



HEALTH PROFESSIONAL AND FAMILY PERCEPTIONS OF POST-STROKE INFORMATION

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Abstract

The global burden of stroke is increasing. Many stroke survivors live with significant impairment; the care and support they and their families require is complex. Literature indicates some evidence to support the routine provision of information to stroke survivors and their families, but the best way to provide information is unclear. We undertook a mixed methods descriptive survey to ascertain information needs of stroke families through identifying current practice and resources, the appropriateness, accessibility, timeliness and information gaps. The survey, which is embedded in a longitudinal research programme titled 'Stroke Families Whānau Programme', was used to gain an understanding of family members' (n=19) and practitioners' (n=23) opinions on information provision post-stroke. Qualitative and quantitative data were collected via face-to-face interviews. Descriptive statistics were used to analyse quantitative data; content analysis was used for qualitative data. We found that for families, access to information was variable, both in quality and timeliness. Most described being overwhelmed initially with information they could not absorb; then later floundering as they had to find their own way through the maze. Few could recall information that focused specifically on them as family members. Health professionals described a range of resources and practices used to provide information. They identified barriers to effective provision of information, including language and other communication barriers, time constraints and workload issues. Most did not assess health literacy levels or consider family needs to be separate to or different from the stroke survivor's. We concluded that access to appropriate information post-stroke was problematic for most families and was compounded by the nature of the experience; shock following the sudden onset and adjusting to changed family dynamics. Health professionals recognised the limitations of resources, time, and funding alongside the need for timely, quality education for families post-stroke, however, a gap was identified between health professionals' theoretical understanding of best practice in information provision and their actual practice.

Keywords

Stroke; patient education; health professionals; families

Introduction and Background

The global burden of stroke is increasing. Despite a decrease over the past twenty years in stroke mortality rates there is an increase in terms of the absolute number of people affected every year (Feigin et al., 2014). There are an estimated 60,000 stroke survivors in New Zealand, many of whom live with impairment and need significant daily support (Stroke Foundation

of New Zealand, 2015). Stroke can have negative consequences on the health, wellbeing and quality of life of both the stroke survivor and their extended family (Ellis, Grubaugh, & Egede, 2013; Yu, Hu, Efirid, & McCoy, 2013). Care and support needs are variable,

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can be complex and are dependent on the severity, origin and location of the cerebral trauma, the time-period post-stroke, socioeconomic variables and ethnicity (Cecil, Thompson, Parahoo, & McCaughan, 2013; Harwood et al., 2012a, 2012b; Moloczij, 2009). Nurses play a pivotal role in stroke care and management across all phases of the stroke trajectory and, along with other health professionals, can help alleviate the stresses experienced by families caring for their whānau member who is a stroke survivor (Cecil et al., 2013). There is strong evidence for the efficacy of a co-ordinated multidisciplinary team (MDT) approach to stroke care (Clarke, 2013). Core members of a MDT in stroke care include nurses (often stroke nurse specialists), stroke physicians, physiotherapists (PTs), occupational therapist (OTs), speech language therapists (SLTs) and therapy assistants (trained to support PTs and OTs). Multidisciplinary teams may also include social workers, needs assessors, and community-based support workers such as the Community Stroke Advisors (CSAs) from the Stroke Foundation of New Zealand. Trained CSAs assist stroke survivors and their families with any stroke-related problems. They make hospital and home visits, support families and can advise on accessing carer-relief services and funding. Some MDTs include stroke co-ordinators (usually a nurse, PT or OT) within the team whose role is to co-ordinate in-patient rehabilitation and services for patients and their families post-stroke. At the participating DHB for this study these stroke co-ordinators are known as key workers.

The importance of information and education provision, alongside the right support, for stroke survivors and their families is well documented (Cameron & Gignac, 2008; Cameron, Naglie, Silver, & Gignac, 2013; Draper & Brocklehurst, 2007; Eames, Hoffmann, Worrall, & Read, 2010; Larson et al., 2005; Temize & Gozum, 2012; Wallengren, Segesten, & Friberg, 2010; Wright et al., 2012). A recent Cochrane review (Forster et al., 2012) showed that information provision for stroke

survivors and families improved their knowledge of stroke and aspects of patient satisfaction. A reduction in depression scores was also noted. Three Cochrane reviews (Forster et al., 2012; Forster et al., 2001; Smith, Forster, & Young, 2009) have concluded that while there is evidence that the provision of information is beneficial “the best way to provide information is still not clear” (Forster et al., 2012, p. 16).

Despite what is known about information provision post-stroke, stroke survivors and their families continue to report a lack of knowledge and difficulty in accessing it (Perry & Middleton, 2011) and feel unprepared for the scope and scale of life changes and life after discharge from hospital (Forster et al., 2012; Perry & Middleton, 2011).

Research Design

Aim

The mixed methods descriptive survey was to ascertain information and education needs of families of those who experience a stroke (stroke survivors) through identifying current practice and resources, and the appropriateness, accessibility, method of delivery, timeliness and gaps in education and information giving. Specifically, we wanted to know:

What information and resources were provided to/received by families across the care continuum?

How information was delivered?

What preferences did families have for the way information was provided?

What, if any, were the barriers and gaps in information provision?

We used a broad definition of ‘information’ to include any information and education provided to families



post-stroke; formal or informal. This study is the first phase of a longitudinal programme to improve support and care outcomes for stroke families. We were particularly interested in what, if any, of the information was specifically family-focused and inclusive of family members beyond the primary carer and stroke survivor.

Methods

A mixed methods descriptive survey design was used to gain an understanding of family members' and practitioners' opinions on information provision post-stroke.

Recruitment

Following ethical approval from the Northern X Regional Ethics Committee (NTX/10/EXP/071) 19 family members and 23 health professionals were recruited using purposive sampling strategies. Inclusion criteria for family members were: (1) being a family member of someone who had experienced a stroke in the previous two years; and (2) adequate spoken English to complete consent and the questionnaire. We invited multiple members from the same family to participate. Family members were invited through flyers posted in clinical areas at the local hospital (which provides post-stroke assessment and rehabilitation services) and the local Stroke Foundation support groups or directly through intermediaries (community stroke advisors and outpatient clinic staff).

Health professionals were invited to participate if they currently worked with people post-stroke, either within the hospital and/or the community. Information flyers were posted in clinical areas. Staff were also invited to a presentation about the study; there was no active recruitment, but contact details were available. Any direct approach to individuals was made via intermediaries.

Information sheets were provided to all potential

participants and consent obtained prior to data collection.

Participants

Family members: Nineteen people from thirteen families volunteered to participate. Demographic data are presented in Table 1.

Health professional-participants: Twenty three health professionals completed questionnaires either by face-to-face interviews (n=21) or electronically (n=2). Their work roles were either for the Stroke Foundation as community stroke advisors (n=5) or administrators (n=2) or for the stroke services, both acute and rehabilitation, of a large district health board (DHB). DHB employees included registered nurses (n=5) and an enrolled nurse, occupational therapists (n=3), a stroke physician, physiotherapists (n=2), speech language therapists (n=2) and therapy assistants (n=2). Demographics for participant health professionals are presented in Tables 2 and 3.

Data collection and analysis

The development of the survey questionnaires was guided by a literature review and stakeholder advisory group. Two questionnaires were developed; one for families of people who had experienced a stroke in the preceding two years (stroke families) and one for health professionals, who work with stroke families. Questionnaires included open and closed questions that enabled collection of quantitative and qualitative data. Both questionnaires were piloted and minor changes made to some questions for clarity. Electronic/postal versions were available; two of the health professionals (both OTs) chose this option. Questionnaires were administered by research assistants in face-to-face interviews with the remaining participants (n=40). Data were collected between September and October 2010. Research assistants received prior training in administering the questionnaires and to avoid introducing bias during the



Table 1.
Participant Demographics: Family Members

	Family member (n = 19)	Stroke survivor (n = 13)
Mean age	53 years	63.7 years
Age range	14-77 years	42-84 years
Gender		
Male	4	2
Female	15	11
Ethnicity		
NZ European/Pakeha	18	12
Other	1	1
Average time since stroke	1.6 years	1.6 years
Time since stroke range	0.4-4.11 ¹ years	0.4-4.11 ¹ years
Employment status (paid employment)		N/A
Yes	8	N/A
No	11	N/A
Change since stroke (total)	11	N/A
Increased hours	0	N/A
Decreased hours	9	N/A
Other change	2	N/A
Living with stroke survivor		N/A
All of the time	11	N/A
Most of the time	0	N/A
Some of the time	4	N/A
Do not live with SS	4	N/A
Caregiving responsibilities		N/A
All of the time	8	N/A
Most of the time	4	N/A
Some of the time	6	N/A
Do not live with SS	1	N/A
Previous experience in stroke care	4	N/A
Relationship to stroke survivor		
Wife (n=7)		N/A
Husband (n=2)		N/A
Partner (n=1)		N/A
Son or Daughter (n=7)		N/A
Brother (n=1)		N/A
Mother-in-law (n=1)		N/A

SS = stroke survivor; N/A = not applicable

¹One stroke survivor whose family participated had a first stroke 4.11 years prior, with a second stroke in the previous two years, therefore meeting inclusion criteria.



Table 2.
Participant Demographics: Health Professionals

Profession	Number	Workplace
Registered Nurse	5	Hospital - Rehabilitation Ward
Enrolled Nurse	1	Hospital - Rehabilitation Ward
Occupational Therapist	3	Hospital - Rehabilitation Clinic
Stroke Physician	1	Hospital - Older Adult Service
Physiotherapist	2	Hospital - Rehabilitation Clinic
Speech Language Therapist	2	Hospital - Rehabilitation Clinic
Therapy Assistant	2	Hospital - Rehabilitation Clinic
Community Stroke Advisor	5	Stroke Foundation - Community
Other	2	Stroke Foundation - Office
Total	23	

Table 3.
Participant Demographics: Health Professionals (cont.)

Health Professionals (n=23)	Number
Work experience in stroke services (no. of years)	
Mean	11.25
Range	1.5-35
Stroke specific skills/education	
Yes	19
No	4
Clients with stroke (% of workload)	
Mean	52
Range	5-100
Time point on stroke continuum where working with stroke families (multiple responses possible)	
Acute	11
Rehabilitation	11
Life after stroke/Community	11



interviews they discussed specific items if necessary, but did not provide further explanation. Interviews lasted approximately 45 minutes and were held at a mutually convenient time and place.

A range of demographic data was collected from all participants. Health professionals were asked about their role in development and provision of information for stroke families, details of what and how they provide information and their opinions on if or how this might be improved. Family members were asked about information provision at the time of the stroke as well as information provision since the stroke survivor's discharge.

All data, including transcribed responses to open questions, were entered into Excel® (Excel 2010, Microsoft Corporation, USA) spread sheets to facilitate analysis. Descriptive statistics were used to analyse quantitative data providing a description of the characteristics of the sample and the participants' responses. Content analysis was used to identify and catalogue patterns of response (Burnard, 1991) in the qualitative data. Key topic areas from the survey questionnaires informed the 'template' approach to thematic content analysis (Newell & Burnard, 2011) where the researchers asked questions of the data set. For example, what teaching strategies did health professionals use? What did families say about information they received on living with a person who has had a stroke? Following this, categories were developed and data organised within these. One researcher (DR) took overall responsibility, but a whole-team approach was used in the process. Category codes are used to present the findings with qualitative and quantitative findings reported simultaneously. Excerpts of qualitative responses are given in italics.

Findings

Health professionals

The participating health professionals were asked

specifically about the information and education needs of families. Many responses given suggest that participants did not consider family needs to be separate to or different from those of the stroke survivor (Table 4).

Information development and preparation:

Participants were asked about their role in the development and/or preparation of information for families. Examples provided included: policy development and sign-off (n=3, including two RNs), development and facilitation of carer-specific support groups (n=2), being consulted on readability and aphasia friendliness (n=1), and developing education packages (n=1).

Information delivery and content:

All health professional participants (n=23) provided written information, with most (n=12) specifically naming material produced by the Stroke Foundation. Eleven participants (including all RNs/EN) provided verbal explanations, including answering questions during consultations and/or caring moments. The RNs in particular highlighted the importance of assessing family needs to identify at what level they are at before providing information. Other modes of delivery reported were follow-up contact (phone or in person), providing hands-on demonstrations (n=3) to stroke survivors and families, and community follow-up (n=4). Five participants indicated they provided audio-visual material while one (RN) advised on suitable websites. A small range of content examples were provided, most of which pertained to the stroke survivor rather than being family-specific.

Teaching strategies:

Health professionals reported a number of strategies used when providing information. Three participants (including two RNs) completed ongoing assessment of family needs and personalised information for specific families. One RN noted the importance of *talking, building trust and relationships*

Table 4.

Findings Summary: Health Professionals (multiple responses possible)

Category:	Examples given:	n=23
Information development and preparation	Policy development	3
	Development and facilitation of support groups	2
	Assessment of readability	1
	Education package development	1
Information delivery	Provided written information from Stroke Foundation (SF)	12
	Answered questions during caring moments	11
	Follow-up post discharge – in person and phone	4
	Hands-on demonstration	3
	Assessed readiness for and understanding of information provided	6
Information format and content	Verbal information	6
	Written information	20
	Audio-visual material	5
	Advice on suitable websites	1
Teaching strategies	Importance of good communication skills ' <i>listening so as to understand what the family needs</i> '	12
	Ongoing assessment of family needs and personalising information for specific family members	3
	Demonstration of techniques and equipment	3
	Individual, group and community based presentations	3
	Role plays, goal setting and use of visual aids	4
Timing of information giving	Timing according to individual families	5
	Acute phase information need	22
	On-going information need in rehabilitation phase	7
Effective methods of information delivery	Combination of verbal and written	11
	Delivered face-to-face	8
	Phone calls, home visits and community group classes	7
	Family meeting with multidisciplinary team	6
	DVDs, diagrams and other visual aids	4
	Key worker to deliver consistent information	1
Effectiveness of available information	Information from Stroke Foundation (SF) is superior especially "Life After Stroke"	8
	SF DVD/video effective	12
Web-based information	Least familiar/comfortable	4
	Useful for 'young ones'	4
	Never use internet for information	5
	Concern about ' <i>unreliable</i> ' information	8
	Need to ensure ' <i>credibility, dependability and appropriateness</i> '	2
	Recommendation of specific site	1



Table 4. (cont.)

Findings Summary: Health Professionals (multiple responses possible)

Category:	Examples given:	n=23
Gaps/omissions/lack in information provision	Gaps identified - <i>'we don't prepare families enough to be caregivers'</i>	22
	Information in a range of languages	3
	Requirements of hands-on care, service access, funding	7
	Information tailored to specific family needs	5
	co-ordination of information giving	3
Health literacy assessment	Yes – informally <i>'I simplify things by not using medical jargon'</i>	10
	No (<i>'not my role'</i>)	13(2)
Barriers in information provision	Language including 'jargon'	4
	Difficulty arranging family meetings	5
	Poor quality & limitations of the written information available	2
	Time constraints and workload issues (including follow-up to assess understanding and the right information at the right time)	6
Knowledge gaps	None	4
	Accessing support services <i>'we need to do more from inside rather than expecting families to contact us' 'post-discharge is scary'</i>	5
Changes to make a difference	<i>'Changing the culture around educating families. Clinicians do not prioritise this. Recognising this is important so staff are allowed time to deliver information and develop skills to do so'</i>	18
	Early family involvement	14
	Assessment of family needs	9
	Professional development for staff on stroke management	7
	Stroke specialists/advanced nursing practice	11
	Improve resources including multiple languages and modalities	4
	Recognising family needs as different from stroke survivor	2
		1

to encourage patient and family participation. Demonstrating techniques and equipment; showing them how to do things was considered important when teaching practical aspects of care provision. Participants used a mixture of individual and group approaches including community-based group presentations. Participants used role-plays, goal setting and a variety of visual aids. The latter was noted as being particularly helpful for families where English

was not the first language. One RN said, it [patient education] is a challenge with non-English speaking families. Using a mixture of visual aids is helpful as well as pamphlets translated into other languages such as Mandarin.

Timing of information-giving: There was general recognition of the need to tailor timing to individual family needs and, as one RN reported, *the state of the*



family; it's not one-size-fits-all, everyone is different. Participant nurses reported that it was important to get information to the family *straight away* in the acute phase and for on-going information-giving that reinforced this. They also said it was important to work with individual family needs and avoid bombarding them with information before they were ready or at a time of acute distress.

Effective methods of information delivery: The importance of good communication skills was reported by many participants, including all the RNs (n=5). *This included listening so as to understand what the family needs, engaging in on-going conversation, and following up discussion with family after written information has been provided.* Verbal communication was considered most effective when supported by written information. Face-to-face was the most often reported means for verbal communication, but telephone calls, home visits and community groups/classes were also considered effective by community stroke advisors. Family meetings with the MDT were mentioned specifically by six participants. Diagrams, DVDs and other visual forms of information were reported (n=4) as being effective. Six participants reported assessing patient and/or family needs prior to giving information, including assessing readiness for information (n=2) and understanding of information given (n=3). One participant (an RN) suggested the use of a *key worker*¹ was an effective method of delivering consistent information to all families.

Effectiveness of available information: Most participating health professionals noted that the Stroke Foundation resources were superior to the DHB material: *The DHB information is boring, too many words, and no pictures. The Stroke Foundation information is better.* The Stroke Foundation *Life after*

Stroke book was specifically mentioned by many participants (n=8). The Stroke Foundation DVD/video was noted by many participants (n=12) as being "useful", "effective" or "very effective". Three participants (RN, OT, PT) were not aware of any such resource being available, while two others (one a RN) thought they were only available for staff training days, but not for families. Participants who saw these as effective noted that they should only be used as part of an overall package of information and *only at the right time and if appropriate.*

Participants were asked their opinion of the effectiveness of web-based information. Overall this was a form of information with which participants were least familiar and comfortable: *it's a bit scary.* Four participants (two OTs, two PTs) thought it would be useful for *young ones* and *likely to become more appropriate as the population becomes more computer literate.* Five participants, including two nurses, *never use* the internet for information or had no idea of effectiveness of this method of delivery and eight identified the potential for *unreliable* information and the need to ensure any material/websites are *credible, dependable, and appropriate.* Only one participant, a RN, recommended specific sites to families; advising them *not to just 'Google' it.* Another RN noted that while she did not provide information about websites, *families will find things and educate themselves.*

Gaps/omissions in information provision: Twenty two participants identified gaps. There was general recognition that *more effort* [is needed] *in supporting families: emotional support as well as imparting knowledge about stroke.* As one RN noted, *we don't prepare the family enough to be carers at home. When the patient goes home the family expect all will be normal; they aren't prepared because they've*

¹Key-worker: a designated health professional (nurse, physiotherapist, occupational therapist or speech language therapist) within the stroke care team at the participating DHB whose role is to co-ordinate in-patient rehabilitation services for some patients post-stroke.



gone from a setting where nurses do things to no professional care being provided at home.

Some (n=3) identified the lack of information available in a range of languages, while others (n=7) identified gaps in provision of information about hands-on care requirements, access to services and equipment and funding options for any such equipment. Others (n=5) identified a lack of information tailored for each family, be this related to cultural norms, family dynamics, or readiness to learn.

Three nurses identified lack of co-ordinated approach to information-giving in the acute (hospital) phase where *wrong or outdated information is given, information is not co-ordinated in the patient's folder or information is missed due to frequent nursing changes.* Finding the right balance between giving too much or not enough information was also identified as a challenge.

Health literacy assessment: Participants were asked if they or anyone in the MDT assessed health literacy levels. Nine answered "yes" and 13 "no"; one participant did not respond. One senior RN responded, *some may say they do, but they don't.* Those who answered "yes" were asked how this is done. Fifteen participants answered in a way that suggested the question was not clearly understood. Another explanation is that participants did not understand what was meant by 'health literacy' or how it might be assessed. Responses that appeared to relate specifically to assessment of health literacy (n=10) identified limited assessment, most often through asking questions of the families to check understanding; *informally (RN), I'm generally aware if patient and family understand (RN), I simplify things by not using medical jargon and I assess through questions asked to the family (OT).* Two participants (both therapy assistants) indicated that assessing health literacy was the role of others in the MDT. One participant (SLT) stated: *there are family meetings to ask questions and assess effectiveness of*

strategies implemented, or what to improve on, but family health literacy is not assessed at all because the main focus is the patient.

Barriers in information provision: Participants identified a range of barriers from language (n=4) and other communication barriers such as health professionals using *jargon*, family meetings being difficult to arrange especially if including a number of family members. One participant, a stroke physician stated, *we need more resources in different languages. I find it frustrating that I don't have time to give families what they would benefit from. Trying to get families all together at once is hard. Family whānau meetings are needed to talk through issues.* The quality and limitations of the written information available was mentioned by two participants, in particular lack of information that focuses specifically on family. Time constraints and workload issues were identified by some (n=6). A senior RN said, *nurses are under-resourced. I used to have the time to talk to every stroke patient and their family, but then some of my clinical roles were taken away and I was given financial roles, so now there's no time to do that anymore.*

There was also recognition that sometimes information was given at the *wrong time* in the post-stroke trajectory: *we give an overload of information at the start and then nothing afterwards.*

Knowledge gaps: Participants who see families post discharge (n=13, only 1 RN) were asked what (if any) information need or gaps in knowledge they identified? Five of the 13 said *no gaps* or described gaps specifically related to the stroke survivor, not the family. Gaps identified specific to families included knowing what, where, and how to access support services and resources in the community, the need for support and education about long-term implications of stroke and the need for health professionals to be proactive in the community in providing care and



support for family: *we need to do more from inside rather than expecting families to contact us. Post discharge is scary ... we don't support people as well as we should.*

What changes would make a difference? One response encapsulated key points raised by many participants (n=14): *Changing the culture around educating families. Clinicians do not prioritise this. Recognising this is important so staff are allowed time to deliver information and develop skills to do so.* Nine participants suggested getting the family involved early and providing on-going information and support. A co-ordinated approach and improved continuity of care was also noted as being important to improving processes. Changing the format and venue of family meetings (*away from the bedside*) was also noted. Seven participants (including four nurses) identified that having more time (*having time to assess family needs*) and funding (including for interpreters) would enable them to be more effective, while 11 (including four nurses) indicated more professional development was required. Four participants (2 RNs, physician, SLT) suggested a co-ordinated proactive team approach utilising health professionals with specialised/specific expertise: *A proactive team approach is needed with more stroke specialists and advanced practice nurses; only these people can educate effectively.*

Improving resources, including availability in multiple languages and a range of modalities such as online and DVDs, and taking a multi-cultural approach were also recommended. One nurse noted: *They [family] should get the level of assessment and caring like the actual patient. Stroke is a family crisis. ... Give information in the early weeks and build trust. Others said: we don't currently engage family as well as possible. Acknowledge that they [family] have complex needs, that they need a different type of communication than the patient.*

Family members

Family members (n=19) were asked their opinions on information provision at the time of the stroke (when the stroke survivor was in hospital) and then about information they had sought or received since discharge. We were particularly interested in knowing about family-specific information; such as taking care of themselves and learning to live with a person who has had a stroke.

Information provision at time of stroke – living with a stroke survivor:

Participants were asked if they had received any information about living with a stroke survivor (as opposed to information about stroke), most (n=14) had not. One participant who stated she had not received information commented: *During my husband's stay in hospital not much information was given. I felt I didn't actually want the information then because my brain felt scrambled, I wouldn't have coped with lots of information.*

The five participants who reported receiving information specifically focused on their needs were asked how the information prepared them to support and care for the stroke survivor. Three reported the information as being useful and that they *felt prepared*. Two participants (sisters whose father had a stroke) reported that rather than preparing them for their role, the information given was *frightening* and *offered no hope, which was devastating*. The prognosis for the stroke survivor was initially very poor and this was communicated to the family; *preparing us for the worst*.

Information provision at time of stroke – information about stroke:

Family participants were asked to identify sources of information (Figure 1). These included nurse (n=5), CSA (n=4), doctor (n=3), PT (n=3), social worker (n=3), OT (n=2), other health professional (n=3), family/whānau (n=3), other family (n=1).

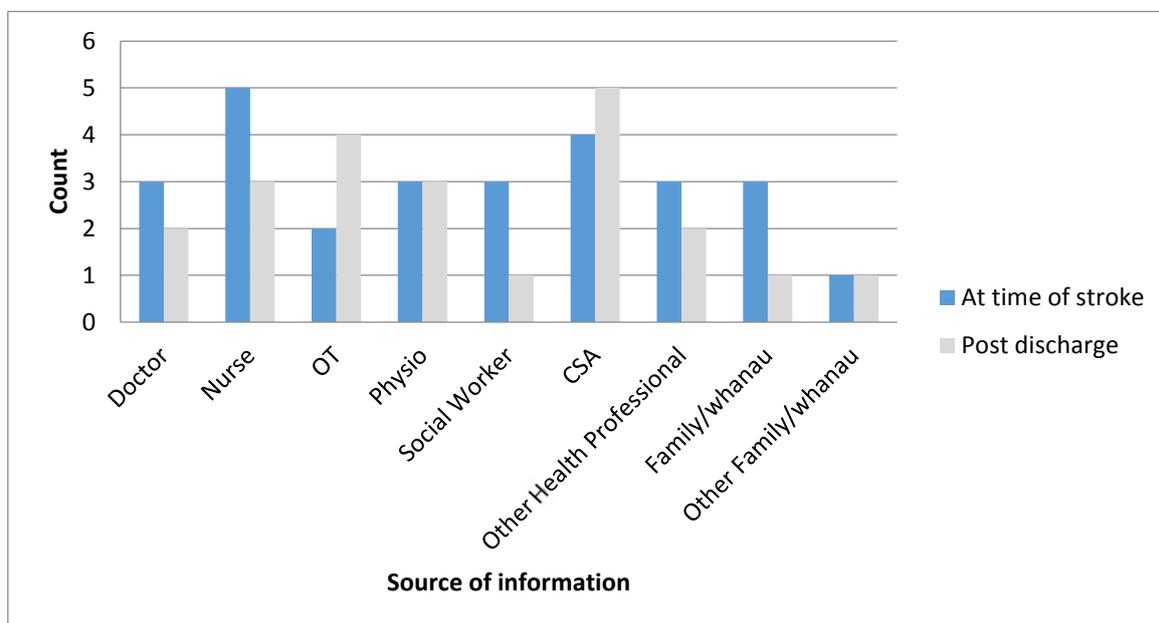


Figure 1. Source of information provision to families (multiple responses possible)

The type of information received varied with booklets or written material (n=5) and verbally (n=4) the most reported forms (Figure 2). The participant who responded 'DVD/video' noted that she had been given

a VHS video but had no capacity to play it: *I was given a video but we had no video player. We only have a DVD player at home.*

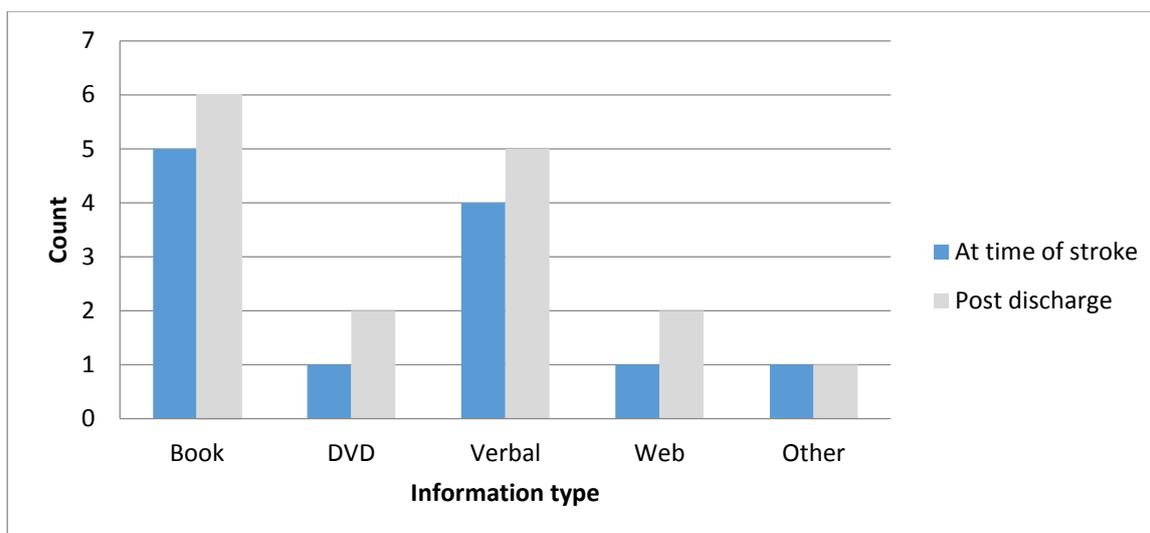


Figure 2. Type of information received by families from health professionals (multiple responses possible)



Participants generally agreed that the information was easy to understand. Free text comments included: *well presented with pictures and easy to understand; the brochure information was good. Talking with staff was also good.* One participant who did not find the information easy to understand commented: *words [terminology] and the process [pathophysiology] of stroke were hard to understand. There were too many medical terms.*

Participants described being *overwhelmed by paperwork initially.* The need to be assertive in information-seeking was also noted: *The hospital staff were marvellous. They gave us information and pamphlets... I asked all the questions; the staff helped. But information was not given voluntarily. Whenever I saw an improvement I asked questions and got the*

answers. Another commented: *If we hadn't made a point of asking and asking again, I don't think we would have received any information. ... Communication was difficult. There were a couple of people who did help but majority seemed too rushed, stressed or lazy.*

Participants were asked if they got information from anywhere or anyone else they had not already told us about (e.g. health professionals, immediate family) (Figure 3). Of the 14 participants who provided details, seven accessed information via the internet. Friends and extended family were also additional sources of information, often providing books or sharing their personal experiences of living with stroke. One participant said: *my brother-in-law is a doctor and my sister-in-law a nurse so I got info from them.*

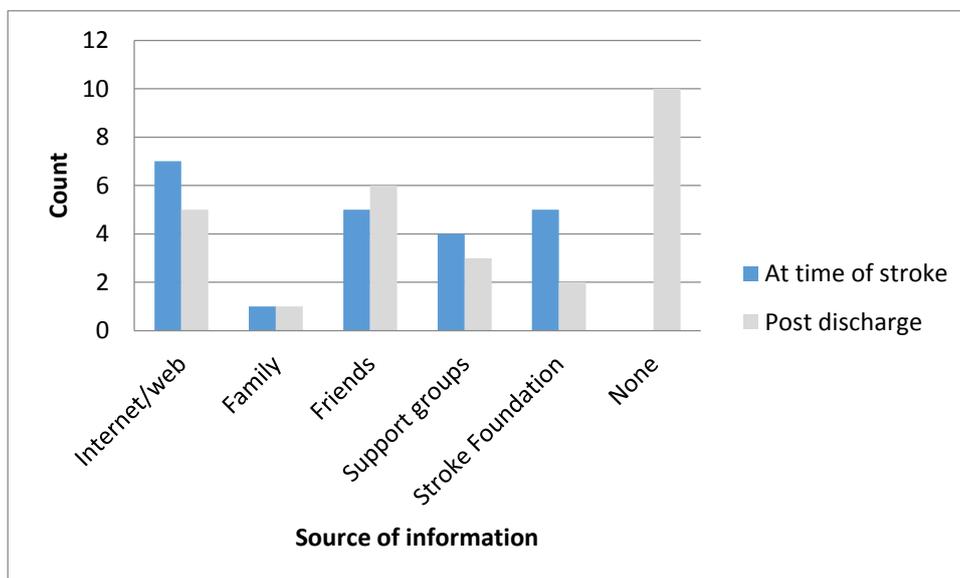


Figure 3. Sources of information additional to that received from health professionals (multiple responses possible)

All family participants (n=19) were asked the question: Remembering back to when your family member was first discharged, what do you wish you knew then that you know now? Seventeen responded. Eight participants wished they had known more about the

pathophysiological effects of the stroke, including *knowing the early warning signs of stroke*, signs of deterioration, the possibility of seizures, and the impact of personality changes. Many (n=10) wished they had been given more information about the demands of



caring for the stroke survivor; the *constant care* with every day being *full-on*, and the stroke survivor not being able to be left alone. While family members *knew it would be tough* they did not realise *how time consuming it would be*. Two participants indicated that *nothing* could have prepared them for their caring role; one stating had she known she *wouldn't be sitting here now*, while the other *might have run a mile* had she known in advance what the demands would be. One said: *I wish I knew how hard it would be for both sides [and] how important to get a break when you can*. Participants reported not being told about support groups and other services available post-discharge (n=4). They thought health professionals should have given them this information *rather than us trying to find out or hearing it from friends*. Participants wanted the whole family, not only the primary carer, included in family meetings with health professionals.

Information provision post-discharge: Ten participants reported receiving no additional information post discharge (Figure 3). Nine participants received information post discharge from a range of sources (Figure 1). Written (n=6) and verbal (n=5) forms of information were the most frequently reported (Figure 2) with most (n=8) indicating the material was easy to understand. One commented: *it was easier than the first time when stroke occurred*, suggesting that there may have been some repetition in information provision that was useful. Six of the nine indicated that their information needs were met at this time.

When asked if the information provided prepared them for their on-going role in supporting and caring for the stroke survivor four responded 'yes', one adding: *I wouldn't have been able to cope without it. It has given me strength. The on-going support keeps me going*. Two said 'no', one saying: *No information can prepare you for that*. The remaining three were positive in regard to the information provided but were more tentative in their response. One said: *In some*

ways, but not really. People told me to set boundaries, but I'm not able to do this with my partner. Sometimes I get frustrated and have to walk away.

Six of the nine thought they had been given the right information at the right time. The three who did not agree, commented on *not getting enough* or only getting it at the time of the stroke when they were in shock and not able to take it in. One commented: *The doctors were really busy. I received confusing information, and I really needed someone to explain the information.*

The final question asked: If you were asked to talk to someone who had a family member who had just had a stroke, what is the one piece of information you think they most need? An extensive range of responses was given. The responses that pertained specifically to information needs included: *There are places out there to get help, when dad first had the stroke mum had no one, but found support groups helpful, make contact with others for support; Get as much information as you can. Get support and have breaks away when possible; Demand information! Or get someone to ask for you; Doctors give horrific details, but nurses give more hope and provide comfort; Seek advice from a professional rather than hearsay; The Stroke Foundation and GP have the best advice; The Stroke Foundation are fantastic; Talk to other people who have been through it, because it's hard to know unless you've been there.*

Two representative general comments were: *Nothing can prepare you for it, it's very sudden and takes time to get through; Family support in those times is very important, be ready for the long haul.*

Discussion

Our study showed that health professionals and families value and recognise the importance of information sharing in improving outcomes post-



stroke. Health professionals were asked specifically about the information needs of families. Their responses, however, suggest that most did not consider information needs of the family to be separate to or different from those of the stroke survivor. The structure of the questions or the way the research assistants asked them may have contributed to this finding, although similar trends were noted in responses of participants (n=2) who completed the questionnaire online. Access to information for families was variable, both in quality and timeliness. Many described being initially overwhelmed with information they could not absorb. Few could recall information that focused specifically on them as family members, yet they identified unmet needs such as understanding the demands of caring and the importance of attending to their own health and well-being. These aspects are consistent with findings of a narrative review of 35 studies exploring information needs of families of people with chronic obstructive pulmonary disease (Caress, Luker, Chalmers, & Salmon, 2009) that identified few studies which addressed, even peripherally, family needs for information.

Health professionals, especially nurses, recognised the limitations of resources, time and funding alongside the need for timely, quality education for families post-stroke. For example, they identified the paucity of information and education material in languages other than English. Consistent with practice guidelines (Stroke Foundation of New Zealand and New Zealand Guidelines Group, 2010) and research evidence (Cameron & Gignac, 2008; Cameron et al., 2013), many spoke of the importance of delivering jargon-free information at the right time and specific to family needs. They identified using 'teach-back' techniques to assess understanding, yet there was little evidence of any formal consideration of health literacy levels of either the stroke survivor or family members. This is consistent with previous research (Eames et al., 2010; Gustafsson, Hodge, Robinson, McKenna, & Bower,

2010). Health literacy has been defined as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Kickbusch, Wait, & Maag, 2005, p. 8). The 2006 Adult Literacy and Life Skills Survey (Ministry of Health, 2010) showed that the majority (56.2%) of New Zealanders have poor health literacy skills. Health literacy demands increase at times of a new diagnosis (Reid & White, 2012), such as stroke. Health professionals can help reduce these demands by incorporating health literacy awareness and best practice strategies when working with stroke families.

Digital literacy is an important component of health literacy. Our findings showed few health professionals (and only one nurse) referred families to suitable websites and were reluctant to or never used web-based resources. This is in contrast to family participants, many of whom used the internet to source information. A recent study of NZ consumers health information needs found two thirds of the 1783 participants had used the internet to access health information (Honey, Roy, Bycroft, Boyd, & Raphael, 2014), which suggests health professionals need to overcome their discomfort and enhance their digital literacy skills and expertise to work with families to identify reliable web-based resources to help meet their information needs.

Despite the theoretical position espoused by many of the health professionals, including nurses, about the importance of identifying the 'right time' for information provision, the practice reality that was evident in both health professional and family data was that of 'dumping' information on families in case they 'missed out', irrespective of family needs. Numerous studies have shown that information needs for stroke survivors and families change across the care continuum (Hanger, Walker, Paterson, McBride, & Sainsbury, 1998; Mak, Mackenzie, & Lui, 2007; Wiles,



Pain, Buckland, & McLellan, 1998) and, consistent with our findings, many families are overwhelmed by the information provided in the acute period only to report unmet information needs post-discharge (Cameron et al., 2013; Eames et al., 2010; Perry & Middleton, 2011). Ameliorating the gap between actual practice and best practice may require reflection on and evaluation of current education provision and a re-assessment of how best to deliver quality education that meets the needs of both stroke survivors and their families. To provide best practice for stroke survivors and their family, post-stroke education should be based on assessment of health literacy and changing needs across the post-stroke continuum.

Recommendations for practice

Family centred approaches in stroke care are advocated to enhance support and improve outcomes for stroke families (Cameron, 2013; Clarke, 2014; Fischer, Roy, & Niven, 2014). Such approaches must include recognition that family needs are inter-linked with but different from the stroke survivor and that needs change over time, often alongside the stages of the stroke trajectory. Nurses and other health professionals need to work in partnership with families, assessing individual and family needs for information not only about strokes but also in maintaining their own health and well-being. Family education in the acute setting tends to be focused on information about stroke and providing care to the stroke survivor on discharge. Equally important is the inclusion of social and emotional support resources (Larson et al., 2005). Effective provision of information can be complex and time-consuming. It cannot be assumed that family members have the same health literacy skills and information needs (Honey, Roy, Bycroft, & Boyd, 2014). It is important to raise staff awareness around the centrality of health literacy as a pre-requisite for health teaching. Nurse-led initiatives that assess

health literacy and the credibility of stroke specific web-based resources as well as advanced nursing scopes of practice, as suggested by a RN participant, have the potential to address unmet needs in this population. Changes in practice and service delivery models may be warranted to enable a proactive co-ordinated approach based on assessed needs for each family across the care continuum.

Strengths and Limitations

A major strength of this study is that we included a range of family members, not only the primary carer, and that we sought the opinions of a range of health professionals who work with stroke families. The non-inclusion of stroke survivors may be seen as a limitation, however this was a deliberate strategy as we wanted to focus specifically on family information needs and stroke survivors' opinions are more widely known. Questionnaires were designed specifically for this study. Our sampling strategy, sample size and limited ethnic diversity within the sample limits transferability of findings.

Conclusions

Access to appropriate information post-stroke was problematic for most families, in both quality and timeliness, and was compounded by the nature of the experience; shock following the sudden onset and adjusting to changed family dynamics. Nurses and other health professionals recognised the limitations of resources, time and funding alongside the need for timely, quality information provision post-stroke, however, a gap was identified between health professionals' theoretical understanding of best practice and their actual practice. Information needs specific to stroke families are often overlooked. It is important to communicate effectively with families and acknowledge that they may have complex needs that are different to the stroke survivor's needs.



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