

Elliot J. Roth, MD, Editor

# Perceived Needs of Stroke Survivors from Non-English-Speaking Backgrounds and Their Family Carers

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The purpose of this article is to discuss current findings in the research literature on the experiences and needs of stroke survivors and their family carers and to provide suggestions for future research. Based on this critical review, knowledge gaps and issues in stroke management in the community indicate that the needs of people surviving a stroke, particularly people from non-English speaking backgrounds, are not being adequately met by community-based health services. There is a critical need for changes in practices to meet the needs of this specific population. Key words: *ethnic groups, family caregivers, health information, health services, rehabilitation, stroke*

**T**here is a growing realization that the needs of stroke patients are not being adequately met by health services (e.g., in the United Kingdom, see *Consensus Statement*<sup>1</sup>; for Australia, see *Strategy for Stroke Improvement in South East Health*<sup>2</sup>). In Australia, this is partly caused by the fragmentation and poor organization of stroke services.<sup>3</sup> Stroke can happen to adults of all cultures and ages, therefore, it cannot be assumed that people's needs after a stroke are either homogeneous or unchanging over time. People from ethnic minorities, for instance, may have ongoing unmet needs with regard to information that is easy to understand, is culturally appropriate, and is in their language. Because of these needs, it is important that research be conducted to ascertain the experiences and needs of people with a stroke from non-English speaking backgrounds (NESBs). Consumer participation must be considered in the design, planning, and evaluation of service delivery programs and these programs must dovetail with gov-

ernment strategies for improving the health of stroke survivors in order to be effective. The purpose of this article is to discuss current research literature on the needs and experiences of stroke survivors and their family carers and to provide suggestions for future research with population groups that have been poorly served to date, such as people from NESBs living in Australia.

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## **Incidence of Stroke in Australia**

Stroke was among the top 10 leading causes of disability in Australia during 1996<sup>4</sup> and was the third leading cause of death overall in 1999.<sup>5</sup> During 1996–1997, the length of stay in hospital in Australia for stroke was twice that for cardiovascular conditions (10.5 days compared with 5.3 days).<sup>6</sup> This creates problems in terms of bed blocking for other acute care cases and is very costly for the health care system. In New South Wales (NSW), Australia, although mortality rates for stroke declined dramatically in the prior decade, strokes caused 10% of all deaths in 1998 owing to the continued growth of an ageing population. Rates for nonfatal stroke in NSW have also increased in the past 9 years, which is manifested in a 16% increase in hospitalizations for stroke. Approximately one third of people who have had a stroke die within the first 12 months and a further third remain permanently disabled.<sup>3</sup>

## **Recent Trends in Stroke Support Services**

Early supported hospital discharge for stroke patients has been well-accepted by patients and families and is shown to be cost-effective by reducing hospital length of stay.<sup>1,7,8</sup> Recovery rates and rehabilitation after stroke are comparable in the home setting and may result in patients' higher level functioning and satisfaction with community reintegration.<sup>9</sup> Early discharge of stroke patients, however, can mean additional utilization (and costs) of community health services during the rehabilitation process and more responsibility for family carers who provide most of the hands-on care, in

particular at earlier stages in the patients' recovery.<sup>10,11</sup> Although a limited number of studies have examined this new trend, there is now evidence to suggest that unless an adequate support system is established, early discharge means more stress for carers. Successful recovery and rehabilitation after stroke require ongoing support from health professionals for the patient and family carers.<sup>1,9,10,12</sup> As these studies indicate, when a stroke occurs in a family member, the need for social and health support for the whole family increases dramatically. Little is known about the particular needs and perceptions of stroke survivors from NESBs and their family carers in Australia. Until these data are available, services cannot be tailored to meet the needs of this population.

## **Australian Government Priorities in Stroke Health**

The NSW State Government of Australia has outlined its priorities with regard to stroke in its 1997 paper, *Stroke in NSW: Priorities and Strategies for Better Care*,<sup>13</sup> which is a response to the Federal Government's *National Stroke Strategy* of 1997. It is acknowledged here that strategies must address issues and concerns across the continuum of care for all Australians. Effective stroke services are required to develop organized systems of care through coordinated and integrated multidisciplinary rehabilitation and to employ staff with stroke or rehabilitation expertise and an interest in pursuing a team approach. The other clear mandate for stroke services is to provide education and training for health staff, patients, and their carers.

This State Government initiative emphasizes the importance of follow-up action post discharge for stroke survivors, improved access to care, and reduced inequalities in service provision to disadvantaged groups, such as people from NESBs.<sup>14</sup> At a local level, area health services within NSW have devised the following strategies for improving stroke health to people from NESBs<sup>2(p18)</sup>:

- Promoting the appropriate use of interpreter services in stroke management;
- Promoting and/or develop [sic] translated information to the major language groups for people with stroke and their carers;
- Utilizing cross cultural sessional health service workers in stroke prevention education to other language groups;
- Staff training in stroke management to include aspects such as working with interpreters and cross cultural communication; [and,]
- Identifying possible research projects regarding the needs of people with stroke and their carers from people from NESBs.

There is recognition across the spectrum of government in all states of Australia that it is of paramount importance to devise the means by which the unmet needs of stroke survivors and their carers are ascertained and redressed, especially for persons for whom English is not a first language.

### **International Research**

Research in many countries has revealed certain themes that characterize life after stroke for those who are discharged to their

own homes. These themes include loss of functional abilities and independence, low self-esteem, sorrow and depression, frustration, fear of another stroke and living in uncertainty, the need to acquire new values in life, the necessity of training to maintain skills, attempts to reduce possibilities of another stroke, personality changes, role loss, changed relations with family and friends, changed appearance, paresis, cognitive impairment, sexual problems, headache, tiredness, and speech problems.<sup>12,15-20</sup> Findings from some studies indicate that there is a link between stroke and frequent falls in older people.<sup>16,21</sup> In their randomized comparison trial of older stroke survivors ( $N = 106$ ) conducted in the United Kingdom, Forster and Young<sup>21</sup> reported that three in four stroke patients were likely to fall within the first 6 months of discharge, and those patients who fell more than once (“fallers”) were found to have less social activity and more depression. This study also showed a strong relationship between those fallers and higher stress levels of their carers due to concerns regarding falls.

Public knowledge about various aspects of stroke and its effects has been shown to be lacking in certain key areas, such as risk factors for stroke and the complexity involved in communication difficulties.<sup>22</sup> Because of this lack of public knowledge of stroke and its effects, there is a need for information and care. To what extent is this need being met by health care systems? When researchers have asked this question of patients and carers through interviews, surveys, and focus group discussions, they have found that the largest proportion of unmet needs lie in the areas of personal/emotional support, advice about regaining

function, interpretation of information about stroke and its aftermath for the survivor, continuity of care, access to expertise, and follow-up by health staff to help people cope with ongoing health concerns.<sup>23,24</sup> Cox, Dooley, Liston, and Miller<sup>16</sup> used in-depth interviews with elderly stroke survivors ( $N = 39$ ) to determine their needs. Their findings indicate that stroke survivors are required to make a range of adjustments in their lives to cope with the impact of stroke, and this poses various challenges to them and to their family carers. In this group, the need for ongoing psychosocial support and stroke education was paramount. The researchers suggest that service providers should utilize stroke survivors' knowledge that is gained through this experience and should encourage their full involvement in the recovery and care process.

Most research that examines the impact of stroke for individuals and their families finds that these people need emotional support. They may require counseling with regard to problems in care arising from changes in dependency.<sup>25</sup> They also may need emotional support in learning to adjust to the use of technical aids, because patients with stroke can be especially susceptible to cultural attributions of stigmas associated with use of such devices and can have difficulties renegotiating their senses of self-identity and social identity.<sup>26</sup> The ongoing need for pertinent information, although it changes over time,<sup>27</sup> is perceived by patients as being unmet. Research participants were keen to know more about the nature and causes of stroke, its short and long-term effects, the social impact of stroke, the cost of ongoing care, and strategies for rehabilitation.<sup>28</sup> Even after 2 years, people with stroke have unanswered ques-

tions and informational needs.<sup>27</sup> Knowledge of complementary therapies such as massage, acupuncture, and the role of food and vitamins has been shown to be a component of one group of survivors' and carers' requirements for information and education.<sup>29</sup> Stroke patients during and after a day hospital rehabilitation program expressed the need to learn and perform activities that could enhance their physical abilities and skills and to learn ways to improve their motivation, morale, and general sense of self that were impaired after stroke.<sup>30</sup>

In a randomized clinical study with 155 stroke patients with persistent impairment and disability who were discharged home after completion of in-patient rehabilitation, patients and families claimed they experienced several unmet needs during rehabilitation, particularly emotional support. This played a part in readmission rates.<sup>10</sup> Emotional support was also found lacking in a large-scale survey conducted in Finland by the Stroke and Aphasia Federation Finland.<sup>31</sup> Social support<sup>31,32</sup> and health follow-up<sup>33</sup> were essential needs of poststroke patients and carers. In a pilot study on the effectiveness of follow-up support that compared home visits and telephone contact with 30 stroke survivors and their family carers, it was found that telephone contact by registered nurses during the 12 weeks postdischarge significantly reduced depression, improved problem-solving skills, and provided greater preparedness for carers after stroke to the same degree or better than the home visits.<sup>34</sup>

### **Health Staff's Response to Expressed Needs**

The literature makes it clear that many areas of information required by patients

and families after a stroke are not supplied by staff for a variety of reasons. To investigate the degree to which patients and family carers have unmet information needs, the majority of researchers have used in-depth interviews and questionnaires. In van Veenendaal, Grinspun, and Adriaanse's study,<sup>35</sup> the following major gaps in information were discovered: how to reduce the chance of a new stroke (for family carers), strategies to cope with stress (for stroke survivors), resources available when requiring assistance, and strategies to assist in performing activities of daily living. Information provided by health professionals, even during the patient's hospital stay, is often perceived to be incomplete and too general. For example, 31 stroke patients and family carers who were interviewed by Wiles, Pain, Buckland, and McLellan<sup>36</sup> stated that the most important information that they needed from staff included an explanation of what a stroke is, its causes, and how it can be prevented, but this information was not generally given.

In one study that used in-depth interviews conducted 1–2 months postdischarge, 31 patients and carers had the perception that staff did not give more information because they lacked the time to give out detailed information, they lacked the knowledge and experience in providing appropriate information, or they found it distressing to communicate the extent of the damage caused by the stroke and the negative outcomes that were likely.<sup>36</sup> Results of in-depth interviews with staff concur with these findings; staff feel uncomfortable about imparting bad news and discouraging patients from rehabilitation when there is little hope of functional improvement.<sup>36–38</sup> Researchers in a United Kingdom study, which used case

studies, interviews, and questionnaires with stroke patients, their families, and staff to determine perceptions of staff's professional responsibility toward stroke patients, found that staff were often unwilling to pass on specific information to patients in case the information might be misleading.<sup>39</sup> In a project commissioned by the NSW Department of Health, 60 patients and family carers responded to in-depth interviews about their information and support needs after stroke. The researchers found gaps in information provided by staff that were similar to gaps found in previously cited studies. One of the reasons for this lack of information was perceived to be the staff's reluctance to add to the burden of already fearful patients and carers.<sup>40</sup> Researchers who conducted a US study that investigated the reasons for staff withholding information from patients and families interviewed 55 family carers, 49 staff, and 39 members of the general public. Staff considered that patients and carers were unable to absorb relevant information because of the distress associated with the recent stroke, therefore they were selective about what information they presented.<sup>41</sup> This view was not shared or accepted by the family carers and general public in this study.

### **Importance of Information from Health Staff**

Interviews with stroke patients and families also provide important data on the implications of staff withholding vital information. Lack of adequate information and/or the receipt of "mixed messages" from health professionals has been shown to negatively affect the motivation for rehabilitation in stroke patients.<sup>23</sup> Mixed mes-

sages may be created through the apparent mismatch between the patient's and family's goals for recovery and health staff's expectations for rehabilitation.<sup>38,42,43</sup> Similarly, there can be incongruity between the information patients and carers perceive they are given about recovery and the reality of their disablement. In both cases, these misconceptions lead to a breakdown in communication between patients, carers, and health staff.<sup>36,37</sup> Patients and families need information that will help them cope better with the aftermath of a stroke. They actively seek out relationships with staff and other patients to gain information that will assist them in understanding the uncertainty ahead of them.<sup>39</sup> People with the poorest outcomes and those experiencing the highest numbers of transfers between wards/units are more likely to be dissatisfied with the information that is provided.<sup>44</sup>

Direct communication with health staff postdischarge has been found to meet many of the patient's and carer's information needs. For example, in the process of testing comprehensive needs assessment survey tools with 47 stroke patients and family carers, Zwygart-Stauffacher, Lindquist, and Savik<sup>24</sup> found that these participants' desired more opportunity to spend time with health professionals to address information deficits on physical, social, and emotional issues and to learn about equipment and technical aids. Stroke patients and their carers discharged from 52 hospitals in Nebraska requested information on ways to maintain safety during transferring and walking.<sup>45</sup> Many studies discovered that patients and carers lacked information about managing daily activities and where to access services to assist them with these aspects of daily living

(e.g., Scholte op Reimer et al.,<sup>32</sup> McLean, Roper-Hall, Mayer, & Main,<sup>25</sup> and Salonen<sup>31</sup>). Given the aforementioned findings, it appears that family carers and patients have very specific needs that can be met through closer communication with health staff.

The literature indicates that the preferred time for families and patients to gain vital information about stroke and follow-up care varies. One Canadian study<sup>46</sup> identified the hospital as the preferred *site* to provide information and education during the discharge planning process. A Dutch study found that the 39 carers identified the hospital doctor to be the most desired *source* of information.<sup>35</sup> However, Tyson and Turner<sup>38</sup> found that the narrow focus of information given to patients and carers about strategies to enhance functional rehabilitation in the hospital sector tends to limit ongoing rehabilitation in the post-discharge context. This was found to be the case, in particular, when hospital staff underestimate the difficulty carers are likely to experience in locating appropriate services in the community.<sup>46</sup> As identified in Zwygart-Stauffacher, Lindquist, and Savik's<sup>24</sup> trial of needs assessment tools for patients and carers in the United States, carers need specific advice about care management and regular follow-up to help them maintain the rehabilitation process once the patient has returned home. This was crucial in potentiating ongoing recovery, satisfaction with services, and feelings of well-being for both client and carer.<sup>47-49</sup> In these studies, even though family carers differed in their preference for the source of the information they received, it is clear they do need a great deal more information than is offered.

### Importance of Follow-up Support Services

Studies show a deterioration in patients who cannot access formal care services, even when informal care is available.<sup>50</sup> According to research conducted over 1 year with nurses providing support services to 101 postdischarge stroke patients and families in the United Kingdom, content analysis of the nurses' clinical notes indicated that there were ongoing and varied support needs for both groups, for at least the first 12 months.<sup>12</sup> Given the many needs of families in their caring roles, there is likely to be a lack of fit between what they want and need and the degree and form of services available.<sup>51</sup> It is insufficient for health providers to meet information needs only. Casas<sup>52</sup> found that the provision of information to carers prior to discharge does not significantly affect their ability to cope. Improved knowledge about stroke does not necessarily lead to improved emotional health for carers; emotional health is more likely to relate to levels of anxiety.<sup>53</sup>

Australian research that used a range of validated stress, anxiety, and health scales has shown a high level of emotional distress among 300 carers a year after the stroke. Many of these carers claimed to have unmet social and emotional needs.<sup>54</sup> It appears that carers' challenges relate less to managing the physical needs of their relatives than to dealing with their feelings of anxiety or uncertainty, in managing their time, and in adjusting to changing relationships.<sup>55</sup> They also claim to having insufficient time to meet personal and leisure needs.<sup>54</sup> Van der Smagt-Duijnste, Hamers, and Abu-Saad<sup>56</sup> interviewed 17 relatives of hospitalized stroke patients in Scandinavia who reported

similar needs to those described previously for the postdischarge period, in particular, the need for information, communication with staff, and access to support services. Rosenthal, Pituch, Greninger, and Metress<sup>57</sup> found that during the acute care phase, wives of stroke survivors perceived the following as their most important needs: knowledge of how they could assist with their husband's care, inclusion in discharge planning, the feeling that nursing personnel cared about their husband, and knowledge about what activities their husband would be able to do after discharge. These wives perceived that two thirds of their needs were not being met well by hospital nursing staff.

In identifying precisely what family carers and stroke patients need during the rehabilitation period, Dowswell, Lawler, and Young<sup>58</sup> reviewed 101 patient clinical records and communicated with the patients and their families over the 12-month rehabilitation period. They found that flexible, individually tailored follow-up intervention and support from health staff was required to achieve planned rehabilitation goals. In Anderson et al.'s<sup>10</sup> randomized control trial of an early discharge and home-based rehabilitation scheme for 86 stroke patients, supported home-based rehabilitation was shown to be a means of preventing unplanned readmission, especially for patients with long inpatient rehabilitation as well.

Information packs about stroke and rehabilitation processes have been found to be useful in providing home-based support.<sup>59</sup> These packs need to be individually customized, depending on the educational level and health status of patients. After examining the information needs of 35 stroke survivors and their families with higher levels of education, van Veenendaal et al.<sup>35</sup>

found that they were not given as much information in prepared packages as they required. There are apparent differences in information needs according to prior experience with stroke<sup>60</sup> and severity of disease and dysfunction.<sup>61</sup> Carers of stroke survivors who have suffered more than one stroke report that they receive more information than they desire.<sup>35</sup> Provision of detailed and clearly presented written information—in an accessible language<sup>36</sup>—has been found to be most effective when it is individualized and addresses the needs and concerns of individual patients.<sup>62</sup> These findings support Dowswell et al.'s<sup>12</sup> suggestion that individually tailored support programs are the most effective means of assisting patients with rehabilitation.

### **Research on the Needs of Older People from NESBs Who Experience Stroke and Their Family Carers**

Persons from NESBs in Australia have been identified as fitting into one of two types<sup>63</sup>: persons who came mostly from Europe in early adulthood, and persons who have apparently adapted to Australia. Persons who have adapted to Australia find themselves losing their English language abilities in later life and longing for their cultural roots. They may experience feelings of disorientation in times of illness, such as when suffering a stroke, or in periods of declining independence. Persons who came from Europe in early adulthood include more recent arrivals who came to Australia as part of either the family reunion or refugee programs. Rapid migration may occur without the psychological and physical capacity to cope with it, hence these people may be bewildered, poor, and/or illiter-

ate. They may lack English language skills, which can become a major barrier to getting information about and access to aged care services.<sup>64-66</sup> In these cases, communication with health care providers becomes difficult and the context is ripe for misunderstanding and potential neglect.

Given the evidence of the physical, psychological, emotional, and social issues that weigh down the “typical” stroke survivor and their family carers within the first 1–2 years after a stroke, the situation for people from non-English-speaking countries is likely to be worse. Their situation worsens if they are unable to raise questions and concerns to health care staff about side effects, the range of services available, or how to receive support in a timely and appropriate way.

A computerized literature search using Medline, PubMed, CINAHL, and PsycINFO shows a significant number of studies on the relationship between stroke and ethnicity (although because definitions and uses of the term *ethnicity* are not clear, it is assumed that NESB status of the study populations is a significant feature in distinguishing different ethnicity in English-speaking populations). These studies, however, focus largely on biological or genetic relationships between stroke and ethnicity or epidemiological descriptions of stroke in different ethnic groups. There is very little research on issues relating to the needs of or health service provisions for stroke survivors from NESBs and their carers.

In their literature review on family caregiving for patients with stroke, Han and Haley<sup>67</sup> conclude that more research needs to consider the caregiver's physical health in relation to ethnicity and caregiver interventions. In a qualitative study conducted

in the United Kingdom, using interviews with Asian ( $n = 15$ ) and non-Asian ( $n = 13$ ) stroke survivors and their carers, Perry, Hsu, Brooks, and Cherry<sup>68</sup> state that persons of Asian (Indian, Pakistani, or Bangladeshi) descent have similar unmet information needs as non-Asians. Both groups reported deficient information on recovery and on the type and range of services available and difficulties with identifying health professionals responsible for their care. Although both groups wanted more reassurance, advice, and emotional support, the psychological impact of stroke on patients and their family carers, such as feelings of isolation and depression, was more commonly found in persons of Asian descent.<sup>68</sup>

Lui and Mackenzie<sup>69</sup> used an ethnographical approach to examine how Chinese elderly stroke survivors in Hong Kong perceive their rehabilitation needs in three different stages: acute care, rehabilitation settings, and 1 month postdischarge. Patient needs were categorized into the following areas: informational, physical, psychological, social, and spiritual. Information on the etiology of stroke and the activities promoting recovery was the most frequently stated, but largely unmet, need throughout all three stages.<sup>69</sup> It is not known whether there is a significant difference between the needs of stroke survivors from NESBs and their carers and persons of English-speaking decent because of a paucity of research in this area. Even though the need for general information in managing stroke may be an equally important issue for both groups, the way these needs can be met may be different. As asserted by Lui and Mackenzie,<sup>69</sup> culture may play a significant role in the process of varying stages of recovery from stroke. For instance, with collectivism pre-

dominant in traditional Chinese culture—in contrast to individualism of Western culture—older Chinese in particular are mostly passive in seeking help and information from others.<sup>69</sup> This passivity can pose problems for health service providers in identifying and understanding the needs of their clients (patients and carers); this difficulty can be compounded by the language barrier. A cultural sensitivity with an understanding of people with NESBs may help health professionals in their care planning and implementation and can further assist with the development of health care services and resource allocations that meet the needs of different ethnic groups.

No research studies were found that focused on the follow-up needs of stroke survivors from NESBs and carers in Australia. Over the next 2 years, we will continue to research the follow-up health service requirements and experiences of groups from NESBs most likely to survive a stroke so that service providers are in a better position to provide information packages and support programs that meet the particular needs of these cultural groups. It is clear that the dearth of information and support for stroke sufferers and their families needs to be countered quickly if their concerns and unmet needs are to be redressed and quality services, across the continuum of care, are to be delivered.

## Conclusion

Both a lack of information and poor communication appear to be the major contributors to stroke survivors' and their carers' unmet needs. This is apparently the case whether these people are native-born or immigrant. However, in the latter instance,

lack of knowledge of the health and community services system and lack of information in the native language is likely to contribute to a greater share of unmet needs and a greater sense of isolation and alienation. This is particularly relevant for older people whose English language skills are being lost as they age.

Research needs to be undertaken as part of a stroke community needs assessment to identify how people with a stroke and their carers perceive their needs for support and information at different stages after stroke.<sup>13</sup> This is now happening in one large area of Sydney, Australia. We have recently completed the first of the four-staged study conducted in the South Eastern Sydney Area Health Service, NSW, Australia, with four of the largest groups from NESBs (Greek, Italian, Chinese, and Hungarian) who have suffered a recent stroke in this region.

Bilingual speakers were integral members of the research team, who surveyed and interviewed clients and close family in their homes up to 12 months after hospital discharge. In Stage 2, once the data on stroke follow-up needs and experiences of these groups become available, service models will be devised to overcome any shortfall in informational needs for people from NESBs. Stages 3 and 4 will be conducted with a second cohort from these particular groups from NESBs who then will have been using revised services from Stages 1 and 2. A process of ongoing data analysis and reporting back to services will continue for a 12-month period. Research such as this will necessitate the provision of coordinated and integrated services from the time the patients are in hospital to their first weeks and months discharged back to their homes.

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