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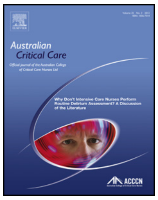

Research paper

Health Related Quality of Life and support needs for sub-arachnoid haemorrhage survivors in New South Wales Australia

Margherita Murgo BN, MN (Crit Care)[a,*],
Kwendy Cavanagh BN (Hons), Grad Cert (Crit Care), Grad Cert (Emergency Nursing), Dip (Tropical Nursing)[b],
Simon Latham BN, Grad Cert (Crit Care)[c]

[a] *NSW Clinical Excellence Commission, Australia*
[b] *Sydney Local Health District, Australia*
[c] *Nursing Administration and Resource Management Unit, Royal Prince Alfred Hospital, Australia*

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ABSTRACT

Background: Subarachnoid haemorrhage (SAH) is commonly a devastating injury with long lasting physical and psychosocial consequences for survivors. Support after hospital discharge through chronic care services for this patient group is limited. This study aimed to measure Health Related Quality of Life (HRQoL) and needs of survivors after discharge from hospital.
Methods: A population of patients that were diagnosed with SAH were contacted, up to 2 years post discharge, to participate in a postal survey including the Short Stroke Specific Quality of Life Scale (SSQoL-12), a service utilisation questionnaire and attitudes towards participating in a support group.
Findings: There were 28 responders. HRQoL was lowest in the psychosocial domain and particularly in relation to fatigue and memory. Most notably many responders indicated they wanted to be interviewed but a support group was not favoured with few responders ($n = 11$) indicating interest with most in favour of a face to face format ($n = 10$).
Conclusions: HRQoL was reduced particularly in the psychosocial domain. Although there was low utilisation of support services in the post-acute care phase, these patients may benefit from greater opportunities to participate in both physical and psychosocial rehabilitation programs.

1. Background

Subarachnoid haemorrhage (SAH) accounts for only 5% of stroke presentations,[1] but is often a calamitous injury with high mortality rate and significant associated disability in survivors.[2] Australian incidence in the year 2000 was estimated at 8.1/100,000 population with a mortality rate of 39%,[3] although more recent data estimated incidence at 10.3/100,000 person-years from 1998 to 2008.[4] Recent worldwide data estimates the mortality rate at around 25%.[5] The prognosis is dependent on a number of variables, including the extent of the initial bleed, the presence of secondary brain injury and re-bleeding.[6] SAH is also more prevalent in women,[3–5,7] ranging from 42 to 83% of patients worldwide.[7]

Amongst patients that survive to hospital discharge, persistent neurocognitive changes can occur.[8,9] These include fatigue,[10] cognitive impairment,[7,11] depression[11,12] and post-traumatic distress,[13,14] which significantly affect quality of life.[1,2,7] This long-term impact suggests that health related outcomes should be measured for this group of patients[8] and that there may be a need for support services similar to those offered to other patients with chronic illness.[9] Health Related Quality of Life (HRQoL) following SAH has been reported[2,7] but not in the Australian population. Given the significant impact on patients and the health system, this study aimed to assess the HRQoL of SAH survivors in Australia, the types of services utilised, the need for post discharge support to ameliorate recovery and ascertain interest in generating a support group either face to face or via other media.

2. Design

After institutional ethics approval was granted, a list of all patients admitted to the Neuroscience Intensive Care Unit (NSICU)

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[*] Corresponding author. Tel.: +61 292695624.
E-mail addresses: margherita.murgo@health.nsw.gov.au (M. Murgo), Kwendy.Cavanagh@sswahs.nsw.gov.au (K. Cavanagh), Simon.Latham@sswahs.nsw.gov.au (S. Latham).

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diagnosed with SAH from January 1st 2011 to December 31st 2012 was obtained from a single site specialised NSICU in New South Wales (NSW). Basic demographic data, including SAH severity scores and contact details, were included. Death registers were searched for the names of all patients listed with an Australian address and a survey was sent with a return postage paid envelope to the last known address of all living patients.

A cover letter from the patient's neurosurgeon and an information sheet were enclosed with the survey emphasising the voluntary nature of participation, confidentiality of data and the right to withdraw at any time. Written consent was not obtained as return of the survey implied consent. No further action was taken if the survey was not returned. To support participation the information brochure included instructions and encouragement of family members to assist with completion if necessary. The study was unfunded so it was not possible to provide the survey in any languages other than English.

3. Tools

SAH severity was measured using the World Federation of Neurosurgical Societies (WFNS) grading system. This ranges from Grade I, which describes a patient with a Glasgow Coma Scale (GCS) of 15 and no motor deficit, through to Grade V, a patient with a GCS of less than 7.[15] WFNS grade was obtained from admission documentation on all patients.

The Rankin scale was first modified for use in the UK-TIA study[16] and has reasonable inter-rater reliability.[17] The Modified Rankin score is an outcome scale that indicates level of functioning following neurological illness.[18] The scale grades level of functioning and ranges from a score of 0, indicating no disability at all, through to 6, indicative of death. The Modified Rankin Scale[18] is routinely collected in the NSICU database along with SAH severity scores. Scores were collected on discharge by the neurosurgical case managers.

The Stroke Specific Quality of Life Scale is a 49 item assessment that has been validated for SAH survivors.[19] The tool was shortened to 12 items and validated using a cohort of SAH survivors and called the Short Stroke Specific Quality of Life Scale (SS-QoL 12).[20] The SS-QoL 12[20] was used in this study. The advantage of this short test includes ease of use and low data burden.[20] The wording of some items was slightly modified prior to distribution to improve readability and understanding. The 12-item scale includes 6 physical and 6 psychosocial items; each scored out of 5, with 1 being the lowest score and 5 the highest. This allows a measure of physical, psychosocial and overall scores for survivors to indicate HRQoL.

Additional items about services utilised and a needs assessment targeting support groups were developed, including questions on current use of electronic devices and preference for face-to-face, telephone or online delivery of a support group.

Statistical analyses were performed using IBM SPSS version 22. Descriptive statistics were used to describe the population. Proportions were used to describe categorical variables and chi-squared tests used to compare groups.

4. Results

Surveys were returned over a period of approximately 6 weeks. There were 28 respondents from 83 sent surveys (34%). The respondents were mainly from NSW, although a small proportion was from other states; 68% of responders resided in metropolitan areas, as did all of the non-responders. The group comparison was based upon the original cohort of 116, comprising the 28 responders and the 88 non-responders – 22 of who died in hospital, 6 who died after discharge and 5 who were lost to follow-up (Fig. 1).

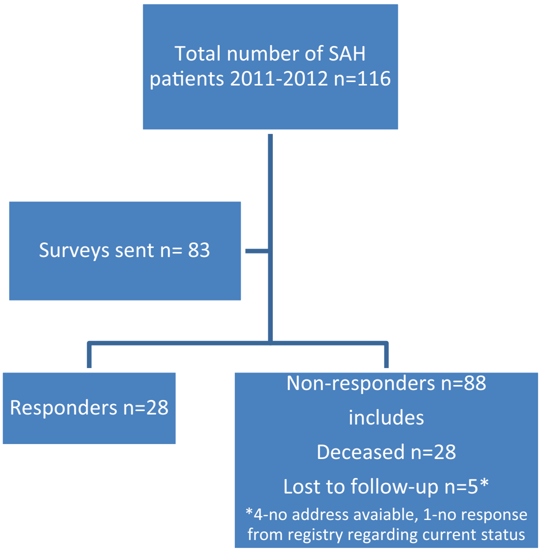

Fig. 1. Study population.

The characteristics of responders and non-responders are compared in Table 1. Age was a normally distributed variable and therefore the means, standard deviations (SDs) and confidence intervals are shown, with a t-test used to compare responders and non-responders. Length of stay (LOS) was not normally distributed therefore the medians and interquartile ranges are shown, with a Mann–Whitney U test performed to compare groups. These comparisons showed no significant difference between the groups in terms of age, gender and length of stay in hospital.

Due to the small number of responses, WFNS scores were reduced to groups (WFNS 1, WFNS 2&3, WFNS 4&5) to facilitate statistical comparison between the responders and non-responders. Similarly, Modified Rankin scores were contracted into four categories: Score 0–1 (No disability), Score 2–3 (Some disability), Score 4–5 (Severe disability), Score 6 (Deceased). No difference was found between the groups in terms of WFNS score; however, the Modified Rankin scores were significantly different due to the inclusion of the deceased in the non-responders group.

Age is a predictor of functional outcome post-SAH, with the suggestion that age 75 signifies a critical point, after which, patients demonstrate significantly worse outcomes.[21] In this study, 16% of the sample were aged over 75, 56% were 50–75 and 28% were under 50 years of age. Table 2 compares WFNS and Modified Rankin Score by age. Proportion of SAH that was mild (WFNS grade 1) decreased with age and the majority of those in the under 50 group made a good recovery with minimal/no disability. The most striking figure is the high percentage (58%) of over 75's who died in hospital from SAH, this proportion is much lower in younger age groups. Notably, 32% of over 75's were discharged with only mild disability (Modified Rankin 2–3), conflicting with other published results.[21] However, the small sample size precludes any definitive conclusions.

There were 1601 presentations to the NSICU during the study period and the SAH sample accounted for 7.2% of admissions. When the LOS of SAH patients was compared to other patients over the same time period, it was found that patients admitted with SAH had a median ICU stay of 12 days (IQR 6–18 days), whereas other NSICU patients had a median stay of 1 day (IQR 1–4 days). LOS was positively skewed and significantly different between these two groups (Mann–Whitney $U = 21{,}387.5$, $p = 0.000$).

The SSQoL-12 apportions scores across both physical and psychosocial domains in addition to an overall score. As the scores demonstrated a normal distribution, means and SDs were

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