

NOVA University of Newcastle Research Online

nova.newcastle.edu.au

Denham, A. M., Wynne, O., Baker, A. L., Spratt, N. J., & Bonevski, B. The unmet needs of carers of stroke survivors: An evaluation of Google search results. Published in *Health Informatics Journal*, 26(2), 934–944 (2020)

Accessed from: https://doi.org/10.1177/1460458219852530.

Denham, A. M., Wynne, O., Baker, A. L., Spratt, N. J., & Bonevski, B. (2020). The unmet needs of carers of stroke survivors: An evaluation of Google search results. Health Informatics Journal, 26(2), 934–944. Copyright © The Author(s) 2019. DOI: <u>https://doi.org/10.1177/1460458219852530</u>.

Accessed from: http://hdl.handle.net/1959.13/1416933

The Unmet Needs of Carers of Stroke Survivors: An Evaluation of Google Search Results

Authors: Alexandra M.J. Denham¹; Olivia Wynne¹; Amanda L. Baker¹; Neil J. Spratt²; Billie

Bonevski¹

¹School of Medicine and Public Health, Faculty of Health and Medicine, University of

Newcastle, Callaghan, NSW 2308, Australia.

² School of Biomedical Sciences and Pharmacy, Faculty of Health and Medicine, University

of Newcastle, Callaghan, NSW 2308, Australia.

Corresponding Author Details

Name: Alexandra M.J. Denham

E-mail: <u>Alexandra.Denham@newcastle.edu.au</u>

Phone: (02) 4033 5712

Institution: School of Medicine and Public Health, Faculty of Health and Medicine, University of Newcastle, Callaghan, NSW 2308, Australia.

Address: Level 5 McAuley Building

Calvary Mater Hospital, CBMHR

Waratah, 2298

Australia

Abstract

Google is the most used search engine in the world, and likely to be used by caregivers of stroke survivors to find online forums and online communities to connect with other caregivers. This study aimed to identify the types of websites accessed by caregivers of stroke survivors to connect with other caregivers, and analyse the online content produced by caregivers to identify their unmet needs. The first 20 websites from eight search strings entered into Google were systematically reviewed. Unmet needs on included websites were identified using a pre-determined coding schedule. Six websites were analysed. Most were discussion boards (n=5, 83%) developed by organisations in the USA (n=4, 66.6%). Overall, 2124 unmet needs appeared in 896 posts from caregivers. 'Emotional and psychological' were the most reported needs across posts (n=765, 36%). Content produced on websites may address social isolation, and provide insight into delivering and developing services to meet the needs of caregivers of stroke survivors.

Keywords: Consumer Health Information, eHealth, Health Information on the Web, Information and Knowledge Management, Social Media

Introduction

Many stroke survivors experience ongoing cognitive and/or physical disabilities post-stroke, and often require a caregiver to support them at home following discharge from acute care. The most common tasks that caregivers report assisting stroke survivors with are related to cognitive or emotional tasks, mobility and health care¹. Many caregivers who assist stroke survivors are informal caregivers, also known as unpaid or primary caregivers. While these caregivers may be family members, friends or neighbours, caregivers of stroke survivors are predominantly female spouses of the stroke survivor². Caregivers of stroke survivors often report feeling underprepared for the caregiving role, receiving inadequate stroke-related information from health-care professionals, loss of autonomy, and increasing social isolation ³⁻⁷. As a result, caregivers commonly experience a decline in their own physical and mental health, and a reduced quality of life after starting the caregiving role⁸⁻¹⁰. The internet is rapidly becoming a major source of health information and social connection, and previous research has found that patients and caregivers most commonly use websites and social media (defined as engaging online user generated content, such as blogs, social networking sites, virtual social worlds, and content communities¹¹) for self-care and as a tool to post and share their experiences¹².

Researchers have attempted to develop websites for stroke survivors and their caregivers which are acceptable and useful in enhancing preparedness for the caregiving role ¹³⁻¹⁵. Rochette et al¹³ piloted a stroke rehabilitation website for stroke survivors and their families called 'StrokEngine-Family'. While participants rated the website as usable and containing valuable information, they also requested more information on emotional support, and local referrals for emotional support¹³. Stone et al¹⁵ conducted a pilot study using an interactive website which aimed to enhance resources for caregivers following the discharge of the stroke survivor. Caregivers felt more prepared following website use; however, the website did not help to meet caregiver needs, and satisfaction with resources did not increase following the pilot. Interestingly, these piloted websites did not have a platform for caregivers of stroke survivors to connect with other stroke survivors, despite connecting with others being the second most common use of social media by caregivers and patients¹². A randomized controlled trial with 144 caregivers (103 identified as novices towards using web-based programs) to assess the effectiveness of an online intervention for caregivers and stroke survivors (Caring~Web) at increasing wellbeing found that caregivers who received access to Caring~Web made more informed health-related decisions, and had a significant reduction in service use compared to the control group¹⁶. These findings highlight that online interventions may be cost-effective, usable, and result in lower burden to the healthcare system by reducing service use.

Google is the most commonly used website and search engine in the world¹⁷⁻¹⁹. Google's unique search engine results are due to their Page Rank Algorithm, which provides access to websites which are ranked as most relevant to the search based on: (1) frequency and location of keywords within the webpage; (2) how long the webpage has existed; and (3) how many other web pages link to that page^{20 21}. Traditionally, health care providers have been the primary source of medical education and services; however, many consumers are turning to Google to obtain health-related information²²⁻²⁴, and these users are likely to encounter information based on the Page Rank Algorithm. Due to the increasing use of Google as a source of health information, the search engine has been reviewed as: a technology to fill the gap for consumers in patient-centred health care provision²⁵; an option for online self-diagnosis of medical issues²⁶; and as a platform for people with chronic illnesses who are seeking health-related information²⁷. While assessing different aspects of Google as a health resource, the various studies all conclude that health professionals should provide patients with high quality and trustworthy online resources. Caregivers of stroke survivors may seek out information on Google to fill in knowledge gaps in stroke-related care^{6 7 28-30} and address other unique unmet needs which are not addressed by available support services and resources.

Caregivers of stroke survivors may turn to online resources to connect with other caregivers and voice their unmet needs and concerns in online communities. Google is the most likely place where carers of stroke survivors would begin to search for information developed and produced by other caregivers of stroke survivors or carer groups^{17 18}. This study aims to: (1) identify the types of websites available to caregivers of stroke survivors who seek support or to connect online with other caregivers of stroke survivors, and (2) analyse the online content produced by caregivers of stroke survivors to identify their unmet needs.

Methods

Study Design

An internet based study was conducted using Boolean search strategies in the Google search engine in October 2017. A Boolean search allows the combination of operators such as "AND" and "OR" to produce more relevant and targeted search results³¹. The study received approval from the University of Newcastle Human Research Ethics Committee, Approval No. H-2017-0274.

Eligibility Criteria

Websites were included if they met the following criteria: (1) websites were produced or developed by carers or carer groups (for example, online chat room, social media forums); (2) contained content that carers of stroke survivors had produced about their unmet needs and concerns in a caregiving role; or (3) were developed by professional organisations (e.g. National Stroke Foundation) and contained first-hand testimonial of the needs and concerns of carers of stroke survivors. These websites included forums, discussion boards and blogs on professional websites where caregivers could provide their stories and experiences

Websites were excluded if they were: (1) intended for carers of other populations such as people with dementia; (2) developed and produced by professional organisations and provided information and/and or help guides; (3) were in languages other than English; (4) other forms of media that did not include first-hand testimonials of carers of stroke survivors including newspaper articles and academic papers; (5) not publicly accessible; that is, required the researcher to register and/or create an account on the website to access private content; and (6) duplicates of other websites brought up in the searches.

Search Strategy

One member of the research team (AMJD) searched the Google search engine using the following search terms: 'carer OR caregiver of stroke survivors' needs', 'carer OR caregiver of stroke survivors' concerns', 'carer OR caregiver of stroke survivors' help', 'carer OR caregiver of stroke survivors' talk', 'carer OR caregiver of stroke survivors' talk', 'carer OR caregivers of stroke survivors' talk', 'carer OR caregivers of stroke survivors' talk', 'carer OR caregivers of stroke survivors' chat', 'caring for a stroke survivor' and 'family of stroke survivor help'.

The authors of this study were using an Australia-based IP address. For unbiased search results, the internet browser history of the research member was cleared, and cookies were erased before each search. The member of the research team who performed the search ensured that they were not logged into any online accounts, such as Google Plus. Based on previous research^{32 33}, the first two pages (20 websites) found in the Google search engine of each search term were reviewed. These results represent the pages that carers of stroke

survivors are most likely to encounter when they search for other individuals and communities of carers of stroke survivors who have unmet needs and concerns. Where possible, forums were searched for caregiving spaces that were identified as sections of the websites as dedicated to caregivers' questions/topics.

Data extraction

One researcher (AMJD) screened the 120 websites for inclusion and exclusion criteria. AMJD then evaluated the content of these websites using a pre-determined coding schedule of unmet needs based on previous on previous research of caregivers of people who have cancer³⁴ and caregivers of stroke survivors^{7 35} (Supplementary Appendix A). Data from these posts was extracted by AMJD, tabled, and all coding was checked for accuracy independently by a second reviewer (OW). The two reviewers discussed these findings, and if a discrepancy existed and a consensus could not be reached, a third reviewer was contacted to make the final decision. General information about the websites was also recorded, including the amount of posts on each website, the population of posters, and type of website that was identified.

Results

Of the 120 Google websites searched on the unmet needs and concerns of caregivers of stroke survivors, six were included in the final analysis. A flow chart of this process is shown in Figure 1.



Figure 1. Flowchart of Google website screening process.

The websites identified were all developed by organisations, and the content was freely available to the public without registering an account with the website. Five websites were online discussion boards (83%), and one website was a single post blog (17%). Some excluded websites also offered links to external online support: 11 discussion boards, four chat rooms and one blog. The majority of the websites were developed by organisations in the USA (n=4, 66.6%) while the remaining two websites were developed in Australia (n=1, 16.7%) and the United Kingdom (n=1, 16.7%).

Overall, 256 threads containing 1,636 individual posts were identified. Threads on websites ranged from 1 to 103 (M = 42.67) and there was an average of 6.3 posts per thread. The two reviewers agreed on over 99% of the unmet needs coding, with further discussion resolving all conflicts. The majority of posters were caregivers of stroke survivors (n=896, 54.8%), however around one-third of posters were also stroke survivors (n=553, 33.8%). Smaller percentages of posters were moderators of the website (n=104, 6.4%), undetermined

posters (n=51, 3.1%), researchers (n=13, 0.8%), health care professionals (n=10, 0.6%) and people posting concern for caregivers or stroke survivors who were not primary or secondary caregivers themselves (n=9, 0.5%). Posters were identified either through the content of their posts, or by their public site profile if possible. More information regarding the characteristics of websites overall and compared by country of origin can be found in Table 1.

	Google Search results by country n (%)			
	Overall	United States	United Kingdom	Australia
		(n=4)	(n=1)	(n=1)
Website details				
Threads	259	167 (65)	88 (34)	4(1)
Posts	1635	1114 (68)	504 (30.8)	17 (1.2)
Population of posters				
Caregivers	896 (54.8)	622 (55.8)	268 (53.2)	6 (35.3)
Stroke survivors	553 (33.8)	361 (32.4)	191 (37.9)	1 (5.9)
Website moderator	104 (6.4)	104 (9.3)	0 (0)	0 (0)
Undetermined	50 (3.1)	16 (1.5)	31 (6.2)	3 (17.6)
Health care professionals	10 (0.6)	1 (.1)	2 (0.4)	7 (41.2)
Researchers	13 (0.8)	6 (0.5)	7 (1.4)	0 (0)
Posting on behalf of	9 (0.6)	4 (0.4)	5 (1)	0 (0)
caregiver				
Total unmet needs reported	2124	1494 (70.3)	612 (28.8)	18 (0.9)
per website				
Unmet needs domain				
Emotional and	765 (46.8)	562 (50.4)	201 (32.8)	2 (11.1)
psychological				
Impact on carer daily	520 (31.8)	401 (36)	114 (18.6)	5 (27.8)
activities				
Comprehensive stroke care	326 (19.9)	191 (17.1)	128 (21.0)	7 (38.9)
Relationship	299 (18.3)	188 (1.2)	109 (17.8)	2 (11.1)
Information	173 (10.6)	128 (11.5)	43 (7.0)	2 (11.1)
Spiritual	41 (2.5)	24 (2.2)	17 (2.8)	0 (0)

Table 1. Proportions of website characteristics and unmet needs domains of caregivers of stroke survivors compared by website country of origin.

Only the posts produced by caregivers of stroke survivors (n=896) were analysed using the predefined coding schedule. Overall, 2124 unmet needs were identified over 896 posts of caregivers of stroke survivors, an average of 2.4 unmet needs per post. It was found that 'Emotional and Psychological' was the most commonly reported needs domain appearing 765 times over 896 posts (85.5%). The most commonly reported subdomain was 'Help Dealing with Own Emotional Distress' which appeared in just under 25% of posts from caregivers of stroke survivors (n=397, 24.3%). Prevalence for each needs domain and subdomain are reported in Table 2.

Domains and categories of unmet needs n			
Emotional and psychological			
Help dealing with own emotional distress	397	24.3	
Know how to provide emotional and/or psychological support for	249	15.3	
stroke survivor			
Deal with uncertainty and life after stroke	80	4.9	
Get emotional support for self/have someone to talk to	37	2.3	
Find meaning (self or partner)	2	0.1	
Impact on carer daily activities			
Financial impact	188	11.5	
Balance own needs with caregiving	112	6.9	
Help looking after own mental and physical health	88	5.4	
Deal with impact on work	78	4.8	
Assistance with patient daily needs (e.g. preparing meals)	15	0.9	
Help from others to manage caregiving roles	14	0.9	
Receiving support to deal with changes in identity	12	0.7	
Impact on lifestyle and schedule	11	0.7	
Know how to maintain a sense of control	2	0.1	
Comprehensive stroke care			
Have a supportive relationship with healthcare professionals	121	7.4	
Access to health services	97	5.9	
Be told about the help healthcare providers can offer	59	3.6	
Have possibilities to participate in the stroke survivors' care	22	1.3	
Obtain the best possible care for the stroke survivor	11	0.8	
Co-ordination and continuity of physical and emotional care	8	0.5	
Information provided by healthcare professionals was appropriate	8	0.5	
Relationship			
Deal with changes in relationship with partner	107	6.5	
Have a satisfactory relationship with others	91	5.6	
Help communicating with others (e.g. family, friends)	79	4.8	
Have an intimate relationship with stroke survivor and	12	0.7	
consideration for sexual need			
Help communicating with the stroke survivor about illness and	10	0.6	
his/her concerns			
Information			
Knowing what to expect	62	3.8	
The illness and management (e.g. diagnosis, prognosis,	62	3.8	
management)			
Providing care to patient	32	2.0	
Death and dying	17	1.0	
Spirituality			
Feel there is hope for the future	23	1.4	
Receive spiritual support	18	1.1	

Table 2. Summary of domains and proportions for subcategories of unmet needs of carers of stroke survivors in identified in Google search results posts (n=2124)

*Multiple unmet needs may appear in a single post

Discussion

This study examined the websites that caregivers of stroke survivors are likely to encounter using the Google search engine to connect with other caregivers of stroke survivors. The findings of this study suggest that for caregivers of stroke survivors using Google for this purpose, the most frequently encountered websites will be discussion boards based in the USA. Importantly, there are few freely available online web resources to enable peer-to-peer connection with other caregivers. Caregivers of stroke survivors are likely to encounter only a very small minority of public access forums to connect with other caregivers of stroke survivors, as only six of the 85 unique websites (7.1%) identified met this study's inclusion criteria. If caregivers were willing to create an account to post on forums or chat rooms, three additional websites were available to connect with other caregivers.

In the current study, the most reported unmet needs domain was 'Psychological and Emotional', in which "Help Dealing with Own Emotional Distress" was the most reported sub-domain followed by provision of emotional support to the survivor. These findings are consistent with previous studies using traditional methodologies. Previous research has found that 47.5% of caregivers commonly used social media for self-care and peer-to-peer support¹², and have requested an emotional support module as an addition to a website which was piloted with caregivers of stroke survivors¹³. The findings suggest that there is a need to provide caregivers of stroke survivors a platform to engage in self-care and provide peer-to-peer and emotional support through exchanging ideas, sharing experiences, and give and receive support to other caregivers of stroke survivors.

The Financial Impact on carer daily activities was reported as the third-most common topic posted on these websites by caregivers of stroke survivors. In previous studies, caregivers have identified that financial aspects of caregiving, such as access to external support, adequate respite care, and financial assistance as important to allow carers to maintain some previous activities and assist them manage their role as a caregiver to a stroke survivor^{36 37}. Often family members give up their jobs to provide care, leaving them without financial support to engage in and maintain previously enjoyed social activities³⁸. As a result, the financial, health and social consequences of being an informal carer are often connected. These results suggest that caregivers of stroke survivors are not receiving the support they need through available social services, and it is possible that they are turning to online communities for support and information.

On average, caregivers of stroke survivors were receiving six replies to their initial question. A large number of people who posted in caregiving spaces and responded to these questions on these websites on these websites were stroke survivors themselves, with over one third of posters identifying as having experienced a stroke (33.8%). Many stroke survivors offered their perspective on the stroke event and provided education and resources for caregivers. This could be interpreted as caregivers of stroke survivors may benefit from online websites, forums and spaces dedicated to connecting with other caregivers to provide and receive support from other caregivers of stroke survivors in an online community.

Health care professionals and website moderators with a health care background are more likely to provide evidence-based information from trustworthy sources³⁹⁻⁴¹, rather than anecdotal evidence health-related information from other users who are caregivers or stroke survivors. Website moderators were also found only on USA websites, while healthcare professionals were the highest reported users on the Australian website for caregivers. Therefore, it is possible that caregivers of stroke survivors who access websites based in the USA and Australia may receive more reliable and targeted support for their needs and interests, compared to websites based in the United Kingdom or other countries. A potential solution to this issue is the development of an international forum for caregivers of stroke survivors, with moderators and healthcare providers who provide information and resources relevant to their healthcare systems and countries. Surprisingly few websites from a limited number of countries met the criteria for our study. In this study, the unmet needs of caregivers of stroke survivors identified on these websites were comparable to previous studies which used more traditional methods such as self-report surveys and researcher-driven qualitative research. There is a need to further develop, evaluate and refine websites which offer country-specific information on local support, services and healthcare systems information which may help reduce the unmet needs of caregivers of stroke survivors.

Practical Implications

These findings have relevant implications for stroke caregivers, clinicians and researchers. During the study, it was impossible to tell the nationality of every caregiver who posted. Some caregivers did identify from being countries outside of the country-specific website seeking help, but the proportion of people who actually identified their nationality was miniscule. An international forum with additional country-specific information would be the ideal outcome for an online resource for caregivers of stroke survivors. Furthermore, an international online platform would allow caregivers of stroke survivors worldwide to connect and share their stories and experiences with other caregivers, engage in self-care and provide emotional support. We recommend that the development of web resources targeted at caregivers of stroke survivors to include and/or refine existing modules or spaces to provide the opportunity for connection between caregivers and needed information provision.

Given the popularity and accessibility of Google worldwide, caregiving organisations worldwide should consider refining existing websites and further developing online resources which allow caregivers of stroke survivors a space to engage in self-care and receive peer-to-peer, emotional and informational support with other caregivers. In previous research, caregivers of stroke survivors have requested self-care and emotional support modules be integrated into online websites and programs^{13 15 16}, which may increase usability and acceptability of programs which are delivered online. An online platform would further allow health care providers the opportunity to reach caregivers of stroke survivors with both international and country-specific information. Furthermore, by identifying areas and raising awareness of active unmet needs within international and country-specific online communities, the provision of care to caregivers of stroke survivors may increase across varying countries and healthcare systems. Therefore, the development of these resources may reduce financial burden on the healthcare system on a wider scale by increasing caregivers of stroke survivors' health and wellbeing outcomes, and in turn increasing the wellbeing of the person that they care for.

Study limitations

One limitation of this study was that Google was the only online platform which was reviewed on the unmet needs of caregivers of stroke survivors. Google was selected for this study as it is the most used website and search engine in the world, and mostly likely to provide the most generalizable results of websites that caregivers are likely to encounter when seeking information and support by the results delivered through the Google Page Rank Algorithm^{20 21}. Other popular online search engines such as Yahoo (the seventh most visited website in the world¹⁹) may provide different search results for the caregivers of stroke survivors who choose to use alternative search engines to Google. Reviewing other highly used social media websites such as Facebook and Reddit¹⁹ in addition to Google websites

may also provide a more comprehensive understanding of the unmet needs of caregivers of stroke survivors.

The second limitation of this study was the exclusion of websites which were not publicly accessible. This limitation may have underestimated the amount of support available to caregivers of stroke survivors if they were willing to make an account on additional websites. The authors excluded sites which were private due to ethical considerations, privacy and respect. Some websites required an account holder to identify as a caregiver or stroke survivor, and others required an account to allow real-time chatting with other people within the forum in online chatrooms. Authors only sought to access testimonials that were freely available to the public. Accessing and reviewing posts on private forums would ethically require the consent of the caregiver who made the post, as they may have viewed private forums as safer and more secure to share their stories. Therefore, it was not feasible to contact all caregivers who posted in private forums to gain consent for this study. As a result, the unmet needs of caregivers of stroke survivors expressed on private websites may be different compared to those on public forums

Most of the identified websites were created in the US, however we were unable to obtain data about the nationalities of people viewing or posting on these websites. Furthermore, only English-language websites were searched, so the findings of our study may not be generalizable to non-English speaking countries in which caregivers of stroke survivors may be experiencing different cultural unmet needs compared to those in Englishspeaking countries. An additional limitation of this study was that the authors were limited to using an Australian IP address, which may have may have influenced the results of the searches to make them more relevant to Australia. The information revealed across platforms and languages on the varying health-care system and country-specific information may offer greater insight into preferences for information and program delivery, and how to improve and refine existing interventions and services which are currently lacking for caregivers of stroke survivors.

Future research

Reviewing Google websites as a resource to identify unmet needs highlights that there are very few support and resources available to caregivers, particularly for those who live outside of the USA. Therefore it is unlikely that those living outside of the USA, even including the single website for caregivers of stroke survivors in Australia and the United Kingdom which met the criteria for this study, there is likely to be little information about country-specific local resources and support services. The Google search engine was also useful for identifying unmet needs, with very similar needs identified to those obtained using more costly methods in previous research using traditional methods. The first-hand unmoderated testimonials from caregivers of stroke survivors could be used to inform and develop services, interventions and trustworthy, accessible information for caregivers of stroke survivors internationally. Using Google may also be beneficial to caregivers of other people, such as those of people with cancer, as it will offer similar insight to their unique needs in addition to other resources.

Conclusions

In this study we found that websites using the Google engine was useful for identifying unmet needs of caregivers of stroke survivors and provide useful information on the resources available to caregivers online in addition to traditional methods. Reviewing online resources such as Google and social media may be beneficial in addition to traditional data collection methods when informing the development of support services and interventions to meet the needs of caregivers of stroke survivors. Emotional and psychological unmet needs

17

were the most reported unmet needs of caregivers of stroke survivors in posts that were made on these websites. It is possible that caregivers would benefit from being provided an online platform to engage in self-care and peer-to-peer support in addition to routine information provision at the time of the stroke survivors' discharge home.

Funding

AMJD is supported by a Research Training Program (RTP) scholarship, and by Emlyn and Jennie Thomas through the Hunter Medical Research Institute (HMRI). ALB is supported by a NHMRC Senior Research Fellowship Grant (APP1135901). NJS was the recipient of a cofunded National Health and Medical Research Council/National Heart Foundation Career Development/Future Leader Fellowship (APPS1110629/100827). BB is supported by an NHMRC Career Development Fellowship (APP1063206) and a Faculty of Health and Medicine, University of Newcastle, Faculty of Health and Medicine Gladys M Brawn Career Development Fellowship.

References

- 1. Australian Bureau of Statistics. Disability, Ageing and Carers, Australia: Summary of Findings, 2015, 2015.
- 2. Greenwood N, Mackenzie A, Cloud GC, et al. Informal carers of stroke survivors–factors influencing carers: a systematic review of quantitative studies. *Disability and rehabilitation* 2008;30(18):1329-49.
- 3. Lou S, Carstensen K, Jørgensen CR, et al. Stroke patients' and informal carers' experiences with life after stroke: an overview of qualitative systematic reviews. *Disability & Rehabilitation* 2017;39(3):301-13. doi: 10.3109/09638288.2016.1140836
- 4. Danzl MM, Harrison A, Hunter EG, et al. "A Lot of Things Passed Me by": Rural Stroke Survivors' and Caregivers' Experience of Receiving Education From Health Care Providers. *Journal of Rural Health* 2016;32(1):13-24. doi: 10.1111/jrh.12124
- 5. Danzl MM, Hunter EG, Campbell S, et al. "Living with a ball and chain": The experience of stroke for individuals and their caregivers in rural appalachian kentucky. *Journal of Rural Health* 2013;29(4):368-82. doi: 10.1111/jrh.12023
- 6. King RB. The Stroke Caregiver Unmet Resource Needs Scale: Development and Psychometric Testing. J Neurosci Nurs 2015;47(4) doi: https://dx.doi.org/10.1097/JNN.00000000000153
- 7. Bakas T, Austin JK, Okonkwo KF, et al. Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *J Neurosci Nurs* 2002;34(5):242-51.
- 8. Han B, Haley WE. Family caregiving for patients with stroke. Stroke 1999;30(7):1478-85.
- Salter K, Zettler L, Foley N, et al. Impact of caring for individuals with stroke on perceived physical health of informal caregivers. *Disability and rehabilitation* 2010;32(4):273-81.
- 10. Rigby H, Gubitz G, Phillips S. A systematic review of caregiver burden following stroke. *International Journal of Stroke* 2009;4(4):285-92.
- 11. Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of Social Media. *Business horizons* 2010;53(1):59-68.
- 12. Hamm MP, Chisholm A, Shulhan J, et al. Social media use among patients and caregivers: a scoping review. *BMJ open* 2013;3(5):e002819.
- Rochette A, Korner-Bitensky N, Tremblay V, et al. Stroke rehabilitation information for clients and families: Assessing the quality of the StrokEngine-Family website. *Disability and Rehabilitation* 2008;30(19):1506-12. doi: 10.1080/09638280701615220
- 14. Bailey F, Reid L, Sommerville M. Why should health and social care professionals recommend stroke4carers website to stroke patients and their carers? *International Journal of Stroke* 2012;7:28. doi: http://dx.doi.org/10.1111/j.1747-4930.2012.00961.x
- 15. Stone K. Enhancing Preparedness and Satisfaction of Caregivers of Patients Discharged from an Inpatient Rehabilitation Facility Using an Interactive Website. *Rehabilitation Nursing* 2014;39(2):76-85. doi: 10.1002/rnj.123
- 16. Pierce LL, Steiner VL, Khuder SA, et al. The effect of a Web-based stroke intervention on carers' well-being and survivors' use of healthcare services. *Disability and rehabilitation* 2009;31(20):1676-84.
- 17. Alexa.com. Alexa.com 2017 [Available from: http://www.alexa.com/siteinfo/google.com].
- ROI.com.au. What percentage of website traffic should be generated from search engines. 2011 [Available from: https://www.roi.com.au/blog/percentage-of-website-trafficgenerated-from-search-engines/].

- 19. Alexa.com. The top 500 sites on the web 2018 [Available from: https://www.alexa.com/topsites].
- 20. Brin S, Page L. The anatomy of a large-scale hypertextual web search engine. *Computer networks and ISDN systems* 1998;30(1-7):107-17.
- 21. Pasquinelli M. Google's PageRank algorithm: A diagram of cognitive capitalism and the rentier of the common intellect. *Deep search: The politics of search beyond Google* 2009:152-63.
- 22. Fox S. Pew Internet & American Life Project. Online Health Search 2006, 2006.
- 23. Fox S. Pew Internet & American Life Project. Health Topics 2011.
- 24. Fox S, Jones S. Pew Internet & American Life Project. The Social Life of Health Information, 2009.
- 25. Kraschnewski JL, Chuang CH, Poole ES, et al. Paging "Dr. Google": does technology fill the gap created by the prenatal care visit structure? Qualitative focus group study with pregnant women. *Journal of Medical Internet Research* 2014;16(6)
- 26. Robertson N, Polonsky M, McQuilken L. Are my symptoms serious Dr Google? A resource-based typology of value co-destruction in online self-diagnosis. *Australasian Marketing Journal (AMJ)* 2014;22(3):246-56.
- 27. Lee K, Hoti K, Hughes JD, et al. Consumer use of "Dr Google": a survey on health information-seeking behaviors and navigational needs. *Journal of medical Internet research* 2015;17(12)
- 28. Pierce LL, Finn MG, Steiner V. Families dealing with stroke desire information about self-care needs. *Rehabilitation Nursing* 2004;29(1):14-17.
- 29. Mackenzie A, Perry L, Lockhart E, et al. Family carers of stroke survivors: Needs, knowledge, satisfaction and competence in caring. *Disability and Rehabilitation* 2007;29(2):111-21. doi: 10.1080/09638280600731599
- 30. Tsai PC, Yip PK, Tai JJ, et al. Needs of family caregivers of stroke patients: A longitudinal study of caregivers' perspectives. *Patient Preference and Adherence* 2015;9:449-57. doi: 10.2147/PPA.S77713
- 31. New York University. Health (Nursing, Medicine, Allied Health): Boolean Searching 2018 [Available from: https://guides.nyu.edu/boolean].
- 32. Thornton L, Handley T, Kay-Lambkin F, et al. Is a person thinking about suicide likely to find help on the Internet? An evaluation of Google search results. *Suicide and life-threatening behavior* 2017;47(1):48-53.
- 33. Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and indepth interviews. *Bmj* 2002;324(7337):573-77.
- 34. Lambert SD, Harrison JD, Smith E, et al. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. *BMJ supportive & palliative care* 2012;2(3):224-30.
- 35. Ang SY, Aung ST, Pavitar G, et al. A qualitative study into stroke caregivers' educational needs Perspectives of caregivers and healthcare professionals. *Proceedings of Singapore Healthcare* 2013;22(3):166-74.
- 36. El Masry Y, Mullan B, Hackett M. Psychosocial experiences and needs of Australian caregivers of people with stroke: Prognosis messages, caregiver resilience, and relationships. *Topics in Stroke Rehabilitation* 2013;20(4):356-68. doi: 10.1310/tsr2004-356
- 37. O'Connell B, Baker L. Managing as carers of stroke survivors: Strategies from the field. International Journal of Nursing Practice 2004;10(3):121-26. doi: 10.1111/j.1440-172X.2004.00469.x

- 38. Anderson CS, Linto J, Stewart-Wynne EG. A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. *Stroke* 1995;26(5):843-49.
- 39. Arora NK. Interacting with cancer patients: the significance of physicians' communication behavior. *Social science & medicine* 2003;57(5):791-806.
- 40. Kaplan SH, Greenfield S, Ware Jr JE. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical care* 1989:S110-S27.
- 41. Zolnierek KBH, DiMatteo MR. Physician communication and patient adherence to treatment: a meta-analysis. *Medical care* 2009;47(8):826.

No.	Label	Definition
1	Emotional and psychological	Unmet needs that involve the emotional and
		psychological aspects of providing care to the stroke
		survivor.
1.1	Help dealing with own	Carer expresses emotional distress (e.g. anger, guilt,
	emotional distress	sadness, anxiety, depression).
1.2	Know how to provide	Carer expresses lack of knowledge on how to provide
	emotional and/or	emotional or psychological support for the stroke
	psychological support for	survivor. This includes but is not limited to: (1)
	stroke survivor	communication/language issues post-stroke; (2) mood
		change post-stroke; and/or (3) personality changes post-
1.0	D 1 11 11 11 11 11 11 11 11 11 11 11 11	stroke.
1.3	Deal with uncertainty and life	Carer expresses fear or uncertainty for the future and/or
1.4	atter stroke	tears about the stroke survivors' condition worsening.
1.4	Get emotional support for	Caref expresses a need to seek support to manage their
	sell/have someone to talk to	emotional distress; advice for other carers on where to
		seek support, and/or a fack of knowledge on now or
15	Find meaning (self or partner)	Carer expresses need to "make sense" of the situation
1.5	This meaning (sen or partier)	or to understand why the stroke event has happened to
		themselves and the person that they care for
2	Impact on caregiver daily	Unmet needs that involve the impact on the partner
2	activities	caregiving daily activities from providing care to the
		stroke survivor.
2.1	Financial impact	Carer describes lack of knowledge of information on
	1	where to get more financial support, such as through
		benefits. This also includes the impact of purchasing
		stroke care related services/products.
2.2	Balance own needs with	Carer expresses difficulty in separating and managing
	caregiving	their own needs from caregiving. This may include their
		mental and physical health, or a need for respite and
		time off from caregiving.
2.3	Help looking after own	Carer describes their own diminishing mental and
	mental and physical health	physical health as a result of providing care for the
		stroke survivor. This includes negative outcomes such
		as anxiety and depression, and also aspects such as
2.4	D 1 41 4 1	being unable to exercise any more.
2.4	Deal with impact on work	Carer expresses the impact that providing care for a
		stroke survivor has on their work. This may include
		from full time to part time, and/or the need to give up
		work completely to become a full-time corer
2.5	Assistance with nationt daily	Carer expresses difficulty in providing care to the stroke
2.5	needs (e.g. preparing meals)	survivor on a daily basis. They may discuss needing
	needs (e.g. preparing meals)	assistance or that daily activities are much harder post-
		stroke than before the stroke event

Appendix A. Pre-determined coding schedule.

2.6	Help from others to manage caregiving roles	Carer expresses a need from others, such as friends, family members or professionals, the assist in managing the caregiving role. This might be friends or family assisting with day-to-day tasks such as food preparation and/or assisted living to help with other tasks such as mobility issues or assistance bathing the stroke survivor.
2.7	Receiving support to deal with changes in identity	Carer expresses difficulty in coming to terms with their change in identity following the person that they care for's stroke. This may include identifying new and/or unwanted roles in their lives, or the feeling of just being a "carer".
2.8	Impact on lifestyle and schedule	Carer expresses the impact that providing care for a stroke survivor has on their lifestyle and schedule. This may include impact on free-time, hobbies or seeing friends.
2.9	Know how to maintain a sense of control	Carer expresses an unmet need of maintaining control of situations surrounding the stroke. This might be sticking to a routine schedule, or making plans to manage aspects of providing care for the stroke survivor.
3	Comprehensive stroke care	Unmet needs that involve the individual care provided to the stroke survivor.
3.1	Have a supportive relationship with healthcare professionals	Carers express a lack of a supportive relationship with healthcare professionals. This includes but is not limited to: (1) poor or rude communication with the carer; (2) deliberately ignoring carer concerns for the stroke survivors needs; and/or (3) deliberately ignoring carer concerns for their own needs.
3.2	Access to health services	Carers describe a lack of understanding regarding the health care services and/or government benefits that they can access as a carer of a stroke survivor.
3.3	Be told about the help healthcare providers can offer	Carers describe a lack of communication with health care providers regarding the support and services they can provide to assist with managing caregiving for a stroke survivor.
3.4	Have possibilities to participate in the stroke survivors' care	Carers describe they desire more opportunities from health care providers to participate in the stroke survivors' care or rehabilitation. This includes expressing a desire to participate more and/or expressing exclusion from participating in the stroke survivors' care.
3.5	Obtain the best possible care for the stroke survivor	Carers express barriers or issues in obtaining the best possible care for the stroke survivor. This includes but is not limited to: (1) needed guidance in preparing medical records; and/or (2) not knowing which information is relevant in obtaining the best possible care for the stroke survivor.
3.6	Co-ordination and continuity of physical and emotional care	Carers describe the lack of co-ordination of physical and emotional care for the stroke survivor. This may happen at any stage of care, from rehabilitation at the hospital,

		to the transition home and the eventual return to the
		community.
3.7	Information provided by	Carers express that the information delivered by health
	healthcare professionals was	care professionals could be improved. This may include
	appropriate	but it not limited to: (1) the type of language used; (2)
		the type of platform (conversation, leaflets, "care
		packages" etc.); and/or (3) the timing of delivering the
		information.
4	Relationship	Unmet needs that involve the relationships changes
		involved with providing care to the stroke survivor.
4.1	Deal with changes in	Carers express difficulty in coming to terms with the
	relationship with partner	changes in the relationship with their partner who has
		suffered a stroke. This may include reminiscing on the
		life with the stroke survivor before the stroke event.
4.2	Have a satisfactory	Carers express a need to have a relationship with people
	relationship with others	outside of the caregiving role.
4.3	Help communicating with	Carers express difficulty in communicating with family,
	others (e.g. family, friends)	friends and others about their caregiving experience.
		Carers express a need to connect with other people
		outside of the caregiving role.
4.4	Have an intimate relationship	Carers express difficulty with having an intimate
	with stroke survivor and	relationship with the stroke survivor that they care for.
	consideration for sexual need	1 5
4.5	Help communicating with the	Carers express difficulty with communicating with the
_	stroke survivor about illness	person that they care for post-stroke. This may be due to
	and his/her concerns	the carer being under emotional distress and
		overwhelmed ("not having the words"), and/or due to a
		language/communication impairment post-stroke which
		makes communicating with the stroke survivor difficult.
5	Information	Unmet needs that involve the information needed to
		provide care to the stroke survivor.
5.1	Knowing what to expect	Carers describe a lack of information or preparation on
		what to expect at any time point in caring for the stroke
		survivor This may happen at any stage of care from
		rehabilitation at the hospital to the transition home and
		the eventual return to the community
5.2	The illness and management	Carers describe the need to understand more about the
5.2	(e.g. diagnosis prognosis	stroke survivors' condition and how to manage the
	(e.g. diagnosis, prognosis,	condition
53	Providing care to natient	Carers describe the need to understand and receive
5.5	Troviding care to patient	guidance on how to adequately provide care to the
		stroke survivor. This may be on a day-to-day basis
		emotional physical and/or pragmatic care
5 /	Death and dving	Carers express barriers and a lack of information around
5.4		stroke survivor end of life care
6	Spirituality	Unmet needs that involve the spiritual aspects of
0	Spirituanty	providing care to the stroke survivor
1		providing care to the subke survivor.

6.1	Feel there is hope for the future	Carers express the need to feel optimism and hope for the future, and confident that they can continue to care
		for the stroke survivor.
6.2	Receive spiritual support	Carers express the need for spiritual support. This may include regular attendance and engagement in a religious practice, and/or expressing that the carer can no longer receive spiritual support due to their caregiving duties. May also refer to marriage and vows.

*Multiple unmet needs may be reported per website