UNIVERSITY OF LEEDS

This is a repository copy of *A qualitative exploration of self-reported unmet need one year after stroke*.

White Rose Research Online URL for this paper:
http://eprints.whiterose.ac.uk/91589/

Version: Accepted Version

Article:

Shannon, RL, Forster, A and Hawkins, RJ (2016) A qualitative exploration of self-reported unmet need one year after stroke. Disability and Rehabilitation, 38 (20). pp. 2000-2007. ISSN 0963-8288

https://doi.org/10.3109/09638288.2015.1107784

© 2016, Taylor & Francis. This is an Accepted Manuscript of an article published by Taylor & Francis in Disability and Rehabilitation on 05 Jan 2016, available online: http://wwww.tandfonline.com/10.3109/09638288.2015.1107784. Uploaded in accordance with the publisher's self-archiving policy.

Reuse

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

White Rose
university consortium
Universities of Leeds, Sheffield & York

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

TITLE PAGE

A qualitative exploration of self-reported unmet need one year after stroke.

Authors:

Rosie L Shannon, MSc[1]

Professor Anne Forster, BA, PhD, FCSP[1]

Dr Rebecca J Hawkins BA, PhD[1]

Affiliations:

[1] Academic Unit of Elderly Care and Rehabilitation, Bradford Teaching Hospitals NHS Foundation Trust and University of Leeds, Bradford, UK

Address for correspondence:

Rosie Shannon

Academic Unit of Elderly Care and Rehabilitation,

Temple Bank House,

Bradford Royal Infirmary,

Bradford, United Kingdom,

BD9 6RJ

Email: Rosemary.shannon@bthft.nhs.uk

Tel: 01274 383405

ABSTRACT

Purpose

Stroke survivors consistently report longer-term problems after stroke, suggesting their needs are not being met. We developed a questionnaire to identify stroke survivor unmet needs. Preliminary questionnaire testing showed that despite residual impairment, nearly one third of respondents reported no/low unmet need. This qualitative study aims to gain insight into why stroke survivors report low/no unmet needs.

Method

People who self-reported zero or one unmet need were purposively sampled, and semi-structured interviews conducted with ten participants. Identification and management of current problems wasdiscussed,and thematic analysis undertaken.

Results

Participants did not report having unmet need. Despite this, all participants identified current issues or problems. Living with problems while reporting no/low unmet need is explained through: acceptance of changed circumstances; making comparisons with other people and circumstances; valuing pride, determination or independence; viewing issues in the context of their expectations and experiences of services. Additionally, all participants were receiving some support.

Conclusions

Self-identification of unmet needs is complex. Further investigation could explore the factors which enable stroke survivors to appropriately identify and experience no unmet needs, and whether these could be applied to reduce unmet needs of others.

IMPLICATIONS FOR REHABILITATION

- Despite self-reporting no/low unmet need, survivors of stroke may still be experiencing difficulties in their daily lives.
- Stroke-survivor-identified low unmet need is influenced by complex factors including: acceptance; expectations of services; and comparisons with other people, which health and social care professionals have a role in understanding.
- Health professionals could assess unmet need by using tools as a guide, supported by individual conversation.
- Factors which enable some stroke survivors to appropriately identify and experience no/low unmet need could be further explored, and considered as strategies to reduce unmet needs of others.

MAIN TEXT

Background

Stroke often has significant and long-term effect on stroke survivors and their families, and can impair a person's physical and/or mental health, cognition, and their ability to communicate [1]. Consequences of stroke are frequently measured using objective tools which focus on health and quality of life. More recently, tools have been developed to measure patient need. Needs have been defined as "the ability to benefit from care" [2], and unmet needs are "expressed needs that are not satisfied by current service provision" [3]. Consistent with a stroke survivor perspective, this study does not differentiate needs or unmet needs by type (health, social, and so on), but takes an inclusive approach of the range of issues relevant to stroke survivors.

A wide range of unmet needs are reported by stroke survivors in the longer term, including those which persist from six months to fifteen years [4-7]. Mapping to frameworks such as the Disability Creation Process [5], and the International Classification of Functioning, Disability and Health [7] demonstrates that stroke survivor needs can relate to a range of factors. Despite this, in the Stroke Association (UK) needs survey (n=799; between one-five year post-stroke), 51% of respondents reported having no unmet needs [8].

We developed a questionnaire called the Longer-term Unmet Needs after Stroke tool (LUNS) to identify unmet needs of stroke survivors living in the community. In the LUNS evaluation study first phase (*n*=350), approximately one third of the sample indicated they had no or a low level of unmet need (median three unmet needs out of a possible 22, 32% reported zero or one unmet need) [9]. Despite this low unmet need, this group also indicated current impairments. This may be contrary to expectation and warranted further investigation; what enables stroke survivors to report having no or low unmet need, particularly while they simultaneously indicate having impairments? This qualitative study therefore aims to explore self-reported low levels of unmet need among stroke survivors.

The self-identification of need may be influenced by multiple factors, as it can be a “complex and negotiated process” [10], involving personal and subjective judgements. Existing literature provides insight into how people experiencing chronic conditions and ageing, adjust and perceive changes in their life. Chronic or sudden onset illness may be seen as a ‘biographical disruption’ in life [11]. However, for some people, illness, especially when combined with ageing or pre-existing comorbidities, may be seen as a ‘normal’ or biographically anticipated part of life [12]. In addition, stroke survivors may play an active role in responding to their situation [13]. Models describe the process of psychological adjustment to changed circumstances; people may adjust to the effect of their stroke by progressing through stages, gradually resulting in greater acceptance and emotional stability [14,15]. Different coping strategies adopted by stroke survivors in the longer term have been outlined, including cognitive approaches such as positive reinterpretation and adjustment [16]. These processes of disruption, adjustment, or illness as normality, could influence the way in which stroke survivors report their unmet needs.

As surveys of post-stroke unmet need may be used to inform service provision, it is important to understand the responses of stroke survivors when they complete questionnaires of unmet need. Existing literature has not directly explored self-reported low unmet needof stroke survivors,therefore there islimited understanding of what shapes their responses. The aim of this qualitative study was to gain greater insight,through semi-structured face-to-face interviews,into stroke survivors reporting no or low unmet need.

Methods

Methods of the LUNS evaluation study

The LUNS tool consists of 22 statements relating to unmet need (for example “I regularly get pain and nothing seems to ease it”) and two possible responses, ‘Yes’ (has need), or ‘No’ (no need or need is already met).Methods of the LUNS evaluation study have been described in detail elsewhere [9]. Participants were aged 16 or over, diagnosed with new stroke, likely to be discharged home, and were recruited at point of hospital discharge. Recruitment was conducted in two phases, the first with a selected cohort of patients to minimise interference from respondent cognitive or language factors (English speaking, minimum length of stay 3 days, excluding people with cognitive impairment) (n=350), the second to capture a broader post-stroke population (minimum length of stay 14 days, including people with cognitive impairment n=500). As well as LUNS, participants also completed four health related questionnaires, including the General Health Questionnaire-12 and the Frenchay Activities Index. Participants completed this questionnaire pack three or six months after stroke, and again two weeks later.

Participants

This is a sub-study of the LUNS evaluation study. A purposive sample of participants who indicated in phase 2 of the LUNS evaluation study that they had no or low level unmet need were identified (a total number of one or zero unmet needs reported) (Please see Supplementary Figure for more information). For practical reasons, participants geographically nearest the study site (Yorkshire) were identified. Their survival status was checked (NHS Spine Portal). They were telephoned to explain that, following their completion of the LUNS questionnaire, they were invited to participate in an interview. Information sheets were posted to them, then they were telephoned again after having time to read the information sheet, and an interview date was confirmed or declined. Written informed consent was obtained prior to interview. As interviews were conducted and similar themes emerged, participant characteristics were considered in order to adapt the sampling strategy. Lower socioeconomic factors are associated with a higher stroke rate [1], certain combined social factors (including living alone) are associated with depression [17], and poorer quality of life outcomes after stroke have been reported for women [18]. It would therefore be reasonable that a sample of stroke survivors includes people from more deprived socioeconomic groups, and that gender and living alone may be important factors for outcomes after stroke. Secondary sampling ensured the inclusion of women, people who live alone, and people whose postcodes lay at the lower end of the Indices of Multiple Deprivation (2007 data) [19]. The Index of Multiple Deprivation (IMD) is commonly displayed by ranking from the 1st decile (representing the 10% most deprived geographical areas) to the 10th decile (least deprived). Recruitment stopped once sufficient data was gathered to address the study aim.

Data collection

Semi-structured interviews were used to capture personal perspectives, and permit flexibility (for example, participant opportunity to raise topics). Interviews were conducted between December 2010 and May 2011 in participant homes; these were digitally recorded and transcribed.

A topic guide,generated through discussion of research aims, was used to provide structure and focus. Questions were asked to elicit understanding of how stroke survivors view problems and things which had changed for them since their stroke. Questions were primarily written for the stroke survivor, with flexibility allowing input from their partner. Thus providing opportunity to explore differing perceptions and information, such as how needs are managed within the context of the relationship.

Informal observations, reflections and key points of the interview were noted after each interview [20]. This data was used to inform subsequent interviews, and to provide contextual information during analysis.

Data analysis

A thematic approach [21] was used, working through the data until a small number of themes were identified which describe the data. Data was managed using Microsoft OneNote and Word. The five main stages were familiarisation with the data; identifying initial codes; coding the data; building the codes into themes and sketching their relationships; and interpretation. The process was iterative as there was overlap between analysis stages, and data collection was ongoing during analysis. Memos recorded questions and comments about the findings, and contributed to the documentation of the analysis process.

Early familiarisation and understanding of the complete dataset was aided by reading transcriptions while listening to interview recordings. A descriptive summary was written, a method suggested by Strauss & Corbin [22], to stimulate thinking about the wider picture, the main issues, and the story being told by the data. Each transcript was systematically analysed by coding text. Emphasis was placed on deriving codes from the data collected, however a priori codes that were developed from the literature and team discussion were also incorporated. A process of building the codes into themes and sketching relationships was used to expand, combine and name them. During this stage, the descriptive summary was referred to, in order to remain aware of the research question and consider the codes within the wider study. By the interpretation stage, themes were refined. Individual cases were used to flesh out themes, considering those which especially did or did not demonstrate a theme. Other contradictions and complexities were sought, to better understand the themes. A chart was used to compare cases and find contradictory data. Themes gradually became more stable, better defined, and encompassed more of the data.

Ethics

The study was given ethical approval from Bradford Research Ethics Committee in September 2010. Pseudonyms have been used.

Findings

Twelve people were approached, two declined, and ten interviews were conducted. Interviews were conducted on average eleven months after stroke, on average four months after completing the second questionnaire, and lasted approximately 40 minutes (range 17 minutes to 1 hour). Table 1 describes participant characteristics. The median age of participants was 78. This study sample showed a spread of deprivation (deciles ranged 3-9) but was skewed toward people from the least deprived areas (median decile 7.5).

Table 1. Participant characteristics.

Pseudonym	Age at interview	Gender	Time since stroke (months)	Lives with / interviewed with	Unmet need (First completion, second completion)	IMD decile (1=most deprived, 10=least deprived)
George	79	M	8	Wife	0,0	9th
Stefan	81	M	8	Wife	0,0	5th
Charles	78	M	11	Wife	0,0	7th
David	78	M	11	Wife	1,0	8th
Bob	70	M	9	Wife	1,0	3rd
Pauline	70	F	11	Husband	0,0	7th

Joan	95	F	12	Lives alone	0,0	8th
Brian	85	M	12	Wife	0,1	8th
James	76	M	11	Wife	1,1	9th
Peter	80	M	11	Wife	0,0	4th

Initial questioning about problems revealed that the meaning of a ‘problem’ varied between individuals and issues, and some rejected the word ‘problem’, therefore, these have been termed ’issues’. A broad range of issues were reported, and while some were described as impairments (e.g. limb weakness, fatigue, difficulty remembering), others were depicted as the impact of impairment (e.g. on social, domestic or leisure activities). These issues were understood as being related to stroke, comorbidities or ageing, and impacted on their daily lives causing some frustration due to limited or inability to carry out tasks or activities. One participant identified a potential future need (moving home), and others indicated changeable scenarios (partner becoming too unwell to continue providing support, icy weather reducing mobility).

Other than contact with their Family Doctor, participants were not receiving formal health or rehabilitation support at the time of interview. However, all participants received some form of support from others, and often relied on this. Primarily this was from their partner if they had one (nine participants), and/or help from others including family, friend or neighbour (six participants), charity (three participants), or paid services (two participants). Support from charities included providing information, emotional support, and services for small domestic repairs. Paid services included use of a gardener and a cleaner. Support could be informational (e.g. knowledge about stroke), emotional (e.g. offering conversation) and practical (e.g. personal care, shopping, cleaning). In addition to talking about support, a minority of participants also discussed a number of practical strategies they had developed for managing regular difficulties, such as taking their time, keeping things close to hand or using specific tools or everyday objects as an aid.

All participants interviewed reported living with current impairments or limitations; and were thus not ‘problem free’. Despite this, participants did not report having unmet need. Four main themes were identified, which help inform the self-reporting of low or no unmet needs on the LUNS questionnaire: level of acceptance, relative situation, presentation of character, and expectations and experiences of services.

Level of acceptance

Most participants described acceptance of the issues identified through a process of adjustment, coming to terms with their health and life changes, or a focus on things they can do (rather than those they cannot). They were also able to provide a positive interpretation of the situation, such as talking about not having to worry, overall contentment, the ability to maintain a good quality of life, noting improvements they had experienced since their stroke, and referring to those they are hopeful for in the future. Participants could also actively engage with their difficulties, for example, acknowledging and facing up to things which have changed, or talking about doing what you can and accepting things you cannot do:

“I still want to do the things that I did previously, I don’t find them as easy to do, but if I can do it I will do it, even if it takes me longer, which it very often does [laughs]….I just have to accept it, if I can’t do it, well I’ve just got to accept it…I think learning to accept what you can’t do is the main thing.” (Joan).

Gradual changes prior to stroke (rather than sudden change) were sometimes noted, such as retirement, transient ischaemic attacks, other health changes, or ageing. Because their health and lives were already changing prior to their stroke, people had begun to adjust their expectations, daily lives, and perception of what might be considered a problem or unmet need:

"You've got to sort of face up to the fact that you're not going to just manage things as easily….My life's changed obviously, I mean, life has changed totally but I think I'm adjusting." (Pauline)

Two participants did not demonstrate the high level of acceptance seen in the majority of the sample. Both had experienced significant changes in roles, routines and activities important to them, perceived these as a negative interruption, and were focussed on returning to pre-stroke activities. When asked what effect the changes had on James' life, he replied:

"The way I feel, drastic. It really had, it's, it's just ruined my life not being able to get out and do me gardens and that."

Relative situation

Participants commonly viewed their lives and issues relative to other people and other circumstances. Being fortunate was reported, that is, feeling contented about how things are compared to how they could be. For example, good stroke recovery, being financially comfortable, and having family nearby. Participants made comparisons to other people, other times, and other outcomes, for example, in the case below, Joan compares her situation to a poorer outcome:

"Everybody says I've done very well, and I really do feel I have, and I'm very pleased about that, could have been a lot worse off…I've been very fortunate, it hasn't affected my speech or it hasn't affected my memory or anything like that, so I've been very lucky really."

Participants received information from peers and family and this appears to shape expectations about their own lives. By talking with others, they ascertain what is likely to happen to them, what difficulties are normal for someone at their age, or for someone who has had a stroke. Participants gather and use information to reflect on their own situation. Considering his own life in the context of others who have had strokes made George feel better about his own situation, and influenced his response on the questionnaire identifying unmet need:

"*I've been to the Stroke Club, and you see people with arms that don't work down there in different forms and some can't speak properly, so I was pleased with that, so that's why I ticked things on the form."*

Presentation of character

Some participants presented their character in a positive or active light, as a way of explaining how they manage their daily lives and difficulties. Determination, pride, and/or independence were noted. Determination at achieving post-stroke recovery and being an active 'doer' was reported, referred to by Charles' wife as his "*sheer guts and determination*" Pauline reported:

"I think you've got to have the willpower. It would be easy I think to sit back and say 'Oh I can't do this, I can't do that, I can't do the other', you've got to be willing to meet it, if you know what I mean, you've got to be willing to meet these things and do what you can."

Pride was identified when talking about good post-stroke recovery:

"I've always been able, since I've come back from hospital, to walk upright and keep my own balance….Dave next door is a professor, and he says from time to time 'He is a miracle.'" (Charles).

Independence, (being independent from the help of others) was reported by some who did not want to seek or receive help:

"*I'm not bothered about anybody helping me. I want to do it on my own."* (James).

The desire to present themselves as having pride, independence or determination helps to explain how participants manage their identified issues, and why no or low unmet need is therefore reported.

Expectations and experiences of services

Expectations and experiences of services appear important to participants in explaining whether they perceive their issues as unmet needs. Three elements of this were; untreatability, rationing, and current contact with services. Untreatability describes participant perception that their issue is unlikely to be helped by contacting services, and an inability to envisage what help could be offered. For example, David received Speech and Language Therapy but still has communication and memory impairment, he therefore tends to think that further help may not be effective, and this influences his responses when asked whether he would like help:

"The speech lady came, didn't she?...She had a nice sense of humour and all this. And I liked her but she didn't help. I was sorry when she stopped coming but... she didn't help, and I thought all these, 'would you like help with this and that and the other'…I couldn't do it, she

couldn't help, though she wanted to very much and I wanted to be helped but I could tell it wasn't going to do it for me."

Participants also described an awareness of limited resources or rationing, frequently perceiving that people other than themselves will be more in need. When reaching the end of community physiotherapy and making the decision whether or not to continue, two participants questioned what more the therapists could do to help, considered that the issue might be untreatable, and knew that other people may benefit more:

"Much as I would have liked for them to carry on, I had to accept that they had other patients that were more of a priority than me, so we accepted that they weren't coming."(Charles)

Perceptions of untreatability or rationing illustrate that participants are unsure whether pursuing treatment is worthwhile or justified, perhaps making them less likely to report unmet needs. Many participants were currently in touch with services and were content with this method of managing their issues, resulting in some needs being met. Family Doctors appeared to be the first point of contact, with participants recently having visited, or intending to visit, their Family Doctor about an identified issue:

"The thing is that this has only just started has this pain since the Physios stopped coming, and I've arranged to go and see my doctor on Thursday to talk about it." (Brian)

In contrast, one participant was concerned that he had received no follow up from a stroke specialist since discharge from hospital, and felt his Family Doctor did not understand his stroke related impairments. Despite this, he intended to continue visiting his Family Doctor, perhaps because this is the only option he has.

Discussion

This study aimed to gain greater insight into stroke survivors, who have some residual impairment, reporting no or low unmet need. From interviewing 10 participants, 11 months post-stroke, it was found that people self-reporting no or low unmet need do not necessarily have no issues (or problems). Participants did not report having unmet need, despite all identifying residual physical or cognitive impairments and experienced problems engaging in routine and leisure activities. This study suggests people negotiate their identification of unmet need through perceptions and experiences. Including: acceptance of the situation, making comparisons with other people and circumstances, valuing characteristics such as independence, and holding assumptions about help and services. These findings also suggest reasons why people may not identify their issues as needs, for example if they feel able to manage the issue (through level of acceptance), or are unclear what help is available (expectations and experiences of services). Participants suggested that their needs were likely to shift over time. This adds to the complexity, as circumstances can change gradually, unmet needs are not simply present or absent, but may slowly increase or decrease over time, affected by shifting circumstances, strategies, resources.

Participants tended to display acceptance, viewing their issues as just one part of who they are now, and they chose to focus on the things they can do. Acceptance may be a reflection of ideas previously reported regarding adaptation to disruption caused by chronic illness [12,16]. Participants in this study judged their issues in the context of recovery from stroke and the experience of ageing. As stroke and its consequences can be experienced as a normal part of ageing [12], people may accept difficulties as the result of stroke, particularly as society promotes low expectations for older adults [10]. Living to the age of 70 could provide people with the skills and experiences to manage and adapt to life changes such as chronic illness [12]. In contrast, low acceptance was also observed for two participants.

Disruption caused by sudden disability and loss of activities has been described elsewhere, especially for those with a desire to return to their pre-stroke life [23, 24]. For those with low acceptance, their reporting of low unmet need may be explained by other factors they identified: existing support from partners, a perception of untreatability, and current contact with services.

A systematic review found a number of studies describing ‘relative situation’ in which participants favourablycompare themselves to other strokesurvivors and to worse outcomes [23]. Similarly, ‘relative situation’ in this study shows that interactions with and knowledge about other people allows stroke survivors to assess their circumstances in relation to others. After appraising their situation in the context of others, stroke survivors may be less likely to perceive the problems they experience as unmet needs. For example, unmet needs could be left unreported if they are judged as less important than other people’s.

Participants in this study and elsewhere have described their post-stroke experience through valued characteristics including pride, independence, and/or determination [23]. Placing importance on such values could make people reluctant seek help [25].

People identifying their unmet needs consider whether services are appropriate and what it is acceptable to ask for [10]. Expectations about what services have the capacity to provide can contribute to a personal perception of need [25]. Perceptions of rationing and inadequate continuity of services into the community [26] influenced participants in this study.These, and othernegative experiences of services may lead to reluctance to receive help in the future [25]. Some people lack knowledge about what treatments are available or how to seek these [5, 26]. Stroke survivors may benefit from clarity of knowing what services are available in the longer term.

While the sample is limited by size and geography, it nonetheless allowed exploratory insight, using participants from a region with a diverse population. Purposive sampling was used as a method to select cases rich in relevant information [27]. Participants in this study were not receiving formal health services, but were all receiving informal support, mainly from partners, potentially reducing their unmet needs. While findings may not generalise to all stroke-survivors, they help inform our understanding of the identification of unmet needs of older stroke survivors one year post-stroke. Although interviewee accounts can be seen as a hybrid of facts and fictions [28,29], where the illness experience can be constructed in different ways depending on the context [30, 31] interviewing participants in their own home was a way of capturing relevant accounts, as well as increasing participant comfort.

Structured tools and systems are being developed in response to UK recommendations to review stroke survivors in the longer term and respond to identified needs [1]. The LUNS tool was carefully designed with significant stroke survivor input, items were clarified from discussions with stroke survivors, and developed to understand and appropriately capture unmet need. However, it remains that when people are completing such tools, this is a complex process shaped by a range of factors, and for example is not necessarily a straight forward reflection of their day-to-day impairments and experiences. Within the current policy emphasis on patient centred measures, it is important that health and social care professionals have understanding of the complexities underpinning patient identification of unmet need.

Themes highlighted in this paper require greater exploration, for example, to tease out barriers of identifying unmet need (not identifying need when there is a need that could be met to benefit the patient) and facilitators of identifying unmet need (appropriately identifying and experiencing no unmet needs). Further investigation could explore whether these facilitators could be applied to help reduce the unmet needs of others (for example, psychological features of acceptance). Given the influence of ageing on the perception of need, future research could ask whether identification of unmet need differs among age groups.

Conclusion

Interviews with stroke survivors supported their self-reported questionnaire data that they have no or low unmet need. Despite this, they still identify living with residual physical or cognitive impairments and experienced problems engaging in routine and leisure activities. The identification of low unmet need is influenced by perceptions relating to acceptance; comparisons to other people or circumstances; characteristics such as pride, independence, and determination; and experiences of services. These findings add understanding of how a post-stroke population identify unmet needs, and the subtlety and complexity of doing so.

ACKNOWLEDGEMENTS

We thank all patients and their caregivers who participated and shared their experiences, Dr Kirste Mellish for support throughout this project, and are grateful to the anonymous referees who contributed valuable comments.

DECLARATION OF INTEREST

This publication presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research programme (Grant Reference Number RP-PG-0606-1128). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

References

1. Department of Health. National Stroke Strategy. London: Department of Health; 2007.

2. National Health Service Management Executive. Assessing health care needs: A DHA discussion paper. London: Department of Health; 1991.

3. Heineman AW, Sokol K, Garvin L, Bode R. Measuring unmet needs and services among persons with traumatic brain injury. Archives of Physical Medicine and Rehabilitation 2002; 83: 1052–59.

4. Le Dorze G, Signori FH. Needs, barriers and facilitators experienced by spouses of people with aphasia. Disability and Rehabilitation 2010; 32:1073–1087.

5. Vincent C, Deaudelin I, Robichaud L, Rousseau J, Viscogliosi C, Talbot LR. Rehabilitation needs for older adults with stroke living at home: perceptions of four populations. BMC Geriatrics 2007;7.

6. Scholte op Reimer WJM, de Haan RJ, Rijnders PT, Limburg M, van den Bos GA. Unmet care demands as perceived by stroke patients: deficits in health care? Quality in Health Care 1999;8:30-5.

7. Sumathipala K, Radcliffe E, Sadler E, Wolfe CDA, McKevitt C. Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health 2011;8:31-44

8. McKevitt C, Fudge N, Redfern J, Sheldenkar A, Crichton S, Rudd AR, et al. Self-Reported Long Term Needs After Stroke. Stroke 2011;42:1398-1403.

9. LoTS care LUNS study team. Validation of the Longer-term Unmet Needs after Stroke (LUNS) monitoring tool: a multicentre study. Clinical Rehabilitation 2013;27:1020–1028.

10. Godfrey M, Callaghan G. Exploring unmet need: The challenge of a user-centred response. York: York Publishing Services; 2000.

11. Bury M. Chronic illness as biographical disruption. Sociology of Health and Illness 1982;4:167-182.

12. Pound P, Gompertz P, Ebrahim S. Illness in the context of older age: the case of stroke. Sociology of Health & Illness 1998;20:489-506.

13. Pound P, Gompertz P, Ebrahim S. Social and practical strategies described by people living at home with stroke. Health and Social Care in the Community 1999;7:120-128.

14. Holbrook M. Stroke: social and emotional outcome. Journal of the Royal College of Physicians of London 1982;16:100-4.

15. Eilertsen G, Kirkevold M, Bjork IT. Recovering for a stroke: a longitudinal, qualitative study of older Norwegian women. Journal of Clinical Nursing 2010; 19: 2004-2013.

16. Ch’ng A, French D, McLean N. Coping with the challenges of Recovery from Stroke. Long Term Perspectives of Stroke Support Group Members. Journal of Health Psychology 2008;13:1136–1146.

17. Hackett ML, Anderson CS. Predictors of Depression after Stroke: A Systematic Review of Observational Studies. Stroke 2005;36: 2296-2301.

18. Gargano JW, Reeves MJ. Sex differences in stroke Recovery and Stroke Specific quality of life. Stroke 2007;38:2541-2548.

19. Noble M, McLennan D, Wilkinson K, Whitworth A, Dibben C, Barnes H. The English Indices of Deprivation 2007. London: Department for Communities and Local Government;2007.

20. Miles MB. Huberman AH. Qualitative data analysis. Thousand Oaks, CA: Sage Publications; 1994.

21. Braun V, Clarke V. Using thematic analysis in Psychology. Qualitative Research in Psychology 2006;3:77-101.

22. Strauss A, Corbin J. Basics of qualitative research: Techniques and Procedures for Developing Grounded Theory. 2nd edition. Thousand Oaks, CA: Sage Publications; 1998.

23. Sarre S, Redlich C, Tinker A, Sadler E, Bhalla A. McKevitt C. A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience. Disability and Rehabilitation 2014;36: 716-26.

24. McKevitt C, Redfern J, Mold F, Wolfe C. Qualitative studies of stroke: A systematic review. Stroke 2004; 35:1499-1505.

25. Cordingley L, Hughes J. Challis D. Unmet need and older people: Towards a synthesis of user and provider views. York: Joseph Rowntree Foundation; 2001.

26. Walters K, Iliffe S. Orrell M. An exploration of help-seeking behaviour in older people with unmet needs. Family Practice 2001;18:277-282.

27. Patton MQ. Qualitative Research and Evaluation Methods. 3rd edition. Newbury Park, CA: Sage Publications;2002.

28. Bury M. Illness narratives: fact or fiction? Sociology of Health & Illness 2001; 23: 263-285.

29. Lawton J. Virtual special issue on ‘Illness, biography and narrative. Sociology of Health & Illness [online]. Available from: http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1467-9566/homepage/illness__biography_and_narrative_virtual_special_issue.htm 2009. [Accessed 26 March 2014]

30. Clark JA. Mishler EG. Attending patients' stories: reframing the clinical task. Sociology of Health and Illness 1992;14:344-71.

31. Hyden LC. Illness and narrative. Sociology of Health & Illness 1997;19:48-69.