

Selected aspects of health literacy among seniors

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Abstract

OBJECTIVES: This study aimed to map the selected indicators of health literacy in the senior population via a qualitative survey that focused specifically on its relationship with autonomy in the context of health literacy among seniors.

METHODS: A qualitative survey focused on the selected indicators of health literacy of seniors living in the South Bohemian Region of the Czech Republic (R1–19). The snowball sampling method was intentionally selected. Completed interviews were transcribed and data was reduced, analyzed, and categorized. The identified categories were 1) information comprehension, 2) decision-making in healthcare, and 3) compliance with nonpharmacologic treatment.

RESULTS: The ‘information comprehension’ category clearly shows that the seniors involved in this study rated the comprehensibility of information provided by medical professionals as being good. An especially positive finding was that seniors do seek information through the internet, print sources, or other media, even though, as one senior (80-year-old woman) said, comprehension of medical information is becoming “*more and more complex*”. The ‘decision-making in healthcare’ category touched upon opinions regarding informed consent and opinions regarding seniors’ own involvement in healthcare. Results from this category suggest that seniors accept informed consent as a routine necessity. Inhibition regarding personal involvement in healthcare was also apparent: “... *I come from a family accustomed to not bothering the doctor unnecessarily, so I just stick out my arm...*” The last category of ‘compliance with nonpharmacologic treatment’ clearly shows that respondents are informed regarding lifestyle modifications that would benefit their treatment, although, few respondents had achieved the desired lifestyle changes.

CONCLUSION: Results of this qualitative research show clear health literacy limits among seniors. As shown in this study, age itself could also be a limiting factor of health literacy.

INTRODUCTION

Health literacy is a topical issue in 21st century medicine. It is one of the modifiable determinants of health. The most widely used definition of health is a definition from 1945 which states: Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (Bártlová 2005, WHO 2015). The World Health Organization (WHO) defines health literacy as, “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintains good health” (Kickbusch *et al.* 2013, p. 4). Health literacy consists of the following three dimensions: 1) healthcare, 2) disease prevention, and 3) health promotion (Kickbusch *et al.* 2013).

In the contemporary concept of health literacy, autonomy represents an individual's ability to make decisions pertaining to their own health (Nielsen-Bohlman *et al.* 2004). Rapid developments in medicine, since the 1970s, has led to an evolution in the relationship between patients and medical professionals (Šimek 2016). The traditional paternalistic (authoritative) relationship between medical professionals and patients is increasingly being replaced with a partnership. Within such a partnership, patient autonomy is key to implementation of medical care. Thus, the patient becomes an active participant in their own healthcare (Bártlová 2005). Replacement of the traditional model has occurred gradually and, for the senior population, for whom medical paternalism was standard, the adoption of such an active role may be confusing for patients.

At minimum, respect for autonomous individuals includes recognition of their right to hold opinions, make decisions, and adopt measures based on their personal values and beliefs (Beauchamp and Childress 2001). Respect for patient autonomy has become a significantly emphasized principle, especially in the field of American bioethics (O'Neil 2002). However, excessive patient autonomy (to the detriment of the beneficence principle, in particular) has been the target of criticism from the beginning.

While the West was debating the principles of biomedical ethics, patient autonomy, self-determination and rights, a profound sense of medical paternalism prevailed in the former Czechoslovakia and other former Eastern bloc countries. The Code of Ethics for patient rights and informed consent, two cornerstones of respect for autonomy, entered the Czech Healthcare system via the Czech Ministry of Health's Central Ethics Committee in 1992 without demand or interest from patients, and often went unnoticed by them.

Patient involvement in the treatment process is referred to by numerous terms such as compliance, adherence, and persistence (Vrablík 2013).

Compliance can be defined as the degree or extent to which patients follow medical and non-medical treatment recommendations given by medical professionals.

It is most often assessed in relation to compliance with prescribed pharmacologic treatment, dietary changes, or lifestyle modifications (Falvo 2011). Information conveyance plays a significant role in patient compliance with medical advice and guidance. Compliance is an important goal of health education (in which the patient typically plays a submissive role) and adherence is decisive for effective health education leadership (i.e. by incorporating medical recommendations and advice into daily life, patients become responsible for their own health) (Rankin *et al.* 2005). The concept of adherence has a much broader dimension in the relationship between medical professionals and patients. It is sometimes understood as a collaborative relationship in which patients actively participate in their own healthcare. It has been shown, for example, that cardiac patients have poor adherence (Vrablík 2013).

Old age may be a factor that limits a patient's capacity to make responsible decisions because this ability is disrupted by numerous external influences during illness and in old age and, over time, decision-making abilities may even change radically (Šimek 2015). In 2006, the U.S. Department of Education published *The Health Literacy of America's Adults* which showed that a lower percentage of adults aged over 65 had average or perfect health literacy compared to adults in other age groups (Kutner *et al.* 2006). Current European studies have also shown limited health literacy among seniors and have classified them (as well as individuals with poor health status; frequent use of health services; low socioeconomic status; and low levels of education) as a group vulnerable to health illiteracy (Sørensen *et al.* 2015).

A current issue in the field of health promotion is the struggle with low health literacy among populations encouraged to make decisions despite receiving insufficient support; according to the WHO, this paradox has led to a health literacy crisis. This indicates that existing health promotion systems focus more on knowledge rather than skills or behavioral patterns. The authors of *Health Literacy – The Solid Facts* described more than half of the adults in European countries as having inadequate or harmful attitudes towards their own health (Kickbusch *et al.* 2013). Holčík (2010) and Kučera (2015) reported that survey data comparable with international studies indicated that Czechs tend to have below-average levels of health literacy. Interestingly, the authors indicated that the worst results were precisely in the area of health promotion. According to the authors, the health literacy index in the Czech Republic is likely associated with low physical activity, a high incidence of smokers, high BMIs, as well as socioeconomic parameters.

Seniors are one of the populations at risk of low health literacy (Eriksson-Backa *et al.* 2012). Health status creates a heterogeneous senior population. Despite illnesses that result in physical limitation, most seniors are capable of independent self-care in old age;

however, roughly 6% require permanent care in institutions (Holmerová 2014). The vast majority of the senior population in the Czech Republic spent most of their active lives in a paternalistically oriented system of state-guaranteed free medical care (including preventive programs).

This fact has become crucial for assessing health literacy among seniors and the role autonomy in healthcare for seniors has become the default issue.

MATERIALS AND METHODS

A qualitative research survey focused on selected health literacy indicators of seniors residing in the South Bohemia Region of the Czech Republic (R1–19; mean age 74 years; minimum and maximum ages 67 and 88, respectively). Snowball sampling was used to acquire new cases through a gradual process of nomination by previous participants. The purposive sampling technique was used to acquire information until the research sample was of adequate size and scope.

Data analyses were conducted for 19 interviews. Audio recordings were transcribed. This was followed by data reduction, when necessary, and subsequent categorization. Semantic units were identified in the interview transcripts. Open coding was used to find and develop the properties and dimensions of individual categories.

Health literacy is determined by several dimensions. The following categories were identified for the purposes of this study: 1) information comprehension, 2) decision-making in healthcare, and 3) compliance with nonpharmacologic treatment.

RESULTS AND DISCUSSION

Information comprehension

A basic component of seniors' health literacy is knowledge of patient rights, such as the right to choose one's physician, the right to informed consent, and the ability to participate in decisions regarding treatment modality. Populations with low health literacy demonstrate less willingness to ask physicians questions, as well as lower comprehension of medical terminology and jargon (Nairn 2014). Routine and formal use of tools designed to ensure patient autonomy (e.g. informed consent in populations with lower health literacy), in conjunction with surviving elements of medical paternalism in post-communist countries, conceals the potential risk for abuse of authority among medical staff – especially physicians – and creates an environment in which conscious or unconscious manipulation may occur. Elderly patients are inherently vulnerable due to advanced age and disease, and this vulnerability increased as a result of lower health literacy. Therefore, deficient health literacy, which can be assumed in elderly patients, places high moral demands on physicians, nurses, and other medical professionals.

All of our research participants were confident that information they had received about their health was understandable and, if something was unclear, most would ask their doctor for clarification. One senior admitted that she prefers to avoid asking questions: *"I don't want to bother them because I think they have a lot of work to do; plus, some doctors and nurses are quite surly like, 'and what do you want now?' so I prefer to not ask too much"* (67-year-old woman). Only 3 seniors actively dealt with information by searching the internet or medical literature: *"I read a lot, too; I don't know if it's good or bad, but usually when I come across an issue that the doctor is treating, I read about it with interest"* (67-year-old woman). One participant highlighted the complexity of technical terms and the role doctors have in their explanation: *"The examination reports are absolutely incomprehensible; they are full of technical terms I cannot understand and almost as many unknown abbreviations. I've had the best experience with 'Dr. X' because she consistently explains everything in complete detail and with layman's terminology"* (68-year-old man). The increasing difficulty of medical information comprehension was pointed out by one participant (80-year-old woman): *"I would say that everything is becoming more and complicated"* Nairn (2014) reported that, for many patients, the use of technical terminology may lead to misunderstandings.

In addition to informed consent and the right to be informed of all aspects of one's health, the Czech Convention on Human Rights and Biomedicine also resulted in a substantial novelty in terms of patients' previously expressed wishes. In the Czech Republic, the concept of previously expressed wishes is still in its infancy; the rate at which patients and physicians have become aware of its existence has been very gradual. Recent research has shown that three-quarters of the Czech public have no idea what it is, and had never even heard it mentioned. Only 4% knew precisely what purpose previously expressed wishes served, while 7% had only a vague idea (Previously Expressed Wishes: Final Report 2015). Likewise, only a few of our participants had heard of the previously expressed wishes concept. Only one senior (69-year-old woman) stated *"I'm considering my options"* and a second senior (67-year-old woman) said, *"I'll probably express my wishes"*. The seniors who participated in our study would prefer to rely on natural family relationships rather than the institute of previously expressed wishes; i.e. they would allow their husbands/wives or daughters/sons to make medical decisions for them. To a large degree, they also held the conviction that physicians should decide for them because *"they are educated about it"* (70-year-old woman). *"The doctor should share information about my health status primarily with me and then, with my consent, my family"* (71-year-old woman). Conversely, in the event that seniors should become incapacitated (e.g. loss of consciousness) and unable to decide for themselves, respondents unambiguously stated that

they would want their family members to determine the treatment approach. The institute of previously expressed wishes was predominantly unknown, and not preferred, by respondents. *"I don't know about the previously expressed wishes option; I would leave the decision-making to my daughter and the doctors"* (79-year-old woman). *"If something were to happen to me, my daughter and I have an agreement regarding what to do and how"* (76-year-old woman).

Even the option to have consent expressed by a designated person or family member is covered by the new Law on Healthcare Services (Section 34, Article 7 of Law No. 372/2011 Coll.); in Western healthcare ethics, such individuals are known as legal representatives. Since the issue of previously expressed wishes predominantly relates to the senior population, the low level of health literacy in this field is very problematic. In addition to surviving paternalistic elements, another obstacle is the enduring taboo of death in Czech society (Beran *et al.* 2010).

The participation of patients (and their families) in their own treatment is a fundamental right, whether in terms of planning and deciding long-term care goals, or in case of acute care (e.g. the issue of previously expressed wishes). Involving patients and family members in decisions about healthcare modalities increases the safety of care (Brabcová *et al.* 2014). Minimizing risks that patients face during hospitalization in medical facilities is associated with a culture of safety, an important aspect of which is the active involvement of patients and their family members to ensure safe care delivery (Brabcová *et al.* 2015).

Decision-making in healthcare

Patients' autonomous decision-making presumes not only the comprehensibility of information, but also the completeness of the information provided. Therefore, Article 10 of the Convention on Human Rights and Biomedicine states that everyone has the right to know all information concerning their health. One respondent aptly described modern medicine's foundation of patient autonomy and the informed consent requirement as a "white lie", which may appear to be psychologically defensible, but is both immoral and difficult to implement: *"Of course I want to know the truth; although, I am certainly aware that sometimes it could be for the worst in terms of treatment and the like, and it could play a negative role. A man can tell when a doctor is using honeyed words to conceal his true state of health"* (68-year-old man). At the same time, some patients have no desire to know all the details of their illness. One such respondent said: *"I'm not overly interested in knowing what the situation is"* (74-year-old man). As noted by Šimek (2015), the right to know information is linked to the right not to know. However, the latter must be clearly stated by the patient; it cannot not be determined by the physician. Moreover, every patient requires different information conveyance methods,

as well as different informational content. Not every patient is interested in disease pathophysiology; some patients simply want to know what they have and what they should, or should not, do about it (Šimek 2015). It is necessary to ask patients what they prefer, even though the level of knowledge, the ability to act, and the willingness to participate in the information conveyance process, may vary among patients and circumstances. Elderly individuals, who were raised in such a way that they seldom question a physician's authority, will likely not ask too many questions during their stay in the hospital (Bártlová *et al.* 2014).

Participants were rather unfamiliar with the concept of informed consent. They often could not recall whether, or in what context, they had provided it; nor the manner through which information had been provided. Seniors responses more frequently indicated that providing informed consent had been a routine process without a thorough discussion with the physician: *"Nobody gave me any information, I just signed it"* (76-year-old woman); *"Now it's required everywhere; when I go to the gastroenterologist, this signature is required everywhere"* (76-year-old woman); *"I read the informed consent form, but I don't know whether a nurse or doctor discussed it with me"* (80-year-old woman).

Informed consent is principal tool that ensures patient participation in making decisions that pertain to healthcare modalities. All procedures performed by medical professionals are conducted with patient consent. As conceived, however, informed consent cannot serve as an instrument to realize patient autonomy and, instead of requiring a higher level of patient health literacy, places patients in a more passive role that only requires their signature on a formal document that they essentially do not understand. Thus, patients often do not regard informed consent obtained in this manner to be a tool used for collaborative decision-making, but rather a means to shield doctors and the healthcare system from potential complaints or legal action.

During the interviews, respondents were asked whether they ever refused proposed treatment (surgical examination) and, if so, for what reason. The majority of respondents stated that they had never refused any treatment proposed by their physician. Only 1 interviewee (81-year-old woman) had refused pain medication, and 1 interviewee (80-year-old woman) regretted that she had consented to a procedure: *"I've never refused planned procedures, but I think I should have. Last time, when I went in for cataract surgery, there were complications. The operation wasn't successful and now I can barely see out of my left eye. I was in the wrong place at the wrong time."* The Czech Republic has very carefully described obligations for obtaining informed consent, the particulars for which are detailed in the following Czech legislation: Sections 34 and 35 of Law No. 372/2011 Coll., on Healthcare Services; and Annex No. 1, item No. 5, of Czech Ministry of Health Decree No. 98/2012 Coll., on Healthcare Documentation. This

legislation is extraordinarily casuistic and detailed. It describes the concrete requirements, forms and methods of documenting informed consent.

The passive role of the patient was also revealed through reluctant responses to the issue of patient involvement in decision-making: *"I don't suspect that doctors would come to me with some alternative options; I've always absolutely accepted the proposed treatment method, and I've always seen it as being the only option"* (68-year-old man). However, as noted by another senior (67-year-old woman), patients often create passive roles for themselves: *"I feel as though I should be out of the clinic as soon as possible. He doesn't hurry me out, I definitely can't say he does that. My family is used to not bothering a doctor unnecessarily, so I just stick my arm out, he does the measurement, writes a prescription, and I leave. It does need to be discussed with the doctor. But I think that's my fault, not his."* Physicians often are not overly interested in the broader context (e.g. family, social, economic) of their patients' lives. As 1 senior (76-year-old woman) bluntly stated: *"He doesn't care; he's completely uninterested in that."* However, some respondents did have physicians who showed interest in such information and recognized its significance well: *"A competent doctor is also a good psychologist; he should read between the lines when discussing what's going on in the family"* (68-year-old man); *"It's very calming when he asks, or says he hopes things turn out well (...) it's good that he knows a situation might arise that needs addressing"* (67-year-old woman). The need to know the context of patients' lives was also stressed by Coulter (1999), who stated that only the patient knows their own experiences with illness, social circumstances, habits and behavior, and their relationship to risk. Such knowledge is necessary for successful disease management and both sides should be prepared to share information and make decisions together.

For the most part, respondents wished to be fully informed, but had not actively used their right to access their medical records; some were not even aware that such a thing was possible. That said, it should be noted that this right is relatively new in the Czech Republic. Prior to its implementation in 2007, patients only had the right to view information about their health status in the form of a summarized extract – they could not view the actual records or copies of them (Haškovcová 2002).

Respondents' answers to the question of information comprehensibility may give the impression that the seniors were well informed about their health status and understood the information received. However, when one focuses on the use of this information for autonomous decision-making, a clear disconnect is evident. As O'Neill (2002) stated, *"We make it possible for individuals to choose autonomously (...), but we in no way guarantee or require that they do so."* The passive role of patients was again highlighted by seniors' responses when asked how important patient rights were. The overwhelming majority had no comment on the con-

cept, and could not even identify its significance. The phrases that most commonly appeared in their answers were *"I don't know"; "I'm not very familiar with them"; or "I don't need them."* The response of 1 senior indicates that Czech patients do not take the Code of Ethics to heart: *"You know, when I hear all of those altruists and those organizations who talk about those things, I simply don't listen (...) as far as whether I'm interested, or investigate what a patient's rights are, I just don't address that issue"* (68-year-old man). The Code of Ethics for patient rights in the Czech healthcare system was created in 1992 – not as the result of efforts for greater patient participation in making decisions about their healthcare but, rather paradoxically, as a declaration by the Czech Ministry of Health, Central Ethics Committee. Informed consent, which is the primary tool in the realization of patient autonomy, was introduced into the Czech legal system in 2001 when the Czech Republic ratified the Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (Convention on Human Rights and Biomedicine), which was adopted by the Council of Europe in 1997, as part of the approximation of Czech law with European standards.

Compliance with nonpharmacologic treatment

As was previously mentioned, compliance is an inseparable component of health literacy. Compliance can also be defined as cooperation with, or adherence to, treatment recommendations prescribed by a medical professional (Dapp *et al.* 2007). The foregoing clearly defines an unequal relationship between health professionals and patients (Falvo 2011). Compliance has a broader dimension than simply adhering to medical guidelines and recommendations; compliance results in patient lifestyles being changed in every aspect. However, modern medicine often merely employs passive information conveyance (Rankin *et al.* 2005). Such practices do not stress the educational elements that are designed to ensure compliance efficacy. On the issue of smoking, only 2 seniors, despite suffering from chronic diseases, reported that they smoked: *"I regularly smoke about 20 cigarettes a day"* (74-year-old man). The other senior smoked 1 cigarette daily (72-year-old woman). Smoking is one of the most significant risk factors that contributes to the emergence of cardiovascular, metabolic, and cancerous diseases. In elderly patients, smoking represents one of the most difficult to influence, and highest risk, health factors. Numerous studies have shown that smoking cessation leads to modified cardiovascular parameters, blood pressure values, and lipid spectrum values. Of the seniors in our sample, 12 were undergoing treatment for hypertension; 3 for diabetes; 3 for dyslipidemia, and 2 for coagulation disorders. Even here, one could observe that hypertension is a protracted and long-term health issue within this sample: *"I've had high blood pressure for about 10 years"* (67-year-old woman). Treatment for these diseases of

civilization requires that medical professionals possess a thorough medical education and, ultimately, enormous patient motivation to comply with prescribed recommendations. Interestingly, 6 seniors reported that their physicians had not told them how to modify their lifestyles. These particular seniors were undergoing treatment for hypertension, for which diet plays an important role. By contrast, one senior reported that: "My doctor supports me very much and he wants me to lose weight" (71-year-old man). Four additional seniors provided similar statements (71-year-old woman, 81-year-old woman, 79-year-old woman, 76-year-old woman) regarding recommendations for diets or weight loss compliance.

Dietary habits in old age may also constitute an important factor that can slow disease progression, and could possibly even delay it. For this area, we focused on respondents' consumption of dairy products, fruit, vegetables, and fish. These foods should be an important part of a senior's balanced diet. The majority of the sample stated that, despite illnesses such as hypertension or dyslipidemia, they maintained a normal diet without any limitations. By contrast, 6 informants stated the opposite; i.e., they complied with their prescribed diets. The only exception was one respondent (79-year-old woman) who practiced strict adherence to a modified diet for kidney disease. A balanced diet undoubtedly includes a daily intake of fruits and vegetables; optimally in a 2:3 ratio. All seniors in the sample ($n=19$) consumed fruit and vegetables daily, the quantity and ratio of which varied according to the fruits and vegetables available in the market: "I eat seasonal fruits and vegetables from my garden" (88-year-old woman). As reported by one participant (69-year-old woman): "I don't buy vegetables, they're expensive; I eat more fruit." Fish consumption ensures seniors' intake of omega fatty acids and vitamin D (and iodine, in case of consumption of marine fish).

More than half of the sample also reported that, with respect to dairy product consumption, yogurt and cheese were especially popular. A smaller number of respondents also reported milk as a favorite. Therefore, even dairy products are an integral part of a senior's balanced diet. It plays an especially important role in terms of preventing and delaying osteoporosis-related complications, which is associated with female gender and advanced age.

CONCLUSION

We have attempted to demonstrate that health literacy among seniors is a phenomenon that has fundamental ethical consequences. Health literacy is closely linked to the manner through which the principle of respect for patient autonomy is applied in practice. If tools that foster respect for patient autonomy (the most important of which is informed consent) are strictly formal and do not anchor patients in dialogical partnerships with their

healthcare providers, patient health literacy cannot be expected to improve. The issue of health literacy cannot be reduced to merely informing the patient. It is a common misconception that a properly informed (educated) patient approaches their healthcare or treatment responsibly, and behaves according to medical professionals' expectations. However, the patient must not only have the ability (capacity) to process such information, but also the motivation to devote their health to it. Likewise, the patient must also trust their doctor. These facets can only be developed through dialogical relationships between physicians/medical professionals and patients; however, unfortunately, these are often neglected (Šimek 2015). The results of this qualitative study have demonstrated the obvious limits of effective health education among seniors. The Czech Republic ranks among countries with low health literacy, and seniors are one of its vulnerable populations. The key to strengthening health literacy (not only) among seniors, lies in the active involvement of well-educated, motivated patients in joint decision-making in healthcare, while taking into account that individual decision-making capacities may vary, and may be limited by various factors, of which advanced age is one. Medical professionals should avoid making decisions for patients in areas where they are capable of making an informed decision. Likewise, healthcare providers should also avoid exerting undue pressure on independent decision-making if the patient cannot cope, but rather expects the trusted advice of their doctors or other medical professionals. We recognize that our results have limitations given ours was a pilot study conducted in only one region of the Czech Republic.

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