief therapy, 29% in CBT, 15% in motivational interviewing, 20% in narrative therapy • Main barriers: time/caseload pressures (72%), feeling under-skilled/lack of training (64%), lack of ongoing support (61%), low service priority (17%). • Main enablers: collaborative working between SLT and clinical psychologist, training in providing psychological therapy, ongoing specialist support or supervision • Theme of concern that people with aphasia receive inadequate psychological support due to constrained resources & lack of aphasia-specific skills of mental health professionals.
<p>Gurr (2009) UK Staff perceptions of psychological care on a stroke rehabilitation unit</p>	<p>28 out of 57 (49%) stroke rehabilitation staff members (therapists, nurses, doctors, managers, administration, caretaker)</p>	<p>To investigate staff understanding of psychological care issues.</p>	<p>Mixed methods – convergent design Two part 24-item non-standardised questionnaire– with closed & open questions</p>	<ul style="list-style-type: none"> • Author reported that all participants agreed emotional care work was relevant to their profession, but had no duties allocated & no scheme in place. • Staff were unaware of if, or how, psychological issues were monitored. • Medical staff supportive of a scheme for psychological care (PC) and reportedly acknowledged links between rehabilitation & PC acknowledged, though this is not explained • Reported lack of training on psychological issues • Expressed need for improved self-care and staff support • Themes formulated as: <ul style="list-style-type: none"> - Understanding of PC

			Quantitative descriptive analysis & grounded theory based on Pidgeon & Henwood (1997)	<ul style="list-style-type: none"> - Training requirements - Implementation of PC approach <ul style="list-style-type: none"> • Suggested all participants had basic awareness of psychological reactions to stroke. Wide range of opinions re. how PC could be implemented. Suggested staff may not include PC in their duties or turn blind eye to issues. Staff emphasised further awareness, training & support from senior staff needed. Mixture of reports regarding formal & informal approaches for addressing psychological needs, reported these were framed as helpful. 2 prerequisites named for providing PC: ability to remain discrete re. patient's concerns & ability to listen attentively in patient-centred way. Range of opinions re. suitable PC for a stroke unit (from integration to antidepressants for all) & suitable staff (from everyone to no-one). Author states access to clinical psychologist is key for maintenance of PC system & self-care.
Brumfitt (2006) UK Psychosocial aspects of aphasia: speech and language therapists' views on professional practice	173 speech and language therapists working with people who have aphasia Purposive sampling	To examine views on the psychosocial aspects of aphasia in current practice, the importance of different dimensions of psychosocial functioning and to obtain information about current practice.	Mixed methods – convergent design Quantitative and qualitative closed and open questions, and rating scales within a 14-item questionnaire	<ul style="list-style-type: none"> • 97% agreed psychosocial aspects important to overall management of clients, 95% agreed importance of aspects to outcome of interventions, 77% felt prepared by SLT training for challenge of psychosocial needs of clients • More experienced SLTs reported spending more time on psychosocial issues; “self and identity” rated as most important psychosocial aspect • 2 SLTs reported using solution-focused therapy and 1 personal construct therapy • Themes: value of working with other professional groups, concerns about training available, difficulties balancing language impairment therapy with work on psychosocial needs, difficulties resourcing psychosocial aspects of practice
Northcott, Simpson, Moss,	23 speech and language therapists (SLTs) from 6	To explore how SLTs conceptualise scope of their	Qualitative 6 focus groups	<ul style="list-style-type: none"> • Main themes & sub-themes identified: <ul style="list-style-type: none"> - <i>How SLTs address psychosocial needs</i> (basic counselling skills; psychoeducation; engaging family; facilitating groups on adjustment; peer-befriending schemes or referrals to local stroke/aphasia groups)

Ahmed & Hilari (2018) UK Supporting people with aphasia to 'settle into a new way to be': speech and language therapists' views on providing psychosocial support.	stroke sites (inc. acute, rehabilitation, early supported discharge, outpatient, community) working with people who have aphasia (PWA)	role; barriers & facilitators to addressing psychosocial needs; SLT experiences of specialist training & support & working with mental health professionals (MHPs)	Analysed using framework analysis (Ritchie and Spencer, 1994)	<ul style="list-style-type: none"> - <i>The SLT role</i> (divergence between SLTs on role of addressing psychological wellbeing & boundaries; absence of MHPs means bigger role for SLTs; direct vs indirect ways of addressing wellbeing; internal conflict between SLT rehabilitation goals & psychological needs) - <i>Factors that enabled SLTs to provide psychological support to PWA</i> (specialist ongoing support via case discussion & reflective practice, emotional support & 'back-up' through reallocation to MHP; peer support from colleagues; support of management/whole team approach; value of experience; personal satisfaction) - <i>Barriers to SLTs delivering psychosocial support</i> (emotionally challenging; feeling under-skilled; caseload & time pressures; attitude of senior managers & commissioners; goal-oriented, outcome-driven services; complex needs or backgrounds of PWA; PWA/family preferences) - <i>Training in psychosocial approaches</i> (great variation in training received, from none to solution-focused, mindfulness, or counselling; perceived benefit for the SLT; influence on the SLT-PWA relationship; changes to assessment & goal-setting process; confidence in exploring emotions; challenges & limitations of training) - <i>MHPs addressing the psychosocial wellbeing of PWA</i> (perceived ability of MHPs to work with PWA; referral systems; communication & collaborative working between SLTs & MHPs; limitations of MH service provision) - <i>The ideal service</i> (would include either MHP skilled in working with PWA or SLT skilled in MH; more in-depth support throughout stroke pathway; whole team to take holistic perspective; better support for delivery of psychological care)
Harrison, Ryan, Gardiner & Jones (2017) UK Psychological and emotional needs, assessment, and support post-stroke: a multi-	66 health professionals of variety of disciplines and grades, from seven specialist stroke services in north of England,	To explore experiences of psychological need, assessment and support post-stroke, in hospital & immediately post-discharge (as part of a	Qualitative Focus groups of staff members and semi-structured interviews with more senior staff Thematic analysis, principles of framework analysis	<p>Two central themes identified:</p> <ul style="list-style-type: none"> • <i>Minding the gap</i>: psychological expertise – describing lack of psychological expertise on stroke units and frustration, concerns about increased psychological responsibility for non-psychology disciplines, lack of expertise suggested to result in over-reliance on medication as first line measure. Staff felt this impacted on amount of rehabilitation received and recovery made. MDT therefore take on psychological roles, but feel inadequately trained or skilled for patients with more severe psychological needs. Positive report around increased routine screening for depression and anxiety. • <i>Protective factors</i> perceived to reduce the need for formal psychological support – describes individual differences perceived to mediate need for formal support,

perspective qualitative study	(study also included plus 31 stroke patients, 28 carers)	wider investigation of post-stroke care)	(Ritchie and Spencer, 2002)	which could include patient's personality and attitude, needs met by family support, peer support on unit where available,
Bennett (2016) UK A culture of caring: how nurses promote emotional wellbeing and aid recovery following a stroke	16 nurses and 17 healthcare assistants in combined acute & rehabilitation stroke unit (within a larger sample including patients & relatives)	To examine how nurses and healthcare assistants use their knowledge to inform their interactions with patients and families	Qualitative Interpretive ethnography, including semi-structured interviews with 12/33 included staff, participant observation & documentary records of all staff.	<ul style="list-style-type: none"> • Emergent theoretical model described process of building, sustaining & reframing relationships between nurses, patients & relatives during patient's stroke journey and centrality of this to promoting emotional wellbeing. Described as complex. • Nurses framed building relationship & trust with patients as key priority, helping to support emotional wellbeing & create opportunity to understand & hear patient concerns, particularly within personal/intimate care. • Suggested that positive attitude, encouragement & reinforcing improvements in abilities helped to motivate patients & support wellbeing. Humour deemed important in helping patients relax & experience positivity on the ward, with positive effect in turn on nursing staff. • Nurses tried to be sensitive & empathetic to emotional wellbeing in order to respond most appropriately. They felt emotional support was expressed naturally & integrated into every interaction with patients. Some consideration for need of specific dedicated time for listening & responding to emotional distress & significance of this. • Stronger relationships understood by nurses as helping to offset frustrations & challenges for patients in hospital, thus supporting wellbeing. • Importance of receiving appreciation & gratitude highlighted by some staff, to know their work is valued.
Hayes, Donnellan, and Stokes (2015) Ireland Executive dysfunction post-	12 physiotherapists with <1 year experience working in stroke	To gain understanding of physiotherapy knowledge and practice in relation to	Qualitative Three focus groups with semi-structured interview schedule	<ul style="list-style-type: none"> • Physiotherapist's lack of knowledge of ED <ul style="list-style-type: none"> ○ Clinical presentation of ED ○ measurement of ED ○ lack of formal education post-stroke • Current physiotherapy practice regarding ED <ul style="list-style-type: none"> ○ Difficulty managing ED during physiotherapy ○ use of alternative treatment strategies to overcome ED

stroke: an insight into the perspectives of physiotherapists		executive dysfunction (ED) post-stroke.	Content analysis in line with Miles and Huberman (1994)	<ul style="list-style-type: none"> • Negative impact of ED on physiotherapy rehabilitation <ul style="list-style-type: none"> ○ Relevance of ED to physiotherapy rehabilitation ○ negative implications of ED for physiotherapy • Future learning and training needs regarding ED optimal management <ul style="list-style-type: none"> ○ Need for future learning regarding ED post-stroke ○ Future learning regarding alternative physiotherapy treatment strategies
Bennett (1996) UK How nurses in a stroke rehabilitation unit attempt to meet the psychological needs of patients who become depressed following a stroke	14 qualified nurses from two stroke units in north of England	To ascertain how nurses working in a stroke setting perceive the problem of depression in stroke survivors and what they do about it.	Qualitative Individual semi-structured interviews Unspecified method of analysis, but referred to 'recurrent themes'.	<ul style="list-style-type: none"> • Nurses described characteristics of depression as 'not wanting to communicate with anybody', being 'very quiet', 'withdrawing', and 'becoming introverted', 'lacking motivation', 'not wanting to do things', 'very miserable', 'just really fed up with life in general'. • Nurses suggested stroke survivors became depressed due to loss, grief, change, disability, losing responsibility for welfare, loss of prior life, and dread of the future. • 13/14 nurses considered depression to be normal, natural response to stroke, likened to grieving • Depression considered to affect rehabilitation participation • 10/14 nurses reported they do not attempt to assess psychological functioning; those who do use observation of facial expression, body language, gestures, and behavioural changes • Nurses reported that to help depressed stroke survivors, they spend more time with them, talk and listen, talk to other members of the MDT and involve relatives, • Precedence given to physical care, but nurses reported wanting to take on more psychological care of their patients, but felt lack of knowledge and skills as well as time, then felt inadequate, disappointed with themselves, or guilty when unable to. • Nurses wanted more training and more emphasis on psychological care

<p>Sekhon, Douglas, Rose (2015) Australia</p>	<p>111 Australian speech-language pathologists (SLPs)</p>	<p>To explore beliefs, attitudes and practices of Australian speech-language pathologists in addressing psychological well-being (PW) in people with aphasia after stroke</p>	<p>Quantitative A 26-item web-based survey consisting of open and closed questions was distributed to Australian speech-language pathologists through four electronic databases (qualitative data not reported in this paper)</p>	<ul style="list-style-type: none"> • 85.5% felt at least 50% of PWA on caseload had poor psychological health; 98% felt they had a role in addressing PW; 47.3% reported they address PW “most of the time” & 28.2% “always.” • All reported informal assessment of PW & 44.1% do not formally assess. • 84.3% reported rarely or not using specific psychotherapeutic techniques. Over 50% reported utilising counselling strategies to address PW “most of the time” or “always”, inc. motivational interviewing (19.8%), narrative therapy (18.8%), coaching (14.4%). • In managing PW, 68.5% did not feel confident, 58.3% did not feel knowledgeable & 69.4% did not feel satisfied & sought support from other HCPs with this (most commonly social workers (81.1%), clinical psychologists (66.7%), doctors (63.1%). • Self-perception of being under-skilled was main barrier identified to adequate practice (63.7%), followed by inadequate time, inadequate staffing & people with aphasia declining professional help • Main facilitators included personal interest, personal and professional experience & availability of counselling health professionals for people with aphasia. • Small-to-medium statistically significant correlations between SLPs reporting additional training in counselling & perceived knowledge of, confidence in & satisfaction with managing PW in people with aphasia (~four times more likely than those with no additional training). • Author states that thematic analysis of open questions will be reported in a separate paper, but this has not yet been published in a peer-reviewed journal.
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Methodological critique

The papers were appraised for quality and this was supported by using the Mixed Methods Appraisal Tool (MMAT), version 2018 (Hong et al., 2018). The five criteria for the relevant sections, or sections for mixed-methods studies, should be used to appraise the quality of the research. The *MMAT appraisal summary table 4* shows the overall quality ratings for each reviewed study and the criteria not met, where applicable.

Following the MMAT appraisal, it was concluded that the papers included in this review were generally of good enough quality, though Gurr (2009) and Bennett (1996) were of lower quality and therefore the results of these two studies were interpreted with particular caution in the synthesis.

Qualitative studies and components

All of the qualitative studies had research questions that were appropriate for qualitative investigation, though these were approached with varying quality. Four studies employed focus groups, while three employed individual interviews. Three further studies had qualitative components to their online surveys. The studies were appraised using the five qualitative criteria within the MMAT. Some of the studies, such as Gurr (2009) and Bennett (1996) lacked transparency and clarity on the specific methodological approach to analysis employed, which made it more difficult to assess the appropriateness and quality of the analysis in relation to the findings. The rest stated employing thematic analysis, framework analysis, content analysis, and interpretive ethnography. Theoretical positioning and epistemological stance were absent from all qualitative reports, except Simpson et al. (2018), who described their research as ‘primarily postpositivist’ in orientation. Accounts of reflexivity were seldom referred to, except Bennett (2016) which mentioned a reflective research journal. It was therefore difficult to ascertain how the researchers’ choices were informed by their preconceptions, assumptions, or beliefs, (Caelli, Ray, and Mill, 2003). The papers that were most transparent and provided the

most information regarding their methodology were Northcott et al. (2018), Hayes et al (2015), and Bennett (2016), which were the only studies to meet all quality criteria in the MMAT. While most studies were clear in providing themes and quotes, Bennett (1996) and the qualitative component of Gurr (2009) both lacked in this and at times there was little evidence provided to support the author's conclusions. Some studies (Harrison et al. 2017) had quotes and themes that were less representative of the entire sample interviewed and reported quotes predominantly from two professions, despite thirteen professions sampled in total. Bennett (2016) appeared to be the most in-depth investigation with the variety of data collection methods. Hayes et al. (2015) also provided depth to its more focused investigation around executive dysfunction and Simpson et al. (2018) offered detail to its qualitative component. Other studies that employed qualitative methodology were limited by the scope of their study, for example open-ended questions in surveys were less likely to provide depth than interviews or focus groups and were optional questions, allowing biased responses.

Quantitative studies and components

The quantitative studies or components were appraised using the relevant quantitative criteria within the MMAT, according to their design. All papers used descriptive quantitative methods, surveys in a cross-sectional design, to investigate the views and practices of participants. One paper (Brumfitt, 2006) additionally explored correlations between some aspects, using Spearman rho two-tailed tests of significance. Studies reported proportions of participants agreeing with statements, used rating scales, or offered options to select (for example, selecting clinical approaches used when working with stroke survivors experiencing psychological difficulties, as in Northcott et al., 2017). The sampling methods employed meant these studies were subject to self-selection bias and reliant on the accuracy and reliability of self-report. In addition, the response rate to surveys was low and it was noted that the studies had a risk of nonresponse bias. Those who chose to respond to the surveys might be more likely

to have an interest in psychological issues and may not capture perspectives of those who do not, or who have less time to participate in research, or see it as less of a priority for them. The use of questionnaires means that participants' responses may be influenced by wording of questions and without opportunity to further elaborate or follow-up to clarify issues. Three studies (Northcott et al., 2017; Gurr, 2009; Brumfitt, 2006) provided a copy of their questionnaire, which increased transparency and is helpful for the reader and researchers, such as for future questionnaire development.

Mixed methods studies

Mixed methods studies were appraised using the qualitative criterion, the relevant quantitative criterion, and the mixed methods criterion within the MMAT. The overall quality of the research is determined by the weakest component of the design. None of the mixed methods studies met all quality criteria.

All the studies appropriately employed a mixed methods design and provided rationales for this. There was more variety in the level of integration between quantitative and qualitative components. Three of the mixed methods studies (Northcott et al., 2017; Gurr, 2009; Brumfitt, 2006) employed a convergent design, while one (Simpson et al., 2018) employed a sequential explanatory design where the results of a non-standardised survey informed the interview guide for focus groups.

While a mixed methods design was appropriate for the aims of some studies, these were not always effectively carried out. Gurr (2009) employed a mixed methods design with the purpose of allowing for greater exploration following initial closed questions, but the execution of the qualitative component was somewhat weak and lacked transparency.

Studies that used questionnaires with both open and closed questions, with space for further comment (Northcott et al., 2017; Brumfitt, 2006) employed both descriptive statistics and qualitative analysis of participant responses, but there was variation in the balance between

the quantitative and qualitative components. Northcott et al. (2017) presented the results of the two components separately, but integrated effectively in the discussion. They provided great detail on the qualitative data with numerous quotes. In contrast, Brumfitt (2006) predominantly presented quantitative data with minimal qualitative results, which were presented separately and with few quotes.

Table 4: MMAT (2018) summary table of appraisal

Study	Design	MMAT score (criteria met)	MMAT criteria not met
Simpson, Ramirez, Branstetter, Reed, and Lines (2018)	Mixed methods	Qual: 4/5 Quan: 4/5 MM: 4/5	Lacking in clarity re. coherence between stages Risk of nonresponse bias Not all quality criteria satisfied for qualitative & quantitative components
Northcott, Simpson, Moss, Ahmed and Hilari (2017)	Mixed methods	Qual: 5/5 Quan: 4/5 MM: 4/5	- Unclear re. nonresponse bias Not all quality criteria satisfied for qualitative & quantitative components
Gurr (2009)	Mixed methods	Qual: 3/5 Quan: 2/5 MM: 3/5	Little info provided on analysis; Lacking in clarity re. coherence between stages Little info on survey development; unclear re. nonresponse bias; little info on analysis Unclear whether divergences or not; Not all quality criteria satisfied for qual. & quan. Components
Brumfitt (2006)	Mixed methods	Qual: 3/5 Quan: 4/5 MM: 4/5	Insufficient quotes provided; unclear if findings are adequately derived from data Risk of nonresponse bias Not all quality criteria satisfied for qual. & quan. components
Northcott, Simpson, Moss, Ahmed, Hilari, (2018)	Qualitative	Qual: 5/5	n/a
Harrison, Ryan, Gardiner, and Jones (2017)	Qualitative	Qual: 4/5	Difficult to ascertain that reported findings are sufficiently substantiated by data
Bennett (2016)	Qualitative	Qual: 5/5	n/a
Hayes, Donnellan, and Stokes (2015)	Qualitative	Qual: 5/5	n/a
Bennett (1996)	Qualitative	Qual: 2/5	Insufficient information given to ascertain coherence between stages of research; difficult to determine if findings adequately derived from the data; insufficient quotes provided
Sekhon, Douglas, Rose (2015)	Quantitative	Quan: 4/5	Risk of nonresponse bias

Synthesis of the studies

The conclusions drawn from the literature here should be considered in the context of the discussed methodological issues. For example, more weight is given to the findings of papers rated as good quality (e.g. Northcott et al., 2018) and less weight to the papers of lower quality (e.g., Gurr (2009)). All papers were included for review due to the paucity of literature in this area.

Terminology

It was noted that when discussing psychological aspects of stroke, there was a variety of terminology employed. This included ‘psychological wellbeing’, ‘psychological needs’, ‘psychological care’, ‘emotional care’, ‘mental health needs’, ‘psychological distress’, ‘psychosocial effects’, and ‘emotional wellbeing’. Across the papers, it appears that they are often referring to the same aspects of psychological functioning and psychological care, though it is not always explicitly stated what aspects they include, nor distinguish between more mild difficulties and severe difficulties. This in itself could have some impact on how participants respond, when there is different wording and it remains unclear what is understood by the differing terminology. Sekhon et al. (2015) addressed this issue somewhat in their study by providing participants with a definition of ‘psychological wellbeing’ at the beginning of their survey, based on the work of Ryff and Keyes (1995). Brumfitt (2006) also spoke to this by acknowledging and discussing this issue and explaining their rationale for using the term ‘psychosocial’, including the fact that their study aimed to explore subjective views and beliefs, as opposed to auditing practice, thereby determining that participants would interpret this however they thought was relevant and important.

This review will refer to psychological aspects of stroke to cover all psychological needs, but the reader should bear in mind that the different papers may have been discussing

differing levels of need amongst stroke survivors from some more minor adjustment needs, to problems that would fall under a serious mental health diagnosis.

Access to psychology expertise

While not all papers referred to this, there was variety reported in the availability of psychological expertise for the MDT professionals. Some reported no access at all, others described minimal presence either within or outside of their service, meaning difficulty in accessing psychologists as needed and insufficient psychological expertise.

Stroke professionals' awareness of emotional and behavioural consequences of stroke

Commonality of difficulties

Most studies referred to the views of participants regarding the prevalence and importance of psychological issues after stroke and these were generally regarded as significant by participants. One study (Gurr, 2009) asked participants to describe difficulties that may be experienced after stroke, to which participants described anxiety, shock, confusion, depression, adjustment, loss, and lack of sleep or appetite.

Sekhon et al. (2015) concluded that speech-language therapists (SLTs) in Australia were aware of the risk of post-stroke poor psychological wellbeing in people with aphasia, with 99% agreement by participants in their survey. While this study did not report further on how participants described what poor psychological health looks like, it did report that a majority of respondents (85.4%) felt at least half of their caseload were struggling with their psychological health, thus suggesting they view it as a very common experience for stroke survivors who have aphasia. It is not known from this study how the SLTs perceive psychological health in stroke survivors who do not have aphasia. Surprisingly, only 40% of the participants believed it was important to address the psychological wellbeing of their patients with aphasia, but the reasons for this are not known from this present paper. It is

possible that participants may have spoken to this within the open-ended sections of the survey, but the qualitative data have not yet been published.

A similar study exploring SLT views of stroke survivors with aphasia was carried out in the UK by Northcott et al. (2017). Half of the SLTs felt that 70-100% of their caseload experienced psychological difficulties.

While Harrison et al. (2016) did not specifically report participant opinions on consequences of stroke, it was reported that staff felt inpatient stroke services were failing stroke survivors by not providing sufficient psychological support while they were in hospital and instead having to wait until they were discharged. They felt this impacted a person's rehabilitation and recovery potential and therefore had long-term consequences. This suggests that staff were quite aware of psychological consequences and needs and the significance of these.

Hayes et al. (2015) was the only study to specifically explore clinical practice with post-stroke cognitive difficulties. This paper provided insight into the perspectives of 12 physiotherapists in Ireland who work with stroke survivors, regarding executive dysfunction (ED). The authors suggest that ED is traditionally under-appreciated and under-diagnosed due to the predominant focus on motor deficits for stroke patients, despite the negative implications for functional recovery (Hayes et al., 2015). However, there is little to no mention by the authors of the additional difficulty whereby symptoms of mood disorders can be difficult to distinguish from behaviours associated with ED, such as reduced concentration or lack of initiation (Bour, Rasquin, Limburg & Verhey, 2010) or the difficulty of knowing what behaviours may be premorbid and personality-based, or rather a consequence of stroke. Despite this, it appeared that some participants did refer to occasions where there was uncertainty about the causes of clinical presentations, but where assumptions may be made; for example: "I suppose I just figured at the time that it was cognitive problems, but didn't look into it".

Physiotherapists self-reported a lack of knowledge about ED post-stroke, uncertainty about measurement of ED and interpretation of such measures, and lack of skills and knowledge for managing ED within physiotherapy sessions. Most did not explore the reasons for their patient's presentations and felt the core focus of all therapists in their stroke teams was to prepare the stroke survivor for discharge, meaning ED issues could be missed and not addressed while the stroke survivor is in hospital. This could be problematic given the potential impact of ED on ability to return to work and other occupational activities, social participation, and functional independence.

Bennett (1996) also explored views on a specific psychological issue, interviewing nurses about post-stroke depression. They described how they understood depression to present in stroke survivors, for example, "not wanting to communicate with anybody" or "lacking in motivation", with explanations offered for why they might become depressed, such as "not being able to do the things they were doing before the stroke". All but one nurse believed depression to be a normal, natural response to stroke and considered it to impact on rehabilitation participation and potential.

Both Hayes et al. (2015) and Bennett (1996) give an indication of how distinguishing emotional issues from cognitive issues and even physical issues can be challenging and assumptions can be made about a stroke survivor's behaviour without careful assessment, which Bennett (1996) warns of.

Approaches and interventions MDT stroke staff take in addressing the needs of stroke survivors

Responsibility for psychological care

A number of studies reported how staff viewed their responsibility for a patient's psychological care (Sekhon et al., 2015; Northcott et al., 2017; Northcott et al., 2018; Simpson et al., 2018; Gurr, 2009; Bennett, 1996). There appeared to be a range of reported views when

it came to assessing and managing this, with some considering it inseparable from their professional role and even their personal self, while others thought there was more of a boundary between what they should do and what a trained mental health professional should do. Some participants in Northcott et al. (2018) described a conflict between these two viewpoints and even feelings of guilt around spending more or less time on communication goals, or psychological goals. Others considered that communication is so tied to a person's psychology, that they are inevitably integrated in practice. It was not possible from the studies reviewed to consider further the differences between these attitudes as this was not explored, but it also raises a question about the difference between psychological 'care' as opposed to 'treatment', distinguished by Scott and Barton (2010), and the MDT roles.

Sekhon et al.(2015) found a very high agreement from Australian SLTs on believing they had a role in addressing psychological wellbeing with their patients with aphasia. However, there was also a high amount of uncertainty about clinical practice boundaries and role definitions, as well as discomfort and dissatisfaction with how they would do this.

While Harrison et al. (2017) did not report specifically on views regarding who has responsibility for psychological care, it was reported that participants felt concerned they were increasingly expected to take on such responsibilities that they felt inadequately skilled and experienced in. They described feeling frustrated and thought these roles were assumed in lieu of sufficient psychological expertise and availability in their services.

Nurses in Bennett (1996) described wanting to provide psychological care themselves, but felt they lacked the knowledge, training, or support in how to do this, including from psychological experts and from the medical setting in which they felt constrained.

Specific approaches employed

A number of the studies described the reports of MDT stroke professionals in what they do to address psychological needs, including emotional, behavioural, and cognitive. This

ranged from formal to informal approaches such as employing formal mood assessments, versus clinical judgment, (Sekhon et al.2015) and general counselling skills, to specific psychotherapeutic training.

Sekhon et al. (2015) investigated what approaches SLTs in Australia were using when working with people with aphasia and did so by separating ‘clinical approaches’ from ‘counselling approaches’ in descriptive tables within their paper, though it is not known how they framed this query within their survey. The paper reports that respondents reported practicing all of the approaches that were listed within the survey, with varying degrees of frequency. Most frequently reported was encouraging patients to return to enjoyable activities, working on communication independence, celebrating achievements in communication and life goals, and encouraging hope and adjustment. The least reported approaches were training other staff or friends and partners in supportive communication strategies, the creation of opportunities for peer support, the use of psychotherapeutic techniques, and supportive counselling. It is interesting to note that training others in being able to communicate effectively with the person who has aphasia was the least commonly reported, given that participants also reported they addressed psychological wellbeing through working on communication independence, which may be helped by improving communication between patients and others. Also of note is that SLTs in this study reported most frequently using communication-focused approaches, within the remit of the professional role, to address psychological wellbeing, which may reflect beliefs about what influences psychological wellbeing, as well as what they feel able and permitted to do within their role.

Encouragement, positivity, recognising achievements, and identifying strengths were also described by nurses in Bennett (2016), as a way of promoting emotional wellbeing in stroke survivors. Such themes of focusing on values, identity, and positivity were noted across a few papers, including Northcott et al. (2017), Northcott et al. (2018), Simpson et al. (2018),

Bennett (2016), and Sekhon (2015). While this positive approach towards stroke survivors is helpful, it leaves a question about when this approach is not appropriate or timely and how staff manage this. Simpson et al., (2018) reported that 61.27% of OTs in their survey ask direct questions about feelings of sadness or anxiety, while 86.87% provide encouragement to talk about things that bother them. Nurses in both Bennett (1996) and Bennett (2016) spoke of listening to patients who were distressed and the importance of allowing time for this, while also feeling concerned and guilty that this time was inadequate.

Participants in some studies reported having had some training (majority less than a day) in specific psychotherapeutic approaches, such as motivational interviewing, narrative therapy, solution-focused therapy (Sekhon et al., 2015; Northcott et al., 2017), cognitive-behavioural therapy, and coaching (Sekhon et al., 2015).

The only paper to explore cognitive difficulties specifically (Hayes et al. 2015) described how physiotherapists tended to struggle to manage executive dysfunction, or to know if the approaches they were using were ‘correct’. A recurrent theme was that they did not explore the reasons for clinical presentations, but tried using alternative treatment strategies to deal with the difficulties of executive dysfunction. For example, verbal cueing, repetitive functional tasks, giving written instructions, and “environmental stuff, like turning off the radio or doing stuff separately in different rooms”.

The role of relationships

While a number of studies referred to approaches taking place within a therapeutic relationship, only Bennett (2016) referred specifically to the relationship between staff and patient. Bennett (2016) developed an emergent theoretical model of promoting emotional wellbeing and recovery through building, sustaining, and reframing relationships with stroke survivors. Nurses described relational processes such as creating trust, building rapport, getting to know patients, using humour, and allowing patients to know them. The perception of nurses

was that patients enjoyed hearing about their lives outside of work, with one nurse commenting: “you have to give a little bit of yourself, don’t you?...let them know that you’re human”.

Staff views about help and support needed to address psychological issues

Facilitators to addressing psychological issues

Facilitators were discussed less frequently than barriers. Across the papers, the most commonly reported enablers to addressing psychological needs were the provision of training, supervision, access to psychological expertise and management support. Some papers (Bennett, 1996; Hayes et al., 2015; Sekhon et al., 2015; Northcott et al., 2018) also indicated support from their MDT colleagues as either an additional form of support, or in lieu of psychological expertise. Northcott et al. (2018) reported SLTs as feeling less anxious about addressing psychological issues when they were supported by a psychologist or stroke-specialist SLT, through facilitating reflective practice, giving advice and strategies, and emotional support. In addition, these SLTs felt reassured they had ‘back-up’ through either joint work or case reallocation, if necessary. Northcott et al. (2018) reported that personal satisfaction was also a facilitator to some SLTs, who enjoyed considering psychosocial issues. While this is not further discussed, it is interesting to note and to consider that the sample in this study may have self-selected to participate because of their interest and motivation in psychosocial issues and therefore it may not reflect the perspective of SLTs in general.

Barriers to addressing psychological issues

The most commonly reported barriers were lack of confidence in psychological knowledge or skills and insufficient resources, (time, staffing, or actual physical resources). Many felt anxious about being able to meet the needs of stroke survivors and to know if what they were trying was appropriate. Linked to this in Sekhon et al. (2015) was some SLTs feeling that there was a lack of research evidence regarding what they should do, though it is worth noting this study only discussed stroke survivors who have aphasia.

There were references to the lack of psychological expertise within services in a number of papers (e.g. Harrison et al., 2017; Hayes et al., 2015) and the consequences of this for both the staff and their patients. One physiotherapist in Hayes et al. (2015) reported that there was “no formal neuropsychological support and very limited services with regards to the emotional-behavioural side...”, while another commented that “clinical psychology would be a luxury!”

Others also referred to systemic and service structure issues that were perceived as barriers to embracing a more psychologically informed approach, where they felt the medical model prevailed strongly and was more valued by management and commissioners and where results were emphasised as physical progress of patients. American OTs in Simpson et al. (2018) additionally identified limitations ensuing from an insurance-based healthcare system that required evidence of ‘approved’ interventions and concrete measureable outcomes. While the USA healthcare system is different from those in other countries, there are funding pressures in other healthcare systems that can affect how healthcare professionals feel they should be spending their clinical time.

Professional training

A few studies referred to a discipline’s formal education and preparedness and the consideration of psychological issues after stroke in their educational programmes (e.g. Hayes et al., 2015; Sekhon et al. (2015)). For example, Simpson et al. (2018) asked within both their initial survey and their focus group interviews how occupational therapists in the USA felt about the education on psychological issues they had prior to qualifying and whether they felt it was sufficient and effective for the work they were currently doing. While the participants generally felt they had good education about mental health needs more generally, there had been much less training in relation to stroke survivors. Many felt that physical health had been emphasised over mental health care and that they had been taught an overarching philosophy of valuing mental health of stroke survivors, but not how to directly support such needs.

Instead, they felt they were taught to know when to refer to psychology professionals. Given that a lack of psychological expertise in stroke settings appears to be a very common occurrence, this dichotomy may have left healthcare professionals feeling unsure of what to do when it is not possible, or very difficult, to refer to psychological professionals.

Discussion

The conclusions drawn from the reviewed literature should be considered with the understanding that much of the information presented in this review is derived from questionnaire data with far fewer participants being interviewed in more depth. The data therefore capture a moment in time for these participants. Furthermore, only three out of ten studies met all MMAT criteria, therefore the available literature is of varying quality. The dates of the studies ranged from 1996 to 2018, over which time there have been many political, economical, and technological changes around the world that are likely to have influenced healthcare, such as policy and provision. However, it is noteworthy that there are many common themes across this timeline, as well as across the countries, and different disciplines investigated. The commonalities in the themes across both qualitative and quantitative literature (albeit from similar questions) does suggest that the literature may be reflecting real and important themes that are resonant for MDT staff across these differing factors.

There was general consensus amongst the different groups that emotional, behavioural, and cognitive issues after stroke are significant and important to address, with more mixed opinions on how involved they should become as a clinician. Generally there was a sense that while participants endorsed a biopsychosocial perspective, this was not always endorsed or supported by their work setting, whether explicitly or more implicitly. There was little reference to how much participants understood about the emotional and behavioural consequences of stroke and the causes of these, as well as their beliefs about the experience of stroke for stroke survivors.

It was interesting to find that across the international studies, there are commonly shared facilitators and barriers reported to addressing psychological needs of stroke survivors. This may suggest universal challenges in non-psychological staff embracing and delivering psychological care and integrating this into their roles. However, it is also worth noting that this small range of countries where these studies were conducted also shared many cultural characteristics, such as being wealthy, Westernised, democratic societies. Yet, the countries represented, have a variety of healthcare models, including insurance-based healthcare in the USA, which creates some differences in the contexts which the healthcare professionals are working within. Despite difference in health care provision, all studies commonly referred to a lack of confidence in addressing post-stroke psychological issues, concerns of overly medicalised models in stroke care, insufficient time, staffing, and lack of other resources to meet the needs of their patients. That said, supply and demand in healthcare is an ongoing debate (Frankel, Ebrahim, & Davey Smith, 2000).

Professional boundaries and responsibility for psychological care was a theme amongst the papers. The literature suggests that staff can find it difficult to know the boundaries between their discipline's and psychologist-specific work, or unsure about their competency in addressing psychological issues. Even where staff recognise, acknowledge and accept they have a role in this, knowing how and what to do seem to be an ongoing challenge. Most support the idea of holistic and person-centred care and of not seeing psychological issues as separate from more physical issues, but in practice, it may be hard to implement due in part to the policies, expectations and service-driven goals and their training. In particular, some MDT roles are more closely aligned to the biopsychosocial model than others, such as occupational therapists who tend to work holistically, while nurses are trained in medical models. Some may also emphasise one aspect more than another, such as the '-social' component for SLTs, due to

the significance of language and communication in human relationships (Northcott et al., 2017).

Given that uncertainty about competency in addressing psychological issues is a common feature, yet staff generally seem aware of the significance of mood and cognition after stroke, this furthers the argument for the need for psychologists embedded within stroke teams able to provide regular and consistent supervision, training, and consultation to their MDT colleagues. It is important that in expecting MDT staff to improve their psychological knowledge and skills, that they are supported effectively through considering their zone of proximal development (Vygotsky, 1978) and ensuring that their needs are met so that they feel secure, needed, and appreciated in their healthcare roles (Benson and Dundis, 2003). It was clear from the participants' responses that the variety of healthcare staff did have some basic skills and knowledge in psychological areas, which they could potentially employ, but that lack of confidence and role confusion meant these were not always employed in a timely way. With appropriate and sufficient support, it is likely that healthcare staffs' confidence in both what they know and what role they could have would grow with time, creating a more skilled and pro-active workforce within stroke settings.

Implications for future research

Given the paucity of research and varied quality of this, more in-depth research is needed on MDT staff perspectives of psychological issues after stroke to reveal further their understanding and beliefs around psychological consequences of stroke. In particular, how UK-based MDT staff talk about these, given there is minimal and low quality research in this area and studies to date have largely focused on one discipline only, or one type of stroke survivor (four of the ten studies here explored only those with aphasia). In the UK, there has been progress in policy papers discussing psychological issues, but it is less known if or how these policy have had influence on MDT professionals. Nursing staff and SLTs, while common in

stroke settings, appear to be over-represented in the literature as compared to other healthcare professionals found in stroke settings, particularly physiotherapists, and there should therefore be more focus on ensuring all staff are included. Those whose models of working are more closely aligned to medical models than other therapists may be less likely to include sufficient education on psychological issues.

The impact on their own wellbeing is yet little understood or considered in the literature and should be explored further. It was clear from the studies included that there is anxiety around addressing psychological issues and this may lead to avoidance for some staff in taking on this role.

Future research could also helpfully consider the language regarding psychological health and interventions. The studies presented here demonstrate the range of terms used by both researchers and participants, including “wellbeing” through to “mental health”. In some cases, this may result in less clarity regarding participant’s descriptions and what they understand about psychological issues, assessment, or intervention. This vagueness in terminology may mean some important information is not captured. In addition more precision in terminology may also reveal where the boundaries of understanding of psychological issues lie. This issue was also raised by Sekhon et al. (2015) when they found a discrepancy between what speech and language therapists reported as the type of counselling approach they take and the actual specific techniques they employ. In other words the specific techniques did not match onto the model of counselling they thought they were using. This interesting finding could be expanded to other disciplines within stroke settings.

Clinical Implications

The reviewed papers suggest that staff clearly self-identify as needing more training, supervision and support for themselves, if they are to provide psychological support to patients and to feel confident to do so. There is a growing recognition of the importance of attention to

the psychological needs of those post-stroke, but without the resources to fill the increased demand. This is not unlike many areas in the NHS where a need is identified, creating a demand which then in turn uncovers a shortage of trained staff to fill this demand. It is highly unlikely that there will ever be enough clinical psychologists to cover all the psychological needs of stroke patients and therefore services may need to determine a model of stepped care that would cover different levels of need sufficiently and effectively. For example, some universal support could be provided by all staff, such as basic psychoeducation on wellbeing, emotions, and coping strategies, as well as listening to patient concerns with empathy and compassion, basic mood or cognitive assessment and recognising when further intervention, at level two, may be required (Kneebone, 2016). It should be considered which types of psychological care could be provided by some staff who receive further appropriate training. With clearer boundaries about their role, staff may feel more able to provide psychological care and there may be less difference between those feel it is their role and those who think it is not.

The review suggested that there were particular areas such as neuropsychological need (and distinguishing this from mental health problems), therefore requiring specialist expertise in assessment and diagnosis (Gilham and Clark, 2011). Freeing psychologists up from other types of support, such as at level one and two of the stepped care model, might mean that they are then more able to concentrate on more specialist interventions such as detailed neuropsychological assessment.

Given the themes of anxiety, lack of confidence, and unclear boundaries or pathways in addressing psychological issues, staff may find that using a model such as the SCoTS (Taylor et al., 2011) a useful framework for mapping the emotional, behavioural, and cognitive aspects they observe in survivors of stroke. It may form a basis upon which MDT staff can begin to learn to formulate and to consider appropriate intervention. In introducing new ways of working such as this, Vygotsky's (1978) zone of proximal development could help

psychologists to consider what staff can already do appropriately on their own, as some staff described within the reviewed studies, and what they are capable of doing with support and scaffolding to build the appropriate skills (Wood, Bruner and Ross (1976).

For level two of the stepped care model, some MDT staff could be trained in more specific therapeutic approaches. For example, Fraas (2015) suggests that clinicians working with survivors of stroke could adopt a narrative approach with their patients, which he posits would benefit both the stroke survivor and the staff. He proposed this approach could facilitate recovery and positive reconstructions of personal identity throughout rehabilitation and help clinicians to explore the individual's perceptions of successful recovery and quality of life. Therefore, Fraas (2015) states that this would help clinicians to develop more effective interventions through better understanding of their patients' psychological state. However, this does therefore require an increase in the amount of training stroke staff should receive, which has been found within this review to be falling short.

Conclusion

This review evaluated studies that have sought to explore stroke healthcare professional awareness of psychological issues after stroke and how they address these. The studies from four different countries encountered similar themes across the range of disciplines and across the timeline from 1996 to 2018. There was a range of opinion on how involved MDT felt they should be in addressing psychological issues, while acknowledging the prevalence of these, and generally low confidence in being able to do so. This review has illuminated the need for further research into MDT perspectives and their understanding of the psychological experience of stroke and roles in relation to this. In particular, a need for more in-depth investigation with UK-based staff following the policy progress in recent years.

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Part B
Understanding the psychological consequences of stroke

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Abstract

There is a paucity of research on how UK-based stroke multidisciplinary staff understand and work with the psychological consequences of stroke, despite growing emphasis on the need for all stroke staff to be able to assess, identify, and appropriately address these. This present study therefore set out to explore how a sample of stroke staff understand the psychological aspects of stroke, the experience of stroke survivors, and their role with psychological consequences.

Thematic analysis was employed to analyse semi-structured interviews with 10 multidisciplinary staff members from hospital stroke settings in the south of England. Analysis suggested two prominent master themes; Understanding stroke takes time and Negotiating the psychological role, each with three sub-themes.

Results indicated that while stroke staff recognise the importance of psychological care and demonstrate some endorsement of a biopsychosocial approach, they experience uncertainty and limitations in how to deliver this. The need for ongoing psychological training and support, particularly with less experienced staff, was highlighted.

Limitations of this study are discussed and future research paths considered.

Key words: stroke, psychological care, understanding, staff, biopsychosocial

Introduction

Stroke is the biggest cause of disability in the UK (Clarke, 2013) and can result in prolonged hospital admission, with physical and psychological impairments. A review by Ferro, Caeiro and Santos (2009) reported that the most common psychological difficulties post-stroke include affective (e.g. depression, anxiety), behavioural (e.g. withdrawal, sudden outbursts), and cognitive (reduced attention, slow processing speed). These difficulties not only reduce quality of life, but also affect an individual's ability to participate in and benefit from rehabilitation to recover from stroke. Other implications include potential impact on family and friends, as well as wider community and even the economy (Clarke, 2013).

With such widespread impact, studies have highlighted the need for improved understanding of psychological consequences to ensure the most effective recovery and quality of life for stroke patients and their families (Ferro et al, 2009). Early intervention has been highlighted as key, given the implications that such difficulties can have on engaging in rehabilitation and in decreasing likelihood of benefitting from rehabilitation with time (Kneebone, 2016).

Theoretical understanding of stroke

Biomedical models have traditionally been dominant within stroke settings; however, this model is increasingly viewed as insufficient for working with complexities of physical illness (McInerney, 2015). Historically there has been little presence of psychological expertise in stroke settings, despite the significant impact such consequences can have (Kneebone and Lincoln, 2012). While this has changed in recent years, it has meant that the multidisciplinary team (MDT) – typically consisting of physiotherapists, occupational therapists, nursing staff, doctors, and speech-and-language-therapists – are positioned on the frontline working with psychological consequences of stroke (Gillham and Clark, 2011). Therefore, their clinical

practice has involved encountering and managing a range of psychological needs while also working within theoretical and clinical models of their own professional specialisms.

With the dominance of medical discourses and physical consequences of stroke both within hospital settings and academic research (Young and Forster, 1992), psychological aspects of stroke have been somewhat neglected (The British Psychological Society, 2010).

Increasingly, the biopsychosocial model (Engel, 1979) has become accepted and employed within physical healthcare settings as a fundamental model of healthcare. Engel (1979) surmised that traditional biomedical models were insufficient for understanding and treating people with physical illness, describing it as disease-oriented, rather than patient-oriented. Engel (1979) reasoned that for patients, the “ultimate criteria” for health and wellbeing are psychosocial factors, regardless of the physical complaint. Therefore, it was emphasised that all healthcare staff should embrace the biopsychosocial model to provide optimal patient care and deliver better outcomes, for both patient and staff. A common set of assumptions and principles between healthcare disciplines was deemed especially necessary (Engel, 1979).

Borrell-Carrio, Suchman and Epstein (2004) further elaborated on Engel’s model to highlight complexity of the relationship between physical and mental aspects of health and therefore the need for staff to develop helpful clinical characteristics including self-awareness, emotional style characterised by empathic curiosity, self-calibration to reduce bias, and emotional education to assist with diagnosis and therapeutic relationships. In practice, this would mean embracing a relationship-centred model where emotional climate of the clinical relationship is considered central to practice (Borrell-Carrio et al, 2004).

More recently, Taylor, Todman and Broomfield (2011) proposed the Social Cognitive Transition Model for Stroke (SCoTS) as a psychosocial explanatory framework for predicting and understanding patients’ adjustment to stroke. It suggested a dynamic process that can lead

to a variety of outcomes for stroke survivors and discussed how all clinicians should facilitate adjustment through assessment, formulation, and treatment. However, it cautioned that some of the suggested processes require appropriate training and experience.

Policy and future directions

Following publication of the Francis Report (Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) there was renewed focus within the NHS on delivering competent, compassionate care to patients. Considering this, the Department of Health outlined its mandate for providing the NHS workforce with continuous development of skills, emphasising evidence-based training to improve quality of care (Department of Health, 2013).

Stroke care was highlighted as requiring improved quality of care, with training of staff necessary to achieve improved understanding and treatment of psychological consequences (Department of Health [DoH] 2007). NHS Improvement paper 'Psychological Care after Stroke' (Gillham and Clark, 2011) addressed the need for increased focus on psychological aspects, with emphasis on MDT members becoming increasingly competent in providing psychological care, using up to level two skills within a stepped care framework. The framework identified different levels of treatment: the first step involves least time and expertise and can be 'stepped up' to more specialist treatment when patients do not benefit from lower steps (Bower and Gilbody, 2005).

Gillham and Clark (2011) stated that psychological care should be accepted as an essential part of stroke care culture and considered equal to physical care and rehabilitation. They indicated that training should be undertaken by all involved in the stroke pathway in the UK. Such training should lead to all staff being comfortable discussing emotions; competence in identifying and assessing psychological difficulties; higher level psychological competencies for key identified staff; and psychological training and competences to be embedded within team objectives and job roles (Gillham and Clark, 2011).

The British Psychological Society [BPS] (2007) stated that clinical psychologists increasingly use consultancy and teaching skills and are therefore well positioned to provide MDT colleagues with enhanced psychological awareness and skills. George (2013) further emphasised increasing importance of the role psychologists have indirectly contributing to stroke care by providing training, supervision, and advice. Furthermore, it would be important to capture the MDT's views regarding this, so that clinical practice and training can be improved (George, 2013).

In light of these guidelines and policies, consideration needs to be given to perspectives of MDT members regarding psychological difficulties after stroke and their related knowledge and skills.

Psychological awareness and skills in the MDT

Kneebone (2016) presented a narrative review and guidance regarding application of stepped care to psychological problems after stroke. This outlined recommendations of psychological interventions suitable for MDT staff, from level one (common sub-threshold problems), to level two (mild/moderate symptoms of impaired and/or cognition). More severe and persistent disorders of mood and/or cognition may be 'stepped up' to specialist intervention by clinical psychology. MDT staff would be expected to be able to identify and assess, provide psychoeducation, actively monitor and refer for further assessment or intervention as necessary. Kneebone (2016) also described key interventions that should be available from the MDT team such as active listening; normalising not minimising patient issues; providing advice and information for adjustment; and problem-solving. Kneebone (2016) is a useful summary and guide, but also states that evaluation is necessary to determine efficacy with this population.

George and Genis (2012) found that psychology-led training in stroke teams appeared effective for improving knowledge and confidence around psychological factors amongst MDT

members, with most salient concerns being emotional and behavioural consequences. Training included cognitive and mood difficulties, challenging behaviour, and falls-related concerns. While positive impact of the training was reported immediately afterwards, it remains unknown how stroke staff experience and understand such difficulties in their clinical work and how this may impact on their work with patients.

There has been some limited research in stroke care with nursing staff, such as exploring how they think about depression after stroke (e.g. Bennett, 1996) and cognitive and mood disturbances after stroke (Kumlien and Axelsson, 2000). Bennett (1996) found that while inpatient nurses were often able to describe characteristics of depression and impact on rehabilitation, they felt constrained by lack of time, training and skills on how to meet needs of patients. There was also uncertainty about the role of cognitive impairment.

Meanwhile, Kumlien and Axelsson (2000) found that nursing staff in care homes spoke more often about cognitive disturbances as opposed to mood disturbances. Staff were uncertain about causes of changes in mental states following stroke and found it difficult to distinguish symptoms of mood disorders from physical stroke symptoms. Furthermore, they felt frustrated in attempting to understand patients and felt additional work-related stress could lead to risk of indifference and neglect of psychological needs. While this study looked at staff within care homes, it gives some insight into perspectives of those who support stroke survivors.

While there is a paucity of research in this area, such studies have identified a lack of confidence and understanding of psychological consequences of stroke. Ferro et al (2009) posit that through increasing knowledge of post-stroke emotional and behavioural disturbances, better understanding of a stroke survivor's behaviour will be established. Like Engel (1979), they suggest communication could be improved between professionals, patients and carers when shared language and understanding of psychological consequences exists (Ferro et al, 2009).

Neumann (2010) highlighted how staff need to feel confident to employ such knowledge and skills and that encouraging MDTs to work within a psychological framework can only function if professionals feel they believe in what they are being asked to deliver.

Improving knowledge

Relatively little research has been conducted into the perspectives of stroke MDT members regarding possible psychological consequences of stroke and particularly so since Gillham and Clark (2011) guidelines on the MDT role. Exploring MDT perspectives may provide further insight into how MDT staff understand the psychological picture of stroke and their role within this. This could help illuminate areas requiring further research and inform our understanding of how clinical psychologists contribute their skills in stroke care. The present study aimed to explore how a sample of MDT professionals working with stroke survivors in hospital describe their understanding of and responses to psychological consequences of stroke.

Method

Design

This study was awarded favourable ethical approval by the university and local R&D. Semi-structured interviews were employed in a qualitative design allowing participants opportunity to discuss their experiences in their own words. Given this is an area of little investigation, this method is helpful in reducing assumptions about what will emerge and offers more depth and richness.

Participants

Ten participants were recruited from an acute stroke unit and neurorehabilitation unit in a large UK hospital. Purposive sampling was employed where participants were selected based on being good sources of information for advancing towards the research goal (Patton, 2002). Posters were displayed in staff areas and an email distributed offering further

information about the study and how to proceed if interested, as well as offering a small voucher as gratitude. The original target was twelve participants; however, recruitment proved challenging, which was initially considered to be due to the project not being perceived as priority for staff working in demanding roles, and later owing to unavailability of staff in their busy working environment, as well as time restrictions of this project. Therefore, ten participants was deemed sufficient for the scope of this study and is in accordance with Braun and Clarke (2013) recommendations for a UK professional doctoral project. Inclusion criteria were for participants to be clinical staff members of the MDT based on a stroke or neurorehabilitation unit. Exclusion criteria included being a psychologist.

Five members of staff from each of the two units comprised of two nurses, three healthcare assistants, three physiotherapists, two occupational therapists. Unfortunately, it was not possible to recruit any speech-and-language therapists or doctors. No participants reported having completed any specific psychological training or education. However, I was aware that such a workshop had been developed within this organisation, which was important to bear in mind. Participant demographics are provided below.

Table 1: Participant demographics

Total participants	n=10
Gender	
Male	n=2
Female	n=8
Age	
Range	23-60 years

Mean	42 (<i>SD</i> =13.12)
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MDT role

Qualified nurse	n=2
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Healthcare assistant	n=3
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Physiotherapist	n=3
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Occupational therapist	n=2
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Stroke setting

Acute	n=5
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Rehabilitation	n=5
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Years qualified in profession

Range	0.5-34 years
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Mean	15.05 (<i>SD</i> =10.13)
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Years working in stroke settings

Range	0.5-26 years
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Mean	8.7 (<i>SD</i> =7.27)
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Reported stroke-related training

Bobath	n=1
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Thrombolysis	n=1
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College OT stroke course	n=1
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STAR competencies in stroke	n=1
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None	n=5
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Interview schedule

The semi-structured interviews aimed to elicit descriptions of how staff understand and respond to people who are experiencing psychological consequences of stroke. It was initially developed based on previous literature that investigated perspectives of stroke nurses (Bennett, 1996). Questions aimed to elicit descriptions grounded in staff experiences and narratives around patients they had worked with, allowing for more ecological validity than may be obtained using case vignettes. The questions were further refined and developed following discussion with the project supervisors. Feedback was also sought from a service user expert group.

Procedure

Participants were briefed about the study, provided with information sheets, and given opportunity to ask questions. They were informed about anonymity and right to withdraw at any time. The interview proceeded once participants confirmed what was entailed and agreed to participate. A consent form was signed and demographic information collected. Interviews were audio-recorded. The semi-structured interview schedule exploring participant perspectives and experiences on psychological aspects of stroke allowed flexibility to follow the direction of participants' discourse so that interesting points could be expanded upon. Interview duration ranged from 28 to 69 minutes. Once the interview schedule had been sufficiently completed and participants felt they had nothing else to add, the interview was concluded. Participants were debriefed and given the voucher. Following each interview, notes were made on initial thoughts about content, process and considerations for subsequent interviews.

Thematic analysis of interviews

Thematic analysis was employed to analyse the transcripts based on Braun and Clarke's methodology (2006). They describe stages of analysis in identifying patterns across qualitative data. Thematic analysis is an approach well suited to this investigation as it allows in-depth exploration of staff perspectives and flexibility with analysis. An inductive approach was employed as this does not assume prior explanations; important given the paucity of research in this area. A theoretical position was taken as described by Braun and Clarke (2006) as 'contextualist method', which they designate as sitting between essentialism and constructionism. This position was felt best suited to the present analysis as it postulates that individuals make meaning of their experiences within broader social contexts, while also recognising limits of 'reality'. As such, it was important to consider the immediate working environments of staff where biomedical models prevail, as well as broader NHS organisational factors and policies set within current political ideology and uncertainties, but also being aware of the personal 'reality' of each individual participant.

Quality assurance was informed by Braun and Clarke's (2006) 15-point checklist of criteria for good quality thematic analysis, from transcription, coding, and analysis through to the written report.

The first stage of analysis involved immersion in the data through transcription and checking for accuracy against audio-recordings, then repeated reading of the transcripts to familiarise further, in keeping with the aforementioned quality checklist. Note-taking of ideas continued throughout the analysis. Transcripts were coded broadly on an inductive basis and ensured to be thorough, inclusive and comprehensive, a criterion of Braun and Clarke (2006) for quality analysis. Broad coding allowed for consideration of a range of possible themes in relation to staff understanding and experience of psychological consequences. Most of the new codes were created in the first six transcripts and fewer novel codes were created in remaining

transcripts. Codes were refined and merged as appropriate and arranged into groups according to similar patterns. The groups began to form the basis of potential themes and were refined further according to similar meaning. During this stage, it was felt that a range of possibilities could be considered for thematic mapping and therefore decisions were made, following discussion and reflexive writing, about the most salient material.

Transcripts were re-read with the refined codes and themes to ensure they made sense of data. The evolving analysis was discussed and reviewed separately with a colleague and a supervisor at different stages to help inform a well-developed and coherent analysis and allow reflections. This included visually mapping out potential codes and themes. A research journal was kept throughout the process to support both functional and personal reflexivity (Wilkinson, 1988), an important component of quality assurance in qualitative research.

Results

Two master-themes were identified from the data: ‘Understanding stroke takes time’ and ‘Negotiating the psychological role’. Both were organised into three subthemes. The master-themes are understood to interact with each other as the process of understanding psychological aspects of stroke appeared to occur in parallel to staff negotiating their role around these.

Table 2: Themes and subthemes

Theme	Subtheme
Understanding stroke takes time	<i>Adapting to an uncertain and unexpected path</i>
	<i>Understanding the individual survivor</i>
	<i>Stroke makes more sense with experience</i>
Negotiating the psychological role	<i>It's everybody's role</i>

	<i>Being a psychological carer</i>
	<i>Limitations and uncertainty</i>

Understanding stroke takes time

This master theme captures how staff perceived the psychological process of understanding stroke and subsequent recovery as taking time for all involved. Subthemes were ‘Adapting to an uncertain and unexpected path’; ‘Understanding the individual survivor’; and ‘Stroke makes more sense with experience.’

Adapting to an uncertain and unexpected path

This subtheme reflects the descriptions staff used about their perceptions of how patients respond to having a stroke and a process of adjustment observed from first meeting the patient in hospital to point of discharge. Most described the nature of stroke from an empathic stance, imagining their patients’ lives before, sudden disruption by a life-changing event and located this in juxtaposition to imagining their patients enjoying their lives previously.

“I mean if you’ve got a 60-year-old who was on holiday enjoying their retirement, and suddenly they’ve completely lost half their movement...” (P2)

Early emotional consequences were framed within this suddenness, with confusion named as a common experience that may lead to aggressive behaviour from lack of understanding, as well as tearfulness and withdrawal as the patient processes shock and attempts to make sense of their situation at this early stage. Staff also reflected on how this could occur despite explanations and information from the beginning:

“Mostly confusion initially, as to what is going on...but then probably anger and disappointment. People are often frustrated, you know, why can't I walk, why can't I even sit up in a chair. They often don't understand what is going on even after the doctors and us, we tell them, you know, there is a big change but they still, you know, have difficulty in understanding why this is happening.” (P6)

This may highlight need for staff to repeatedly provide information throughout the recovery process, as it can be difficult to comprehend at earlier stages and is crucial to the adjustment process (Forster et al, 2012).

Staff described patients as struggling to cope when realising the extent of losses and the trajectory ahead of them, and how difficulty in coping may be unexpected by patients.

“They're like, right, I'm going to deal with it. I'm going to cope with it, and then suddenly it just gets to them and they realise their loss I think of the lifestyle they had.” (P5)

The apparent unexpectedness of such difficulties may in part reflect dominance of medical models and visual dominance of physical impairments, that may have neglected the reality of the impact of possible psychological aspects (Hochstenbach, 2000). Patients and caregivers therefore may not appreciate possible psychological complications and how these may hinder recovery (Chriki, Bullain and Stern, 2006). This highlights the important role staff have in helping patients and their families to understand psychological consequences and confidence in their ability to do so.

There was also a sense that staff can experience a parallel process of acceptance and adjustment when feeling limited in options to support recovery. Some staff described how, at times, they had to accept the reality of stroke consequences and in turn, help patients process

this. They described how this involved a change in how they approached the patient and their work with them.

“It can be quite sad, but if you understand the process of stroke, you could see...you can see that they’re really not going to... so you change your way of treating them. You can’t be so positive with them. It’s an acceptance then and it’s an acceptance of how they are going to be and helping them accept that. So, you change slightly and come down slightly... You have to be, look this is where we’re at. This is what we’re going to aim for. You’ve reached that goal. We need to move on now and then you can start asking, where do you want to go?So, it’s changing... lowering the tone and moving in a different direction.” (P1)

This could be a particularly emotionally taxing role for staff to fulfil, especially when several staff spoke of motivation and enjoyment of working in stroke and attributed this to observation of their contribution to a patient’s improvement.

“It’s amazing working in stroke care, especially...I think it’s mainly because...one thing is I can support people...if there is a movement coming back, just a flicker, that gives you joy. So, that really fascinates me...If your arm or leg is not working and if you can bring back movement in to it, it would be satisfactory.” (P3)

While staff value seeing such improvement, patients may feel otherwise if they expect better recovery. This could be challenging for staff when they don’t see patients improve as hoped:

“...there’s always those patients that pull at your heartstrings a little bit and you just feel really sorry for them. You’re quite helpless that you can’t really change their situation for whatever reason, generally because the physical problem is just so severe

perhaps that you just... you can try, but I think just knowing that you're probably not going to make an awful lot of difference.” (P9)

This kind of emotional impact was acknowledged by most staff and often set in the context of having built a relationship with a patient through spending time with them and getting to know them.

“I do think people don't quite appreciate how much of an emotional battering it can be, especially if you are with someone for a long period of time.” (P7)

In considering this impact of disappointing patient outcomes on staff, it may be important to consider potential impact on their ability to engage in a 'psychological carer' role if they protect their own wellbeing by withdrawing emotionally:

“I think, probably, in a way trying to get less emotional about it or just sort of, in a way, trying to withdraw yourself from what they are thinking about, emotional point-of-view wise.” (P6)

Several participants also referred to this as professional behaviour:

“it's not professional if you show that to the patient. It's not like your family. If that happens in your family then you might empathise with them, but then you have to keep your professional boundary.” (P3)

This apparent detachment from emotions could describe a process of empathy becoming blocked and may lead to staff inadvertently failing to attune to psychological needs of patients, potentially leading to both feeling vulnerable (Abbot Moore, 2010).

Understanding the individual survivor

This subtheme encapsulates talk around attempting to understand the individual, their needs and importance of this to working effectively with them. Staff discussed individual

differences as impacting on the stroke survivor's recovery and on how they would work with them:

“Everybody is different and everybody will have a different strategy. The strategy that's appropriate to them... and that's one thing you need to know when you do stroke medicine is that everybody's stroke journey is completely different. Everybody's stroke is going to affect them in a different way depending on where they were before and where has been affected.” (P10)

There was acknowledgment of only knowing the individual post-stroke and within the hospital setting, therefore limiting and shaping how they understand the stroke survivor and interpretation of behaviour:

“I think when we have people come in, we don't know who they were before...so I think some people struggle to realise that just because this person's literally cursing at you and throwing stuff at you and going mental at you, that's not necessarily the person they were....you just have to accept their feelings and understand, just because they're being angry, it's not aimed at you.” (P5)

It was often highlighted how spending time with patients was important in order to understand them and their needs better, as well as for finding patient-centred ways of attending to these:

“I think the more time you spend with patients, the stronger the relationship is I think because you get to know them. They get to know you....because you actually know a bit more about them don't you, so you know what they're going through or what they want to go through...” (P4)

Describing their relationships with patients in this way suggested a psychosocial perspective may be framed within the context of developing empathy through building relationships.

Stroke makes more sense with experience

This subtheme reflects the views of staff that stroke and psychological consequences are hard to understand with little experience and that these make more sense over time.

“It’s not until you’ve been doing it for a little while that you understand why they’re being like it.” (P5)

Participants therefore identified more junior staff as struggling with psychological aspects of stroke and particularly where there is behaviour that challenges:

“I do think the behaviour side of things is something...because some of these young ones haven’t got a clue how to deal with someone who is standing in front of them waving their arms around. They can’t cope with it.” (P1)

This highlights a need for staff who are less experienced in working with stroke survivors to receive training and support to better understand emotional and behavioural consequences, in order to be able to work with patients more effectively and compassionately. Staff who had been working in stroke for many years tended to speak with more authority about how they understand the experience of the stroke survivor and psychological issues.

“Having done it for 26 years, you can judge somebody quite easily if...you can tell which ones are up for it and which ones are not.” (P10)

However, while increased staff confidence can be positive, overconfidence may hinder a “beginner’s mind” (Borrell-Carrio et al, 2004) and thereby understanding individual patients and meeting their unique needs.

Negotiating the psychological role

This master theme captures how staff members discussed their acknowledgement and understanding of needing to play their part in the psychological care of their patients, of providing basic psychological care, but identifying challenges and limitations to this. Three subthemes were identified as ‘It’s everybody’s role’; ‘Being a psychological carer’; and ‘Limitations and uncertainty.’

It’s everybody’s role

This subtheme encapsulates how staff generally held consensus in describing psychological care as part of their role as they felt psychological issues cannot be disentangled from the overall stroke experience.

“I think with the psychological aspects I don’t think it can ever not be your role. I think you are always going to be involved in that side of it because if you are seeing that patient...it is not just about getting them up, it is about looking after their emotional needs and how the patient is feeling as well. That is our role...we look at patients from a holistic view.” (P6)

While participants generally positioned themselves as all equally occupying this role, there was also some disparity around how other members of the staff were perceived as better placed to meet the psychological needs of patients. There was a sense that those who spent more time with and who learn more personal details about the patient were more likely to be in the position of listening to concerns of patients and perhaps understanding them better. A nurse commented about a therapist colleague:

“I think because they also spend a lot of time doing their assessments and things like that, they do let things out and explain things to them with regards to what...because they discuss what their home situation is and the houses and things like that. They do

tend to talk to them a lot as well. So, we get a lot of background history from them.”

(P2)

This may reflect some tension amongst staff around perceived expectations and reality of providing a psychological role to patients. In addition, some felt the goals of their discipline-specific role may not allow for consideration of psychological aspects and were unsure how they could integrate these:

“When you’re physio, you don’t get that much chance to do, like, assessing the cognitive impairments or do more things in detail, because you always work on the physical side of things. So, I’m always a bit unsure how that happens. What could we do?” (P3)

However, others described ways in which they tried to incorporate identification and consideration of psychological needs:

“It is sort of an ongoing thing, you know, as you go up to the patient you ask them how they are feeling, you have a look at their body language, their posture, things like that, how they are responding to things that you are telling them and that you are doing to them.” (P7)

This suggests differences between staff in how able they feel to encompass psychological needs within their roles.

Being a psychological carer

This subtheme summarises how staff described how they attempt to meet basic psychological needs of patients. Staff described ways in which they do this: e.g. offering reassurance, providing information and basic psychoeducation, spending time with patients and listening to their needs, being positive and providing hope and encouragement.

“I think it’s just the talking and the explaining of the disabilities and giving them the confidence and saying, you can do this really well instead of focusing on the negatives and the bits that they can’t do...giving them that confidence that they can do stuff and they’ve not just got a one-sided weakness and they can’t do anything. It’s giving them that boost and making them see that they actually can. I think sometimes they think to themselves, yes, I can do this. I’m going to give it a go.” (P8)

Staff also spoke of the importance of good communication with their patients and the difference that can be made by the language used and manner in which it is spoken:

“I think communication is a big part of it. Talking to a patient one way rather than another can change a person’s mood...”(P9)

This reflects an awareness of how staff can have an impact on their patient’s mood state through any interactions and therefore the need to consider this. This was also reflected in descriptions of staff efforts to help calm distressed patients:

“You could try and have a conversation with her which was a load of rubbish, but it’s keeping her calm.” (P4)

This had a sense of being framed by the participant as an improper way to manage a patient’s distress, but effective nonetheless. This may reflect some uncertainty on the part of staff around what constitutes psychologically-informed care.

Limitations and uncertainty

This subtheme summarises ways in which several staff described feeling uncertain about how they should be providing psychological care and whether there was a better way to do it, as well as identifying barriers to providing this care. There seemed to be uncertainty around whether what they are doing is ‘right’ and of trying to determine through trial and error what seems to work.

“I’d like to learn more about the cognitive impairments in stroke and how to manage them, maybe just to reassure myself that I’m dealing with it the correct way...I don’t know if that would help me to talk to the patients in a better way....just to reassure myself that I’m doing it properly, dealing with it properly.” (P8)

A few participants also referred to uncertainty around what psychologists do with patients, but that it seems to help.

“I always wonder how do they go in to the patients? They start a conversation and the patients open up really well with them. I have no idea how they do it, but yes, most of the patients, they do appreciate the support from the psychologist.” (P3)

This may reflect a lack of awareness and understanding of psychological models and approaches and perhaps speaks to the still developing role of clinical psychology within stroke care.

Limitations of time and high demand, as in previous literature (e.g. Bennett, 1996), were particularly salient topics named as preventing staff from attending to the patient’s psychological needs. With restrictions to their time, some spoke of how they hoped psychological issues could be addressed elsewhere and by others.

“You want to be able to give them the time to talk about it and...or cry, or say how frustrated they are and you want to...you don’t want to come across as not listening to them or understanding their views, but equally, when you’re on timescales that you’ve got lots of patients to see, it’s just not always possible... Knowing you’ve got a community team behind you who...I guess putting out the referrals and just hoping that would be addressed in the community...” (P9)

This may help to illuminate how recognition of psychological issues and how to address them may not be enough when there is a sense that time and other work demands do not allow

for implementation. This quote suggests that some staff may manage feelings of guilt by holding hope or expectations that someone else may be able to provide psychological care instead.

Recognition of the impact of limited time to be with patients was also described as being potentially harmful to their psychological state and phase of adjustment.

“Someone could be having an okay day and then five minutes later...you’re too short staffed to get there before they have an accident, or before they drop their food. Their dinner is in front of them, but they can’t feed themselves....they try and do it themselves and they knock it over and then they feel they’re a failure. Emotionally I suppose, that will put them backwards. They’re feeling good about themselves and then getting dragged back down.” (P5)

There was a sense of frustration about this, but also helplessness of how this could change without improved resources and staff availability.

Another limitation articulated by staff was related to differences in ability to tend to emotional patients and how some staff seemed less well equipped, sometimes because of their own wellbeing.

“Some of the staff don’t really know what to say to someone who is sitting there crying their eyes out, and why they’re crying their eyes out. They don’t deal with the emotional side... can’t deal with the emotional side. So, it’s... you get specific staff who can and staff who can’t...I think also, sometimes it depends on what is going on in their own life. If they’ve got issues themselves, they can’t really cope with someone else’s personal issues.” (P1)

There was also acknowledgement of this as a problem:

“it can be quite tricky and if there’s nobody around, then I’m not quite sure what happens really.” (P1)

It suggests patients may not have access to emotional support when they need it, even if staff are present, as the staff member may not feel capable of attending to their needs. This is a problem for both parties and perhaps speaks to how a perceived lack of compassionate care may arise, as found by the Francis report (Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013).

Discussion

This study set out to explore how stroke MDT staff understand psychological consequences of stroke and their role in relation to these. It adds an interesting insight to the literature in this area where there has been little research from this perspective. The results are framed within the context of two different teams who had some access to clinical psychologists; one unit had two psychologists based on site, the other had access to one psychologist approximately once a week. While there has been an increase in presence of psychologists in stroke settings, sufficient access continues to be problematic (Gilham and Clark, 2011). It is interesting to note therefore the perspectives of the present teams within the context of access to psychological expertise, including a trust-wide workshop on psychological consequences of stroke.

Interviews allowed for healthcare professionals to reflect on their experiences and understanding of stroke and psychological caring for stroke survivors. A few participants commented on how their participation gave them time and space that tended to be unavailable or scarce, particularly for those working on the acute unit. This perhaps provided an opportunity to consider psychological aspects of stroke in a different and slower-paced context and for exploration of issues that may sometimes be taken for granted in their busy working environment.

The themes identified how staff tended to consider working in stroke as challenging due to its complexities and varied presentations, and uncertainty was a core concept within this. The experience of uncertainty that staff observed both in stroke survivors and in themselves may suggest a high level of anxiety within stroke settings. Menzies Lyth (1959) identified how strong emotions can be elicited within the act of nursing and caring for patients and staff may therefore attempt to reduce emotional overwhelm and anxiety, such as through denial of feelings and avoidance of extended contact with the patient. This may speak to some of the experiences described by participants in this present study. The need to consider and address psychological consequences, while agreed with, seemed to be viewed as an extra challenge requiring additional time and that this may be atypical compared to other areas of physical health that MDT members had experienced. This was despite acknowledgement by staff that psychological issues was everybody's business and could not be separated from the overall stroke experience. This suggests that integrating psychological thinking and skills can be a challenge, which may be further understood by references to limitations and uncertainty that staff made. In addition, staff spoke of the emotional impact on themselves and their efforts in putting aside their own emotions, or even withdrawing physically or emotionally from patients. This would be an important area to continue investigating as it has been emphasised how important it is for staff to employ an empathic, emotionally attuned stance and to know how to use and express their emotions and when it is appropriate to set limits and boundaries, all in the aim of creating a functional relationship (Borrell-Carrio et al, 2004). However, many spoke of sharing their experiences with their colleagues and described the support that can exist within the team for managing this.

Time and experience were considered necessary for understanding psychological aspects and how to address these, suggesting that ongoing training and support would be important for gaining psychological knowledge and skills. While there was talk of more

experienced staff having better understanding and confidence, it could be beneficial to encourage a ‘beginner’s mind’ to remain empathically curious and open to unique experiences of individual stroke survivors, consistent with a biopsychosocial approach (Borrell-Carrio et al, 2004). Given that staff perceive this as complex and emotionally investing work and are expected to deliver up to level two of the stepped care framework, it is important to consider how they can be further supported with delivering this expectation.

It was recognised that individual stroke survivors have individual experiences of stroke due to individual differences, such as in coping styles. Such differences were related to how emotional and behavioural difficulties may present and be understood by the staff. This fits well with the SCoTS model (Taylor et al, 2011), which recognises individual differences in a person’s ‘assumptive world’ based on life experiences, cultural and social factors, and how consequences of stroke may confirm or disconfirm their assumptions. This suggests that while there was a theme of limitations and uncertainty, some of their understanding was in line with this existing psychological model and therefore supported by clinical and research evidence.

The descriptions of how staff perceive the experience of having and recovering from a stroke are largely in line with descriptions produced by stroke survivors in qualitative research. For example, Salter, Hellings, Foley, and Tesell (2008) conducted a meta-synthesis of literature exploring the experience of living with stroke. They identified five themes: change, transition and transformation; loss; uncertainty; social isolation; and adaptation and reconciliation. This suggests that staff may have some insight into experiences of their patients that can support the challenges stroke survivors face in hospital. However, Salter et al (2008) also noted that discrepancies often occurred between the goals of healthcare professionals and stroke survivors and recommended investment in patient-centred care that allows for personal narratives to be heard and used in discussion around their needs and rehabilitation goals, with a view to improving how meaningful and therefore perhaps how motivational these goals can be. How

this could be implemented requires further exploration, particularly bearing in mind time and workload pressures identified by staff.

It was noticeable that cognitive issues were less often talked about by participants and while it is beyond the scope of this study to explore this in depth, there are some possible explanations. There could be a lack of shared language around cognition, less knowledge or confidence in talking about cognitive difficulties, or it may be due to framing of the questions, which may fit with the findings of Bennett (1996) and Smith, Craig, Weir and McAlpine (2007). Bennett (1996) found that while inpatient nurses were more able to discuss depression, they were uncertain about the role of cognitive impairments. Smith et al (2007) later found in a survey of stroke staff of different disciplines that the management of cognitive difficulties was ranked as the highest learning need amongst all surveyed and therefore may reveal lack of confidence in this area.

Clinical implications

Addressing uncertainty

The subtheme around uncertainty highlights an area of training that is needed to improve confidence of staff in working with psychological consequences of stroke. Incorporating biopsychosocial models into formulating within teams, such as that described by Borrell-Carrio et al (2004) and the Social Cognitive Transition Model for Stroke [SCoTS] (Taylor et al, 2011), may be helpful. Staff indicated that they understood they had a role in providing psychological care. Explicitly using such models may help to provide context to the skills that staff employ and continue to develop their understanding, empathic curiosity, emotional education, whilst fostering containment. This could help to address the emotional impact on staff while they negotiate their psychological role.

Clarke and Forster (2015) state that all members of a stroke team should understand principles underpinning rehabilitation interventions in order for effective implementation. This is especially relevant for psychological interventions where integration in other aspects of stroke care is key. As the present study suggested, staff feel it takes time to understand stroke, such principles could therefore be made clear and given as rationale to all staff from the outset of their work in stroke settings. This could be a key role for psychologists and fits with the need to “give psychology away” as first stated by Miller (1969) and reiterated in stroke strategies, such as Psychological Care after Stroke (Gillham and Clark, 2011). This same strategy proposed the need for regular supervision, peer support and reflective practice for MDT staff when expected to deliver psychological support. This was reflected in the present study when staff described difficulty in coping with the patient’s and their own emotions, and may manage this by withdrawing emotionally or even physically. This is an area where clinical psychologists could use supervision and consultation skills, to ensure that staff are adequately supported to deliver psychological care; for example, facilitating regular reflective practice groups that allow space for staff to reflect on the emotional aspects of their work and how they manage this.

Frameworks for training MDT staff

A helpful framework that clinical psychologists could employ for MDT training may be patient-centred interprofessional learning using narratives in educational workshops (Blickem and Priyadharshini, 2007). This approach used narratives developed in case vignettes to help staff notice various processes that occur within their roles and to recognise where their own prejudices, beliefs, attitudes, or experiences may affect how they understand patient behaviour.

The psychological stepped care model discussed by Kneebone (2016) may be helpful approach for considering the warranted level of intervention and identifying appropriate staff for this. The psychological care described by staff in this study appear in line with some key interventions and skills outlined in level one of the stepped care framework and gives some insight into how staff report their psychological role. Strengthening skills at this level for all MDT members would be beneficial for staff before identifying key members of the team who may be able to deliver step two level care, as advised by Gillham and Clark (2011). Those who are trained in level two interventions could model to their colleagues the delivery of psychological interventions as non-psychology professionals, which may help to reduce a sense of mystery about what psychologists do and any 'us and them' split between psychology and non-psychology staff.

Research implications

The themes identified in this study may be further explored in qualitative and quantitative research. For example, in development of surveys for staff in other stroke settings, that could seek to explore the extent of these experiences for staff and therefore may contribute to informing clinical psychologists when developing training programmes and interventions.

While staff identified confusion, unexpected psychological consequences and importance of information-giving, it is unknown how this translates into practice. Lack of information and understanding of stroke is often reported by patients and carers, though it is difficult to know whether this is true lack of needed knowledge or a reflection of ongoing uncertainty of post-stroke life (Clarke and Forster, 2015). Either way, uncertainty after stroke was a significant concept and would benefit from further exploration of its impact on staff and consequent impact on patients.

The stepped psychological care model for stroke could be further explored for its usefulness as a framework for staff, as suggested by Kneebone (2016), including implementation of level one and two skills and impact on patients. Research could also be carried out on feasibility and efficacy of reflective practice groups where implemented and exploring any change in staff psychological skills and confidence. Furthermore, perspectives of stroke survivors should continue to be explored in regard to how their psychological needs are met.

Limitations

This research was carried out with a small sample of multidisciplinary stroke staff from two hospital units within one NHS trust. However, a small sample size is adequate for a qualitative design (Braun and Clarke, 2013) and for the scope of this present study, where the aim was to begin to develop a richer understanding of the perspectives of staff that can be further explored with future research. As opposed to generalisability, the findings may have transferability to other similar groups; its applicability can be determined by the reader based on details presented here of the setting, context, and participants (Braun and Clarke, 2013).

Qualitative analysis inevitably involves influence from the researcher in the process and findings of research and existence of multiple realities is thus acknowledged (Braun and Clarke, 2013). Another researcher may have developed different themes from the same data, but the researcher's active engagement with participants in the process of interviewing adds important meaning and context to the content. Bracketing, embedding oneself in the data, reflective writing, and considering previous literature and context helped to inform this process. Critical reflection was engaged in throughout and discussions with supervisors and colleagues helped to ensure findings were grounded in data collected.

It is also important to acknowledge potential impact of the researcher as a psychology professional while interviewing non-psychology staff about psychological issues. This was considered during the recruitment and interview process, including through emphasis on confidentiality and independence of the researcher. The researcher also aimed to approach from a ‘curious outsider’ position and to create a climate of non-judgmental openness and warmth, to help reduce any possible effects (Gallais, 2008).

Conclusion

This study explored perspectives of MDT professionals working with stroke survivors in stroke settings in regard to understanding psychological aspects of stroke and their role with these. Two master-themes were identified: ‘Understanding stroke takes time’, with subthemes of ‘Adapting to an uncertain and unexpected path’, ‘Understanding the individual survivor’, and ‘Stroke makes more sense with experience’; and ‘Negotiating the psychological role’, with subthemes ‘It’s everybody’s role’, ‘Limitations and uncertainty’, and ‘Being a psychological carer’. These themes organised descriptions given by staff participants in relation to how they understood the psychological experience of surviving a stroke, as well as their role in relation to psychological needs of patients. Staff described feeling limited or uncertain about meeting the psychological needs of patients. Future research should explore how staff can be supported to work psychologically, improve confidence in doing so, and support their own emotional wellbeing. Stroke services should consider how they can address these issues, including through clinical psychology expertise.

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BETHANY STROYDE BSc Hons

SECTION C:
APPENDICES OF SUPPORTING MATERIAL

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

April 2019

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Appendix A: Quality appraisal tool

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Appendix B: University ethics approval

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Appendix C: Participant information sheet

Information about the research

Title of Project: Understanding the behavioural and emotional consequences of stroke

Hello. My name is Beth Stroyde and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you.

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

What is the purpose of the study?

The purpose is to explore the perspectives of multidisciplinary stroke staff who work with people who experience emotional and behavioural changes following a stroke. We hope this will inform our understanding of how best to meet the psychological needs of people following a stroke.

Why have I been invited?

You have been invited to participate because you work with people who have suffered a stroke.

Do I have to take part?

We should be grateful for your time and contributions. However, you are under no obligation to join the study. If you agree to take part, I will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

Your involvement would entail us meeting on one occasion in your workplace to complete a semi-structured interview (1 hour maximum) and a short questionnaire (5-10mins). The interview would be about your experiences of working with patients who are recovering from stroke and the psychological and behavioural changes that they may encounter. The interview will be audio-recorded with a Dictaphone so that it can be transcribed afterwards. Both the audio-recording and the transcribed interview will be stored securely on an encrypted memory stick and the transcriptions will be anonymised so that you are not identifiable. I may include some verbatim quotes from your interview in the write-up of my research paper, but these will be fully anonymised. The questionnaire will also be anonymised so that you are not identifiable.

What will I have to do?

All you have to do is agree to participate. I will then ask you to sign a consent form, and then arrange a meeting for the interview and questionnaire. I will meet with you in your workplace at a time that is convenient with you.

What are the possible disadvantages and risks of taking part?

You may have some concern about disclosing thoughts, feelings, and experiences in relation to your job role. Please be assured that I am bound by the ethics policy of my organisation (Canterbury Christ Church University) to protect your anonymity. I will not share your data with anyone.

What are the possible benefits of taking part?

We cannot promise that the study will help you personally, although you may find it helpful to have an opportunity to discuss freely and openly your experiences of working in stroke care. We hope that

the information we collect will help us to better understand the perspectives of staff who work in stroke care and the psychological consequences of stroke. We hope that this will also help us to consider how psychological care may be developed in stroke services.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will remain confidential. The details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don't want to carry on with the study?

If you decide you no longer wish to participate then we will discard the audio-recording and any transcriptions that may have been made. We may ask for your permission to use the data collected up to the point of your withdrawal but will respect your decision if you decline.

What if there is a problem?

I will endeavour to address any unforeseen problems that may arise during the course of the research.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to answer your questions [contact number]. If you remain unhappy and wish to complain formally, you can do this via your manager or the Research Director of my clinical psychology training course, Professor Paul Camic, on 0333 011 7114 or paul.camic@canterbury.ac.uk.

Will my taking part in this study be kept confidential?

During the study the data will be collected by recording your interview on dictaphone. This recording will then be transferred securely onto an encrypted memory stick. The recording will be transcribed anonymously so that you will not be identifiable. Anonymised transcripts will be shared with the project's two supervisors (Dr Monika Hunter and Dr Melanie George). Recordings will then be destroyed. Participants have the right to check the accuracy of data held about them and correct any errors. Anonymised data will be kept for 10 years after the end of the study. There are limits to confidentiality should there be any circumstances in which I would have a duty to pass information on to a third party.

What will happen to the results of the research study?

The results will be made available to participants of the study and you may wish to provide your contact information for this to be passed on. It is also intended that the study will be published and so there are likely to be some anonymised quotes used within this.

Who is organising and funding the research?

The research is organised through Canterbury Christ Church University and Kent and Medway NHS and Social Care Partnership Trust.

Who has reviewed the study?

All research in the NHS is evaluated by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Canterbury Christ Church Research Ethics Committee.

Further information and contact details

If you would like to speak to me and find out more about the study or have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 0333 011 7070. Please say that the message is for me [Beth Stroyde] and leave a contact number so that I can get back to you.

Appendix D: Consent form



Participant Identification Number for this study:

CONSENT FORM

Title of Project: Understanding the behavioural and emotional consequences of stroke

Name of Researcher: Beth Stroyde

Please initial box

1. I confirm that I have read and understand the information sheet dated.....
(version.....) for the above study. I have had the opportunity to consider the
information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at
any time without giving any reason, without my legal rights being affected.

3. I understand that the interview will be audio-recorded and transcribed
anonymously and the questionnaire will be anonymous.

4. I agree that anonymous quotes from my interview may be used in published
reports of the study findings.

5. I agree to take part in the above study.

Name of Participant _____ Date _____

Signature _____

Name of Person taking consent _____ Date _____

Signature _____

Appendix E: Interview guide

Open-ended questions for semi-structured interview

- In your experience, what sorts of behaviours/emotions have you come across when working with people who have suffered a stroke? What do you understand about these?
- What do you find to be the most time-consuming or significant issues for you when working with people who have suffered a stroke?
- Tell me about a patient whom you have found particularly challenging to work with in terms of how they behave? What was your impression of them? How have you tried to explain this to yourself, or make sense of it, or is it really just puzzling? If so, how do you understand it?

Prompts if necessary:

- What kinds of things made it difficult for you?
- How did it make you feel?
- What was your initial reaction?
- Why do you think the patient may have responded like this?
- Do you think that [these behaviours] are surprising following a stroke?
- In what way might their stroke have contributed to their behaviour/responses?
- How do you think this might affect their recovery/rehabilitation?
- What do you think has led you to understand this patient in this way?
- What would you do better if you could?
- What ideally do you think might help you to work with [these behaviours]?

- Tell me about a patient whom you have found particularly challenging to work in terms of mood or emotional problems? What was your impression of them? How have you tried to explain this to yourself, or make sense of it, or is it really just puzzling? If so, how do you understand it?

Prompts if necessary

- What kinds of things made it difficult for you?
 - How did it make you feel?
 - What was your initial reaction?
 - Why do you think the patient may have responded like this?
 - Do you think that [these emotions] are surprising following a stroke?
 - In what way might their stroke have contributed to their emotions/mood/responses?
 - How do you think this might affect their recovery/rehabilitation?
 - What do you think has led you to understand this patient in this way?
 - What would you do better if you could?
 - What ideally do you think might help you to work with [these emotions/mood problems]?
- Is there anything else you want to add about working with people who have suffered a stroke?

Appendix F: Abridged research diary

Research diary notes

I enjoyed the research fair and heard some interesting proposals. The one that stood out most for me was a project on evaluating a workshop on educating a stroke MDT about psychological consequences of stroke. Given my background in neuropsychology as an assistant, I was listening out for any neuro-related ideas. Also, the neuropsychologist who presented the idea is a psychologist I have come across in my reading and I heard from a former trainee that she is great to work with, so I have decided to approach her about the project.

I spoke to the psychologist who presented the project and have begun thinking about this project might be taken forwards. I'm also keen to be supervised by the Salomons lecturer whose background and research interests are in neuropsychology.

I had my proposal reviewed and found it tough and it has not been passed yet. I was told that as the aim is to evaluate a workshop, it is more like a quality improvement project currently than empirical research and therefore I need to reconsider what I will do and how I will do it. I'll need to discuss this with my external supervisor who proposed this research. Hopefully I can still do something that will be useful for her.

Meeting with internal and external supervisors. Considered how we could adapt the research question so that it meets the needs of the course requirements for my MRP, while also helping my supervisor to work towards her aims. Difficult conversation, but it seems that my idea of a grounded theory approach about staff perspectives on psychological consequences is being accepted.

Submitted a new proposal with the grounded theory idea and it has been accepted, dependent on a few minor adaptations in the proposal. Great news! Now I can begin to think about the next stage.

Found out that my internal supervisor is leaving the course very soon. Not sure what this means for my research, but it's been a bit stalled recently anyway due to events outside of the course and other assignments I have been struggling with. I recently had to agree to prioritise other assignments on the course to ensure I pass those and have a learning support plan in place now. Confidence is quite low at the moment.

Found out my new supervisor is actually just temporary until they have recruited a new member of staff. Feels a bit un-containing as I was already feeling quite stuck with my project and I'm less sure about what I can do now.

Found out now that my temporary supervisor will in fact remain my new supervisor! We've had a conversation about stuck I have become and how the struggles with the course alongside difficulties in my personal life have really affected progress on my MRP. Considered how we can make the project feel more manageable at this time. Decided that perhaps a thematic analysis might be more appropriate for my research and my supervisor is more comfortable with this method too. She also suggested adding a quantitative element through a questionnaire about behavioural consequences, as she feels this will help to strengthen the work. I'm not sure, but I've been feeling so stuck that I am grateful for these suggestions. However, it means writing and submitting another proposal with these changes and the question is also changing slightly too, to accommodate these.

Had to do a few re-drafts of my proposal before it was accepted, but I just narrowly had it accepted so I can submit to the ethics panel tomorrow! I am quite far behind my peers now, but at least this is good news for me today.

Worked on the questionnaire, re-read past emails of discussions with supervisors about this – it helped to clarify matters I was less sure about. Also typed up draft inclusion and exclusion criteria and search terms for part A. Checked and uploaded documents to IRAS form and requested authorisation from my supervisor and institution sponsor.

Sent my interview schedule and questionnaire to be reviewed by an expert service user research panel. Feedback was generally positive, not much to change.

Keep phoning IRAS and can't get through! Left answerphone messages and emailed IRAS help. Finally had to ring HRA and someone is looking into it for me. It's been weeks since I submitted my form and I've heard nothing back.

Recruitment proving difficult. Still no contact from anybody about participating in my research. I will liaise with my supervisor and contacts to consider what the problem might be and what I can do.

Spent time on part A and initially thought there is very little relevant research out there on MDT staff and psychological issues, but when I expand my search criteria to be worldwide and more broad around psychological issues after stroke more generally, I feel quite overwhelmed! I think I need to narrow my focus again.

Had some feedback from staff on the units that the poster was not standing out enough around their wards. I've redesigned it and had a useful suggestion that it could go on the back of the staff toilet door to get their attention! I also heard there has been an increase in anxiety on one of the units recently due to some service changes.

Finally had contact from somebody interested in participating! A nurse who has worked in stroke care for many years. We have arranged a date to meet. I'm feeling more hopeful now.

I had a conversation about my research and expectations with a peer, as a way of bracketing my own thoughts around this. It was helpful and brought some things to my mind that I hadn't really considered until now. One thing I realised was my "insider" position (Gallais, 2008) given that I have worked as an assistant psychologist on a neurorehabilitation unit in the past and therefore learned quite a lot about working with people who have survived a stroke, although that was from the position of being a psychology professional. I think it's useful to remember what my experiences were back then and of how my MDT colleagues worked and spoke about psychological issues and how I myself perceived and understood the patients I worked with. I might have some expectations about how MDT staff talk about psychological issues given my past experience. I might also need be aware of where things may seem like 'common sense' to me, that it's because of my psychology education and experience and this may not be the case for the participants. I am curious about and interested to hear what participants have to say and this is something I didn't get to explore with my own former colleagues. Perhaps this is where I am also an outsider, as I certainly am an outsider to the organisation where I am collecting data, having not had any previous connection to the trust or staff groups I am now recruiting from and I am also more of an outsider to the experiences of people who don't have psychology degrees or psychology jobs in stroke care. I understand more now about my biased position of considering the psychological aspects of stroke as very apparent and crucial to understand, with medical aspects much less prevalent in my mind. This is important to be aware of during my interviews and analysis.

Completed not only my first interview, but my second and third on the same day! I'm quite relieved and grateful after it took so long to recruit my first person. I was pleasantly surprised by how welcoming and friendly the staff were on the unit and their interest in helping me, only because I'm aware how much stress there is in the team currently. It seems that it was probably difficult for them to hold my research in mind and to make contact as they are just very busy and spend very little time at their computers. In the debriefing, I have also heard how staff have quite enjoyed talking about their experiences of working with people who have survived a stroke and noticed they do so with pride and interest. I took notes immediately afterwards of what I thought about what I had noticed in terms of content and process. Arranged to return to interview another two members of staff. I'm going to transcribe the interviews straightaway, so I can begin to immerse myself in the data and notice what themes are arising and how my reflections might influence the rest of the interview process.

Managed to complete 6 interviews now and I've really been enjoying the process of talking to staff members. Despite all the stress of getting to this point, I remember why I have a preference for this qualitative approach as it allows me to have these interactions and to hear different experiences from different people. It feels quite rewarding actually, after all the difficulty in getting to this point. I need a minimum of four more participants and I'm trying to get as closely as possible a representation of different disciplines, years of experience, age and gender and from across the two units. I have two more people who have said they are interested, so I will return to the hospital next

week to see when they are able to meet, as they were unable to give me a specific date and time before.

One thing I have noticed so far is perhaps less tendency from participants to talk directly about cognitive issues and more preference to talk about emotions and how they understand why people feel this way after stroke. It's an interesting trend to notice and I am wondering about a number of reasons for why this appears to be occurring. I've been reflecting on my insider/outsider position again and the impact of me introducing myself as a psychologist to potential participants, given the topic is framed around understanding psychological issues in stroke. Despite my reassurance and clarity that I am independent of the service and that I have the title "trainee" too, perhaps some people feel they have to talk about the topic in a particular way or maybe feel unsure about their level of knowledge. I have noticed a couple of younger participants appear a little nervous, so I was considering how I position myself to them, not as an "expert", but as a curious outsider to their workplace and experiences within it, while also making sure to adopt a warm and friendly approach to help them feel comfortable and valued. I also wonder though whether people might feel less confident to talk about cognitive issues, as this has been found in previous research, or if my questions aren't eliciting this well enough, or if perhaps this says something about what discourses might be more common day-to-day, perhaps with emotional issues making more sense to staff and easier to empathise with? Maybe this gives some insight into emotions being at the forefront of what staff experience and perceive from their patient? It's something I will consider more with the remaining interviews and in my analysis.

Completed one more interview, for which I waited around the ward for a few hours before this person volunteered. It was interesting as the participant is fairly newly qualified in their discipline but had worked with stroke patients before. I noticed that they seemed to speak in more of a professional tone and less personally, which I have wondered if might be due to a sense of being new and wanting to sound as knowledgeable and confident as possible, or maybe something around not feeling able to or wanting to connect more emotionally with the content? I've tried to bring a sense of independence from the service and a conversation where they are situated as the expert in their role and experiences, but it feels even more important with this person to create a vibe and frame where the interview doesn't feel testing in any way. However, as I don't know this person outside of the interview, it might well be how their normal style of communication.

The two people I was supposed to be meeting today were unable to in the end, but luckily I found someone else who could! I feel very fortunate given that it's been hard to find staff who can spare the time to meet with me. I've rescheduled with the other two for next week, so hopefully they will work out next time. It's a bit disappointing after having travelled so far to meet with them, but I also understand the time pressures they are under at work.

I'm really noticing where there are similarities in the things staff talk about, such as what seems to be most commonly experienced after a stroke in terms of psychological consequences. However, I am continuing to notice that cognitive issues are spoken about much less than emotional or behavioural aspects are referred to. I'm wondering how much of that is due to my questioning,

although I have tried to prompt discussion in that direction when it's not brought up towards the end of interview. I'm also wondering how much of it might be due to the possibility that cognitive issues are less recognised or understood, or harder to speak about? This would again seem to fit with previous research I have seen around what stroke professionals understand the least or want more training on.

I have now recruited and interviewed 10 participants! I was originally aiming for 12, but recruitment has been slow recently and time is running out. Therefore, after speaking with my supervisor, we've decided that 10 is sufficient as I have noticed themes being repeated anyway. I also checked with the Braun and Clarke (2013) guidelines I'm following and they do say 10-12 for a UK doctoral research project is sufficient. The next step is to transcribe, get a feel for my data by lots of reading and re-reading and then coding for analysis of themes.

Met with my supervisor and shared initial ideas following the interviews. She seems pleased with what has come out of it. I've agreed to go and get started on coding and we will meet again in two weeks.

I've been reading and re-reading my data and making notes and feel like there's many different directions I could take! I've been checking Braun and Clarke (2006) alongside this to ensure I'm following their guidelines and they do speak about this potential for lots of different ideas from the data set. It makes me feel a bit anxious about making the right analytical decisions, but also good to know that this is a common and likely experience with this methodology. I've also been learning how to use the Atlas software as I'm new to this, but it looks pretty good albeit lots of different and confusing functions.

I've started coding on a broad basis, partly to keep my options open, but also as I'm new to this method and I feel it is helpful to code lots of different ways at the moment. It means that some sections of text have up to 10 codes for the same segment of data though! I will have to make some decisions about how to narrow this down, such as see what is most relevant to the research question and merge codes.

Met with my supervisor again and shared the codes I have so far and quotations to go with these. I have over 300 codes currently! It's quite overwhelming. I've been merging them where I can and reviewing how relevant some are to my question. As the methodology I'm following by Braun and Clarke is quite flexible, they describe scope for adapting my question or focus slightly based on what came out in the interviews. I have a lot of data about working in stroke care and how staff feel about this and it feels quite important to acknowledge and relate this to the topic of psychological consequences - maybe useful to ponder in future about how being asked to further integrate psychological aspects into their role relates to how they perceive their stroke role/job satisfaction/motivation, etc.

I've also realised that I have almost forgotten about my questionnaire. I think this might be because it felt a bit detached from the interviews and less important than what was spoken about. I'm not sure how useful the data is from this and now I've actually spoken to the stroke staff in interviews and begun the process of making sense of their words, I'm less sure about how I will relate it to the interview data. Discussed this with my supervisor and how it feels like it doesn't add much to the interview data and I have a lot of data from the interviews anyway, which feels like enough. I'm not sure about discarding it at this stage, but after further discussion we agree that I will not include it for now. However, we are aware that I may be asked about this in the viva and that they may wish me to include it. I will have to think about how I write this up.

I've managed to cut out 170 codes and I'm working on reducing the rest. Now I've got a more manageable number, I'm grouping codes on Atlas and seeing potential themes. I've written these out on paper and am using post-it notes to move ideas around. It feels like there are so many ways I could arrange these at the moment, so I'm hoping I will find a point where it 'fits'.

I asked a colleague to listen to me talk through my initial theme ideas and the codes within them to see how they are sounding so far. I showed her the post-it notes and we had a go at moving them around and trying out different ways of fitting things together or wording things. It was really helpful to have another psychologist's eyes and mind on this and reassuring to hear they had a similar experience. I think we have managed to make some sense of what I have. I am also aware that Braun and Clarke (2013) emphasise that there will never be a 'perfect' analysis and the process could be infinite, so it will involve making a decision about when to stop.

I had another conversation with my supervisor about the themes and sent her my doodles, photo of the post-it notes and a table of themes. I talked them through with her and she said they made sense and so I think it is time to write them up!

In the process of writing up I am noticing that I am having anxiety about my research. I'm worried that my results feel a bit like 'common sense' to me, but I have to think about why this is and remember that even if something feels this way, there might not be any research to show that 'common sense' has some evidence to back it up. In conversation with others, it seems that this isn't uncommon and I am probably just anxious because of lack of experience and I don't consider research or decision-making a strength of mine. This is a big learning curve. I need to remind myself that there was a process to arriving at what I have and that others I have shared this with have agreed it makes sense, so I'm sure it will be fine.

I am making progress on my writing, but it is a slow process and I'm becoming more and more aware of how I feel when I sit down to it. The MRP feels like a growing monster, it seems to be becoming increasingly anxiety-provoking and I've been trying to understand this with both my supervisor and my personal therapist. I think it relates to so many other issues, many of which are outside of the doctorate, and the MRP has become wrapped up with these and almost symbolic of so much more than a university project now. This is making it increasingly difficult to focus on what I'm doing and

how to do it and feels quite paralysing at times, but I'm trying to manage my anxieties and move away from any perfectionism.

Both my external and internal supervisors have now read my first draft of part B. I've had some helpful feedback, but there is lots to work on. I understand and agree with many of their points. Discussed theory and particularly biopsychosocial approach, which we understood as underlying the rationale for including psychology in stroke services.

My supervisor read a redraft of my part B and they are happier with it now. Still a few things to think about and change, but they seem pleased with the progress and direction. After making a few more edits, I'll turn my attention to completing a full draft of part A.

Appendix G: Table of themes and codes

Master theme	Sub theme	Code
Negotiating the psychological role	It's everybody's role	We're in it together
		Psychological aspects are inseparable
		Everybody's role
		Differing capabilities for the role
		On the frontline of psychological difficulties
	Limitations and uncertainty	We don't have time for it
		Uncertainty about "doing it right"
		Desire for more understanding
		Lack of psychological skills in the team
		Psychological work is challenging
		How do psychologists do it?
		Withdrawing to protect self emotionally
		Precaution over words used
		Emotional toll on staff
		Seeking support
	Being a psychological carer	Developing a trusted relationship
		Providing reassurance
		Preventing further distress

Being a listening ear
Communication skills are important
Providing information and education
Hope and positivity
Helping patient to accept and adjust

Understanding stroke takes time

Adapting to an uncertain and unexpected path

Stroke brings sudden disruption
Confrontation with changes and loss
All about adjustment
Acceptance is paramount
Recovery trajectory affects staff
Information-giving helps with adjustment
Confusion common initial reaction
Impairments can affect recovery
Parallel process with staff adjusting
Different people cope in different ways
Adapting style to different patients
Getting to know them so we can understand them
Empathising with experience
Considering explanations for the patient

Understanding the individual survivor

Stroke makes more sense with experience

Psychological consequences make more sense with time

You learn how to manage things over time

Creating a shared understanding

Emotional experience seems easier to understand

Complex and wide-ranging consequences

Behaviour seems strange at first

Appendix H: Extracts from coded transcripts

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Appendix I: Results summary for participants

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