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Delivery styles and formats for different stroke information topics:
patient and carer preferences

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Abstract

Objective

To identify the preferences of patients with stroke and their carers for format and delivery style, of different categories of stroke information, and whether these preferences changed over time.

Methods

A semi-structured questionnaire, designed to explore preferences for four topic categories was administered to 34 acute stroke unit patients and 18 carers prior to discharge and again, 3 months after discharge to 27 of these patients and 16 of these carers.

Results

Overall format preferences were a combination of face-to-face, written and telephone for both patients and carers prior to discharge. This combination continued for carers following discharge, while patients preferred face-to-face, written and alternative formats of online and audiovisual at this time. Patients and carers most frequently preferred delivery styles appeared to be a mix of active and passive delivery styles, across all topics. Access to a telephone hotline was a popular delivery style.

Conclusion

Patient and carer preferences varied, supporting the need to offer a variety of formats and delivery styles at each point of contact.

Practice implications

By focusing on specific formats and delivery styles for different topics, health professionals may maximise the access to, and relevance of, stroke information for patients and their carers.

1. Introduction

International guidelines recognise the importance of providing information after stroke, but offer little direction on how, where or when this provision should occur {National Stroke Foundation, 2007 #291; Intercollegiate Stroke Working Party, 2004 #358; Duncan, 2005 #873}. Stroke patients and their families need and want information after stroke {Hoffmann, 2004 #29; Hanger, 1998 #13; Wellwood, 1994 #16} but the desired type and format of information can vary from person to person according to individualised circumstances, such as prior knowledge and time since stroke. Therefore, identifying preferred content, format and delivery style of desired information will allow tailoring of educational opportunities to suit individualised needs.

In identifying desired content of stroke information, Wiles et al. found information was desired under three broad categories: practical information, information about continuing care and resources, and clinical information {Wiles, 1998 #107}. Practical information may include strategies to assist in the day-to-day management of stroke impairments, returning to daily activities, exercises, and equipment. Information regarding continuing care and resources may include available community services, legal and financial benefits, and sources of additional information. Clinical information may include an explanation of stroke and its effects, prognosis and treatment. While information relating to secondary stroke prevention may be considered under this clinical category, given the often detailed healthy lifestyle advice it incorporates {National Stroke Foundation, 2007 #291}, it may best be considered a category in its own right. Therefore, stroke information can be

broadly categorised into four topics: clinical, practical, services and benefits available and healthy lifestyle.

Several studies have explored both the topics and formats desired by stroke patients and their carers {Hoffmann, 2004 #29;Garrett, 2005 #74;Wachters-Kaufmann, 2005 #73;Hanger, 1998 #13;van Veenendaal, 1996 #44;Wiles, 1998 #107} {National Stroke Foundation, 2007 #318}. Garrett and Cowdell found that over the first 3 months post-stroke, patients and carers' information needs expanded and diversified from clinical information to include practical information about available services and benefits {Garrett, 2005 #74}. Hoffmann et al. also found that clinical information, healthy lifestyle information, and information about services and benefits available were frequently desired topics while in hospital, with the latter remaining as a frequently desired topic six months post-discharge {Hoffmann, 2004 #29}. Finally, Wachters-Kaufmann et al., found that 12 months after stroke, both patients and carers regarded clinical information as the most important {Wachters-Kaufmann, 2005 #73} type of information that they had needed.

These studies, along with others, demonstrate that information needs of stroke patients and their carers change over time. But the format preferences for receiving information in these studies appear more consistent over time. These studies describe participant preferences for a primarily verbal format, that is supplemented by a secondary format, like written or audiovisual at several points in time post-stroke {Hoffmann, 2004 #29;Wachters-Kaufmann, 2005 #73;Garrett, 2005 #74}.

One issue not considered by these studies is whether format preferences vary according to the topic that is being conveyed. For example, for practical management strategies such as how to assist a person with hemiplegia to transfer from sitting to standing, carers may prefer to receive this information in an audiovisual format with verbal supplementation, rather than a verbal-only explanation, whereas clinical information such as the risk factors for stroke may be best explained verbally and supplemented with a written summary that can be referred to at a later stage. While the previous studies reported stroke patients' and carers' desired topics and formats, format preferences have only been explored broadly, typically with one global question that addresses all topics collectively. No studies have explored in depth whether patients' and carers' format preferences vary according to different categories of stroke information and whether these preferences change following hospital discharge.

In addition to the format that is used to provide stroke information, the teaching or delivery style that is used should also be considered. When providing information, it is generally recommended that individuals' preferred delivery style should be considered in order to maximise their motivation to learn, as well as their ability to process and recall information {Van Wynen, 2001 #172;Duffy, 1998 #769;Arndt, 1990 #774;Chase, 2001 #776} and several studies have reported making a variety of learning experiences available to patients and their families {Denby, 2003 #26;Schure, 2006 #5}. Interactive delivery styles that encourage active participation of the person

who is receiving the information, such as discussion, hands-on training and self-management are recommended over more passive interventions, such as written information only or didactic interventions {Smith, 2008 #303;National Stroke Foundation, 2007 #291;Kalra, 2004 #50;Kendall, 2007 #190;McKenna, 2006 #353;Rankin, 2005 #348;Janz, 2002 #343}. No research has explored the delivery style preferences of stroke patients and carers.

Identifying patients' and carers' preferences for both format and delivery style across topic categories, and whether, like informational needs, they change over time, would enable the educational experience to be tailored according to individuals' needs. Interventions that are tailored to individual patients have been found to have increased effectiveness {van der Meulen, 2008 #894;Strecher, 1999 #907}. This study aimed to (a) identify the stroke patients' and carers' preferences, for content, format, delivery style, according to different categories of stroke information and (b) whether these preferences change over time.

2. Methods

2.1 Participants

Participants were patients admitted to a major metropolitan hospital acute stroke unit in Brisbane, Australia, and their carers. Inclusion criteria were: (1) current acute stroke unit admission for stroke (first or subsequent), or caring for patient with same; (2) 18 years or older; (3) adequate English, cognition, communication, vision and hearing to provide consent and complete the questionnaire and (4) living within 50 km of the hospital (for ease of follow-up).

Patients were excluded if they had a poor medical prognosis, or were admitted from residential care or had residential care as the planned discharge destination. Carers were still invited to participate even if the patient was ineligible for the study due to criteria 3. Invitation of patients with aphasia to participate in the study was completed after consultation with the treating speech pathologist. Aphasia friendly principles, such as the use of pictures, white space, prompt sheets, gestures and repeating of information {Worrall, 2005 #286} were used throughout the consent process and interviews to maximise the understanding and participation of patients with aphasia.

2.2 Procedure

Ethical approval was obtained from the relevant hospital and university ethics committees. Suitable participants were identified by the acute stroke unit's multi-disciplinary team. Initial interviews were completed in the week preceding discharge from the acute stroke unit (mean 11.2 days since patient stroke, SD 8.6) with follow-up interviews completed approximately 3 months later (mean 102.4 days since patient stroke, SD 10.4). All interviews were conducted face-to-face by the lead author (SE).

2.3 Data collection and analysis

Data were collected via face-to-face interview and review of the patient's medical chart. Demographics details included type of stroke, number of previous strokes, stroke-related impairments, age, gender, living situation, relationship to stroke patient (for carer), and years of education achieved. In addition, the Rapid Estimate of Adult Literacy in Medicine (REALM) {Davis,

1993 #247} was administered to obtain an estimate of participants' reading ability. A REALM total score is interpreted as a grade equivalent, with scores of 0-18 approximating 3rd grade and below, scores of 19- 44 between 4th and 6th grade, scores of 45- 60 7th-8th grade and scores of 61- 66 9th grade and above.

As no suitable questionnaire was identified, a semi-structured questionnaire, with five sections, was designed for this study. The first section used a multiple response option (sourced from previous research {Hoffmann, 2004 #29;Hoffmann, 2007 #96}) to identify current information needs, according to four topic categories (clinical information, practical management strategies, services and benefits available, and healthy lifestyle information). The final four sections explored format and delivery style preferences, with one section for each of the four categories. Of these four category-specific sections, participants only completed those relating to the categories that they had identified as a current information need.

In each of these four sections, participants were asked to select their first, second and third preferences for media format (from the options of face-to-face, telephone, written, internet or audiovisual), and delivery style (from the options of didactic, the provision of a list of contact details, talking through written information , discussion, demonstration, role play, a telephone hotline and peer support). Examples of each of the options were explained to participants. A copy of the questionnaire is available from the authors on request.

Data were analysed using a combination of narrative reporting and descriptive statistics using SPSS version 15. Participants' top three format preferences were ranked, with first preferences scored as 3, second preferences as 2 and third preferences as 1, with scores totalled for each format, giving an overall score.

3. Results

Between November 2007 and June 2008, 132 patients and 44 carers were screened for eligibility. Initial interviews were conducted with 34 stroke patients and 18 carers and follow-up interviews were completed with 27 patients and 16 carers. Fig. 1 shows the flow of patients through the study.

[insert Figure 1 here]

3.1 Demographics

Demographic details of participants are presented in Table 1. For fifteen carers (83.3%), the patient was their spouse, and for the remaining three carers (16.7%), the patient was a family member (two patients being a parent and one being a sibling). Stroke-related impairments with the potential to impact on information processing such as visual perceptual difficulties, cognitive difficulties, and aphasia were recorded for seven (20.6%), eight (23.5%) and five (14.7%) patients respectively.

3.2 Desired content

The proportion of patients and carers who desired information from the four different topic categories is shown in Tables 2 and 3.

[insert Tables 2 and 3 here]

3.3 Desired format

The overall scores for format preferences are presented in Tables 2 and 3. Although the order of preference changed, face-to-face, written and telephone were the most frequently reported format preferences of both patients and carers across all topic categories, prior to discharge. This trend continued for carers at follow-up, with patients' third preference shifting, at follow-up to include audiovisual and internet as formats for receiving information.

With the exception of services and benefits information at follow-up, the most frequent format preference reported by patients was face-to-face. Carers reported a variety of format preferences across categories at both points in time. McNemar tests showed no statistically significant differences between the two points in time, indicating participants' preferred format did not vary significantly in the 3 months following discharge.

3.4 Delivery style

Table 4 demonstrates the three most preferred delivery styles both prior to discharge and at follow-up for both patients and carers.

For clinical information, both patients and carers mostly preferred a hotline, discussion and talking through written information. For service and benefits, both patients and carers most frequently desired the provision of a contact list, however, discussion as a preferred delivery style was noticeably absent for this topic category. Both patients and carers mostly preferred a hotline, discussion and a didactic delivery style for practical information. However, for healthy lifestyle information, there was no clear trend as to the preferred delivery style, with variation between the preferences of patients and carers and between the two points in time. McNemar tests showed no statistically significant differences between the two points in time, indicating that participants' preferred delivery style did not vary significantly in the 3 months following discharge.

4. Discussion and conclusion

4.1 Discussion

Overall, patients and carers most frequently preferred delivery styles appear to be a mix of active and passive delivery styles, across all topics. General health and stroke-specific education literature recommends interactive delivery styles over didactic delivery styles {Neufeld, 2006 #352;McKenna, 2006 #353;Rankin, 2005 #348;Janz, 2002 #343;Gallagher, 1999 #330}, but this study found that for some topics, such as information about services and benefits and healthy lifestyle information, patients and their carers preferred a didactic delivery style (for example being told directly). This could indicate that the more time-intensive interactive styles are not required for all topics of information, and a more efficient service provision could be achieved by

matching an individual's preferred delivery style to the topic of information being provided.

A telephone format ranked within the top three preferences for all topics. Of interest is this preference prior to discharge. It is understandable that carers with limited time or ability to visit the hospital during regular hours may appreciate telephone contact with a health professional if face-to-face contact is not possible. Using the telephone as a means to provide information has been suggested by the authors of other studies of stroke patients and carers. Schure et al. concluded that telephone contact should be offered in addition to their home visiting and group program interventions {Schure, 2006 #5} and Goldberg et al. reported that 95% of patients felt that telephone calls were as helpful, or more helpful, than the in-home visits in providing case-managed information and psychosocial support {Goldberg, 1997 #87}. In the current study a telephone format ranked within the top three preferences for all topic categories and many patients desired a telephone hotline as the delivery style. This finding suggests, where it is a suitable match with patients' and carers' abilities, telephone support should be offered in combination with the other two most frequently reported format preferences, namely face-to-face and the written provision of information.

Problem solving and role-playing were not frequently desired delivery styles, perhaps because of a lack of exposure to or prior experience with these styles. Although there are inconclusive results when applied to people with stroke {Lui, 2005 #66; Grant, 2002 #89} problem solving training is

recommended in general health education literature {Neufeld, 2006 #352;Baranowski, 2002 #349;Wenzel, 2002 #350;Roberts, 1995 #138} and perhaps these less traditional delivery styles would gain support if consumers were exposed to them. Alternatively, they may be suitable for a minority of patients with stroke and their carers.

Generalisability of the results of this study is limited by its small sample size and inclusion criteria. Further research is needed with a larger sample of patients with aphasia, and those with more severe levels of impairment, such as severe cognitive impairment, severe aphasia or those patients returning to residential care, because the delivery style may need to be tailored according to the nature and severity of the impairment. While these groups may prove difficult to study due to the nature of their neurological deficits, it is worth exploring the optimal way of modifying the communication of information to these people, in addition to pursuing supplemental information by proxy report of carers.

Future research could also explore the impact of other stroke-related consequences, such as depression or fatigue, which can also affect the uptake of information and were not a focus of the current study. Additionally, research that replicates and extends this study beyond a 3 month follow-up period post-discharge would also be valuable. Because stroke information needs continue to change over time {Hanger, 1998 #13;Hoffmann, 2004 #29;Garrett, 2005 #74;Wiles, 1998 #107}, it is possible that as patients and

carers become disconnected from the hospital service, that their preferences for receiving this information also change. Our recent study found that community-based services most frequently reported using an interactive delivery style and talking through written information in providing stroke information to patients and their carers {Eames, 2008 #562}, but whether this is suitable to stroke patients and their carers in the community is yet to be determined.

4.2 Conclusion

Patient and carer preferences for the format and delivery style of stroke information varied across different topic categories and at different points in time, supporting the need to offer a variety of formats and delivery styles at each point of contact. Consideration of these preferences would allow the tailoring of the education experience to stroke patients' and their carers' individualised needs. The results of this study were used to inform the design of an education and support package that can be tailored to stroke patients' and carers' needs and preferences. Evaluation of this package is currently underway in a randomised controlled trial.

4.3 Practice implications

The results of this study suggest that using a combination of face-to-face, written and telephone support to provide information is preferred by many stroke patients and carers. Providing written material is important prior to discharge and a few months post-discharge, across all desired topics, but

particularly for information about services and benefits. This study found that prior to discharge, there should be particular emphasis on providing carers with practical and healthy lifestyle information in written form. Prior to discharge, clinical information and information about services and benefits may best be delivered face-to-face, and access to a telephone hotline is a popular delivery style across all topics, by both patients and carers. By focusing on specific formats and delivery styles for different topics, health professionals may maximise the access to, and relevance of, stroke information for patients and their carers. Additionally, whether it is hospital or community-based services that are best suited to provide this post-discharge information requires further clarification, but regardless of their location in the continuum of care, services should strive to provide quality information, tailored to patients' and carers' preferences, at the time it is needed and wanted.

References

Legend

Figure 1: Participant flowchart

Table 1: Demographic details of participants at initial interview

Table 2 Patients' format preferences for each of four
topic categories

Table 3 Carers' format preferences for each of four topic categories

Figure 1 Participant flowchart

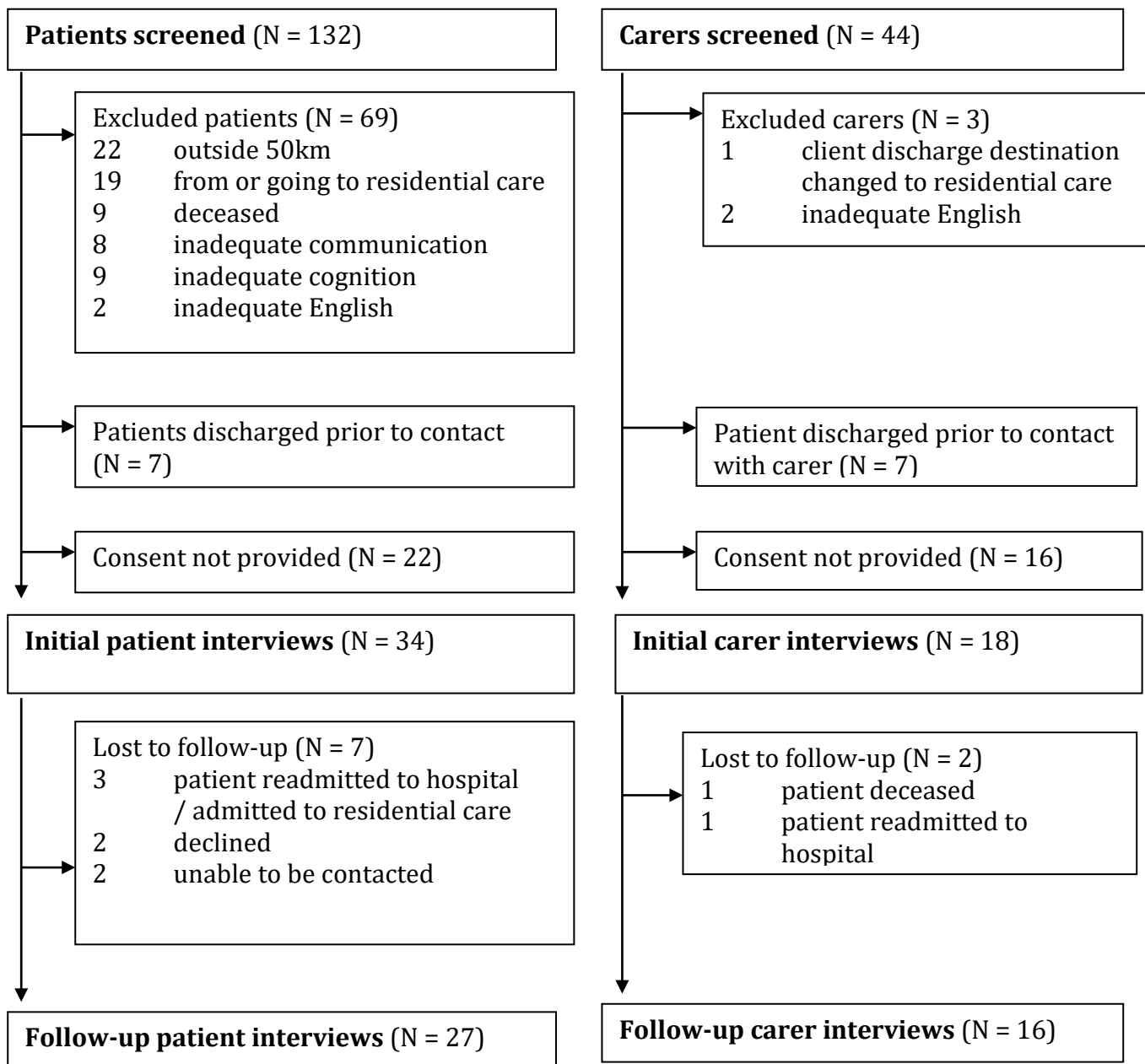


Table 1 Demographic details of participants at initial interview

	Patients (N = 34)	Carers (N = 18)
Female (%)	14 (41.2%)	13 (72.2%)
Age (years) – mean (SD), range)	63 (16.0, 28-85)	58 (26-77)
Years of education – mean (SD), range	12 (3.9, 7-22)	12 (7-24)
Mean REALM score (range)	61 (23-66) ^a	63 (52-66)
Living situation:		
Alone	7 (20.6%)	0
With spouse	22 (64.7%)	17 (94.4%)
With family or friend	5 (14.7%)	1 (5.6%)
First ever stroke:	27 (79.4%)	16 (88.9%)
Type of stroke:		
Ischaemic	23 (67.6%)	Not applicable
Haemorrhagic	11 (32.4%)	Not applicable
Side of stroke:		
Left	18 (52.9%)	Not applicable
Right	15 (44.1%)	Not applicable
Bilateral	1 (2.9%)	Not applicable

^a Two patients were unable to complete the REALM

Table 2 Patients' format preferences for each of four topic categories

Topic	Proportion of patients desiring topics prior to discharge (N=34)	Proportion of patients desiring topics at follow-up (N=27)	Format preferences	
			Three highest scoring media preferences prior to discharge (score)	Three highest scoring media preferences at follow-up (score)
Clinical	34 (100%)	19 (70.4%)	(1) Face-to-face (74) (2) Written (47) (3) Telephone (32)	(1) Face-to-face (36) (2) Written (30) (3) Audiovisual (16)
Services and benefits	30 (88.2%)	16 (59.3%)	(1) Face-to-face (68) (2) Written (41) (3) Telephone (32)	(1) Written (27) (2) Face-to-face (26) (3) Audiovisual (14) (3) Internet (14)
Practical	31 (91.2%)	15 (55.6%)	(1) Face-to-face (65) (2) Written (41) (3) Telephone (38)	(1) Face-to-face (27) (2) Written (23) (3) Internet (10)
Healthy Lifestyle	25 (73.5%)	12 (44.4%)	(1) Face-to-face (46) (2) Written (42) (3) Telephone (27)	(1) Face-to-face (26) (2) Written (18) (3) Audiovisual (11)

Table 3 Carers' format preferences for each of four topic categories

Topic	Proportion of carers desiring topic prior to discharge (n=18)	Proportion of carers desiring topic at follow-up N=16)	Three highest scoring media preferences prior to discharge (score)	Three highest scoring media preferences at follow-up (score)
Clinical	17 (94.4%)	13 (81.3%)	(1) Face-to-face (33) (2) Written (30) (3) Telephone (16)	(1) Face-to-face (25) (2) Telephone (20) (3) Written (17)
Services and benefits	16 (88.9%)	11 (68.8%)	(1) Face-to-face (30) (2) Written (29) (3) Telephone (14)	(1) Written (24) (2) Face-to-face (16) (3) Telephone (12)
Practical	14 (77.8%)	12 (75.0%)	(1) Written (30) (2) Face-to-face (25) (3) Telephone (14)	(1) Face-to-face (22) (2) Telephone (20) (3) Written (18)
Healthy Lifestyle	11 (61.1%)	6 (37.5%)	(1) Written (26) (2) Face-to-face (16) (3) Telephone (11)	(1) Face-to-face (13) (2) Telephone (12) (3) Written (7)

Table 4 Three most frequently preferred delivery styles of patients and carers according to each topic categories

Topic category	Patients		Carers	
	Prior to discharge	At follow-up	Prior to discharge	At follow-up
Clinical	<i>N</i> =34	<i>N</i> =19	<i>N</i> =17	<i>N</i> =13
	(1) Talking through written information (<i>n</i> =21, 61.8%)	(1) Hotline (<i>n</i> =12, 63.1%)	(1) Discussion (<i>n</i> =13, 76.5%)	(1) Hotline (<i>n</i> =9, 69.2%)
	(2) Hotline (<i>n</i> =19, 55.9%)	(2) Talking through written information (<i>n</i> =11, 57.9%)	(2) Hotline (<i>n</i> =9, 52.9%)	(2) Discussion (<i>n</i> =7, 53.8%)
	(3) Discussion (<i>n</i> =14, 41.2%)	(3) Discussion (<i>n</i> =10, 52.6%)	(2) Talking through written information (<i>n</i> =9, 52.9%)	(3) Didactic (<i>n</i> =5, 38.5%)
Services and benefits	<i>N</i> =30	<i>N</i> =16	<i>N</i> =16	<i>N</i> = 11
	(1) Contact list (<i>n</i> =16, 53.3%)	(1) Contact list (<i>n</i> =14, 87.5%)	(1) Contact list (<i>n</i> =9, 56.3%)	(1) Contact list (<i>n</i> =9, 81.8%)
	(2) Didactic (<i>n</i> =13, 43.3%)	(2) Hotline (<i>n</i> =7, 43.8%)	(2) Talking through written information (<i>n</i> =8, 50%)	(2). Didactic (<i>n</i> =5, 45.5%)
	(3) Talking through written	(3) Didactic (<i>n</i> =6, 37.5%)		(3) Discussion / Hotline

	information (n=12, 40%)		(3) Hotline (n=7, 43.8%)	(n=4, 36.4%)
	(3) Hotline (n=12, 40%)			
Practical	N=31	N=15	N=15	N=12
	(1) Hotline (n=17, 54.8%)	(1) Hotline (n=8, 53.3%)	(1) Didactic (n=9, 60%)	(1) Hotline (n=9, 75%)
	(2) Discussion (n=14, 45.2%)	(2) Discussion (n=7, 46.7%)	(2) Hotline (n=8, 53.3%)	(2) Discussion (n=6, 50%)
	(3) Didactic (n=12, 38.7%)	(2) Didactic (n=7, 46.7%)	(3) Talking through written information (n=7, 46.7%)	(2) Didactic (n=6, 50%)
			(3) Discussion (n=7, 46.7%)	
Healthy Lifestyle	N=25	N=12	N=11	N=6
	(1) Hotline (n=14, 56%)	(1) Didactic (n=7, 58.3%)	(1) Hotline (n=5, 45.5%)	(1) Discussion (n=4, 66.7%)
	(1) Didactic (n=14, 56%)	(2) Discussion (n=6, 50%)	(1) Didactic (n=5, 45.5%)	(2) Contact list (n=3, 50%)
	(3) Talking through written information (n=9, 36%)	(3) Talking through written information (n=4, 33.3%)	(1) Discussion (n=5, 45.5%)	(2) Didactic (n=3, 50%)
		(3) Hotline (n=4, 33.3%)		