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User profile of people contacting a stroke helpline (StrokeLine) in Australia: a retrospective cohort study

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Background: StrokeLine is a specialised telephone helpline led by health professionals in Australia.

Aims: (i) To describe the profile of StrokeLine callers; (ii) to understand the reasons people engage with the service and (iii) how StrokeLine responded to the caller's needs.

Methods: Routine call data were obtained from the StrokeLine between November 2019 and November 2020. Data were extracted and descriptive analyses performed. De-identified free-text data were obtained separately for November 2019 and June 2020 and analysed using qualitative content analysis.

Results: Of the 1429 calls most were from carers, family and friends (38%) or the stroke survivor themselves (34%). Most calls were made by women (64%) and the average age of the stroke survivor was ≥65 years (33%) with the time since the stroke occurred <1 year. The main reason for calling was to manage stroke-related impairments (40%). Providing information, support and advice was the most common action provided by StrokeLine staff (25%). Content analysis of 225 calls revealed most stroke survivors called for emotional support, while carers sought more practical guidance. StrokeLine provided information for referral to relevant services and guidance on what to do next.

Conclusions: Most calls were received from family and carers, as well as stroke survivors. They contacted StrokeLine for information and advice, practical solutions, emotional support, and referral advice to other services.

Keywords: telestroke; helpline; stroke; telehealth; selfcare

Impact statement

StrokeLine provides a critical helpline for stroke survivors, their carers, family and friends. StrokeLine staff provide information, emotional support, practical advice and referral advice to other services. The main reason for calling was to seek advice on managing stroke-related impairments.

Plain language summary

This study describes the use of a stroke-specific helpline, collected from callers to StrokeLine (a national stroke helpline). The study found StrokeLine staff provide information, emotional

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support, practical advice and referral advice to other services. The main reason for calling was to seek advice on managing stroke-related impairments.

Introduction

Stroke is a leading cause of long-term disability worldwide with more than 80 million stroke survivors globally (Johnson et al., 2019). In 2012, the Stroke Foundation (Australia) reported that by 2032, an estimated 700,000 Australians will be living with a stroke-related disability. The impact of stroke is significant and long-term management is often challenging (Boehme et al., 2021). Stroke survivors experience a range of motor, cognitive and psychosocial impairments that persist into the chronic stages of recovery (Hawkins et al., 2017). Approximately two-thirds of stroke survivors will live with residual cognitive or functional impairment, including limitations to mobility, sensation, balance and communication (Arienti et al., 2019; Broussy et al., 2019). Other residual effects such as depression, fatigue and pain further reduce quality of life (Broussy et al., 2019).

Care needs change and evolve, at each stage of recovery (Chen et al., 2019). As with most chronic conditions, sustainable recovery relies on engaging stroke survivors and their family caregivers to promote self-management of their condition (Taylor et al., 2014; Walsh et al., 2015). Stroke survivors report low satisfaction with post-discharge education and information provision, especially addressing long-term management of disability and accessing support services (Ferguson et al., 2016; O'Connell et al., 2009). Stroke survivors express feelings of abandonment, when they require navigate between complex transitions of care through the often-fragmented healthcare system (Ghazzawi et al., 2016; Wissel et al., 2013). Improvements should be made to the continuity of care provided to stroke survivors and their families after being discharged from hospital (Ferguson et al., 2016), focusing on patient-centred support, and interventions that support transition (Pearce et al., 2015).

Telehealth-based models of stroke care may be key to supporting stroke survivors in transitioning between care settings (Schwamm, 2019). Phone-based services are thought to play an integral role in the ongoing care of people living with chronic health conditions, especially in facilitating cost-effective support for self-management of care (Hanlon et al., 2017; Taylor et al., 2014). Specialised helplines allow healthcare professionals to provide timely and relevant information and advice to support a caller's immediate needs (Ekberg et al., 2014). It is therefore important to understand the role of such services in addressing the needs of the caller.

In Australia, the Stroke Foundation is a not-for-profit organisation that provides information and advice services to people affected by stroke, as well as advocacy for prevention, management and support for people affected by stroke. Among these services, StrokeLine has existed since 2002, as a nationwide stroke-specific helpline that allows users to make inbound contact with a qualified registered health professional (such as nursing or allied health professional), via phone, email, or social media. The helpline supports stroke survivors, their families and friends and aims to educate the wider community on stroke detection and prevention.

Research into phone-based services aims to improve our understanding of how telehealth services are currently being used to obtain information and advice, and what role the service plays in attaining a successful outcome for the caller (Harding et al., 2018). Analysis of phone-based support services could reveal common issues people living with stroke experience, and whether these issues can be resolved using phone-based intervention. Few studies have described how callers use stroke-specific phone services (Dickerson & Forster, 2015; Hanger & Mulley, 1993), and no previous study has described an Australian service. Therefore our aim is (1) to describe the callers engaging with StrokeLine; (2) their reasons why they contacted the service; (3) and to describe the actions taken by StrokeLine in response to the callers' needs.

Methods

Design

A retrospective cohort study using routine call data from the StrokeLine customer relationship management (CRM) system. Ethical approval was provided by the Human Research Ethics Committee at the University of Technology Sydney (Ref: ETH20-5088). Data transfer was approved by the Stroke Foundation (Australia) (19/02/2021).

Database

The CRM system collects data throughout a total episode of a caller's care. An episode of care was defined as one or more episodes of service provided by StrokeLine to address a caller's needs, with an episode of care ending only when no further service delivery is expected by the caller. An episode of service was any occasion of service delivery and can include other methods of delivery such as email follow-up. For each episode of care, demographic details about the caller and reasons for the call are recorded using pre-defined categorical variables by StrokeLine staff. A combination of predefined responses and free-text boxes capture user information such as constituent type (i.e. a stroke survivor, carer, family etc.), caller's age range, gender, when the stroke occurred, language spoken, where the caller is calling from and if the caller identifies as Aboriginal or Torres Strait Islander. Call information about reasons for calling was logged under predefined categories such as current symptoms, risk factors, prevention, health service treatment and care, community services treatment and care, managing stroke impairments, adjustment coping, practical issues, vulnerability, and risk. The pre-defined categorical variables related to why a person was seeking care included practical issues (e.g. accommodation, driving, finances), adjusting/coping issues (e.g. family relationships, occupation) and the type of health service treatment and care being sought (e.g. questions about tests and treatments, access to rehabilitation). A summary of the episode of care was entered by the staff member using free text outlining the issues discussed and actions taken. Evidence of any email follow-up provided to the caller is also attached to each call record. The total duration spent on each case was noted as the combined total of one or more episodes of service associated with the episode of care. The total time spent on other tasks (e.g. follow-up emails, calls to others) associated with each episode of care was recorded under 'call liaison'. We obtained categorically logged calls from the StrokeLine CRM system between 1 November 2019 and 30 November 2020. Free-text call data from the StrokeLine CRM system was supplied for two separate months: November 2019 and June 2020. All data were provided by StrokeLine as an Excel file and organised under variable labels and codes. We excluded cases from people living outside of Australia, public enquiries not related to the support of a stroke survivor and enquiries from health professionals. All identifying information was de-identified by a volunteer of the Stroke Foundation prior to data transfer to researchers.

Analysis

Microsoft Excel was used to analyse categorical variables and NVivo to analyse the free-text data. Data cleaning was undertaken to detect and remove duplicates, incorrect or unexpected data that could not be verified. The proportion of missing data for each variable was calculated and reported.

To understand 'who' was contacting StrokeLine, demographic data were presented as frequencies and proportion of total calls over months. To understand 'why' people were contacting StrokeLine, categorical data about the reason for the call was described and free-text data stored

under 'Issue' in the CRM system was coded using content analysis (Graneheim & Lundman, 2004). To understand 'what' was provided by StrokeLine, the type of action provided was determined using content analysis of the free-text data stored under 'Description' and 'Actions/Plans' (Graneheim & Lundman, 2004). Finally, the 'Call Log History' outlining the summary of interaction between the caller and StrokeLine staff was analysed using content analysis to understand the number of interactions required to resolve the issue.

Results

Dataset

The StrokeLine data set contained 1429 individual cases and 159 variables. Unfortunately, many of the categories contained no data at all (missing data), some categories contained repeated data and several categories had only a few cases (Supplementary 1).

The number of calls received varied between 80 and 140 calls per month (an average of 109 per month). Most calls originated from Victoria, Queensland and New South Wales (Figure 1). Call duration ranged from 15 to 30 minutes ($n=352$, 25%), less than 15 minutes ($n=263$, 18%), 30 minutes to an hour ($n=218$, 15%), an hour to two hours ($n=23$, 2%) and 1 call (0.07%) taking over 3 hours.

Population

Most calls received were from carers, family members or friends ($n = 545$; 38%) or stroke survivors ($n = 482$; 34%). Only 86 calls (6%) were received from a person not having a stroke, but indirectly affected by stroke and 6% ($n = 86$) from donors to the foundation. Three percent of calls ($n = 43$) were recorded as volunteers and advocates and were excluded from analyses. Callers were 31% ($n = 443$) female and 11% ($n = 152$) male, and 51% ($n = 734$) of calls had no record of gender.

There were 778 calls (54%) where the age of a stroke survivor was recorded. Most of the callers were aged over 50 years ($n = 618$; 79%) and only 3 calls concerned a person under 18 years. Time since the stroke had occurred was reported for 822 calls (58%), with most callers concerned about a stroke that occurred less than a year ago ($n = 566$; 69%). There were also 67 calls (5%) where the caller was potentially experiencing stroke symptoms with further medical attention required.

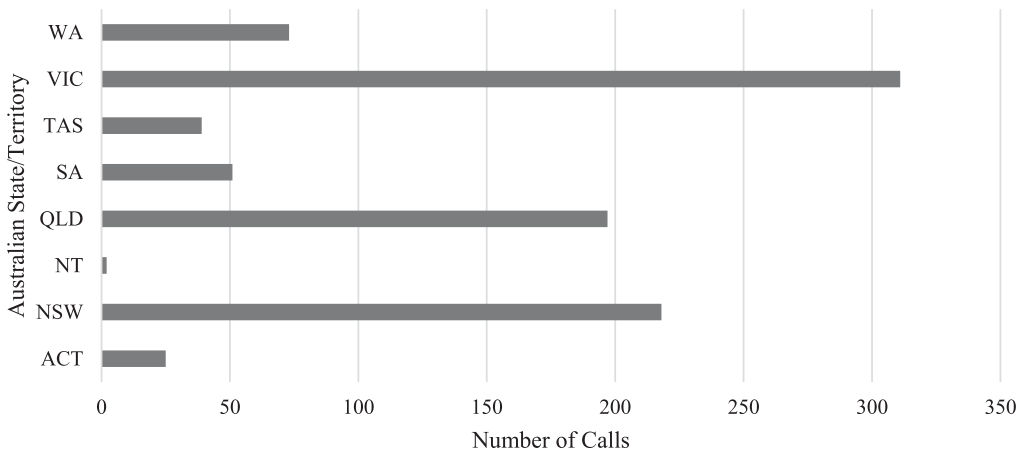


Figure 1. State-wise distribution of StrokeLine calls between 1 November 2019 and 30 November 2020.

Only 88 calls (6%) indicated whether a caller identified themselves as Aboriginal or Torres Strait Islander. Of 425 calls (30%) the data provided information about languages spoken at home, including English (29%), Russian (0.14%), Greek (0.14%), Dutch (0.07%) and Korean (0.07%).

There were 394 calls (28%) that provided information on pre-existing risk factors for stroke categorised under 19 variables, including high blood pressure (5%), high cholesterol (4%), cardiovascular disease (4%) and atrial fibrillation (1.5%). Vulnerability and risk for depression, drug and alcohol use, family violence and suicidal ideation were captured for only 67 calls (5%).

Reasons for calling

The reason for calling were captured under seven different categories (Supplementary 2). Most calls were categorised as ‘Managing stroke impairments’ and ‘Community services treatment and care’.

Actions provided by StrokeLine

The type of actions provided were reported for 404 calls (28%). These included 362 calls where information, support, advice, or referral was provided, for 20 calls a ‘brief intervention’ (such as informal counselling for health promotion or disease prevention) was provided, and for 17 calls a letter or call to someone else was provided and for 4 calls (0.3%) provided with care coordination (Supplementary 3).

Free-text data

The free-text dataset included 103 calls from November 2019 and 122 calls from June 2020, with a similar number of calls received by stroke survivors and carers/family across the two months (Supplementary 4 and 5). Data were categorised into four themes:

Issue

Most calls from stroke survivors across both months included seeking emotional support, especially in seeking reassurance of post-stroke-related impairments, including both ongoing physical and cognitive symptoms. Most calls from carers/family included seeking practical guidance on how best to support a stroke survivor, especially regarding managing a stroke survivor’s cognitive decline and transition from acute hospital care.

Description

Calls from both stroke survivors and carers were often prompted by a lack of information or when all other avenues of seeking guidance had been exhausted.

Action plan

For both November 2019 and June 2020, most calls received by stroke survivors concerned providing information on how to best manage their stroke-related impairments, along with providing reassurance and validation of the individual’s experience with managing these. For carers/family, StrokeLine staff most often provided guidance and advice on what to do next regarding stroke survivors’ care.

Emails and comments

Calls answered on the first try included 90 calls (87%) in November 2019 and 15 calls (12%) in June 2020. In November 2019, a voicemail or message left with reception was the first point of contact for 13 calls (13%), with a call-back provided by StrokeLine to initiate further episodes of service to resolve the issue. This was similarly the case for 107 calls (88%) in June 2020. Email follow-up after the call was provided for 38 calls (37%) in November 2019 and 29 calls (24%) in June 2020. Most email follow-ups provided included links to resources discussed during the call (eg. information sheets, websites or video links about stroke-related impairments and community services).

Discussion

Most calls received were from stroke survivors and carers, family members or friends. Most callers were female, 65 years or over, and related to a recent stroke. However, those who identify as Aboriginal or Torres Strait Islander descent may have been under-recorded in these data. The need for an interpreter was also the main method of identifying culturally diverse callers, which again are assumed to be underrepresented in these data. The main reasons to call StrokeLine were related to health or community services for treatment and care and how to manage stroke-related impairments. A lack of direction around ‘*what to do*’ and ‘*where to go*’ were common motivating factors prompting someone to call StrokeLine. In most instances, people contacted StrokeLine, when previous avenues for seeking information were exhausted, or they were dissatisfied with the quality of care provided in other settings. Most often, StrokeLine staff provided both stroke survivors and carers with actionable items to discuss with their GP or specialist and helped formulate a plan of how to do this. For stroke survivors, StrokeLine provided reassurance and validation of the individual’s experience with managing stroke-related impairments.

The geographic location of the caller was limited to only the state/territory the call was received from, with most calls received from Victoria and New South Wales (NSW). The strength and relevance of telehealth services lie in their cost-effectiveness and ease of accessibility. As such, it is important to understand the specific remote, regional, or metro locations of callers to provide better insight into what concerns are prompting enquiries both in the absence or presence of other healthcare services in each area.

Interpretation

StrokeLine’s ability to provide practical guidance is well aligned with studies reporting on the importance of social support from friends, family or stroke support groups in helping to normalise experiences (Jones et al., 2013). Such informal methods of accessing support emphasise the importance of self-management as a collective experience rather than one undertaken in isolation. One study found that when services designed to aid in self-management of care in stroke fail to account for individual needs and circumstances, the relevance of the information provided is un conducive to real behaviour change and addresses only basic educational needs (Jones et al., 2013). The real underpinning of supporting self-management relies on organisational structures that facilitate a relationship between individuals and health care professionals, allowing for the time and flexibility to enable active problem solving and shared decision-making. In many ways, the StrokeLine database is reflective of the complexities of stroke and the multi-faceted ways it can affect an individual. This study has highlighted the complexities of balancing person-centred care provision in a telehealth setting with data-driven processes that are needed to best support this.

Limitations

A major limitation of our study was the volume of missing data. Although all information under each category should be collected during an episode of care, in most instances it appeared a data summary for each call was recorded instead using free text and much of the categorical data was left blank. This resulted in a considerable amount of missing data under most categories, but some of this data was able to be retained through content analysis of the free-text summary. Secondly, it was only feasible for StrokeLine to provide us with two months of de-identified free-text data for analysis and this may have influenced our findings, due to seasonal variation for example. Thirdly, we also did not include enquiries received via email or social media in analyses. Despite these limitations, a major strength of this study is the ability to provide a unique user profile and evaluation of the StrokeLine service in Australia.

Implications

Clinical implications

Findings from this study can be used to improve service delivery of StrokeLine and other comparable health care services. Exploring retrospective data collected routinely as part of service provision allows for an insight into the way a helpline works and can benefit the callers as well as their carers/family.

For StrokeLine, the current study highlights the express need for better processes to capture data and data infrastructure capabilities to support these. In turn, the need for appropriate staffing and training remains paramount. As the StrokeLine CRM system continues to evolve and the data entry procedures become more streamlined, improvements in the quality of the service are likely to better inform strategic planning and increase outreach. An ongoing challenge will be ensuring that the StrokeLine data infrastructure remains well supported by appropriate staffing and data-management procedures. With the remarkable growth of telehealth-based innovation in recent years, translating this to existing services to better adapt their role within a changing digital landscape should not be neglected. Building on StrokeLine's existing capabilities, further work may look at service redesign to better capture those not actively seeking support to self-manage their condition, especially in the earlier stages of transitioning between care settings. Incorporating a greater outreach component to the current inbound service model may enhance the role StrokeLine plays in providing continuity of care.

Research implications

Appropriate funding and support from policymakers are needed to improve the quality of the data collection and improve the validity and generalisability of the findings. Several changes in data collection procedures have been implemented by StrokeLine following this study. As such, routinely reviewing caller information is an important component of improving service delivery and ensuring the service remains relevant to those affected by stroke. Further research is needed to understand how people are using the information and advice provided by StrokeLine and whether there are measurable benefits of contacting the service.

Conclusion

This study describes the utilisation of a stroke-specific support helpline by people affected by stroke. Understanding the issues prompting callers to seek care and what can currently be offered by StrokeLine staff, provided insight into the needs of survivors and potential gaps

within stroke care in Australia. Inbound helplines such as StrokeLine are well-placed in disseminating timely and person-centred information and advice across the trajectory of stroke care.

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Disclosure statement

CF is a member of the Stroke Foundation (Australia) Research Advisory Committee. SR and KY are employed by the Stroke Foundation (Australia).

Guarantor: CF.

Contributor statement

MTC, AM and CF contributed to the conceptualisation and design of the study. MTC, AM, CF, SR and KY contributed to the acquisition and collection of data. MTC, AM, CF, SR, KY, SCI and AV contributed to the analyses of data and report writing. All authors approved the final version of the manuscript.

Data availability statement

Due to the sensitive nature of the data collected for this study, requests to access the dataset from qualified researchers trained in human subject confidentiality protocols may be sent to the corresponding author.

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