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Is health-related quality of life between 90 and 180 days following stroke associated with long-term unmet needs?

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Abstract

Purpose Understanding the relationship between health-related quality of life (HRQoL) and long-term unmet needs is important for guiding services to optimise life following stroke. We investigated whether HRQoL between 90 and 180 days following stroke was associated with long-term unmet needs.

Methods Data from Australian Stroke Clinical Registry (AuSCR) registrants who participated in the Australian Stroke Survivor Needs Survey were used. Outcome data, including the EQ-5D, are routinely collected in AuSCR between 90 and 180 days post-stroke. Unmet needs were assessed at a median of 2 years and categorised into: health; everyday living; work/leisure; and support domains. Multivariable regression was used to determine associations between the EQ-5D dimensions and the likelihood of experiencing unmet needs and the visual analogue scale (VAS) (rating 0–100) and number of reported unmet needs.

Results In total, 173 AuSCR registrants completed the Needs Survey (median age 69 years, 67 % male; 77 % ischaemic stroke). VAS scores were negatively associated with the number of reported long-term unmet needs [irr 0.98, (95 % CI 0.97, 0 99) $p < 0.001$]. Having EQ-5D activity limitations was associated with unmet living needs (aOR 4.5, 95 % CI 1.1, 18.8). Requiring living supports at 90–180 days was associated with unmet health needs (aOR 4.9, 95 % CI 1.5, 16.1). Those with pain at 90–180 days were less likely to report unmet health (aOR 0.09, 95 % CI 0.02, 0.4) and support needs (aOR 0.2, 95 % CI 0.06, 0.6).

Conclusion Routinely collected HRQoL data can identify survivors at risk of experiencing long-term unmet needs. This information is important for targeting service delivery to optimise outcomes following stroke.

Keywords Health-related quality of life · Stroke · Unmet needs · EQ-5D · Long-term outcomes · International Classification of Function

Introduction

Stroke is the third leading cause of disability-adjusted life years (DALYs) lost worldwide and the leading cause of disability in many developed countries [1]. Many survivors of stroke (over 80 %) have reported having unmet needs at 12 or more months following stroke [2, 3]. In these studies, a need was defined as "something or help from someone that would help the survivor to overcome some of the effects of their stroke and resulting difficulties" [2, 3]. Levels of unmet needs have also been shown to vary depending on the age, functional disability and geographic location of the survivor [2] and to impact negatively on caregivers [4]. Despite this, there is limited understanding of how health-related quality of life (HRQoL) in the early period following stroke influences unmet needs of survivors of stroke longer term.

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Identification of unmet need from the patient perspective and identification of patient subgroups at risk of experiencing unmet needs are important for service planning and the provision of efficient and effective service delivery to maximise survivor outcomes. However, information regarding long-term unmet needs in survivors of stroke and other clinical groups is not routinely collected at a population level and is currently limited to cross-sectional surveys [2, 3]. Health-related quality of life (HRQoL), on the other hand, is often routinely collected in stroke as part of data collection systems such as clinical registries [5, 6] and epidemiological studies [7]. Although HRQoL as a concept is important, it does not provide practical guidance with regard to service delivery and requirements for ongoing support in the community.

To date, most studies that have been designed to explore the relationship between unmet needs and HRQoL have focused on the HRQoL consequences of not meeting needs in chronic disease groups [8, 9]. However, there is no information on how quality of life in the early period following stroke relates to the development of longer-term unmet needs. This evidence is needed to generate solutions through understanding the personal, social, environmental and organisational factors that may lead to survivor needs not being met and to identify those who are “at risk” of developing unmet needs so that targeted interventions can be implemented.

The aim of our study was to investigate attributes of HRQoL using the EQ-5D dimensions and visual analogue scale (VAS) between 90 and 180 days following stroke and their association with long-term (12+ months) unmet needs.

Methods

Data from survivors of stroke who were registered in the Australian Stroke Clinical Registry (AuSCR) database and completed the Australian Stroke Survivor and Carer Needs Survey (Needs Survey) were included [2]. The AuSCR is a collaborative national registry designed to monitor, promote and improve the quality of acute stroke care (www.auscr.com.au). The AuSCR collects nationally representative and prospective data on all stroke admissions from participating hospitals using a nationally endorsed, minimum clinical performance data set. Registrants are also routinely followed up between 90 and 180 days post-stroke by staff from a central coordinating office not employed by the participating hospitals. At follow-up registrants are asked about their living situation, whether or not they have been readmitted to hospital and their HRQoL is assessed using the EQ-5D-3L [10].

The Needs Survey was a national survey of survivors of stroke and their caregivers, commissioned by the National Stroke Foundation ($n = 765$). The aim of the survey was to describe the levels and types of unmet needs experienced by survivors living in the community one or more years following stroke. To be eligible to participate in the Needs Survey, participants needed to: (1) be aged 18 years or over; (2) be living in the community; (3) have a clinical diagnosis of stroke; (4) have had their first stroke at least 1 year prior to survey completion; and (5) be able to complete a survey with or without assistance. A detailed description of the Needs Survey has been published elsewhere [2]. In brief, the Australian Needs Survey was an adaptation of the UK Stroke Survivor Needs Survey [3]. The Australian adaptation was developed in conjunction with an expert advisory group that included representatives from the Australian National Stroke Foundation, stroke researchers, the UK research team, general practice and consumers and was pilot tested with a sample of survivors of stroke ($n = 15$) [2]. The UK survey included questions from a number of validated questionnaires [3]. The Australian survey mainly differed from the UK survey in that it was restructured to allow unmet needs to be calculated across a number of domains rather than just health. Our Needs Survey also has a high level of consistency with an unmet needs screening tool later developed in the UK, the Longer-term Unmet Needs after Stroke (LUNS) questionnaire [11]. Ninety-five per cent of the questions contained in the LUNS are covered in the Australian Needs Survey. The LUNS has been validated in a stroke population against a number of health status measures and was shown to have moderate to good reliability [11]. Further, in our final survey ($n = 765$), most respondents (88 %) felt that their unmet needs had been well covered by the survey indicating good content validity.

A multifaceted strategy was used to recruit participants to complete the Needs Survey. This meant that participants were recruited from a number of sources, one of which was the AuSCR. For those recruited through the AuSCR, eligible registrants who had indicated at their follow-up interview that they were willing to participate in future research were sent a participant information sheet and paper-based survey by AuSCR office staff. Due to funding restraints, it was only possible to use a single mail-out process. Options for completing the survey online and over the phone were also provided and outlined in the participant information sheet [2]. Surveys were completed anonymously, and a record of the participant project ID, with reference to their AuSCR ID, was maintained by the AuSCR staff. In 2014, separate ethical approvals were granted to allow data from the Needs Survey to be linked to respondent’s AuSCR data. To maintain the privacy of those that completed the surveys, the de-identified AuSCR data, with the Needs Survey ID attached, were securely submitted to Monash University whereby a researcher (NA) merged the data sets using the Needs Survey ID number.

Outcome measures and mapping to the International Classification of Function Disability and Health (ICF)

The International Classification of Function Disability and Health (ICF), developed by the World Health Organisation, is a universal classification system that can be used to describe a range of health-related outcomes [12]. The ICF is based on a biopsychosocial model that provides a broad definition of health and disability and acknowledges the complex interaction between a person's physical and emotional state and their environment [12]. The ICF covers the broad components of body functions and structures, activity and participation and how these categories are impacted on by personal and environmental factors (Fig. 1). Each broad component can be further refined depending on the level of detail required. The ICF is particularly applicable to stroke given the range of disabilities experienced by survivors of stroke and the context within which they need to manage these disabilities. The ICF provides a framework that is capable of capturing these complex interactions and is well suited to explore the relationship between HRQoL and unmet needs [13, 14].

The EQ-5D provides a measure of HRQoL over the dimensions of: (1) mobility; (2) self-care; (3) usual activities; (4) pain/discomfort; and (5) anxiety/depression. Dimensions one to three primarily relate to the ICF components of activities and participation, whereas dimensions four and five primarily relate to body functions [15]. Based on previous work by Geyh et al. [13], the EQ-5D contains 14 concepts 93 % of which can be mapped to the ICF with the majority pertaining to the ICF activities and participation component [13, 16]. A VAS where participants rate their health from zero (worst imaginable health) to 100 (best imaginable health) is also contained within the EQ-5D and provides a global measure of HRQoL.

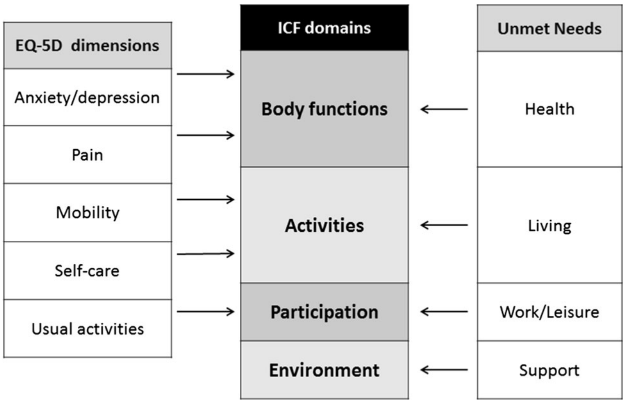

Fig. 1 Interactions between the International Classification of Function components (ICF), health-related quality of life measured using the EQ-5D and unmet needs from the Australian Stroke Survivor Needs Survey

As part of the Needs Survey, the extent to which needs were met was assessed over five domains (health, everyday living, leisure, vocational work and support). Each domain contained between one and thirteen questions. The domains of unmet needs covered in the survey were mapped to the four main components of the ICF: body functions (unmet health needs); activities (unmet living needs); participation (unmet leisure or work needs); and environment (unmet support needs). The specific areas of need covered in each domain are outlined in Table 1.

Ethics

The project was approved by the Monash University Human Research Ethics Committee (approval number: CF13/918-2013000394). Approval was also granted by the AuSCR Research Task Group and Management Committee and the National Stroke Foundation.

Statistical analyses

A need was defined as not fully met if it was reported as "not met at all" or "only met to some extent". For the denominator we combined the responses "I did not want help", "I did not have difficulties" and "yes definitely" (I have had enough help) so that comparisons could be made between those whose needs were not being met and those whose needs were either being met or who did not have needs. This categorisation is similar to that used for the LUNS survey [11]. Univariable analyses were performed using the Chi-squared test or univariable logistic regression for categorical variables and the Wilcoxon Mann–Whitney rank-sum test for continuous variables. The EQ-5D dimensions were dichotomised into "no problems" (level 1) and "problems" (level 2 or 3) to preserve subgroup numbers. Missing data were excluded from the analyses. However, 99.4–100 % of all EQ-5D data were complete, 100 % of VAS data were complete, and completeness for the unmet needs domains ranged from 94.2 to 100 %.

Multivariable analyses were performed to assess for factors associated with unmet needs across each of the unmet needs domains. The association between the proportion of respondents reporting unmet needs for each domain and relevant variables was tested using univariable analyses, and variables with an association of $p < 0.1$ were included in the multivariable models (parsimonious model). Variables tested for inclusion in the models were:

Table 1 Specific areas of need covered by the domains of the Australian Stroke Survivor and Carers Needs Survey mapped to the International Classification of Function

ICF body functions Health unmet needs	ICF activities Living unmet needs	ICF participation Leisure/work unmet needs	ICF environmental Support unmet needs
Mobility	Personal care	Returning to leisure activities	Emotional support (outside family and friends)
Falls	Household chores	Returning to work	
Bladder/bowel	Home adaptations		
Pain			
Swallowing			
Fatigue			
Emotions			
Concentration			
Memory			
Speech			
Cognition			
Reading			
Vision			

ICF International Classification of Function

each of the five EQ-5D dimensions; living supports needed at 90–180 days; whether or not they were living alone at 90–180 days; age; gender; stroke type; stroke severity (as indicated by ability to walk on admission [17]); documented evidence of a previous stroke; recurrent stroke within 180 days; and Index of Relative Socio-economic Advantage/Disadvantage [18]. The parsimonious models were compared to models containing all possible independent variables (full model). Both the parsimonious and the full model were compared using Bayesian information criteria (BIC) [19]. The parsimonious models were chosen as in all instances the BIC was lower for the parsimonious model (up to 24 points lower for some domains) and provided smaller confidence intervals but with similar odds ratios to the full model indicating more precise estimates.

Multivariable models were tested for interactions between logical combinations of variables, and models with and without the interaction terms were compared using likelihood ratio tests. Models were tested for patient clustering by hospital and by state of residence (rho < 0.001). Neither interactions nor clustering effects were detected (results not shown). Our sample size was limited to the number of Needs Survey respondents recruited through AuSCR. However, it complies with that proposed by Long et al for predictive modelling, i.e. that sample sizes should be no less than 100 and that there should be at least 10 observations per parameter [20]. Models were also tested for goodness of fit using the Hosmer–Lemeshow statistic.

To assess the direct association between overall VAS scores and the total number of long-term unmet needs, Pearson's correlation was performed. This association was also assessed using multivariable negative binomial regression with models adjusted for factors known to influence stroke outcomes. These were the same as those included in the logistic regression models but without the EQ-5D dimensions. To better understand the relationship between the number of reported unmet needs and VAS scores, we then calculated the predicted number of unmet needs at each 10th percentile of the VAS holding all other variables in the model constant. The margins obtained and their 95 % confidence intervals were plotted to show the graphical relationship between the EQ-5D VAS scores and the predicted number of unmet needs.

Results

A total of 602 surveys were sent to AuSCR registrants as part of the Needs Survey recruitment strategy. From these 173 (29 %) completed surveys were returned between March and August 2012. Comparisons between responders and non-responders are shown in Table 2. There were no statistically significant differences between AuSCR registrants that participated in the Needs Survey and those who did not based on age, proportion born in Australia, location (state), stroke type and stroke severity. However, males were significantly more likely to respond to the survey than females ($p < 0.004$). The AuSCR participants who completed the survey were also similar to survey participants recruited from other sources (Table 2). The median age of participants at survey completion was 70 years [quartile 1

Table 2 Baseline comparisons between AuSCR survey respondents, AuSCR non-responders and all survey respondents

Variable	AuSCR responders $N = 173$ n (%)	AuSCR non-responders $N = 426$ n (%)	Non-AuSCR needs survey responders $N = 591$ n (%)
Age median (Q1, Q3)			
At stroke	69 (60, 79)	70 (59, 80)	NA
At survey completion	70 (60, 78)	NA	69 (60, 77)
Male	115 (67)*	227 (54)	326 (60)
Born in Australia	119 (73)	270 (66)	382 (72)
State†			
New South Wales	36 (21)	93 (22)	169 (32)
Queensland	49 (28)	131 (31)	55 (11)
Victoria	48 (28)	103 (24)	114 (22)
Western Australia	40 (23)	97 (23)	74 (14)
South Australia	NA	NA	73 (14)
Tasmania	NA	NA	34 (6)
Stroke related			
Ischaemic	134 (77)	347 (82)	NA
Able to walk independently on admission#	71 (45)	146 (39)	NA
Years since stroke at survey completion median (Q1, Q3)	2 (2, 3)	NA	2 (2, 4)
Stroke-related problems at survey completion	107 (68)	NA	505 (73)

NA not applicable to that data set, *AuSCR* Australian Stroke Clinical Registry; *Q1, Q3* quartile 1 and quartile 3

* Statistically significant difference compared between responders and non-responders ($p < 0.05$)

Stroke severity is indicated by ability to walk on admission

† Data are currently only collected by AuSCR for hospitals in NSW, VIC, QLD and WA

(Q1), quartile 3 (Q3): 60, 78], and the majority were male (67 %), were born in Australia (73 %) and had experienced an ischaemic stroke (77 %). Median time from stroke symptom onset to AuSCR follow-up was 147 days (Q1, Q3: 114, 198), and median time from stroke onset to Needs Survey completion was 2 years (Q1, Q3: 2, 3). The median score on the VAS was 70, 10–15 points lower than age-matched population normative data from similar countries [21]. In addition, the median number of unmet needs reported by participants was four (Q1, Q3: 0, 7). Figure 2 shows the proportion of participants reporting unmet needs across the four Needs Survey domains.

Participants EQ-5D VAS scores between 90 and 180 days were negatively correlated with the number of unmet needs reported at a median of 2 years following stroke ($r = -0.43$). Using multivariable analysis, we found a strong association between the EQ-5D VAS scores and the number of reported unmet needs at a median of 2 years [irr 0.98, (95 % CI 0.97, 0.99) $p < 0.001$]. For every one point decrease in a survivors VAS score, there was a significant likelihood of them having a 2 % increase in the number of unmet needs reported. The VAS scores had the strongest association with the number of long-term unmet needs out of all of the variables included in our multivariable model. A negative exponential relationship was observed between the VAS scores and the number of predicted unmet needs such that the lower the reported VAS scores at 90–180 days the greater were the predicted number of unmet needs (Fig. 3). Further, those with a VAS score greater or equivalent to population normative data, matched to the median age of our study population (VAS = 85), reported a median of one unmet need (Q1, Q3: 0, 5), whereas those with a VAS score below 85 reported a median of four unmet needs at a median of 2 years post-stroke (Q1, Q3: 2, 8).

Univariable analyses in which the relationship between the EQ-5D dimensions and long-term unmet needs was examined are shown in Table 3. A significantly greater proportion of those who reported having problems with mobility, self-care and usual activities between 90 and 180 days reported having long-term unmet needs in multiple domains. However, those who reported having pain or anxiety/depression between 90 and 180 days following stroke were less likely to report having unmet needs at a median of 2 years following stroke for most unmet need domains.

In the multivariable analyses, one or more EQ-5D dimensions were significantly associated with domains of unmet needs at a median of 2 years following stroke (Table 4). Having difficulty with usual activities between

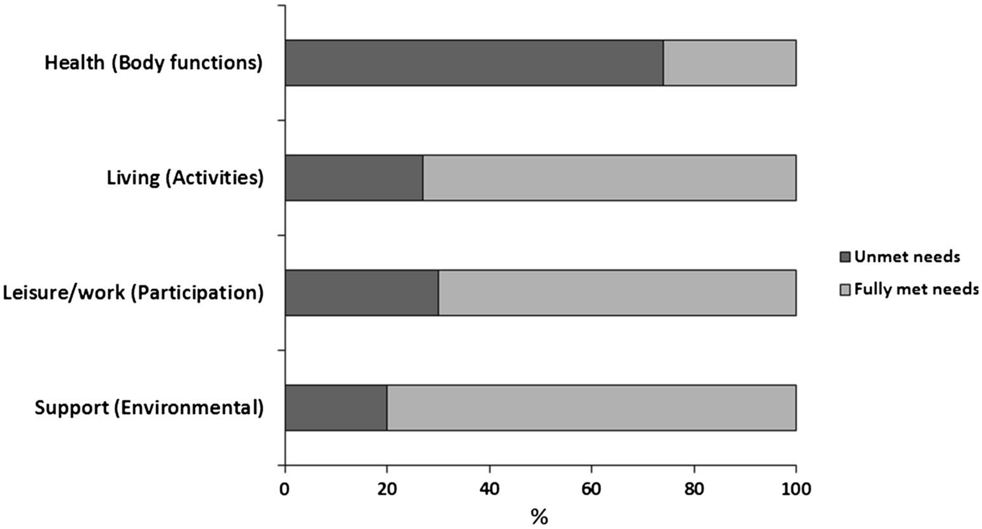

Fig. 2 Proportion of participants with unmet needs in each International Classification of Function component

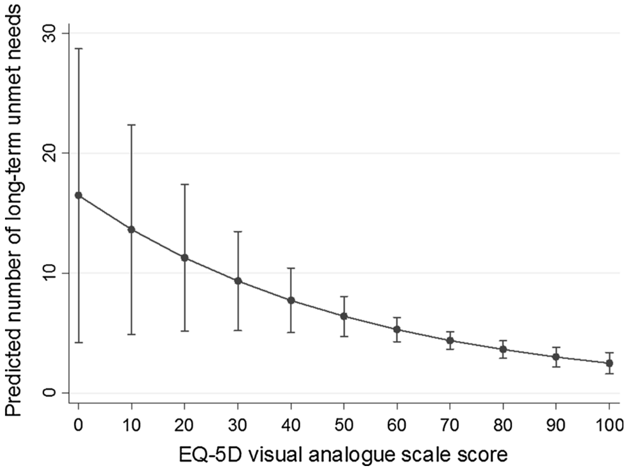

Fig. 3 Adjusted prediction of the number of long-term unmet needs associated with EQ-5D visual analogue scale scores at 90–180 days post-stroke, with 95 % confidence intervals

90 and 180 days had the strongest positive association with long-term unmet living needs (ICF activities component) (aOR 4.5, 95 % CI 1.1, 7.3). There were no factors in our model that were positively associated with unmet support needs (ICF environment component). However, those with pain, according to the EQ-5D between 90 and 180 days, were significantly less likely to report long-term unmet health needs (aOR 0.09, 95 % CI 0.02, 0.4) and unmet support needs (aOR 0.2, 95 % CI 0.1, 0.6) [Table 4].

Discussion

This is the first study in which the association between HRQoL within the first 6 months following stroke and long-term unmet needs in survivors of stroke has been described. By presenting this information within the framework of the ICF, we have broadened the applicability of our results to provide information that can be viewed within the context of current and future healthcare models and rehabilitation efficacy research. We have demonstrated a strong association between HRQoL in the early period following stroke and the number of long-term unmet needs reported at a median of 2 years post-stroke. We also provide evidence that those who report having long-term unmet needs are more likely to have experienced reduced HRQoL in the early period following stroke. This information is useful in identifying those most at risk of having long-term unmet needs and may enable early identification of survivors of stroke who require additional assistance or support, once they are back in the community.

The strong relationship between the EQ-5D VAS scores and number of reported unmet needs demonstrated the ability of the VAS to capture the complexities and the HRQoL burden of having multiple unmet needs (i.e. the lower a survivors HRQoL the more unmet needs they were likely to report). The predictive value of the VAS as shown in Fig. 3 means that the VAS may be a powerful tool for early identification of survivors of stroke at risk of experiencing multiple unmet needs.

The EQ-5D dimensions were analysed with regard to their ability to predict the odds of having a long-term unmet need in a related domain. The association between the EQ-5D dimensions and domains of unmet needs was less straight forward than the association between the VAS and number of unmet needs. Some aspects were consistent, especially the univariable results, in that having problems in some EQ-5D dimension was positively associated with having long-term unmet needs in related domains. However, these were not always the strongest predictors of unmet needs as was apparent from our multivariable results. For example, problems in the EQ-5D dimension of self-care

Table 3 Univariable results showing the association between EQ-5D dimensions plus living supports between 90 and 180 days following stroke and the proportion of participants with unmet needs at a median of 2 years following stroke grouped according to the International Classification of Function components

Unmet needs[+]	International Classification of Function components							
	Body functions		Activities		Participation		Environmental	
	Health		Living		Leisure/work		Support	
EQ-5D[#]	OR	95 % CI	OR	95 % CI	OR	95 % CI	OR	95 % CI
Body functions								
Experienced anxiety/depression	0.2	(0.1, 0.6*)	0.4	(0.2, 1.0*)	0.2	(0.05, 0.7*)	0.3	(0.1, 0.6*)
Experienced pain	0.2	(0.1, 0.4*)	0.4	(0.1, 0.8*)	0.3	(0.09, 1.1)	0.2	(0.1, 0.5*)
Activities								
Problems with mobility	6.9	(2.7, 17.4*)	2.3	(1.0, 5.4)	4.4	(1.1, 16.8*)	3.0	(1.4, 6.8*)
Problems with self-care	9.8	(2.2, 42.4*)	3.0	(1.3, 7.1*)	6.6	(1.9, 23.3*)	4.7	(2.0, 10.6*)
Participation								
Difficulties with usual activities	5.8	(2.7, 12.4*)	6.6	(1.9, 23.0*)	3.4	(0.7, 16.0)	4.9	(1.8, 13.4*)

* Statistically significant ($p < 0.05$)

[#] Recorded in the Australian Stroke Clinical Registry at 90–180 days following stroke

[+] Australian Stroke Survivor and Carer Needs Survey

(ICF activities component) was associated with unmet living needs (ICF activities component) on univariable analysis, but this association was not significant in our multivariable analysis. What was unexpected was the inverse relationship between the EQ-5D dimension of pain and long-term unmet health needs and support needs both on univariable and on multivariable analyses. One explanation for these findings may be that the EQ-5D dimensions that relate to the ICF body function component are primarily managed medically. Consequently, those with pain or anxiety/depression may have had more frequent contact with their general medical practitioners or other health professionals in the early period following stroke [22–25]. This may have created opportunities for discussions about other needs and increased the likelihood of referrals to additional services such as allied health or community services which addressed unmet needs in other domains. This hypothesis is supported by qualitative research in which survivors of stroke have reported feeling unsupported and “lost” in the early period following stroke and that once they are back in the community, their general medical practitioner is the primary point of contact [26]. These data suggest that increased and regular contact with appropriate health or community services in the early period following stroke may reduce long-term unmet needs.

The perception of medical services as an illness or disease-based treatment service is a reflection of healthcare delivery systems currently in place in most developed countries. These systems often focus on disease-related problems rather than broader aspects such as participation, thereby influencing patient health service seeking behaviours (i.e. people feel that they need to have a disease or illness requiring treatment to access a medical practitioner). Although a disease-based model may be important in the acute phase of stroke, it does not address the more complex issues associated with long-term disability, especially with regard to reintegration into the community and developing meaningful roles within the context of their disability [12, 27]. The concept of unmet need is an important factor in providing patient-centred healthcare and differs from the concept of just need in that it is specifically related to the ability of current service provision to satisfy a need. For example, we showed in our previous Needs Survey that having a problem in a specific area was not always indicative of having an unmet need in that area [2]. We also showed that the extent to which needs were met was reliant on a number of factors. These included personal factors such as age, socio-economic status and health literacy and environmental factors such as geographic location, and availability and accessibility of appropriate services [2]. It is likely that models of care that have a strong focus on being responsive to peoples’ needs and providing connectedness across the different health sectors [28], will be more effective in reducing unmet needs than other models [29, 30].

Support and rehabilitation services available to long-term survivors of stroke are limited, fragmented and often difficult to access once the stroke survivor has returned to the community [31]. Survivors are also not well equipped to know what types of services they need, what is available

Table 4 Multivariable regression results showing associations between EQ-5D and patient factors with long-term unmet needs

Health unmet needs[#] (ICF body functions component) OR (95 % CI)	Living unmet needs[#] (ICF activities component) OR (95 % CI)	Leisure/work unmet needs[#] (ICF participation component) OR (95 % CI)	Support unmet needs[#] (ICF environment component) OR (95 % CI)
EQ-5D mobility* 2.8 (0.7, 12.2), $p = 0.2$	EQ-5D mobility* 1.0 (0.3, 3.4), $p = 0.9$	EQ-5D mobility* 2.2 (0.2, 19.3), $p = 0.5$	EQ-5D mobility* 0.8 (0.2, 3.2), $p = 0.7$
EQ-5D self-care* 0.7 (0.09, 5.0), $p = 0.7$	EQ-5D self-care* 1.3 (0.4, 4.4), $p = 0.6$	EQ-5D self-care* 2.2 (0.4, 14.0), $p = 0.4$	EQ-5D self-care 1.4 (0.3, 5.6), $p = 0.6$
EQ-5D usual activities* 2.8 (0.9, 8.7), $p = 0.08$	***EQ-5D usual activities*** ***4.5 (1.1, 18.8), p = 0.04***	EQ-5D anxiety/depression* 0.3 (0.07, 1.6), $p = 0.2$	EQ-5D usual activities 2.0 (0.5, 8.4), $p = 0.3$
EQ-5D anxiety/depression* ***0.3 (0.08, 0.8), p = 0.02***	EQ-5D anxiety/depression* 0.5 (0.2, 1.4), $p = 0.2$	EQ-5D pain* 0.7 (0.2, 3.6), $p = 0.7$	EQ-5D anxiety/depression 0.5 (0.2, 1.4), $p = 0.2$
EQ-5D pain* **0.09 (0.02, 0.4), $p = 0.001$**	EQ-5D pain* 0.6 (0.2, 1.6), $p = 0.3$	**Age at stroke onset** **0.9 (0.9, 1.0), $p = 0.001$**	**EQ-5D pain** **0.2 (0.06, 0.6), $p = 0.006$**
Able to walk on admission 1.1 (0.4, 3.2), $p = 0.8$	**Sex** **2.9 (1.1, 7.3), $p = 0.03$**	Living supports* 6.1 (0.5, 80.4), $p = 0.2$	Able to walk on admission 0.9 (0.3, 2.5), $p = 0.8$
Living supports* **4.6 (1.4, 15.3), $p = 0.013$**	Living supports* 1.1 (0.3, 3.5), $p = 0.9$		Living supports 1.9 (0.6, 6.3), $p = 0.3$
Socio-economic status **0.99 (0.98, 1.0), $p = 0.03$**			Socio-economic status 1.0 (1.0, 1.0), $p = 0.05$
Living alone* 0.7 (0.2, 2.2), $p = 0.6$			

Socio-economic status is measured using the Index of Relative Scio-economic Advantage/Disadvantage

Factors considered for inclusion in the model were: the five EQ-5D dimensions; living supports needed at 90–180 days; living alone at 90–180 days; age; gender; stroke type; stroke severity; documented evidence of a previous stroke; recurrent stroke within 180 days; and socio-economic status

OR odds ratio, *CI* confidence interval; *ICF* International Classification of Function

* Recorded in the Australian Stroke Clinical Registry at 90–180 days following stroke

[#] Unmet needs measured at more than 1 year (median 2 years) post-stroke. EQ-5D dimensions, living supports and living-alone status were measured at 90–180 days following stroke

Bolded indicates factors that were statistically significant within the model

Bold italic indicates independent variables that were significant in the above models but not significant when all of the factors listed above were included in the model

and how to access services [26, 31]. This may in part be related to how stroke recovery is measured and how rehabilitation and other services are funded. Outcome measures routinely collected in the acute clinical setting, such as the Modified Rankin Score (mRS), or the inpatient rehabilitation setting, such as the Functional Independence Measure (FIM) and the Barthel Index, do not fully address aspects of recovery associated with community and instrumental activity participation or the environment [28, 31, 32]. These clinical measures focus on body functions and performance of activities associated with physical independence [15], measure disability from a hospital or clinical perspective (i.e. is this patient able to complete the basic activities necessary for discharge to the community) and suffer from ceiling effects in those that require higher levels of function in order to participate in society [33, 34]. In fact, many survivors of stroke who are deemed “recovered” according to the Barthel Index continue to have disability-related problems many years following stroke [35]. There is little routinely collected information available on survivors once they are back in the community, making it difficult to identify those in need of further support.

Clinical registries such as the AuSCR may be one means of filling this gap. We have demonstrated the utility of the EQ-5D, which is routinely collected in AuSCR, to broadly identifying those who are likely to experience more tangible consequences of stroke, such as unmet needs, once they have integrated back into the community. Having routine data that correlate with or predict unmet needs may provide a mechanism for linking survivors of stroke who may be “at risk”, with disability support based on patient-centred criteria within the framework of the ICF [28]. By using a combination of the EQ-5D dimensions and the VAS, it may be possible not only to identify those who are most likely to experience multiple unmet needs but also to identify the specific domains or types of unmet needs that may be impacting on their HRQoL. For example, if someone was identified as having difficulties with usual activities between 90 and 180 days following stroke and had a reduced VAS score, they could be referred to a service aimed at reducing everyday living needs thereby reducing their overall levels of unmet need.

Limitations

Despite the novelty of this research, there are some limitations to our study. Although all of the concepts contained in the EQ-5D can be mapped to the ICF, the brevity of the EQ-5D means that there are a large number of concepts in the ICF that it does not cover such as body structures and environment, and only a small proportion of possible body functions are represented [13, 16]. Nevertheless, the EQ-5D has sufficient validity to provide a broad measure of HRQoL within the ICF framework [36]. Another limitation is that the Australian version of the Needs Survey has not been fully validated in its current form in a stroke population. However, this survey was based on and is consistent with similar surveys validated in the UK and face and content validity was received from feedback from Australian consumers. Anxiety and depression can occur acutely as a direct consequence of stroke or can develop later once the survivor becomes fully aware of their situation [37]. The time frame during which the EQ-5D data were collected means that the relationship between late-onset anxiety or depression and unmet needs may be very different to the relationship between early-onset anxiety and depression measured in our study. We are also unable to account for pre-morbid pain or anxiety/depression in our study. Our response rate means that there may be response bias associated with our results. However, responders were similar to other Needs Survey participants and to other AuSCR registrants that did not respond to the Needs Survey. Finally, our sample size is on the lower end of what is considered acceptable for multivariable predictive analyses. The relatively small sample size and the large confidence intervals associated with some of the independent variables in our multivariable models meant that there was the potential for type 2 errors when identifying associations between these variables and the unmet need domains. Further work to test the concepts that we have identified and further research to explore the robustness of the EQ-5D as a tool for predicting long-term unmet needs, using larger population samples, are needed.

Conclusion

This is the first study to explore the relationship between HRQoL in the early period following stroke and long-term unmet needs. We have shown that the lower the EQ-5D VAS scores reported by survivors of stroke in the early period following stroke the greater are the number of long-term unmet needs that they are likely to report at a median of 2 years. This has the potential to be a powerful tool for predicting long-term unmet needs in survivors of stroke. We also identified important factors at 90–180 days, including EQ-5D dimensions, associated with the types of long-term unmet needs likely to be experienced by survivors. This information is important for identifying those who may benefit most from tailored early interventions following discharge to the community from hospital to reduce long-term unmet needs and aid more efficient and effective health service delivery.

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Compliance with ethical standards

Conflict of interest The Needs Survey was commissioned and funded by the National Stroke Foundation (NSF). The Trust Company contributed funds via a grant to the NSF. This substudy involving Australian Stroke Clinical Registry participants was funded by an NSF Small Project Grant. Dominique Cadilhac is supported by a National Health and Medical Research Council (NHMRC)/National Heart Foundation Research Fellowship (1063761), and Nadine Andrew is supported by an NHMRC Early Career Fellowship (1072053). The authors have no other known conflicts of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individuals that participated in the Australian Stroke Survivor and Carer Needs Survey.

References

1. Senes, S. (2006). *How we manage stroke in Australia. AIHW cat no CVD 31*. Canberra: Australian Institute of Health and Welfare.
2. Andrew, N., Kilkenny, M., Naylor, R., Purvis, T., Lalor, E., Moloczij, N., & Cadilhac, D. (2014). Understanding long-term unmet needs in Australian survivors of stroke. *International Journal of Stroke, 9*(Supplement A100), 106–112.
3. McKevitt, C., Fudge, N., Redfern, J., Sheldenkar, A., Crichton, S., Rudd, A., et al. (2011). Self-reported long-term needs after stroke. *Stroke, 42*, 1398–1403.

4. Andrew, N., Kilkenny, M., Naylor, R., Purvis, T., & Cadilhac, D. (2015). The relationship between caregiver impacts and the unmet needs of survivors of stroke. *Patient Prefer Adherence, 9*, 1065–1073.
5. Cadilhac, D. A., Lannin, N., Anderson, C., Levi, C., Faux, S., Price, C., et al. (2010). Protocol and pilot data for establishing the Australian Stroke Clinical Registry (AuSCR). *International Journal of Stroke, 5*, 217–226.
6. Asplund, K., Hulter Asberg, K., Appelros, P., Bjarne, D., Eriksson, M., Johansson, A., et al. (2011). The Riks-Stroke story: Building a sustainable national register for quality assessment of stroke care. *International Journal of Stroke, 6*(2), 99–108.
7. Sturm, J. W., Donnan, G. A., Dewey, H. M., Macdonell, R. A., Gilligan, A. K., Srikanth, V., & Thrift, A. G. (2004). Quality of life after stroke: The North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke, 35*(10), 2340–2345.
8. Miranda-Castillo, C., Woods, B., Galboda, K., Oomman, S., Olojugba, C., & Orrell, M. (2010). Unmet needs, quality of life and support networks of people with dementia living at home. *Health and Quality of Life Outcomes, 8*, 132.
9. Hansen, D. G., Larsen, P. V., Holm, L. V., Rottmann, N., Bergholdt, S. H., & Sondergaard, J. (2013). Association between unmet needs and quality of life of cancer patients: A population-based study. *Acta Oncologica, 52*(2), 391–399.
10. The EuroQol Group. (1990). EuroQol—A new facility for the measurement of health-related quality of life. *Health Policy, 16*, 199–208.
11. LoTS care LUNS study team. (2013). Validation of the Longer-term Unmet Needs after Stroke (LUNS) monitoring tool: A multicentre study. *Clinical Rehabilitation, 27*, 1020–1028.
12. World Health Organisation World Bank. (2001). *The international classification of functioning, disability and health (ICF)*. Geneva: WHO.
13. Geyh, S., Cieza, A., Kollerits, B., Grimby, G., & Stucki, G. (2007). Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): A systematic review. *Quality of Life Research, 16*, 833–851.
14. Sumathipala, K., Radcliffe, E., Sadler, E., Wolfe, C., & McKevitt, C. (2011). Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health. *Chronic Illness, 8*, 31–44.
15. Andrew, N., Gabbe, B., Wolfe, R., & Cameron, P. (2010). Evaluation of instruments for measuring the burden of sport and active recreation injury. *Sports Medicine, 40*, 141–161.
16. Cieza, A., & Stucki, G. (2005). Content comparison of health-related quality of life (HRQOL) instruments based on the international classification of functioning, disability and health (ICF). *Quality of Life Research, 14*, 1225–1237.
17. Counsell, C., Dennis, M., & McDowall, M. (2004). Predicting functional outcome in acute stroke: Comparison of a simple six variable model with other predictive systems and informal clinical prediction. *Journal of Neurology, Neurosurgery and Psychiatry, 75*(3), 401–405.
18. Australian Bureau of Statistics. (2011). *Socio-economic indexes for areas (SEIFA)*. Canberra: Australian Bureau of Statistics.
19. Long, J., & Freese, J. (2014). *Regression models for categorical dependent variables using Stata* (3rd ed.). Texas: Stata Press.
20. Long, J. (1997). *Regression models for categorical and limited dependent variables: Beverley Hills*. CA: Sage.
21. Szende, A., & Williams A. (2004). *On behalf of the EuroQol Group's international task force on self-reported health. Measuring self-reported population health: An international perspective based on EQ-5D*. Rotterdam: EuroQol
22. Ghose, S., Williams, L. S., & Swindle, R. W. (2005). Depression and other mental health diagnoses after stroke increase inpatient and outpatient medical utilization three years poststroke. *Medical Care, 43*(12), 1259–1264.
23. Lim, K., Jacobs, P., & Klarenbach, S. (2006). A population-based analysis of healthcare utilization of persons with back disorders: Results from the Canadian Community Health Survey 2000–2001. *Spine, 31*(2), 212–218.
24. Ullrich, P. M., Smith, B. M., Blow, F. C., Valenstein, M., & Weaver, F. M. (2014). Depression, healthcare utilization, and comorbid psychiatric disorders after spinal cord injury. *Journal of Spinal Cord Medicine, 37*(1), 40–45.
25. Blyth, F., March, L. M., Brnabic, A. J. M., & Cousins, M. J. (2004). Chronic pain and frequent use of health care. *Pain, 111*(1–2), 51–58.
26. Hare, R., Rogers, H., Lester, H., McManus, R., & Mant, J. (2006). What do stroke patients and carers want from community services? *Family Practice, 23*, 131–136.
27. Green, A. R., Carrillo, J. E., & Betancourt, J. R. (2002). Why the disease-based model of medicine fails our patients. *The Western journal of Medicine, 176*(2), 141–143.
28. Madden, R., Ferreira, M., Einfeld, S., Emerson, E., Magna, R., Refschauge, K., & Llewellyn, G. (2012). New directions in health care and disability: The need for a shared understanding of human functioning. *Australian and New Zealand Journal of Public Health, 36*, 458–461.
29. Department of Health and Ageing. (2009). *Primary health care reform in Australia: Report to support Australia's first national primary health care strategy*. Canberra: Commonwealth of Australia.
30. WHO Regional Office for Europe. (2013). *Strengthening people-centred health systems in the WHO European Region: A framework for action towards coordinated/integrated health services delivery*. Copenhagen: WHO Regional Office for Europe.
31. Wissel, J., Olver, J., & Sunnerhagen, K. S. (2013). Navigating the poststroke continuum of care. *Journal of Stroke and Cerebrovascular Diseases: The Official Journal of National Stroke Association, 22*(1), 1–8.
32. Madden, R., Marshall, R., & Race, S. (2013). ICF and casemix models for healthcare funding: Use of the WHO family of classifications to improve casemix. *Disability and Rehabilitation, 35*(13), 1074–1077.
33. Duncan, P. W., Samsa, G. P., Weinberger, M., Goldstein, L. B., Bonito, A., Witter, D. M., et al. (1997). Health status of individuals with mild stroke. *Stroke, 28*(4), 740–745.
34. Hall, K., Mann, N., High, W., Wright, J., Kreutzer, J., & Wood, D. (1996). Functional measures after traumatic brain injury: Ceiling effects of FIM, FIM + FAM, DRS and CIQ. *The Journal of Head Trauma Rehabilitation, 11*, 27–39.
35. Lai, S.-M., Studenski, S., Duncan, P. W., & Perera, S. (2002). Persisting consequences of stroke measured by the stroke impact scale. *Stroke, 33*, 1840–1844.
36. Dorman, P. J., Waddell, F., Slattery, J., Dennis, M., & Sandercock, P. (1997). Is the EuroQol a valid measure of health-related quality of life after stroke? *Stroke, 28*(10), 1876–1882.
37. Hackett, M. L., Yapa, C., Parag, V., & Anderson, C. S. (2005). Frequency of depression after stroke: A systematic review of observational studies. *Stroke, 36*(6), 1330–1340.