

Stroke survivor follow-up in a national registry: Lessons learnt from respondents who completed telephone interviews

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Abstract

The Australian Stroke Clinical Registry (AuSCR) collects patient-reported outcomes at 90–180 days post-stroke. During telephone interviews, stroke survivors or their carers/family members often explain why they did not respond to a previously mailed survey. This feedback is useful to explore respondents' experiences of the follow-up process. Three main reasons for not returning surveys included: health-related time constraints, confusion about survey questions, and stroke denial. Such information is helpful in improving procedures for clinical quality disease registries and researchers using postal questionnaires.

Keywords

Follow-up, survey methods, stroke, clinical registry, quality improvement

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“The survey forms were sitting in a big pile of papers...”

“I didn’t know how to answer the questions...”

“I didn’t have a stroke...”

Background

There is growing interest in collecting patient-reported outcomes (PROMS) to explore patient-perceived health status for informing service improvement.¹ Here, we describe our experience in collecting PROMS using postal surveys and why some registrants preferred to complete surveys over the telephone.

The Australian Stroke Clinical Registry (AuSCR) was established in 2009 to monitor and improve the quality of stroke care within Australian hospitals.² The registry provides ongoing, prospective data on care processes and outcomes for patients with acute stroke or transient ischaemic attack (TIA). The follow-up process includes a modified Dillman protocol³ involving distribution of a postal survey (two attempts), and then a telephone interview for non-respondents. The validated modified Rankin Scale

(mRS)⁴ and EuroQol-5D three-level version (EQ-5D-3L)⁵ are used to capture post-stroke PROMS.

During the telephone follow-up interview, registrants or their carer/family members—proxies, often volunteer useful qualitative feedback which we have explored in order to: identify reasons for non-response to mailed surveys; compare the strengths and limitations of telephone versus mail follow-up⁶ and, reflect on the patient/carer experience of the follow-up procedure. We include information specifically collected between October 2012 and October 2013, which reflects similar ongoing themes.

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Reasons for not completing mailed surveys

Time constraints

Registrants, or proxies, commonly reported that they had insufficient time to complete the mailed survey; this lack of time was often related to the many hospital, medical or rehabilitation appointments in the initial months after returning to the community. If a registrant was physically or cognitively unable to complete the survey, they might rely on a proxy. However, proxy responders regularly explained they were too busy, as they were often a son or daughter of the registrant and were “juggling” their own work or children, or caring for their parent. The survey was frequently referred to as “sitting in a big pile of papers,” with respondents stating its completion was one of many waiting tasks.

The reported lack of time to complete the mailed survey accords with the concept of treatment burden after stroke,⁷ attributable to the many health-related appointments after hospital discharge. There is much effort involved in coordinating appointments and arranging attendance, particularly if stroke survivors cannot drive.⁸ Therefore, the treatment burden is shared by survivors and their caregivers, who are also trying to manage their own busy lives.⁹ Our telephone call was often a welcome way for respondents to complete the survey and they were relieved to take the survey out of the “big pile of papers.”

Confusion about survey questions

Many interviewees stated that they felt that the multiple-choice questions in the EQ-5D-3L needed more options to enable an accurate response, thus sometimes resulting in non-completion. The three levels of the questions in the EQ-5D-3L were not deemed comprehensive enough to reflect registrants' actual status. For example, there is no available option between: “*I have some problems in walking about*” and “*I am confined to bed*.”

Additionally, some reported that they found the visual analog scale (VAS) in the EQ-5D-3L difficult as they were unsure of what factors to consider when selecting a number from 0 to 100 for their overall health state. For example, if there were pre-existing conditions such as arthritis or diabetes, they questioned whether those co-morbidities should be considered in their response. Similar to the VAS uncertainty, some reported confusion because they thought the whole survey was only related to stroke. Others felt that the questions were not pertinent, and their input to the registry was not useful, because they only had a “minor” stroke or a TIA with no ongoing detrimental effects.

As a result of this feedback, the AuSCR Steering/Management Committee are considering using the five-level version of the EQ-5D (EQ-5D-5L). The five-level version has shown some psychometric advantages when compared to the three-level¹⁰ and may facilitate a higher mail response rate. Consequently, fewer registrants would need telephone contact, thus reducing registry running costs.⁶ However, in relation to the VAS queries, or relevance of respondent input to the registry (regarding stroke type), the telephone interview is well suited to clarifying any confusion quickly and potentially obtaining another completed interview.

Denial of stroke

A number of respondents said the survey was not returned because they did not think they had had a stroke. Denial of stroke diagnosis was especially frequent among registrants with a TIA or “mini stroke.” A common (mis)conception was that experiencing a stroke meant extreme disability.

This denial of stroke theme has led to the establishment of new processes for the registry, whereby hospital confirmation is undertaken, as required. In a few cases, the final discharge diagnosis was not stroke, but the hospital had not subsequently updated the registry. At other times, the hospital confirmed that the registrant had experienced a stroke or TIA. In such cases, the need for hospital staff to provide ongoing education and clarity about a diagnosis was identified since patients with stroke may fail to remember (e.g. if they have cognitive impairment).

Conclusions

Ensuring an adequate response rate for surveys of patient outcomes is essential for reporting accurate and reliable data. While the majority of respondents complete and return postal surveys, our experience suggests that about 20% would prefer completion by telephone. The feedback provided revealed the need to provide better information about stroke and improve written registry information. Furthermore, our work highlights that some people just prefer personal communication and support when time poor or overwhelmed by their new circumstances post-stroke, and that reaching out to them is valued.

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Ethics approval


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