

Health Literacy Skills in Relatives' Speech: A Canadian Case-Study

Marie-Eve Mc Clure¹ and Annie Rochette^{1,2*}¹School of Rehabilitation, University of Montreal, Montréal, Canada²Centre for Interdisciplinary Research in Rehabilitation of Greater Montréal, Montréal, Canada

Abstract

Objective: Exploring how health literacy skills are expressed by relatives of two first stroke survivors and the influence of such skills on their participation in the rehabilitation process.

Methods: This case study consists of a secondary analysis of qualitative material focusing on perceived health services received by relatives post-stroke. Two cases were purposively selected for their contrast in educational attainment.

Results: Four core concepts, in accordance with current health literacy conceptualization, emerged from the analysis. Themes related to understanding and communicating health-related information was prominent. More specifically, comprehension and linguistic skills, and particularly the use of medical terminology, as well as self-confidence appear to be conducive to a better dialogue with health professionals and lead to more satisfactory answers.

Conclusion: The relatives' speech provided indications about health literacy skills and confirmed their importance in developing self-determination. Fostering an open dialogue with relatives represents an opportunity to consider their skills when establishing a partnership and thus contributes to the development of greater health literacy and participation.

Keywords: Health literacy; Speech; Stroke; Relatives; Case study; Attitude; Practice; Professional-patient relationship

Introduction

To cope with the illness of a loved one, whether sudden or chronic, relatives must deploy affective, cognitive and relational strategies to support their own towards recovery [1]. Such experience is demanding in itself and several factors may facilitate or hinder the adoption of attitudes and behaviors conducive to better health. For instance, considering the number of health professionals often involved, one's communication skills are central when learning, as a family, to manage a new chronic condition. The ability to access and to appraise the appropriateness of health-related information is also crucial. The Canadian healthcare context is now strongly supporting greater involvement of the individual and his/her family in the care process, however, little is known about the prerequisites of such a partnership in terms of health literacy skills [2,3].

From the ability to navigate an often puzzling healthcare system to abilities required to find, manage and discuss health-related information; adopt a healthy lifestyle, heal and maintain good health may prove to be a daunting challenge. Albeit many conceptual variations, this set of competencies, abilities and skills is now widely referred to as health literacy (HL) [4]. Initially understood as part of a general literacy issue, HL has emerged as a distinct concept. Still relatively new, the concept of HL is drawing significant attention in the field of health promotion and is now recognized as a public health priority in several countries, including Canada [5]. However, the rehabilitation literature on HL is still scarce [6-8].

The aim of this case study is to explore how HL skills are evidenced in the narratives of two relatives when discussing their experience about the stroke rehabilitation process. More specifically, HL skills are explored questioning how they facilitate or hinder participation in the rehabilitation process.

The concept of health literacy

General literacy or literacy is conceptualized as individual skills in reading, writing and arithmetic. Specifically, it is defined as "The ability to identify, understand, interpret, create, communicate and

compute, using printed and written materials associated with varying contexts" [9]. Literacy is also to be considered as a social practice [10], subject to social organization and reflecting different life domains. Thus, to fully participate in contemporary society, an individual must gain literacy skills in the scientific, technological, cultural, media and computer domains [11] in addition to HL skills. Zarcadoolas et al. [12] suggest that competencies pertaining to health integrate many abilities belonging to these different types of literacy.

HL being a relatively recent field of research, the notion has not yet reached a consensual conceptualization. As such, main variations are mostly arising from two standpoints: the medical and the public health perspectives [4,11,13-17]. If most current definitions entail more than individual literacy and numeracy skills, the medical perspective remains the most functional one focusing on individual skills involved when consulting, navigating or interacting within the health system and clinical encounters [16]. Moving toward a more collective vision of HL, the concept has been further developed to consider cognitive and social skills allowing generalization and critical appraisal of health-related content to daily life contexts and furthermore to community settings and political arenas [18]. Nonetheless, to improve HL, anywhere on the continuum from an individual to a population level, skills must be built [16] primarily through health education, but also through innovative [14] and concerted [3,5] communication strategies. Moreover, interactive understanding and critical thinking are pivotal when it comes to establishing partnerships [19], managing one's health or support's health and the wellbeing of one's family and community

***Corresponding author:** Annie Rochette, OT, PhD, Occupational Therapy Program, School of Rehabilitation, University of Montréal, Pavillon Parc, 6128 Succursale Centre-Ville, Montréal (Québec), H3C 3J7, Canada, Tel: 514-343-2192; Fax: 514-343-2105; E-mail: annie.rochette@umontreal.ca

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[5]. The functional, interactive and critical dimensions of HL has been initially proposed by Nutbeam in his *Health Literacy Framework* [18]. These dimensions of HL are now widely accepted [4,20]. Therefore, the ability to establish causal links, to recognize the organization of services and to express one understands refers to functional HL. Furthermore, interactive and critical HL refers to more extensive cognitive and social skills allowing an individual to act upon health-related information, to get involved in one's community, to defend one's rights and initiate broader changes within society [18,21].

For the purpose of this case study, we adopted the definition proposed by the Canadian Public Health Association (CPHA) for its emphasis on the evolving nature of health-related competencies within various contexts. Hence, "*The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course*" [5] gives us a sufficiently broad scope to explore HL skills in a family-centered approach to stroke rehabilitation.

Health literacy and participation

Participation and partnership approaches acquired a substantial recognition among decision makers, healthcare professionals and academic programs in health sciences [3,19,22]. Participation can take several forms from involvement in the decision-making process concerning one's treatments and interventions through active communication and information gathering, to engagement in advocacy or patient's rights groups and activities [3,22]. In Quebec, the Act in respect to health and social services clearly states that citizen participation to healthcare and services is "*a purpose, a right and a responsibility all at once*" [3]. Participation and literacy are linked by social norms as both are social practices drawing upon relational values, attitudes and behavior [10]. Different studies have concluded that HL levels were associated with participation in medical encounters and communication with healthcare providers [15,22-24]. Higher level of HL is associated with more active participation in medical encounters and decision-making process while individuals with lower HL skills tend to communicate less, ask fewer questions and defer health-related decisions to healthcare providers [23,24]. Hence, to foster partnership between healthcare professionals and service users, not only the use of a common language is essential, but moreover the search for an egalitarian dialogue sharing common purposes [3]. For healthcare professionals, considering patient's HL skills then becomes part of sharing responsibility towards better health and wellbeing. Various health contexts would greatly benefit in being perceived by healthcare professionals as opportunities to improve health-related skills [12]. Adopting a family-centered approach post-stroke represents one of these opportunities [1]. Neglecting to take into account the level of HL of patients and relatives while developing participation strategies could contribute to maintain inequities in access to health services by favoring individuals with higher skills [2,19]. Since efforts to improve HL also support self-determination [11] - an essential component to create a partnership [2] - the relatives' experiences allow us to objectify indicators as to how HL skills facilitate or hinder participation.

Methodology

Study design

This case study consists of a secondary analysis of qualitative material aiming at documenting the experience of relatives of individuals who have had a first stroke; and more specifically the clinical and ethical issues related to a family-centered approach in post-stroke care. As one of the clinical concern the initial study was trying to answer pertained

to when and whom should ideally transmit general information to the family for an effective transition home, the present case study proposes an analysis of two selected relatives verbatim, to reflect on how to tailor this information most effectively using a HL perspective.

Data collection

This case study used data obtained from a larger study where twenty-five semi-structured interviews were conducted with relatives of individuals who have had a first stroke. All interviews were audio-recorded and transcribed verbatim. Accuracy of transcription (quality check) was done by two different individuals. An interview guide was elaborated in order to facilitate the expression of individual perceptions about services and support, relationship with healthcare professionals as well as involvement in decision-making processes in acute post-stroke care. The interview guide was composed of four open-ended questions aimed at documenting the perspectives of individuals related to 1) the involvement of relatives in decision making regarding the timing and destination of discharge; 2) health services actually received 2) health services perceived as ideal; and 4) the quality of relationships with health professionals. Each question was followed by a list of themes to explore. This content was considered significant for secondary analysis as HL is still rarely addressed directly in clinical settings [6]. Consequently, it was hypothesized that eventual limitations or difficulties that could be associated with HL competencies, were likely to emerge from material discussing relatives' broader experience with a specific episode of care.

Selection criteria

Two interviews from the initial study were purposively selected for this exploratory case study. Cases chosen had to be as similar as possible for age (difference of 10 years or less), sex, perception of the stroke severity (mild versus moderate or severe) and destination at discharge while presenting differences for educational level (primary or high school versus post-secondary) in order to allow the emergence of distinctive features. Although educational level as a contrasting criterion was based on an a priori, it reflects, in our opinion, clinical reality where HL is rarely evaluated and individual's educational attainment is more likely to be considered as a general comprehension ability indicator by several health professionals. However, we are aware that while educational attainment is an indicator of general literacy, it does not necessarily reflects one's HL level [11]. As HL is a set of competencies and skills specific to the health domain, it is possible for an individual to possess an adequate level of general literacy while having deficient skills as it pertains to health.

Ethical considerations

Written consent of the participants was obtained according to ethical standards in effect as provided by the initial research protocol.

Data analysis

The systematic qualitative data analysis was guided by the framework approach [25,26]. This structured method supports thorough data analysis through the use of several codification grids, which allow summarization in every step. At first, the transcribed verbatim were manually coded using spreadsheets to facilitate identification of initial categories. From this initial coding and re-reading process, 56 categories emerged from the two cases. These initial categories were then combined together and iteratively refined leading to the identification of recurrent themes. Ultimately, those themes were consolidated into four core concepts corresponding to the constitutive elements of the definition adopted.

Results

Selected interviews were conducted with two women who had been actively involved in their relatives' post-stroke rehabilitation from the beginning of the care episode. Table 1 features the demographic characteristics of the two cases.

This case study reveals that core elements of HL construct appear spontaneously in relatives' speech as they share their experience about the stroke rehabilitation process. Themes emerging from data analysis pointed out to several concerns raised by participants, which can be understood in terms of HL. For instance, the use of medical

vocabulary, the uneasiness of communication with professionals, as well as the questioned ability to identify a health problem or appraise the quality of the services received where all specifically mentioned by both participants. Hence, the fifty-six themes that emerged from the interviews could be linked to HL. Themes such as *requesting and obtaining services for a relative, knowing the role of health professionals, identifying an access problem or featuring confidence* can all be addressed according to one of the four defining aspects of HL, namely: *Access, Understand, Evaluate and Communicate*. Table 2 presents verbatim excerpts illustrating each of the four core concepts that have been mentioned in the interviews. These selected excerpts are the main manifestations of individual HL skills in our sample.

	P18	P7
Age	65 years old	55 years old
Gender	Female	Female
Educational attainment	High school	University
Perceived stroke severity	Severe	Moderate
Destination upon discharge	In-patient Rehab. Center	In-patient Rehab. Center

Table 1: Demographic characteristics of relatives.

Participant P18	Participant P7
ACCESS	
- You don't know who to refer to... You know, sometimes nurses do it, but... - I've got a friend who's a nurse and when I had a problem, I called her. - Well, I still read at home because I've got a medical book there. - Even family doctors don't have time to tell us. You know they don't have time to tell us how to prevent that. It's when it happens that we know. I: It's a little delicate to think that it's the family doctor's role. P: Well, can't you think?	- Are there places, you know, for example, the Canadian Cancer Association you've got resources, you've got places [...] you've got Websites [...] you've got support, you've got support groups. - I went on the Internet and, uh, that's it. - But I dealt with the OT... Because she needed help to eat since she's partially sighted, and with the tube she couldn't manage to be coordinated.
UNDERSTAND	
- And at the same time I learned that the days that I spent with him, you know. For the ultrasound, I don't know, he went through tests everywhere. - I: Ok, so they explained to you what a stroke was. P: Yes, a little, but I didn't really... I: Understand? P: No, well, yes, I knew that it was, paralysis and all that... - I: For real, he stayed 10 days at the emergency. P: Uh, in a transition room they called it (I: Yeah) well, it's still at the emergency? - If I'd had it right away [the information conference], I think I would've been more able to understand the whole process there after. - I: So that, you had more or less understood what a stroke was. P: But it's my own training the problem, it's my training that was...	- She didn't sleep at all because I understood that in neuro we, you couldn't uh, no sedative. But incidentally it got her in real bad shape... - in sequence mom was hospitalized like about two, three weeks, in ORL, following her surgery for tongue cancer. She went to XXX two, three weeks. There she had aspiration pneumonia so she went back to the hospital and, then she stayed again [...] in ORL that time. - So, for me, giving oxygen, is it part of a level two, a level three, a level four, I didn't know. I was just telling myself; I want her to be comfortable.
EVALUATE	
- But also I didn't even know that the first three hours, it matters, the arrival at the hospital because they could give a medication, we don't know. We don't know until it happens to us, you can't know. - I: It's the doctor who decided he was going to rehabilitation. P: Ah yes, that he needed it to continue. I: did you have anything to say? P: No. I: Didn't they ask for your opinion? P: No [...] No, it's alright because they know better than me.	- If I hadn't been there, she wouldn't have had nothing during the first three weeks that she was there, so in the three months we'd lose three weeks. Uh, so I thought, that it wasn't, the person is not treated as a whole. - So for me giving oxygen, is it part of a level two, a level three, a level four, I didn't know. I was just saying to myself that I wanted her to be comfortable. [...] helping her to breathe, yes there, I don't want her to suffer, but in a way I went with a level that if I had known, it wouldn't have been that level that I would've chosen, I would've expressed myself differently.
COMMUNICATE	
- I: They showed you some tricks. P: Well I was watching. I: Ah, you observed. P: Well yes, well, I asked them how to do it. They don't have time to show you, I don't think so. I don't think so, not at the hospital. - P: Even sometimes, I had them [questions] asked by... I: By your spouse. P: Yes, that's it, himself goes further than me in all this. - Now, I have a lot of little questions. But it's about, especially in his head, his neurons and all that, I, because it gets reattached apparently. I have questions about that. - I: [...] I don't know if you've made remarks, comments to the team, [...] P: Well I'm not, nor my spouse, it's not, you know it's the person who's gonna wait, who will be patient, who won't say a word. - But I had her do her exercises when she, after breakfast, when I was there or at supper - And you know I even took him to do the groceries, walking a little since he had to walk more more more more all the time.	- But I had all my wits and I wanted to know what was going on. So I was there and I asked questions. Sometimes it must be bothering for them I think. But I was given answers. - The instructions from occupational therapists were not necessarily read. Sometimes we'd put them on the stove, on the the, the wall. Uh, like Help Ms to eat. Because my mother is partially sighted. - It was more through nonverbal [...] the team of doctors [...] answered my questions at some point, towards the end I'd think, well, I won't ask any more questions, 'cause I feel I'm getting on their nerves a little[...] we'd leave quickly. - What I would have liked is maybe, I don't know if it's possible, but maybe, uh, if there are multidisciplinary meetings. - I was afraid she'd end up under guardianship and all that. So that, it worried me and that's when I call on the social worker. - like the 3-months range, you know, that, when I discovered that, of course I pushed when she changed teams at the rehabilitation center or even when she came back. I pushed for her to see an occupational therapist or physiotherapist. - I was proactive in all that. I've been proactive. I'd get the information. I didn't feel like they were to give me any. - I had things done, but I'm the one who took the initiative.

Table 2: Verbatim excerpts illustrating main aspects of health literacy.

Hence, comments addressing information gathering issues as well as personal initiatives to gain knowledge or to obtain health services are comprised under the *Access* concept. Examples cited by relatives showed that the ability to adequately identify healthcare providers, departments and services is fundamental, and yet problematic, when navigating through the health system. In our sample, the concept *Understand* refers to the ability to understand a relative's health status as well as their treatment, the explanations and/or recommendations conveyed by health professionals, the organization of services as well as their own role in the rehabilitation process. The concept *Evaluate* refers to the ability to appraise information and services as well as to adopt a self-reflective attitude according to the context. However, these concepts are interdependent as illustrated by this comment from participant P18: "*But also I didn't even know that the first three hours, it matters, the arrival at the hospital because they could give a medication, we don't know. We don't know until it happens to us, you can't know*". This example shows how knowledge, attitude and context are closely related when one needs to evaluate a particular health situation to choose the appropriate course of action.

Finally, the concept *Communicate* describes the ability to translate needs and expectations into words and actions. More specifically, it reflects the ability to generate meaningful knowledge in daily life and the ability to actualize information as well as recommendations in order to ensure personal and familial health and wellbeing through informed choices.

In our sample, participant P7 demonstrated higher HL skills, evidenced by more frequent use of medical vocabulary, a detailed description of the clinical journey, which reflects a better understanding of the care organization, as well as an information seeking behavior. This participant also had a more active participation. This relative's narrative contains several examples of active communication with various healthcare team members and clearly states the desire to be more actively involved in the post-stroke rehabilitation process: "*What I would have liked is maybe, I don't know if it's possible, but maybe, uh, if there are multidisciplinary meetings.*" Contrastingly, several barriers in accessing, understanding, evaluating and communicating health-related information emerged from participant's P18 discourse. This participant also demonstrated a less active participation, particularly in the decision-making process as evidenced by this quote: "*(Participant): It's the doctor who decided he was going to rehabilitation. (Interviewer): Did you have anything to say? (P) No, it's alright because they know better than me.*"

Discussion

The main objective of this case study was to explore the expression of individual skills related to health in the speech of relatives and their influence on participation in post-stroke rehabilitation process. By discussing their experience, services and support received, relationships with healthcare providers and their involvement in the decision-making process, participants spontaneously refer to several aspects of HL. The relatives' speech provided indications about HL skills and confirmed the importance of those skills in the development of self-determination [3,11].

The comments gathered indicate that the context is a pivotal parameter to account for a person's HL. The ability to understand and use medical vocabulary also appeared as a determining factor of the relatives' participation in the rehabilitation process. This observation leads us to the following questions: beyond the functional level, would adaptability and mastery of various linguistic registers be more evocative than specific health-related knowledge in order to account

for a person's ability to access, understand, evaluate and communicate health-related information?

Data analysis has revealed specific characteristics to account for each conceptual aspects of HL. For instance, functional *Access* can be distinguished from the interactive level through a person's ability to access information outside their immediate environment. A person who is able to target a variety of resources will be more effective in finding information to fulfill their needs. Developing some kind of fluency with health specific vocabulary constitutes an inherent strategy for improving functional HL. With functional skills, the mechanisms underlying the decision-making process [2] are not fully expressed which impede a person's capacity to seize all the possible options. Skills needed to make informed and responsible choices are built upon proper understanding of the health status and available services. We cannot achieve an informed decision process without an actual appropriation of some basic information. Furthermore, if functional HL includes the ability to evaluate treatment options, the quality of services and some self-criticism, it seems clear that these skills should be addressed early in the episode of services.

The relatives' experience is also expressed through their interpretation of various messages, which are addressed to them, directly or not, by the health system. Decoding a message draws upon the capacity to infer a specific meaning in a given context. Besides the utterance context, subjectivity and individual skills contribute to shape the meaning derived from a message. Consistent interpretation of a message depends, among other things, on its type, the presence of common referents among the interlocutors and the representation of its complexity as perceived by the receiver of the message [27]. In a clinical setting, numerous elements are to be considered to establish literacy requirements for an accurate interpretation of a message. Communication mode as verbal exchange, customized written documentation, pamphlet; the location, the moment in which the communication act is carried out as well as the interlocutors in attendance are all factors to be appraised. Thus, the communication act informs us about the content of a message and on the relationship existing between the issuer and receiver where both interlocutors belong to a specific culture, in this instance the medical and the popular culture. The comments of both participants highlighted the importance of oral communication during the episode of care. Being invited to attend a conference or a multidisciplinary meeting, as reported by both participants, encourages relatives' participation in the rehabilitation process and provides an opportunity to improve HL. It is important to mention that written documentation belongs to traditional health-education strategies and draws upon functional literacy. However, resorting only on such strategies proved to be insufficient to generate lasting change in behavior and lifestyle [18].

From a HL perspective, education aims to foster self-determination. By changing the goal of health education, a lower HL is no longer perceived as an obstacle to overcome through the elaboration of new material, but rather as a starting point for building new skills [16]. For healthcare professionals, considering HL skills is an initial step to support greater participation and profitable engagement toward better satisfaction and health outcomes [23]. Finally, such a focus on HL and participation emphasizes the importance of developing capability beyond functionality [11].

Strengths and limitations

This study demonstrates that without being directly questioned about their HL competencies, relatives address them spontaneously when they share their post-stroke rehabilitation experience. The

manifestations explored are consistent with other results obtained in similar studies [28,29] and provide additional evidence to support the development of effective and ecological strategies to foster HL. These results also contribute to raise awareness among healthcare professionals about the role of HL skills in a family-centered approach to communication and participation. However, results can not be generalized as it consisted of a case study. Also, this case study did not address the perceptions of health professionals. A design including direct observation of interactions would have enriched our representation to better untangle everyone's needs.

Conclusion

The relatives' speech comprises several elements to be observed from a HL perspective. The content analysis has led to the emergence of manifestations corresponding to defining aspects of HL, allowing insights on greater participation to post-stroke rehabilitation process. For healthcare professionals, efforts to foster HL competencies would benefit from directly addressing issues related to *Access*, *Understand*, *Evaluate* and *Communicate* with relatives in an open dialogue. Creating opportunities for relatives to act upon health-related knowledge and competencies according to their needs and abilities is essential to greater participation in health care.

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