

# Written Education Materials for Stroke Patients and Their Carers: Perspectives and Practices of Health Professionals

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Inadequacies in the provision of written education materials to stroke patients and their carers have been reported. In this study, 20 stroke team health professionals were surveyed regarding their use of and perspectives on written education materials. Seventy percent of participants provided materials to 25% or fewer stroke patients and 90% believed that patients and carers are only occasionally or rarely provided with sufficient written information. Health professionals were uncertain which team members provided written information and identified the need to improve the quality of materials used. Stroke teams should implement a system that facilitates the routine provision of quality written materials to patients and carers, communication among team members, and documentation and verbal reinforcement of the information provided. **Key words:** *health professional, patient education, stroke, written education materials, written information*

The importance of providing information to stroke patients and their carers has been well documented.<sup>1-3</sup> Education has the potential to enhance knowledge, reduce anxiety, influence behavior, and empower individuals.<sup>3</sup> Education also has an important role in secondary stroke prevention and facilitating the successful self-management of this chronic disease. Inadequate provision of information and poor communication while in hospital and following discharge are the main areas of dissatisfaction for stroke patients and their carers.<sup>4,5</sup>

There are a variety of formats that health professionals can use to educate patients and carers. One of these is written materials, which have a number of advantages. They offer message consistency, aid recall, and clarify verbal information, and they can be referred to when required.<sup>6,7</sup> Ideally, written education materials should be used as an adjunct to, rather than a substitute for, verbal education.<sup>8,9</sup>

Many stroke patients and their carers are dissatisfied with the amount and quality of written information provided to them.<sup>10,11</sup> Wellwood et al.<sup>11</sup> interviewed stroke patients and carers approximately 4 weeks post discharge and found that only 12% of patients and 15% of carers had received any written materials. Of those who had not re-

ceived any written information, 53% of patients and 75% of carers would have liked to. Stroke-related topics that are most frequently sought by patients and carers are reported to be prevention of further stroke, causes of stroke, risk factors, effects

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of stroke, where to source further information, and available services.<sup>1,7,10,12,13</sup>

Patients' and carers' informational needs change over time.<sup>7,10</sup> Although there is no consensus about the ideal time to provide education after stroke, anxiety can make it difficult for patients and carers to retain information in the period immediately following the stroke.<sup>14</sup> This emphasizes the important role of written information as a supplement to verbal information to aid recall during this period.<sup>12</sup>

In addition to concerns about the quantity of information provided to people who have had a stroke, the quality of the written education materials provided has also been investigated.<sup>13,15,16</sup> Written education materials can only be effective if they are able to be read and understood by the intended recipients. The comprehensibility of written materials is influenced by their reading level and the patient's reading ability. Furthermore, factors such as layout, graphics, literacy demand, and cultural appropriateness can affect the suitability of the design of written health education materials.<sup>17</sup> Although there are published guidelines<sup>18</sup> that provide recommendations regarding the desired reading level of written health education materials, no research has investigated whether stroke health professionals consider the reading level and design of the written education materials before distributing them to patients and carers.

Despite numerous studies that have considered the inadequacies in the provision of information to stroke patients and their carers, health professionals' use and perceptions of written education materials with stroke patients and carers have not been explored. In a study of the educational needs of stroke survivors and their family members from their perspective and the perspective of health professionals, the topics that health professionals thought should be provided to patients and families were different from the topics that patients and families indicated they wanted to know about. According to the findings of Sharry et al.,<sup>19</sup> patient characteristics can influence health professionals' decision to use written education materials with particular patients. In their study of the use and perceptions of written education materials by occupational therapists, the patient's education level was a stronger influence on therapists' decision to

provide written materials than other factors such as age or past health history.

The provision of education to stroke patients and their carers should be an integral part of any poststroke intervention. However, if quality written materials are to be used effectively by health professionals, an understanding of their perceptions and patterns of use of these materials is necessary. This will help bridge the gap between the informational needs of stroke patients and the actual provision of information by health professionals. The aims of this study were to examine, from the perspective of health professionals who work in acute stroke teams,

1. What information they provide to stroke patients and their carers, when, and why;
2. Their perceptions of the effectiveness and quality of written education materials; and
3. Their perceptions of the optimal use of written education materials with stroke patients and their carers, in terms of content, timing, and method of distribution.

## Method

### Participants

Participants were health professionals from three major hospitals in the greater Brisbane (Queensland, Australia) area. Participants were eligible for inclusion if they were members of a multidisciplinary stroke team. Targeted health professionals included dietitians, medical staff, nurses, occupational therapists, physiotherapists, social workers, and speech pathologists who were present at team meetings on the day of data collection.

### Procedure

Two of the authors (C.H., S.W.) attended a scheduled meeting of each stroke team and distributed questionnaires to all members of the stroke team who were present at the meeting. Completed questionnaires were collected at the next scheduled meeting of the stroke team. Approval to undertake this study was provided by university and hospital committees. Written consent was obtained from participants prior to their involvement.

## The questionnaire

The questionnaire used in this study was based on previous questionnaires used to explore patients' perspectives about the written stroke education materials they receive<sup>13</sup> and the perspectives of occupational therapists about the written materials they distribute to patients and families.<sup>19</sup> A copy of the questionnaire is available on request from the authors. The questionnaire contained four sections:

1. Participants' demographic and caseload details (health profession, gender, postgraduate qualification, years of clinical experience, and years working in stroke teams);
2. Participants' patterns of use of written education materials;
3. Participants' perceptions of the effectiveness and quality of written education material; and
4. Participants' perceptions regarding the optimal use of written education materials.

In section two, participants were asked about the proportion of stroke patients to whom they provide written information, the timing of and reasons for providing this information, the type of written materials provided, whether they discuss the information with the patient, and if they assess the readability of the written materials. Participants were also asked about the patient characteristics they consider prior to deciding whether to use written materials with a particular patient, how often they provide written information to patients' family members and/or carers, and whether this information differs from the information provided to the patient.

In section three, participants rated the overall quality, presentation, and content of the written materials they distributed to patients and carers on a scale from 1 to 10 (where 1 = *very poor* and 10 = *excellent*) and were asked if they had received feedback about the written materials from patients and carers. They were asked if they believe that written materials can have a positive impact on the health outcomes of stroke patients, if patients and carers generally read the information, and if patients and carers are provided with sufficient written education materials by the stroke team.

Section four asked participants to identify and rank which professions in the stroke team they

believe provide the most written education materials to patients (where 1 = *provides the most information* and 7 = *provides the least information*), which professions should provide the most written information, and from which professions they believe patients would prefer to receive written information. Participants indicated the topics about which they felt it was important for patients and carers to receive written information (during acute care and after discharge) and what would assist them to use more written education materials with patients and carers.

## Data analysis

Data were analyzed descriptively using the Statistical Program for the Social Sciences (SPSS, Inc., Chicago, IL). Responses to open-ended questions were analyzed according to common themes.

## Results

### Demographic and caseload characteristics

The demographic and caseload characteristics of the 20 health professionals who completed the questionnaire are presented in **Table 1**. All seven targeted health professions were represented. The majority of participants were female (80%) and had fewer than 5 years' experience working in stroke teams (85%). Fifty-five percent had fewer than 10 years clinical experience.

### Health professionals' patterns of use of written education materials

Most participants ( $n = 14$ ; 70%) provided materials to 25% or fewer stroke patients in their caseload. Of these, five participants (25%) reported never providing written education materials to stroke patients. Of the 14 participants who reported providing written education materials to stroke patients, 11 (55%) did so just prior to discharge and 7 (35%) at discharge.

The most frequently provided types of written materials were information/booklets produced by the participant's own stroke team or hospital (70% of participants), patient leaflets from organizations such as the National Stroke Foundation (55%), and customized proformas or handouts (55%)

**Table 1.** Demographic and caseload characteristics of the participants

Demographic and caseload characteristics		n (%)
Health profession	Occupational therapist	4 (20)
	Physiotherapist	4 (20)
	Nurse	3 (15)
	Speech therapist	3 (15)
	Doctor	2 (10)
	Social worker	2 (10)
	Dietitian	2 (10)
Gender	Female	16 (80)
	Male	4 (20)
Postgraduate qualification	Yes	7 (35)
	No	13 (65)
Years of clinical experience	Less than 10 years	11 (55)
	10–19 years	2 (10)
	20–29 years	4 (20)
	30–39 years	3 (15)
Years working in stroke teams	Less than 3 years	12 (60)
	3–5 years	5 (25)
	6–9 years	1 (5)
	Greater than 9 years	2 (10)

such as exercise sheets. The majority (75%) of health professionals either frequently or always discussed the written information they provided with the patient. Nine (45%) participants had assessed the reading level, either formally or informally, of the written education materials.

Just over half of the participants (55%) frequently provided written information to family members. Sixty percent of participants reported that the written information they provide to family members differed from the written information they gave to patients. Typically the information differed in terms of either comprehensiveness, with family members given more detailed information, or content, with family members more likely to be provided with information about available services. Most participants (90%) believed that patients and family/carers were only occasionally or rarely provided with sufficient written education materials by the stroke team.

Most participants provided written education materials to help patients remember information that had been presented verbally (ranked as main reason by 55% of participants) and to pass on

**Table 2.** Patient characteristics influencing participants' decision to provide written materials

Characteristic	n (%)
Cognitive abilities	18 (90)
Visual abilities	17 (85)
Severity of stroke	17 (85)
Perceptual abilities	16 (80)
Level of communication	15 (75)
Primary language	15 (75)
Motivation/attitude to recovery	13 (65)
Prognosis	12 (60)
Family communication skills	12 (60)
Mini-Mental State Examination score	12 (60)
Age	11 (55)
Rehabilitation referral possibility	11 (55)
Hearing abilities	11 (55)
Living setting	10 (50)
Education level	10 (50)
Living situation	9 (45)
Physical abilities	7 (35)
Past health history	6 (30)
Occupation	5 (25)
Length of hospital stay	5 (25)
Gender	4 (20)
Financial status	3 (15)

information to family and carers (ranked as main reason by 30% of participants) who are often not present during therapy times and doctors' rounds. Only one participant indicated that the main reason for using written education materials was to provide patients with information that she did not have time to discuss.

The patient characteristics that were considered by most participants prior to deciding whether to use written education materials included cognitive abilities, severity of stroke, visual abilities, perceptual abilities, communication abilities, and primary language. **Table 2** displays the number and proportion of participants indicating the influence of patient characteristics on their decision to provide written materials.

### Health professionals' perceptions of the effectiveness and quality of written education materials

When rating the written education materials available for their use, participants' mean scores were 6.4 (*SD* 1.7; range, 3–9) for content, 6.4 (*SD*

1.3; range, 4–9) for presentation, and 6.0 (*SD* 1.8; range, 3–9) for the overall quality. All but two of the participants (90%) believed that patients and carers read the written education materials provided to them. Nearly all participants (95%) felt that written education materials can have a positive impact on the recovery and/or health outcomes of people who have had a stroke. When participants were asked to expand on how written materials could have a positive impact, common themes were that written materials increase understanding, reduce anxiety, improve motivation, and enable patients and their families to make informed decisions.

### Health professionals' opinions about the optimal use of written education materials

Regarding the timing of providing written education materials to patients, 60% of participants believed that materials should be distributed frequently or always in the acute care phase, 85% indicated that materials should be distributed frequently or always in the rehabilitation phase, and 75% of participants reported that written education materials should be provided either frequently or always just prior to discharge. Only 10% of participants reported that written education materials should be provided either frequently or always at 6 months post discharge.

When participants ranked the different professions in the stroke team on the amount of written information they provided to patients and carers, occupational therapists, social workers, and speech pathologists were considered to be the most prolific providers of written information, while doctors were ranked as providing the least amount of written information to patients. **Table 3** presents the mean ranking for each health profession.

The majority of participants (65%) identified occupational therapists, physiotherapists, speech pathologists, and social workers as the health professionals from whom patients and carers preferred to receive written education materials. This was explained in terms of patients wanting information on the management of impairments and available services and how to continue therapeutic interventions after discharge.

**Table 4** shows participants' perceptions of the

**Table 3.** Participants' perceptions of the professionals providing the most written education materials to patients

Health professional	Mean rank [1 – 7 <sup>a</sup> ] ( <i>SD</i> , range)
Occupational therapist	2.40 (1.35, 1–5)
Social worker	3.00 (2.27, 1–7)
Speech pathologist	3.13 (1.73, 1–6)
Physiotherapist	3.87 (1.41, 1–6)
Nurse	4.31 (1.74, 1–6)
Dietitian	4.66 (1.40, 2–7)
Doctor	6.59 (1.06, 3–7)

<sup>a</sup>Where 1 = provides the most information and 7 = provides the least information.

topics on which stroke patients should receive information during acute care and after discharge. In the acute care phase, the most frequently identified topics were the following: what is stroke, what are the causes of stroke, and what to expect in rehabilitation. After discharge, the most frequently identified topics were stroke support groups, community services available, effects of stroke on family or marriage, and where to obtain further support/information.

Participants reported that their use of written education materials would be facilitated if they had more knowledge about and support in the development and design of written materials (75% of participants), if they had more time to retrieve/organize information (65%), and if they had greater knowledge of where and how to access written materials (60%).

### Discussion

This study aimed to examine current practices in the provision of written education materials to stroke patients and their carers from the perspectives of health professionals working in acute stroke teams. The results of this study highlight the small proportion of patients who are provided with written education materials by stroke unit health professionals. Most participants in this study reported that they provide written materials to 25% or fewer stroke patients in their caseload. This finding is supported by Hoffmann et al.<sup>13</sup> who found that only 23% of stroke patients reported

**Table 4.** Participants' perceptions of the topics about which clients with stroke should receive written information during acute care and after discharge

Topics	Acute care	After discharge
	n (%)	n (%)
What is a stroke	19 (95)	1 (5)
Causes of stroke	18 (90)	4 (20)
What to expect in rehabilitation	18 (90)	2 (10)
Stroke risk factors	17 (85)	6 (30)
Treatment available after stroke	17 (85)	5 (25)
Medications prescribed after a stroke	17 (85)	8 (40)
Effects of stroke (e.g. physical, cognitive, communication, swallowing, incontinence, behavior, etc.)	17 (85)	4 (20)
Equipment and aids necessary after stroke	17 (85)	8 (40)
Information about exercises/activities to do after a stroke	15 (75)	11 (55)
Tips for performing self-care tasks	15 (75)	5 (25)
Helpful tips for carers	14 (70)	12 (60)
Financial information following stroke (e.g., benefits and allowances)	13 (65)	11 (55)
Recovery after a stroke	12 (60)	12 (60)
How to prevent further strokes	12 (60)	11 (55)
What to expect at home	12 (60)	12 (60)
Tips for performing household tasks	12 (60)	8 (40)
Effects of stroke on family and/or marriage	11 (55)	14 (70)
Legal information following stroke	9 (45)	10 (50)
Community services available to stroke patients	9 (45)	15 (75)
Information about healthy living (e.g., tips for exercising, healthy eating, quitting smoking)	9 (45)	12 (60)
Returning to driving	8 (40)	13 (65)
Stroke support groups	7 (35)	17 (85)
Returning to community activities	6 (30)	13 (65)
Where to obtain further support/information	5 (25)	14 (70)

receiving written information about stroke while in a hospital stroke unit.

Numerous studies have reported that people who have had a stroke and their carers are dissatisfied with the amount of information provided to them and that the informational needs of stroke patients and their carers are not being met by current practice.<sup>1,7,11-13</sup> The finding in this study that 90% of participants indicated that patients and their families are only occasionally or rarely provided with sufficient written education materials by the stroke team suggests that health professionals are aware of the inadequacies of current practice. Although not specifically focused on written information, the health professionals in van Veenendaal et al.'s study<sup>12</sup> were also concerned about the provision of information, with only 7.1% of health professionals perceiving that patients received the right amount of information.

The most common reason for participants to

provide written education materials was to help patients remember information that had been conveyed verbally. Few participants indicated that their reason for providing patients with written information was to provide information that they did not have time to discuss with the patient/carers. Supplementing written education materials with verbal information is the method considered most effective in enhancing recall of information<sup>9,20</sup> and is the method preferred by patients.<sup>21</sup>

The majority of health professionals in this study believed it was most appropriate for stroke patients to receive information during acute care, rehabilitation, and at discharge. Few indicated that written materials should be provided 6 months post discharge. These findings reflect those obtained by Hoffmann et al.<sup>13</sup> who investigated current practice in the provision of written information from the perspectives of the patients and carers. Only 6% of patients reported receiving writ-

ten information between hospital discharge and a follow-up interview at 6 months post discharge. However, 75% of the patients and all of the carers indicated that they wanted to receive further information at this stage, with most patients identifying written information as their preferred method for receiving additional information. Hanger et al.<sup>10</sup> also found a high proportion (80%) of stroke patients with unanswered questions at 6 months post stroke. The low proportion of health professionals in this study that endorsed the need for patients to receive written information post discharge may indicate a lack of understanding of patients' continuing informational needs post discharge. It may also reflect the role of stroke unit health professionals, which typically does not involve ongoing contact with patients following their discharge. The provision of information needs to extend well beyond the hospital phase.<sup>3,13</sup> Possible mechanisms for patients and carers obtaining information post discharge are stroke support groups, general practitioners, quality-assured websites, and home visits from stroke family support workers.

Not only is information that is provided post discharge likely to be relevant to the current problems that the patient or carer is experiencing, but it also provides an additional opportunity for secondary prevention education. Information about how to prevent another stroke has been reported as patients' and carers' most desired topic,<sup>12,13</sup> yet this informational need is often not met by health professionals. In this study, only 60% of health professionals responded that written information about secondary prevention should be provided during acute care and 55% responded that it should be provided after discharge. Wellwood et al.<sup>11</sup> interviewed stroke patients and carers approximately 4 weeks post discharge and found that 70% of patients and 81% of carers thought they had received no information (verbal or written) about the risk of stroke recurrence. Given the high risk of stroke recurrence<sup>22</sup> and patients' endorsement of the importance of receiving information about this topic, it is surprising that a higher proportion of participants in this study did not believe that written information should be provided on this topic. It may well have been that participants discussed

this important information verbally with health professionals. Given the recognized difficulties that patients may have in recalling information that is presented verbally, the provision of reinforcing written information could only assist the education effort. A recent national audit of acute hospital stroke care in the United Kingdom led Rudd et al.<sup>23</sup> to conclude that major opportunities for secondary stroke prevention are being missed while patients are in hospital.

Comparing the findings of this study to those of Hoffmann et al.,<sup>13</sup> there appear to be discrepancies between the topics that health professionals and patients identify as most important. In this study, most health professionals identified that topics including what to expect in rehabilitation, tips for performing self-care and household tasks, equipment and aids, tips for carers, and financial information were the most important for patients. This compared to Hoffmann et al.'s<sup>13</sup> findings that patients wanted the most information about how to prevent further strokes and where to obtain further support and information.

No other studies have examined factors that influence stroke unit health professionals' decisions to provide written education materials to patients. However the patient characteristics that participants in this study considered when deciding to provide written information to stroke patients were similar to those reported in a study of occupational therapists' educational practices with older people.<sup>19</sup> Patients' cognitive ability was the most frequently identified characteristic in both studies. Other frequently reported characteristics in both studies were primary language, communication skills, and vision. Although there were similarities in the characteristics identified in both studies, other characteristics considered to be important influences on the decision to provide written information by participants in this study were stroke-related characteristics such as the severity of stroke and perceptual abilities. The possible influence of these characteristics on reading ability may explain why health professionals reported frequently giving more detailed information to family members than they did to patients. Health professionals should be cognizant of the potential for stroke-related impairments to influence reading ability and for each patient con-

sider whether written materials are appropriate. If written materials are used, those that have incorporated aphasia-friendly principles<sup>24</sup> and techniques for preparing written materials for low-literacy readers<sup>17</sup> and people with cognitive impairment<sup>25</sup> are recommended.

Occupational therapists, social workers, and speech pathologists were considered to be the most prolific providers of written education materials to stroke patients by the members of the stroke teams. This may be reflective of the amount of time that these professionals typically spend with patients. Tooth and Hoffmann<sup>26</sup> noted that therapists, who typically spend more time with patients in rehabilitation than doctors, may be in an optimum position to ensure that patients' informational needs are being addressed. It may also be reflective of the role of these health professionals in teaching specific tasks and providing information about services, as well as their commitment to client-centered practice, which recognizes the importance of informing clients to enable them to collaborate in decisions about their health care.<sup>27</sup> The fact that occupational therapists were the most prolific providers of information concurs with the results of other studies. In a survey of the treatment media that Australian occupational therapists who work in adult physical dysfunction settings use, education and counselling was ranked as the most frequently used treatment, with three quarters of the respondents stating that they use it often or most of the time.<sup>28</sup>

Participants from the same hospital provided varying answers to the question about which team member/s provides the most written information to patients and carers, indicating a lack of knowledge about their team members' practices. The low proportion of health professionals in this study who reported providing written information to patients and carers may be due to their assumption that other team members have or will do so. This is most likely to occur when education interventions are not formally documented or reported.<sup>29</sup>

### Practice implications

Increased communication between health professionals within the stroke team is essential to

ensure the appropriate and comprehensive provision of written education materials to stroke patients and their carers.<sup>26,30</sup> One team member could be responsible for providing generic written stroke information, which should be consistently reinforced by other members of the team. Further discipline-specific education could be provided by the relevant health professional. As well as having explicit practice guidelines for what, when, and how information should be disseminated to clients, it is important to document what has occurred so that all team members are informed. A checklist that forms part of the patient's medical file could easily be used as a log of the information that has been provided and discussed.<sup>30</sup>

For written education materials to be effective, they must be of adequate quality, readability, and presentation.<sup>31</sup> Copies of the written materials distributed by participants in this study were not collected and analyzed for their reading level and design, however participants' ratings of the quality, content, and presentation of the materials they used indicated that they could be improved. Less than half of the participants had assessed the reading level of the written materials they distribute, and most of those who did reported doing so only informally. Seventy-five percent of participants indicated that learning about how to design and develop quality written materials would facilitate their effective use of this educational medium. Health professionals should consider using a reading level assessment, such as the SMOG readability formula,<sup>32</sup> and design audit, such as the Suitability Assessment of Materials,<sup>17</sup> to determine the suitability of the materials they use and changes required to improve them.

Lack of access to written materials and time to retrieve and organize information were issues that the majority of participants identified as hindering their use of written materials. A number of participants suggested that a well-designed stroke information package, developed with input from patients, carers, and all members of the multidisciplinary team, that is used consistently across the country may assist in reducing the discrepancy between health professionals' actual and preferred practice. If this material could be accessed electronically, such as via the Internet, it

could be maintained, updated regularly, easily accessed, and adapted for individual patients and carers.<sup>33</sup>

### Limitations

A number of limitations of this study should be acknowledged. The small sample size of only 20 health professionals from three hospitals within the same metropolitan area limits the generalizability of the results. The validity and reliability of the questionnaire has not been established and the self-report nature of the questionnaire resulted in a small amount of missing data for some questions. As this was a retrospective study, the responses obtained from the participants were subject to recall bias. Because occupational therapy was the discipline of both the health professionals found to provide the most information to patients and the authors of this study, this issue requires consideration as a potential bias when interpreting the results.

### Future research

Further research is needed to explore the reasons why health professionals provide written education materials to only a small proportion of stroke patients and their carers, despite their acknowledgement of the importance of this infor-

mation medium and their awareness that these materials are provided infrequently. Research into the optimal method of stroke unit team members providing education that is comprehensive yet individualized to patients and their carers is needed. Exploration of effective methods of facilitating health professionals' development and use of well-designed written education materials would be valuable.

### Conclusion

This study supports findings in the literature that a low proportion of patients are provided with written education materials by stroke unit health professionals. As revealed in this study, health professionals recognize the inadequacies of current practice and there appears to be a lack of understanding about who in the stroke team provides written information. Strategies are needed to ensure that patients and carers receive comprehensive education while in hospital and after discharge and that health professionals have access to and the skills to prepare high quality written education materials. Increased communication between health professionals within the stroke team and documentation of information provided are also essential to ensure the appropriate and comprehensive provision of written education materials to stroke patients and their carers.

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