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Self-evaluation of personal needs by community-living young stroke survivors using an online English language questionnaire

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Abstract

Background

Identifying personal needs of young stroke survivors is crucial for their recovery.

Purpose

Identify factors, burden and significance of unmet needs of young community-living stroke survivors.

Materials and Methods

We used online advertising and word-of-mouth snowballing to recruit participants for an English language online questionnaire constructed for this purpose. Eligible participants aged 18-55 at time of stroke. Needs were classified into seven domains: Healthcare Experience, Impairments from Stroke, Everyday Activities, Work/Study, Finances, Relationships, and Social Participation. Random-effects logistic regression was used to determine the probability of unmet needs and X^2 test to determine significance of distribution across domains.

Results

137 responses were recorded. 32 did not meet inclusion criteria. 29 duplicates identified were discarded. 76 eligible participants were analysed. Respondents were median 37 (IQR 32-47) years at time of stroke, median 3 (1-5) years since stroke. 58 (76%) females. MRS median score of 1 (1-3). Of 48 identified potential needs, 25 (IQR 19-30) were rated unmet. Twenty (IQR 15-25) considered of high significance. Unmet needs most frequently occurred in the domains: Impairments from Stroke, Finances and Social Participation.

Conclusions

There is high burden of unmet needs in community-living young stroke survivors which are spread disproportionately across the identified domains.

Key Words: Stroke, Young stroke, Needs, Questionnaire, Impairment, Social Participation, Finance

Introduction

In the community, stroke is often regarded as a condition of the elderly, however almost 60% of all strokes each year occur in people under the age of 70 years and 8% in people under 44 years of age [1]. Globally, between 1990 and 2013, there were significant increases in absolute numbers and prevalence rates of stroke for younger adults aged 20 to 64 years [2]. Stroke in a young person is particularly heinous as the chronically disabling results occur in a period of their life when they are focusing on forming and maintaining an active social life, finding a partner and starting a family, as well as career advancement. These are key milestones that less frequently occur in older stroke patients and so the post stroke care and rehabilitation that younger patients require must be focused differently to achieve the best patient centered outcome. It also comes with significant socioeconomic impact as a percentage of the young stroke population never return to work and those that do may not remain for long or function at their original level. There may also be ongoing medical costs associated with stroke rehabilitation. An Australian all-ages study found that younger stroke survivors reported more unmet needs than elderly stroke survivors [3]. This study will be used to inform the creation of dedicated young services.

Our search of stroke needs assessment questionnaires did not find one that was tailored to young stroke persons, especially with regards to studying and access to education, care of young children, age appropriate healthcare and developing and maintaining relationships. This study aimed to: (1) develop a community based young stroke consumer needs assessment questionnaire (2) describe the burden of unmet needs in the English speaking young stroke population, (3) detail the perceived significance of each of these needs to those that experience them, (4) identify factors associated with increased numbers of unmet need or increased reported significance to stroke survivors, and (5) evaluate whether unmet need occurs at a similar rate in the domains of Healthcare Experience, Impairments from Stroke, Everyday Activities, Work or Study, Finances, Relationships, and Social Participation.

Materials and Methods

This study aimed to reach persons who had experienced a stroke at a young age and had returned to the community where there is less direct support than the acute hospital setting. Our lower age cut-off was 18 and our upper cut-off age was 55. There is not a well-defined age range for young stroke and previous studies have used upper cut-offs age of 45 [4], 50 [5, 6], 55 [7], 60 [8], and 65 [9-11]. We chose 55 years of age as it provided a large sampling but was distant from retirement age in participating countries where desire to return to work would be more probable and barriers to this need could be better explored. Retirement age is 65 in Australia and New Zealand, 66 in America, and 65/62.7 respectively for men/women in the United Kingdom [12].

Young Stroke Needs Assessment Questionnaire for use in Community Settings

A new needs assessment questionnaire was constructed following a review of the relevant literature [3-11, 13-28] and consideration of previous unmet needs questionnaires. While we looked at previous tools that examined needs, neither were targeted at young stroke, therefore we needed to be informed by previous qualitative studies describing unmet needs in this cohort, which we integrated into our questionnaire. Previous stroke tools such as the Australian Stroke Survivor and Carer Needs Assessment Survey [3] and the NHS Stroke Survey [23] were a starting point to develop the questionnaire used in this study. Our questionnaire was tailored specifically to identify unmet needs of young stroke persons [3-11, 13-28]. Some of these needs included access to education, care of young children, age appropriate healthcare, developing and maintaining relationships and social participation.

The next step was to explore with a young stroke consumer volunteer the applicability of the questions, clarity and sensitivity of the question wording and identify if there were any missed needs. This individual was a young stroke consumer advocate and engaged with young stroke support groups, so able to provide feedback both from their own experience but also from discussions they have had with other stroke consumers. We asked our volunteer to assess if the questions were easily interpretable and if any wording might appear offensive or upsetting. While the key domains were determined via a literature review, we also asked our volunteer if there were any areas of need we might have missed. Their view was the exploration of needs was comprehensive. A few language modifications were suggested and changes subsequently made. Overall the session affirmed that the questions were acceptable and that a questionnaire tailored to young stroke survivors was welcome.

The seven distinct domains of unmet need for young stroke survivors were: Healthcare Experience (questions 6 to 39 in the questionnaire), Impairments from Stroke (questions 40-80), Everyday Activities (questions 81-94), Work or Study (questions 95-116), Finances (questions 117-124), Relationships (questions 125-137), and Social Participation (questions 138-146). The questionnaire used for this study is available as a Supplemental online document.

Participants were asked yes/no questions to identify whether they had an unmet need, and then given a 6-point Likert scale to rate how significant they felt this unmet need was to them, with 1 indicating not significant and 6 indicating highly significant. In some instances, additional questions were asked to identify to what extent certain factors played in a need being unmet.

The participant eligibility, consent forms and questionnaire were constructed using online Google forms software and were filled out using a link to the online form. Data were only accessible with a password protected account. All questionnaire data collected were anonymous.

Recruitment strategy

Participants were recruited using a coordinated advertisement campaign using community stroke support services in Australia and America. The Australian Stroke Foundation hosted a short summary of our research as well as a link to the questionnaire on their website under the "Research projects seeking consumers" tab. The Stroke Association of Victoria, Stroke Support and Awareness Australia, and Young Stroke Group all posted on their Facebook groups a short summary and a link to our participant information document. Brain Injury Australia also presented a short summary of the research and a link in their monthly newsletter. A post was made on *Enableme*, a Stroke Foundation support and information forum, summarizing our research and inviting participation. The Florey Institute of Neuroscience and Mental Health Twitter account was also used to advertise a link to the questionnaire. Local support groups that were registered on the Stroke Foundation website were also contacted and asked to distribute copies or links to the participant information document. After a trial period advertising in Australia, the research and questionnaire was advertised in America through a young stroke information group (youngstroke.com). The technique of snowballing was employed, whereby people who had been contacted or seen our research advertisements were encouraged to share knowledge of it with anyone they thought it may apply to. Screening and informed consent was completed before participation as part of the online interface.

Ethical approval was attained from Austin Health Human Research Ethics Committee (Reference number HREC/16/Austin/451).

Target participants and demographics

We recruited people who had experienced at least one stroke (haemorrhagic or ischaemic) and were aged between 18 and 55 at the time of their stroke(s), currently living in the community (i.e. discharged from hospital and not living in a residential care facility). As the questionnaire tool was in English, participation was limited to those who understood English. We excluded those with disabling chronic illness(es) that were not a result of their stroke. Demographic information was also collected in the questionnaire and included: sex, country of residence, post code, marital status, formal education, and tobacco smoker status.

Other stroke and care related data

We gathered stroke characteristics; time since stroke, location of stroke, time spent in hospital following stroke. Support information; hours of funded support for primary carer, relationship with primary carer. Employment information; hours of employment before and after stroke, and health insurance status; private health insurance pre and post stroke. Participants were also asked a series of questions to determine their score on the modified Rankin Scale (mRS).

Statistical methods

Excel formulas were used to convert the raw questionnaire data to a format that was then fed into STATA (StataCorp. 2015. *Stata Statistical Software: Release 14.* College Station, TX: StataCorp). To determine the burden of unmet need in this population, we looked at the average number of unmet needs reported by an individual. A need was considered unmet depending on the answer to a yes/no question. To determine what the perceived significance of each unmet need was, Likert scales were used; not significant (1) to very significant (6), and not at all (1) to very much (6). Needs were considered a high burden if they were rated to have ≥4 on a 1-6 scale for participant perceived significance. Both total unmet needs, and high burden unmet needs were analysed. Random-effects logistic regression modelling was used to determine if there was a significant difference in the probability of having an unmet need regarding the variables of age, mRS score or country of residence. The mRS was dichotomized into good (0 – 1) and poorer outcomes (2 – 5) for analysis. X^2 test was used to determine if the distribution of unmet needs across the domains were significant. It was also used to determine if the likelihood of having an unmet need in any given domain differed significantly from having one in the domain of Healthcare Experience. The domain of Healthcare Experience was chosen as the point of comparison as it was assumed all participants would experience a similar environment. Demographic data were expressed as frequencies or means (Standard Deviation, SD) and medians (interquartile range, IQR) and range.

Results

Recruitment

Screening and recruitment took place from 1st February 2017 until the 30 May 2017. 137 responses were recorded. Eligibility criteria was assessed at the beginning of the questionnaire and if a participant was not eligible the questionnaire was terminated. Thirty-two were found to be not eligible: 28 did not meet the inclusion criteria and 4 were excluded after completing the questionnaire as subsequent replies to survey questions indicated their stroke had occurred outside of the age criteria. A further 29 were identified as duplicate submissions due to a software issue. Submissions were identified as duplicates if they were identical in every answer including demographic data to another submission. In each instance, the original submission was kept for analysis and the remaining duplicates discarded. This left a total of 76 responses for analysis.

Demographics and stroke characteristics

Of the 76 responses analysed, 45 (59%) were from Australia and 26 (34%) from the United States. Although not advertised in other countries, one individual from New Zealand and 4 from the United Kingdom responded the questionnaire likely due to the snowballing technique used.

The median age at time of stroke was 37 years old (IQR 32-47). The median number of months since stroke was 33.5 (IQR 12-70). The median number of days spent in hospital following their stroke was 12 (IQR 6-30). Forty-two (55%) stroke survivors spent at least 1 day in a rehabilitation facility, and in those that did the median was 60 (IQR 17-161) days. Participant's reported left side of brain stroke in 38 (50%) cases, right in 23 (30%) cases, both sides in 10 (13%) cases, with 5 (7%) reporting they did not know. Forty (53%) stroke survivors scored a 0 or 1 on the mRS at the time of the questionnaire and 36 (47%) scored between 2 and 5. Demographics are described in table 1.

Twenty-nine (38%) stroke survivors did not have a primary carer (funded or unfunded). Nine (12%) persons were receiving new or increased funding support for their primary carer since their stroke. In 37 (79%) cases the primary carer was the participants' partner. In only 1 case was the role filled by someone who was not a member of the stroke survivor's family. Sixteen (21%) people were working the same number of hours or more now than they did before their stroke. Thirty-six (47%) people worked at least 1 hour per week before their stroke but no longer worked post stroke. Fifty-five (72%) stroke survivors had private health insurance before their stroke. Fifty-two (68%) had cover post stroke, 9 (12%) people ceased having cover, and 6 (8%) gained cover.

Assessment of Needs

Of the 48 potential needs investigated, a median of 25 (IQR 19.3-29.8) were unmet. If looking at only high burden unmet needs (≥4 on a 1-6 scale for participant perceived significance), the median number of needs that were unmet was 20 (IQR 15-25).

The distribution of unmet needs across the domains was statistically significant ($p < 0.0001$). The same was true when looking at high burden unmet needs ($p < 0.0001$) (table 2).

The chance of having an unmet need was not found to change significantly with age year on year, nor between sexes, nor between country of residence. However, a stroke survivor with a mRS score of 2 or more had a significantly higher chance of having an unmet need ($p < 0.0001$). Significance was still present when looking only at high burden unmet needs ($p < 0.0001$) (table 3).

The Impairments from stroke (OR 1.43, CI 1.2-1.7) ($p < 0.0001$), Finances (OR 2.38, CI 1.6-3.5) ($p < 0.0001$), and Social Participation (OR 2.1, CI 1.6-2.7) ($p < 0.0001$) domains all had a significant higher chance of participants expressing an unmet need when compared to the Healthcare Experience domain. The Activities of Daily Living domain (OR 0.39, CI 0.3-0.5) ($p < 0.0001$), and Work/Study domain (OR 0.62, CI 0.5-0.8) ($p < 0.0001$), had a significant lower chance of participants expressing an unmet need when compared to the Healthcare Experience domain. Significance was still present in all cases when looking only at high burden unmet needs ($p < 0.05$) (table 4).

Discussion

We developed and employed a new community based consumer needs assessment questionnaire for young stroke survivors. Our major finding was that younger stroke survivors have a large number of unmet needs, the majority of which they consider to be significant in their lives. Compared to many previous studies [5, 7-9, 17] our participants were younger, with a median age of 43 years. The group were however predominantly female (76%) which differs from previous research [6-9, 17, 25]; the cause we can only speculate on. We used multiple sources to attract participants: Facebook stroke groups, brain injury newsletters, clinicians, and in person stroke groups; with most participants citing Facebook as their point of contact. Importantly, we asked participants to self-assess their level of disability using the mRS. While many participants would be considered to have low levels of disability, which matches existing literature [22], over 30% of participants had moderate disability or greater. It is perhaps not surprising that very few participants reported no disability at the time of completing the questionnaire. An mRS of 2-5 doubled the odds of a participant reporting an unmet need compared to an mRS of 0-1. On average, participants were in their third year of survivorship, a likely stable period [26] during which to record their unmet needs. Partners as the dominant carers is consistent with previous literature [15].

Gender and current age were not found to alter the odds of reporting an unmet need. When comparing the level of unmet needs between Australian residents and USA residents there was no statistically significant difference.

The unmet needs reported by participants were spread disproportionately across the domains. Participants were most likely to report a need as unmet in the Impairments from Stroke, Finances, and Social Participation domains. While the Everyday Activities, and Work or Study domains were the least likely to have a need unmet relative to the other domains. The young stroke needs assessment questionnaire used in this study can assist future evaluation of unmet needs in young people after stroke [29].

Impairments from stroke domain comprises a wide range of impairments, such as mobility, speech, fatigue and cognition (Supplemental online document, table 5). Difficulties in this domain may directly affect other domains. Impairments from stroke may lead to loss of independence, high burden to carers and mood disorders. The study showed that for the Impairment domain, falls and swallowing difficulties were considered high burden in just over half of those who experienced them. Other impairments were also considered high burden by >75% of participants, indicating high levels of unmet need in this domain. It is worth noting that while difficulties with bladder or bowels was a relatively uncommon impairment, it was highly significant for those that did experience it. Surprisingly, just because a person indicated an impairment as having high burden, they did not always want assistance with the problem. Future research could explore this relationship.

Unmet needs in the Everyday Activities domain were relatively uncommon but were highly impactful in those that did experience them. This can happen as impacts in this domain may affect simple daily activities such as personal care. This matches with a review of 18 studies reporting on 3538 participants by Varona [27], who found that 70-80% of stroke survivors have no significant problems with daily activities at long term follow up, and only 10% report major handicaps. Difficulty travelling outside the home was most commonly due to the physical impact of their stroke, however the emotional impact should not be ignored as it was a factor noted by almost half of participants.

Financial stress has been found to be a key unmet need in young stroke survivors [9], and to occur far more commonly than in an elderly stroke population [3]. Problems in this domain could impact on long-term socio-economic status. Our findings also suggest this is a key area as participants were over 2 times as likely to have an unmet need in the Finances domain as in the domain of Healthcare Experience. Employment (at least 10 hours/week) fell sharply post stroke from 88% to 43% of participants. Ongoing stroke related costs (55%) and their changed ability to earn money (88%) were reported as causes for financial stress. Dissatisfaction with welfare benefits for their stroke was associated with difficulty applying for benefits (55%) and wanting help in applying (66%).

Social Participation was also found to be a key area of unmet need as participants were 2 times as likely to have an unmet need in this domain as in the domain of Healthcare Experience. Impacts in this domain could affect young people's ability to socialize, make new friends and attend social events. Other research has reported loss of pre-stroke leisure activities and social groups [30]. In this study participants report going out for fun less often than desired, seeing their friends less, and attending social events less since their stroke. Many people were not given information about stroke support groups during their acute hospital stay (77%), however this information was highly desired (90%). Additionally, over half wanted help finding activities that would suit their post stroke situation.

Reviews of stroke survivors' experiences in hospital were mixed. A minority did not feel they were involved in the decision making about their care despite valuing this highly. A similar number were not given answers to their questions that they could understand, which may be a factor in low rates of satisfaction regarding information given regarding their stroke (Supplemental online document). Less than half the participants were satisfied with how much they could guide the direction of their in-hospital rehabilitation, which they valued highly, and less felt that this rehabilitation effectively prepared them to return home. At discharge, stroke survivors were not told who to contact if they were having trouble managing, but this information was highly desired. Additionally, post-stroke checklists [30] which have been designed and adapted to help stroke survivors identify and express their needs to health professionals were rarely given at discharge, something they reported they would have found useful.

The feeling that having a stroke had strained the participant's relationship with their family was common (Supplemental online document). Being unable to communicate their needs and increased dependence both contributed. However, counselling was desired in less than half of those who described strain. A similar pattern was seen in those who felt their stroke had negatively affected their sexual life, where only half wanted to talk to a profession regarding the matter.

For those that wanted to return to work almost 90% felt their stroke had impacted their ability to work (Supplemental online document). Difficulties in returning to work could impact personal finances and even lead to long term mood disorders. Causes were multifactorial, with physical capabilities, emotional impact of stroke, cognitive impact of stroke, and fatigue all found to play a role. Psychiatric morbidity and physical disability have previously been found as determinants of return to work [17]. Job satisfaction was very low, this may be in part due to employers not adequately understanding the capabilities of individual stroke survivors. Future research may investigate influential factors. Return to study received similar responses, but notably the emotional and cognitive impacts of a person's stroke were influential in over 80% of those who felt their ability to study had been impacted.

The likelihood of experiencing an unmet need was not statistically significantly different between Australians and Americans. This aids the generalisability of our results to countries with a western health model.

The limitations of this study include those common to questionnaires. Persons with stroke who respond to questionnaires are not representative of the general young stroke population. For instance, persons that are more affected by stroke may be more motivated to improve future care and participate in surveys. Additionally, our online survey was not formally psychometrically validated. Neither did we assess reliability. Although the questionnaire had inbuilt sanity checks, the supplied data were not formally verified. Also, requiring the questionnaire to be filled out online may select against those more severely disabled or those who are older or less technology literate. As the questionnaire was anonymous we were unable to determine if the participant truly had experienced a stroke, however the length of the questionnaire as well as the targeted nature of advertising make false submissions unlikely. The gender balance in this study is not similar to young stroke gender prevalence (female 31.4% [31]), which reduces generalisability of this study. Finally, no formal sample size calculation was performed for this survey.

Conclusion

We developed and employed a new community based young stroke consumer needs assessment questionnaire. We showed the high number of unmet needs experienced by the young stroke population and that most of these needs are considered high burden to those individuals who experience them. Unmet needs were disproportionate, occurring most commonly in the Impairments from Stroke, Finances, and Social Participation domains. The current long-term care provided to stroke survivors may not be addressing their key areas of need, with new strategies or models needing to be developed. A targeted and individualized approach may be necessary, and a post stroke checklist may assist this approach.

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Declaration of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Sharing Statement

Consent to share data was not obtained from participants.

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Tables

Table 1: Demographics

Age median (IQR)	37 (32, 47)
Gender, n (%)	
Male	18 (23.7%)
Female	58 (76.3%)
Time since stroke median (IQR)	2.8 (1.0-5.3)
mRS, n (%)	
0	2 (2.6%)
1	38 (50.0%)
2	12 (15.8%)
3	19 (25.0%)
4	4 (5.3%)
5	1 (1.3%)
Residence, n (%)	
Australia & New Zealand	46 (60.5%)
United States of America	26 (34.2%)
United Kingdom	4 (5.3%)

IQR=Interquartile range; mRS=modified Rankin Scale

Table 2. Unmet needs across domains

All unmet needs								
	Healthcare experience	Impairments from stroke	Everyday activities	Work or study	Finances	Relationships	Social Participation	Total
Met	532	444	215	324	47	108	102	1772
Unmet	532	620	89	208	105	120	202	1876
Total	1064	1064	304	532	152	228	204	3648
X^2 p < 0.0001								
High burden unmet needs								
Met	529	534	242	332	72	127	145	1981
Unmet	387	530	62	200	80	101	159	1519
Total	916	1064	304	532	152	228	304	3500
X^2 p <0.0001								

Table 3. Unmet needs as per demographics

	Any unmet need		**High burden unmet need**	
	Odds ratio [95% CI]	P value	Odds ratio [95% CI]	P value
Current age (per year increase)	0.997 [0.984, 1.011]	0.713	0.997 [0.981, 1.013]	0.728
Dichotomised mRS (0 – 1) and (2 – 5)	1.882 [1.432, 2.475]	***< 0.0001****	2.014 [1.458, 2.781]	***< 0.0001****
Sex	1.157	0.402	1.090	0.676

(female compared to male)	[0.823, 1.627]		[0.729, 1.629]	
Country of residence (USA compared to Australia)	0.957 [0.716, 1.279]	0.767	0.952 [0.676, 1.340]	0.777

mRS=modified Rankin Scale; USA=United States of America

Table 4. Domains compared to the domain of Healthcare Experience

	Any unmet need		**High burden unmet need**	
	Odds ratio [95% CI]	p value	Odds ratio [95% CI]	p value
Impairments from Stroke	1.435 [1.201, 1.714]	**_< 0.0001*_**	1.377 [1.142, 1.661]	**_0.001*_**
Everyday Activities	0.387 [0.291, 0.515]	**_< 0.0001*_**	0.312 [0.226, 0.430]	**_< 0.0001*_**
Work or Study	0.620 [0.497, 0.772]	**_< 0.0001*_**	0.792 [0.629, 0.997]	**_0.047*_**
Finances	2.380 [1.631, 3.473]	**_< 0.0001*_**	1.561 [1.086, 2.245]	**_0.016*_**
Relationships	1.121 [0.832, 1.509]	0.453	1.077 [0.791, 1.465]	0.639
Social Participation	2.091 [1.585, 2.758]	**_< 0.0001*_**	1.539 [1.169, 2.025]	**_0.002*_**