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STROKE LITERACY AMONG STROKE SURVIVORS' FAMILY CAREGIVERS

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Abstract. Stroke literacy among family caregivers of stroke survivors is important to avoid stroke and manage the situation after stroke. The stroke often causes serious health problems; therefore, the patient's family members are usually those who guide his/her stroke treatment and rehabilitation process, do homecare and prevent stroke recurrence. Accordingly, qualitative and clear information as well as skills in obtaining, evaluating and using it are important competences for caregivers. The aim of this study is to better understand stroke literacy among family caregivers of stroke survivors in Latvia, with a focus on information sources family caregivers used, on issues family caregivers feel the most / least informed about. The research object is stroke survivors' family caregivers. Two methods – survey and qualitative content analysis – were applied in this study. Total of 51 caregiver in the survey completed a self-administered questionnaire, and 100 articles in the Internet have been analysed. The study results show that the Internet is an important source to obtain information about stroke and caregivers who search information on the Internet feel less informed about several stroke related issues. Study results also indicate many cases when caregivers had not obtained or had not understood the information provided by doctors, as well as show the limited amount of useful information about stroke treatment, rehabilitation, and support.

Key words: stroke, stroke survivors' family caregivers, stroke literacy, the Internet.
JEL code: I120

Introduction

The article gains understanding about the stroke literacy among family caregivers of stroke survivors in Latvia, with a focus on information sources family caregivers used, on issues family caregivers feel the most / least informed about. Four research questions were defined in this study:

6) How do the family caregivers obtain information about stroke issues?
7) What are the stroke issues family caregivers feel the most / least informed about?
8) What information about stroke issues is available for caregivers in the Internet?
9) Does the feeling of being informed about stroke issues differ between the caregivers who have used the Internet to obtain stroke related information online and those who have not used the Internet to obtain the stroke related information?

Stroke is a widespread cerebrovascular disease that may cause significant effects on the person's life. According to World Health Organization, there are 15 million persons suffering from stroke. For about five million people of them die and five million become disabled (Yu et al., 2013). About one third of stroke survivors need help with daily tasks after stroke (Wang et al., 2015). In Eastern Europe, the incidence of stroke is higher than in Western Europe: 300 – 500 stroke cases per 100.000 inhabitants in Eastern Europe vs. 200 – 250 stroke cases per 100.000 inhabitants in Western Europe (Millers, 2010). Similar statistics can be observed with mortality – Eastern Europe shows higher death-rates from cardiovascular diseases than Western Europe (World Health Organization, 2012).

Higher incidence and death-rates of stroke are strongly related to society's ability to pay for health care services and their accessibility. The socio-economic situation varies in different regions of Latvia. Comparing mortality from circulatory diseases (incl. stroke), expressed per 100.000 inhabitants, in 2015 the highest death rate was in Latgale (1057.2) and Vidzeme (914.4); the lowest was near the capital of Latvia – in Pieriga region (660.2). Lower stroke incidence rates in Pieriga region can be explained by better availability of services, a lower demographic load over working age, and higher average revenue per household member; thus, more people can afford to

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pay for health care services (Human Development Report 2015/2016). Quality of roads, especially in winters, and availability of public transport is also crucial, firstly, for avoiding stroke via visiting doctor regularly, and, secondly, for getting specialized aid at a stroke unit as soon as possible in the case of stroke.

Stroke is also associated with various lifestyle factors, such as alcohol abuse, smoking, preventive health measures, and healthy lifestyle. As it is known, half of the main stroke risk factors are modifiable, such as high blood pressure, diabetes, cardiovascular diseases, high cholesterol, alcohol abuse, cigarette smoking, physical inactivity, obesity, atrial fibrillation, asymptomatic carotid stenosis, and dyslipidemia (Wong et al., 2012). Thereby, knowledge on healthy lifestyle and stroke symptom awareness has an important role in stroke prevention, especially after the first stroke accident, as the risk of stroke recurrence becomes higher. Unfortunately, in real life not enough attention has been paid to stroke prevention. According to the McKevitt et al. study, in Riga, Latvia the need to prevent stroke recurrence was not generally regarded to be the priority among stroke survivors. More attention was paid to dealing with consequences of stroke (McKevitt et al., 1993).

Awareness of stroke related information is defined as stroke literacy, which is analysed in this study. Stroke literacy is a very recent concept – it refers to the situation when a person demonstrates stroke risk factors and symptoms' awareness, and correctly identifies the brain as the place where stroke occurs (Morren et al., 2013). This concept has evolved from the concept 'health literacy'.

Stroke literacy studies carried out so far have not analysed the caregivers' awareness of stroke rehabilitation and aspects of care giving to stroke survivors. These are important aspects as at the end of treatment in hospital caregivers sometimes feel not enough informed about the state-funded rehabilitation possibilities and conditions of receiving homecare; caregivers lack sufficient knowledge and skills in everyday work (washing, dressing, and cooking etc.) (Egbert et al., 2006), in care giving (Mak et al., 2007), as well as they lack awareness of the nature of the disease and the support available (Giosa et al., 2014). Therefore, in stroke literacy analysis, rehabilitation and care giving dimensions must be addressed, as both of them are essential components of the stroke recovery process and in coping with the new situation. In stroke literacy analysis, attention should be also paid to other competences examined in health literacy researches:

1) person's ability to access, understand, appraise, and apply stroke information in order to make judgments (HLS-EU Consortium, 2012);
2) health care provider and patient interaction – to evaluate patient's ability to understand instructions for medication and to follow a health care provider's recommendation for a diagnostic test;
3) prevention - to evaluate patient's ability to maintain and improve health, to identify signs and symptoms of health problems that should be addressed together with a health care professional and to understand how eating and exercise habits decrease risks of serious illness development;
4) navigation of health care system - to observe the person's knowledge of the health care system and its functioning, the person's knowledge of individual rights and responsibilities, competencies to give informed consent for a health care service (Kutner et al., 2006).

Stroke literacy is an important issue due to several reasons - low stroke and health literacy may result in poorer health outcomes (Wallace et al., 2016), it may result in more often health problems because of medication errors and misunderstanding of treatment (Kanj et al., 2009), it

may result in more use of hospital services with higher emergency risk and mortality, and poorer self-management skills (Rowlands et al., 2014). It might also lead to unhealthy lifestyle (Kanj et al., 2009).

As stroke may cause significant impact on person's health, including physical and cognitive consequences, the family members are often those persons who look after stroke survivors - guide their treatment and rehabilitation processes, perform in homecare and prevent stroke survivors from stroke recurrence, especially when stroke consequences are severe and when the cognitive function of stroke survivor is affected. Therefore, high quality understandable stroke related information as well as the caregivers' skills to obtain, evaluate, and use such information is important competences nowadays.

For the analysis of the stroke literacy among family caregivers of stroke survivors, two methods have been applied in this study. The first method used was a survey of the caregivers of stroke survivors. The survey was conducted at four public and private rehabilitation centres and hospital departments in Latvia (near the capital city, in the Eastern part and in the Western part of Latvia). The author chose to recruit respondents in rehabilitation institutions as no stroke survivors' database was available due to the security of personal data. Respondents filled in a self-administered questionnaire. The sample size and survey method obtained do not reflect the target group as precisely as needed for national and representative sample, but results allow exploring the dominant views of the group.

The survey was carried out in March – May 2016. A total of 51 respondent participated in the survey. Majority of the respondents were women (38); there were 13 men. The mean age of respondents was 48.3, ranging from 20 to 81. Majority of the caregivers were immediate family members. The survey was administered in two most used languages in Latvia - Latvian and Russian. Mainly all questions were open-ended and contained linear scale. Data were analysed using various methods. Descriptive statistics were used to describe the information sources and stroke knowledge. To find out whether there are significant differences between the answers given by the two groups of respondents (caregivers who had used the Internet to obtain stroke related information (n=24) and respondents who had not used the Internet to obtain stroke related information (n=24)), the Chi-Square Test and T-test have been used. Level of significance in crosstabs and t-test was set at 0.05 (Trochim, 2006).

The second method used in this study was a qualitative content analysis with aim to analyse what information is available to caregivers in the Internet. Content analysis was carried out in April-May 2017. A total of 100 web articles in different websites have been analysed. The articles were selected in "Google.lv", using five specific key words, which matches the way information is searched by family caregivers: „stroke", „stroke treatment", „rehabilitation after stroke", „stroke survivors' home care", and „support for stroke survivors". Using each keyword, first 20 articles in Google search were selected for analysis. Articles were in Latvian language (Table 1).

In the content analysis the author drew attention to the following indicators: (a) who is the author of the article (is it public authority, NGO, hospital, mass media, social portal or other), (b) are there references in the article, (c) is there further guidance on sources where to get more information about stroke, and (d) does the article provide the necessary information to the question searched.

Table 1

Articles analysed in the qualitative content analysis

No	Articles found by the keyword:	Mass media website	State, municipality website	Hospital, medical institution website	Blog, forum	Other	Total
1.	"stroke"	7	1	2	0	10	**20**
2.	"stroke treatment"	6	0	2	1	10	**20**
3.	"rehabilitation after stroke"	6	4	5	3	2	**20**
4.	"stroke survivors' home care"	4	3	4	3	6	**20**
5.	"support for stroke survivors"	2	8	4	0	6	**20**

Source: Author's calculations based on qualitative content analysis

Research results and discussion

1. Acquisition of information

Improvement in stroke prevention and modifiable risk factors requires effective health communication strategies to address knowledge gaps about the fact that stroke can be preventable and to improve modifiable lifestyle factors, e.g. smoking and obesity (Appleton et al., 2015). Survey results show that the most popular source used to obtain stroke related information was the chief doctor (n=36), the general practitioner (n=29), the Internet (n=26), and acquaintances, friends or family members (n=23). Other stroke survivors and their family members (n=12) and medical books (n=11) were more rarely used information sources.

The study results show that obtaining and understanding the wide range of stroke related information and understanding the medical terms and language are a challenge for patients. According to the survey:

- 28 of all (51) respondents assessed their skills in obtaining the information (from doctors, media, acquaintances and other sources) to be "good / very good", 18 of all respondents assessed their skills to be "average" and five to be "poor / very poor".
- 15 of all respondents rarely or never obtained answers to the questions they had searched for (from doctors, media, acquaintances and other sources), 24 of all respondents often obtained answers to the questions they had searched and 11 – always obtained answers to the questions they had searched;
- 12 of all respondents rarely understood the information provided by the doctors, 23 of respondents often understood the information, while 14 of respondents – always understood it;
- from all respondents, who once experienced situation when they had not understood the information provided by the doctor (incl. persons who rarely or often understands information provided by the doctors), 22 respondents answered that they rarely or never tried to clear it out or to find more information about the issues they had not understood.

Significant support in understanding the information should be provided by the doctor, especially the general practitioner. However, according to the survey results, only 29 caregivers (out of 51) had asked for information to the general practitioner. In Latvia, a general practitioner is a primary care physician who takes all care of a patient. General practitioner is supposed to consult patient in all uncertainties, explain medical information and guide the patient in treatment, rehabilitation or illness prevention processes to avoid negative consequences that might appear

from incorrect self-treatment or inactivity. Survey results show that the general practitioner's role in case of stroke should be strengthened.

Survey results provided above also show that the Internet is an important source of information – 26 of all (51) respondents have searched stroke related information online. Statistics also prove the important role of the Internet. In 2016, 81 % of population in Latvia aged 16-74 used the Internet in last 3 months (in 28 EU countries - 82 %) (Eurostat, 2016). The use of the Internet has increased in last years. Often, better ICT skills also correlate with better health literacy skills, as concluded by Rowlands et.al. (2014) and Wong et al. (2012).

The Internet has a great potential to provide understandable and useful health information, providing information in more visual and interactive way (Christmann, 2005), e.g. video streams, applications and others. The Internet ensures an easy access to information and provides various possibilities to find the latest information worldwide. Interaction possibilities, like online social networks and forums on special health topics, can also support information extraction. One of the EU studies shows that half of the society who seeks information on the Internet thinks that the Internet plays the main role in the fact that they understand health related information and can interact with doctors (Christmann, 2005). Due to a widespread pool of information, the Internet is a great tool that might help to enhance stroke literacy, health knowledge and support people to become responsible for their own health. However, at the same time it involves danger that the information provided via Internet is false, low quality or too complex for the users (Christmann, 2005). One of the Australian studies shows that readability of Australian health websites is above the average Australian level of reading (Mak et al., 2007). Therefore, clear information in the Internet related to stroke and health topics, as well as patients' skills in information evaluation are important issues to be addressed in future.

2. Information available in Latvian websites

To find out what information is available to caregivers in the Latvian websites, the author made the qualitative content analysis. Content analysis shows that information about stroke as a disease, stroke causes and risk factors, stroke symptoms and action in case of observing these symptoms can be found easily. Mainly these online articles are published in mass media websites and can be found there more often than in governmental sites. Information about stroke as a disease, stroke causes and risk factors, stroke symptoms provided in mass media websites has been displayed correctly. This is indicated by the fact that such information can be found in scientific publications and is provided by medical specialists. However, articles rarely contain references, therefore the lack of references makes difficulties for the reader to verify the facts and be sure about them. Also links to other sources are usually not provided.

Regarding to the articles found using keyword "stroke treatment", the main available information in the Internet is the fact that the patient should get first aid and undergo thrombolytic treatment at a specialized stroke unit (Latvijas Ārstu biedrība, 2008). Two articles analysed provide information on the number of days to be spent in hospital in acute stroke treatment (Millers et.al., 2010 & Liepājas reģionālā slimnīca, 2010). There is limited information on the specifics of stroke treatment in hospital after receiving the thrombolytic treatment, e.g. treatment in neurology department and early rehabilitation. In articles analysed, two articles partly explains the acute stroke treatment process (Liepājas reģionālā slimnīca, 2010). One of them - clinical guidelines - is highly medical, with many medical terms, and is difficult to understand (Latvijas Neirologu

biedrība, 2013). Thereby, the author concludes, information found in the Internet does not help caregivers and stroke survivors to feel competent about stroke treatment process and its requirements. Sufficient information, especially published by public authorities, is missing despite the fact that it is essential for stroke survivors' caregivers. Moreover, this information is relevant and essential for a large number of individuals who face the stroke for the first time, as the stroke is one of the most widespread diseases.

Analysing the available information about stroke rehabilitation, the author concludes that a person can obtain information about state-funded in-home rehabilitation service and can find links to the National Health Service website, where information about institutions providing home rehabilitation service is given (Veselības ministrija, 2017). A lot of articles found are published in 2012 when home rehabilitation service was established. After year 2012, articles have been published less often. The author concludes that no information is available on where to receive state-funded or private ambulatory and stationary rehabilitation services - which institutions provide such rehabilitation, what are the queues for the services, how many days of rehabilitation is ensured, how much does it cost, what are the special requirements for rehabilitation etc.

Information regarding the stroke survivors' home care aspects can be rated on average. In articles found using key word "home care", information is given mainly about the medical rehabilitation, three articles give information about bedsores and ways how to avoid them (Medicine.lv, 2015), some articles give information about the fact that there are care services and that they are expensive (Gruntmane, 2017). There is information about palliative care, and two articles give advices in home care (washing etc.). The author believes that the articles found should contain information not only about these topics, but should also provide information about specially adapted exercises for stroke survivors, psychological condition of a person after stroke, and recommendations in interaction with the stroke survivor.

Regarding to the support measures for stroke survivor, articles contain information about the medical rehabilitation. There are also articles that provide information about the social support provided by the municipality. One article provides information about professional and social rehabilitation, technical aids and social support for disabled persons. One article gives recommendation on food choice after stroke. Useful article found is also one made by the organization VIGOR containing information that the organization provides free psychological help to stroke survivors and their caregivers. In the author's opinion, more articles should be published about psychological support services for stroke survivors and their caregivers and practical aspects how to apply for social support.

3. Stroke issues family caregivers feel the most / least informed about

Evaluating the topics stroke survivors' caregivers feel the most and least informed, survey results show that the caregivers felt most informed about the necessary health checks and their frequency to reduce the risk of stroke (1.67 points, where 1 - well informed and 4 - not well informed) and patient's care at home (1.71 points). The caregivers felt least informed about the place where to seek social assistance if necessary (1.88 points) and about healthy lifestyle requirements after stroke (1.83 points). Their being informed about the time when stroke rehabilitation has to be started (after stroke) and their being informed about stroke risk factors were evaluated with average 1.79 and 1.75 points relevantly. When comparing these results between two groups – caregivers who had used the Internet to obtain stroke related information

(n=24) and respondents who had not used the Internet to obtain stroke related information (n=24), statistically significant differences were observed. Two T-test results approved Chi-Square test results saying that respondents who had sought information on the Internet evaluated their knowledge of healthy lifestyle requirements after stroke and stroke risk factors lower than those who had not sought information on the Internet. Here are the results (lower average quantity means being informed better):

- feeling informed about healthy lifestyle requirements: those who had used the Internet (mean 2.21), those who had not used the Internet (mean 1.46);
- feeling informed about stroke risk factors: those who had used the Internet (mean 2.08), those who had not used the Internet (mean 1.42).
- additional T-test showed one more significant difference - respondents who had sought information on the Internet evaluated their knowledge of where to find social support lower (mean 2.13) than those who had not used the Internet for seeking information (mean 1.63).

These results indicate that information search on the Internet is linked with insufficient knowledge of healthy lifestyle requirements after stroke, knowledge of stroke risk factors and knowledge of where to find social support. In author's opinion, information search on the Internet might be related to lower patient-doctor interaction skills, poorer understanding of information given by physicians, and insufficient information provided by doctors. Patients may feel uncomfortable asking more questions and admitting they do not understand physician's provided information. Further analysis of this topic is recommended to find out the real underlying causes.

Conclusions, proposals, recommendations

1) Obtaining and understanding a wide range of stroke related information is a real challenge for patients - 23 of 51 respondents assessed their skills in obtaining information to be "average / poor or very poor"; 15 of all respondents rarely or never obtained answers to the questions they had searched for; 12 of respondents rarely had understood information provided by the doctors, and from all respondents, who once had experienced situation when they had not understood the information provided by the doctor, 22 respondents rarely or never tried to clear it out or to find more information about the issues they had not understood. Simpler information, indications where to find information and avoiding jargon in communication with patients might improve caregivers' stroke literacy.
2) The role of the general practitioner in Latvia should be strengthened. It is the primary care and the most accessible physician, who holds full medical history of the patient, who is supposed to consult the patient in all uncertainties, explain medical information and guide the patient in the treatment and rehabilitation processes. But according to the survey, only 29 from 51 caregiver asked for the necessary information to their general practitioner.
3) Survey approved that the Internet is an important source of information. Survey results indicate that information search on the Internet is linked with insufficient knowledge of healthy lifestyle requirements after stroke, knowledge of stroke risk factors, and knowledge of where to find social support if necessary. It might be explained by lower interaction skills with doctors, poorer understanding of information given by physicians, or insufficient information provided by the doctor or the hospital / health centre. Such results indicate that more attention should be paid to ensuring information about healthy lifestyle and stroke risk factors, especially by general practitioners.

4) The Internet has a great potential to provide clear and useful stroke information, especially to caregivers with low stroke literacy, providing information in more visual and interactive way. However, in Latvian websites, incl. public authorities' website, there is a lack of information that (a) explains the specifics of stroke treatment after receiving the thrombolytic treatment, e.g. treatment in neurology department and early rehabilitation, (b) that explains where stroke survivors can receive state-funded or private ambulatory and stationary rehabilitation services - which institutions provide such rehabilitation, the queues for the services, how many days of rehabilitation is ensured, how much does it cost, what are the special requirements etc., (c) that explains specially adapted exercises for stroke survivors that can be done at home, (d) that explains what is psychological state of a stroke survivor and how to communicate with stroke survivor, (e) that explains what psychological support services are available for stroke survivors and their caregivers. A special website for stroke related information has to be created by public authorities including all the necessary information about stroke – the disease, stroke phases, rehabilitation, treatment, and lifestyle requirements etc. – to ensure people that they do not have to find it by themselves.

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