

Participation of adult patients in healthcare

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Abstract

In this study, the question of health literacy in adult patient population in the Czech Republic is explored in the context of healthcare, particularly in the South Bohemian Region. The study is based on the analysis of qualitative data which were collected during the first half of 2016. The study included 34 adult participants at the age range between 18 and 64 years.

The study is focused on the involvement of adult patients in the process of decision making concerning the healthcare provided. The views of this sort of problems were recorded by the technique of semi-structured dialogues. The study results have suggested that adult individuals accept the healthcare provided by doctors or nurses prevailingly with trust. In addition, they have shown that in the sphere of health education, the adults lack the knowledge of the right for information about the individual's health condition and information about the service provided by the health insurance agency. It is regarded as desirable to deal with the topic of health literacy of adult population, particularly in the area of internet counselling and telemedicine, and to develop the space for information sharing between the doctor and nurse on one side and the patient on the other.

INTRODUCTION

At present, the Czech healthcare system increasingly emphasizes the patient involvement in the decision making concerning their treatment. However, as mentioned by Příbová and Votinský (2008), the communication with the doctor or nurse is difficult for a large part of general public; it may be the main obstacle for active patient involvement in healthcare. Both sides must be trained to enable successful communication. In the patients, so called health literacy needs to be developed which involves, among others, the ability to

be active in communication with the healthcare staff and to become their partner (Příbová and Votinský 2008).

With the development of healthcare, an increasingly stronger emphasis is placed on patient becoming an active participant in healthcare, not only a passive recipient (Nielsen-Bohlman *et al.* 2004). Parnell (2015) mentions in this association that to achieve this reality the recipients naturally need to have sufficient knowledge and skills focused on the patient effective participation in the responsibility of their health (Parnell 2015). In the context with this phenomenon, the term

of “health literacy” is used more and more frequently. Holčík (2010) defined health literacy as the ability to behave on the basis of health information and to make use of this information to improve health.

When we stop to think about what is, on one hand, pointed out by Příbová and Votinský (2008) and, on the other hand, by Holčík (2009), it can be seen at first sight that there is no agreement. The agreement can be probably found by a certain interconnection of the views of the above mentioned authors concerning the discussed problems, where it can be supposed that the individual’s capability of being actively involved in medical care is a result of the high awareness of this sphere of problems, which warrants the effective understanding of the information on the patients’ part followed by health improvement thanks to effective utilization of this information for their own benefit. According to Zarcadoolas *et al.* (2006), the support of this trend is important particularly because the low health literacy leads to a generally poorer health condition, a higher occurrence of life threatening situations and, as a result, to higher cost of health care. It results from the above mentioned text that the concept of health literacy is not only important for an individual but it is also contributive for the whole society.

In comparison with other countries, there are few studies dealing with the problems of health literacy in the Czech healthcare or educational setting. Currently, there are studies focused on these problems published by Holčík (2001, 2005 *et al.* 2009). Furthermore, the results of Kučera’s study were published (2015).

This study deals with two areas. The first area is focused on the patient participation in healthcare, which is monitored at two levels: first, whether patients are active in their contact with the doctor and step in diagnostic and therapeutic procedures with their questions or suggestions; second, whether they take the opportunity of looking into their healthcare records or whether they check the account in the health insurance agency, or whether they know about these possibilities. As results from the above mentioned definition by Příbová and Votinský (2008), such a behaviour is a direct proof of the level of the patient’s health literacy.

The second area studied dealt with the fact where or whether, patients look up information on healthcare problems and how they evaluate this information from the point of view of accessibility and quality. This area was studied because an active approach in health awareness is a precondition for achieving an effective level of health literacy.

The main goal of the study is to identify the ways of patient participation in healthcare, first, at the level of a personal contact with the doctor during diagnostic and therapeutic procedures and, second, at an administrative level including the inspection of healthcare documentation and the account in the health insurance agency. Another goal was to identify the adult patient’s personal involvement in looking up information about

health problems and the patient’s personal opinions of the availability and quality of this information.

MATERIALS AND METHODS

With regard to the main goal of the study, a qualitative method was chosen for the implementation of the study, the data were collected by the technique of a semi-structured dialogue. As the study was performed in the scope of a team research project (ZGO2016_001) of the Faculty for Health and Social Sciences called Health Literacy in Selected Groups of Population of the South Bohemian Region, the basis for the semi-structured dialogue was divided into six independent areas (availability of information, motivation for looking up the information, orientation in the Czech healthcare system, participation in healthcare, knowledge of health prevention and knowledge of the health condition). Due to the large quantity of obtained results, only partial results relating directly to the above defined goals are presented in this study. The studied sample was constructed by means of a deliberate selection after setting three criteria: the age of the participants between 18 and 64 years, permanent address in the South Bohemian Region and previous experience with medical practice – diagnostic or therapeutic procedures. During the data collection, attention was also paid to the distribution of the studied subjects across the defined age range and to the most even possible representation of sexes. The actual semi-structured dialogue was performed at the presence of the questioner and the participant, who had been made acquainted with the purpose of the study in advance. Furthermore, each participant was made acquainted with the anonymity of the study and the opportunity to quit the project any time. The course of the dialogue was recorded by the Dictaphone, in the case of the participant’s disagreement, only a written record was made immediately. The data collection was performed in February and March 2016 and finished at the moment when the dialogues were not bringing any new information. This can be referred to as a certain theoretic saturation of the sample. In the association with the above mentioned anonymity, each participant was awarded a code of P1–P34.

Analysis

The first analysis of the rewritten dialogues was performed in the MAXQDA 10 PLUS program, which gave the basic structure of categories and subcategories and the matrixes of quotations for a better orientation in the large amount of data. Later, the results relating to the goals of this study were selected, which enabled secondary rearrangement of some categories and subcategories. In the scope of this study, two categories will be discussed (Figure 1):

- **patient participation in the health care;**
- **personal involvement in looking up information about health problems.**

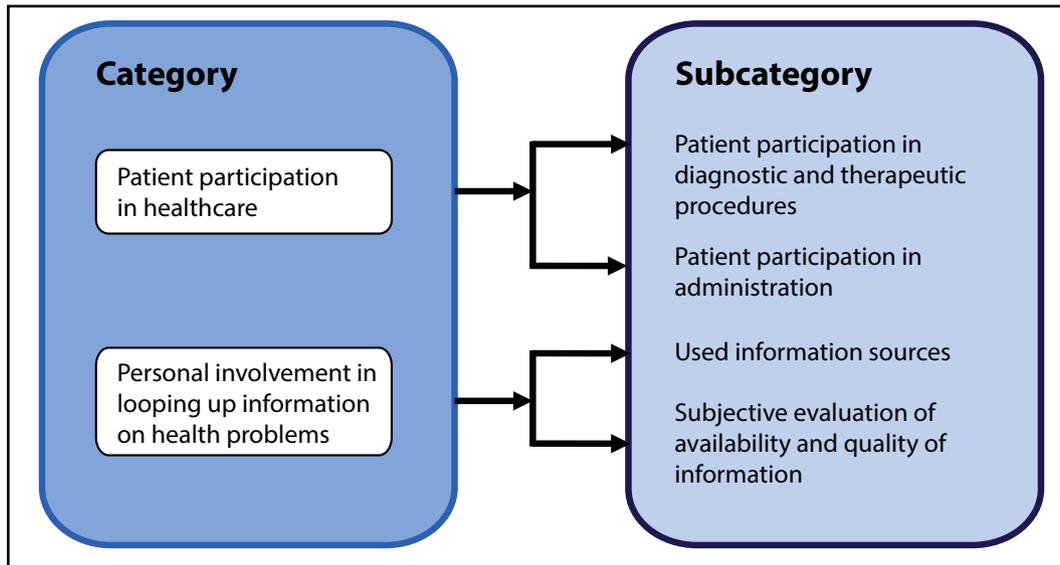


Fig. 1. The ways of the adult population's participation in healthcare.

The former of the categories includes two subcategories:

- *patient participation in diagnostic and therapeutic procedures,*
- *patient participation relating to administration.*

The latter of the categories includes two subcategories:

- *utilized information sources,*
- *subjective evaluation of the availability and accessibility of the information.*

RESULTS

The patient participation in the healthcare is a category focused on the description of the fact how much the “adult general population”, represented by the study sample (see Materials and Methods), trust their doctors and to what degree they actively interfere in diagnostic and therapeutic procedures.

The first subcategory, i.e. the *participation in diagnostic and therapeutic procedures*, includes the participants' answers to the question whether they ask the doctor or the nurse any questions when they undergo an examination. In the prevailing majority, the participants answered that they fully trusted the doctor and did not step in the procedure in any way. In five cases it was found out that they trusted their doctor but were interested in details. Seven participants in the study stated that they usually interfere in the medical procedures. “*I participate in the decision making; I get most of the information from Internet or from similar patients*” (P10). One of the participants, particularly P20, does not trust the doctor at all because he states: “*When I know something about it, I ask him and don't believe him very much because I feel that he wants to do it in a way which is the easiest for him, not for me. Since my belly was cut, though laparoscopy could have been done, I haven't trusted them. I hadn't been informed that there was another option, I learned about it only after the*

intervention, when somebody found it. The doctor had not informed me about that option at all.” It results from the following quotations that four respondents did not fully trust in the procedures chosen by their doctors. “*Nothing can be done but trust him but I don't have a good feeling, and so, after a visit to my doctor, I phone my friends – doctors to tell me whether something else can be done or not. If they tell me that there are other options, I want to use them and ask for them*” (P22). P19 said that “*it is better not to ask about anything because if you ask, they let you feel you are stupid or that you are bothering them*”. The answer of P12 was similar: “*If I undergo a medical examination, I can't take part in decision making – they would tick me off. Just try it!*” As follows from these statements, the participants are put to the role of passive recipients without the chance to participate in their health condition.

In the scope of the subcategory of *patient participation in diagnostic and therapeutic procedures*, it was explored whether the individuals – if they take any prescribed medicaments – proactively step in this process and ask about the details of the prescribed medication. The participants' answers, which were very similar, can be (except for three cases where the respondents expressed no opinion saying that they do not take any medicines) divided into two groups. One third of the respondents stated that, except for the indication, they were not interested in the medicaments more closely. Two thirds of respondents look up additional information while the most common source of information is the enclosed leaflet or internet.

In this subcategory, the prevailing part of the respondents stated that they felt free to ask the doctor or the nurse. The remaining part expressed opposite answer for various reasons. In two cases, it was explained by shyness, in three cases the doctor's unwillingness to answer questions was mentioned. One of the par-

ticipants answered that it depended on the particular doctor. Another of the respondents added that one question did not cause him any problems but repeated questioning did.

The subcategory called *patient participation in the scope of administration* was focused on the findings whether adult patients make use of the opportunity to look into their personal healthcare documentation. The obtained results can be evaluated from two points of view. First, whether they used this opportunity or not, and, second, whether knew about this opportunity. More than a half of the sample answered that they had never taken this opportunity. The remaining part stated that, under certain circumstances, they had looked into the documentation. Six respondents answered that they had peeped into the records when they were carrying them to another doctor. Two respondents mentioned that they studied the documentation secretly when nobody saw them. One of the respondents even mentioned that she had supposed that it was forbidden to look into one's documentation.

The other area studied in the subcategory of *patient participation in the scope of administration* collects, from the answers of the participants, the information to the question whether they regularly monitor their

account in the health insurance agency. Most of the respondents answered that they did not do so; four of them completed the answer by the information that they did not know what it meant. In five cases it was found out that the respondents had sometimes used this opportunity. Unfortunately, only one respondent does so every year. In this connection, a finding needs to be mentioned saying that the general practitioner is given as the most common *source of information about the patient's health condition*, followed by doctors-specialists, if they are visited. Only two of the respondents are aware about the possibility to get the information about their health condition from the health insurance agency. As an example, the answer of P17 can be given: "I get the information about my health condition from my general practitioner and from the health insurance agency – so called life card."

In the scope of the second studied category of the *personal involvement in looking up information about health problems*, in the part concerning the *utilization of the information sources* in association with the health condition, the attention was paid to the possibilities of supporting the health literacy of the adult population. In this connection, the Pareto analysis was used, the results of which are presented in the Figure 2. Pareto's

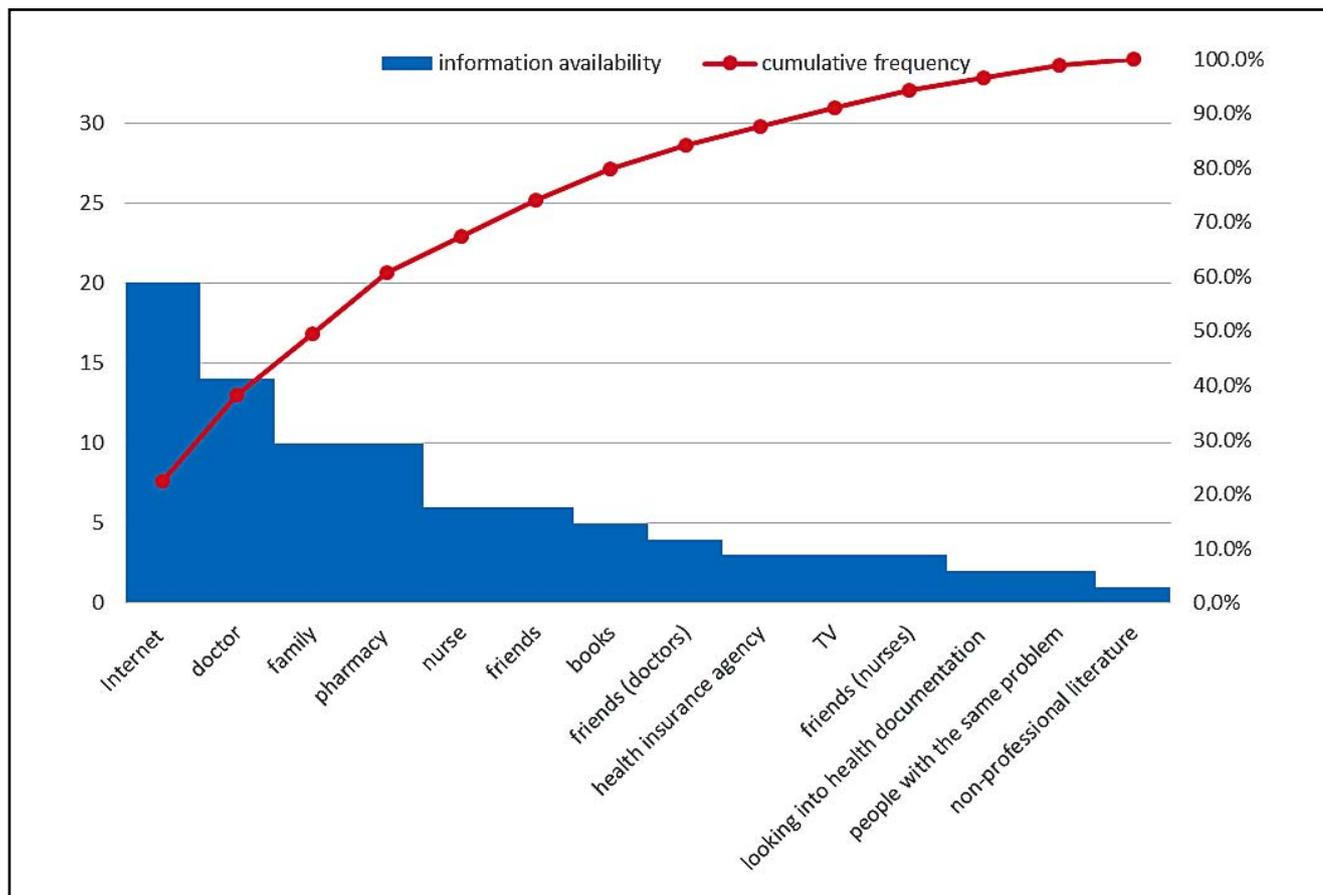


Fig. 2. Utilized information sources. (Internet – doctor – family – pharmacy – nurse – friends – books – friends (doctors) – health insurance agency – TV/friends (nurses) – looking into health documentation – people with the same problem – non-professional literature).

method assists to establish the priorities during the removal of main problems which hamper the optimum to be achieved. Vilfredo Pareto defined that 80% results were caused only by 20% causes. If 80% of losses want to be removed, the activities are focused on the pre-defined problems in the range of 20% (Koch 2015).

It follows from the Figure 2, that in the area of information availability, the attention needs to be paid to the supporting of the influence of internet counselling and healthcare professionals because these areas represent a potential for further development of healthcare literacy.

The second part concerning the *subjective evaluation of information availability and quality* suggests that there is no problem to obtain information, particularly by means of internet. It needs to be mentioned that the respondents have problems with the choice of true information, as mentioned e.g. by P25: *"If I need to find out something, it is not so difficult. I just switch on the computer and look it up. But it is true that you can find there plenty of things – only disasters. So, you can't take it so seriously."*

As the most common source of information relating to one's own health, healthcare professionals, such as doctors and nurses, are mentioned; as the next source, internet is given. Other sources included professional literature, people with the same problem and watching television programs focused on health problems. In some cases, friends employed in healthcare, pharmacies or spouses were mentioned.

Although it follows from the dialogues that the respondents obtain the information mainly from internet, the possibility if internet counselling is offered by doctors only to three respondents. Seven respondents do not know about the possibility of internet counselling at all, the others do not have this opportunity.

DISCUSSION

Currently, simultaneously with the development of health care, an increasingly stronger emphasis is placed on patient to become an active participant in the care of his/her health instead of being just a passive recipient (Nielsen-Bohlman *et al.* 2004). To achieve such a reality, however, patients need to have sufficient knowledge and skills which would lead to their effective participation in the responsibility for their health (Parnell 2015). This study tried to reveal the ways of the patient participation in healthcare at the level of personal contact with doctors in the scope of diagnostic and therapeutic procedures and at the administrative level. In association with the data analysis of the above mentioned areas, it needs to be mentioned that the individual categories did not occur in the participants' answers with same frequency.

The results presented in this text confirm that the respondents are not ashamed of having an active dialogue with the doctor in charge about the course of the healthcare provided, which is an evidence of the

increase of health literacy, which is, according to Holčík (2010), defined as the ability to behave on the basis of information and utilize this information for health improvement.

In this association, it can be supposed that adult patients implicitly think about their participation in health improvement or strengthening. Another finding of this study can be associated with the above mentioned – the prevailing part of the participants fully trusts their doctors and do not interfere in the therapeutic procedure. 5 participants ask about details because they do not fully understand the problems. It needs to be added that there were answers: *"I look up the information on the internet"* (P10), *"I phone my friends – doctors"* (P22) or *"I don't trust my doctor very much"* (P20). From these answers, not fully blind trust in the doctor's practice can be judged, which results in the increase of health literacy through drawing information from other sources. As mentioned by Svačina (2015), the communication between patients and doctors is based on individualities because, as also follows from the results, the individual does not always approach his/her doctor with trust; the information provided by the doctor is verified by other doctors or on internet (Svačina 2015). Interestingly, this aspect also appears in a study performed in Slovakia, which is focused on the satisfaction with the quality of healthcare provided by dentists in Slovakia (Samohýl *et al.* 2016).

The results of the second studied part dealing with *utilized information sources* also suggest that adult population uses internet to obtain information about health problems. It follows from the results from this area that the participants are explicitly interested in increasing health literacy because the majority of the respondents mentioned internet as the most common and useful source of information. In this association, the patients' interest in decision making about the therapeutic procedures was identified. Patients' significant interest in the participation in treatment was also presented by a study focused on the patient role in safe care (Bártlová *et al.* 2014).

However, the high degree of trust in the doctor needs to be mentioned and attention drawn to the fact that the doctor was named as one of the information sources and, at the same time, the most useful one. More than one half of the respondents would address the general practitioner or the specialist with trust in an emergency case.

The relationship of trust between the doctor (and/or a nurse) and the patient is implicitly confirmed by the answers to the question whether the respondents are ashamed of asking their doctor or nurse for the advice repeatedly. It must be agreed with Betz *et al.* (2008) that to some degree, nurses represent a link between the doctor and the patient and so they can contribute to a more effective understanding of the healthcare information and, as a result, increase the level of health literacy. In this association, a finding from a study focused

on community care needs to be mentioned – it follows from the study results that the nurse's position in preventive care could lead to the improvement of the health education of adult population (Tóthová *et al.* 2014).

The results of this study show that the respondents are interested in increasing their health literacy; however, the obstacle may be, to some degree, their shyness. This is naturally not in order because systematic education in the area of health and active involvement in the process of healthcare can, e.g., contribute to the decrease of the risk of mistakes made by healthcare professionals (Brabcová *et al.* 2014). Another phenomenon appearing in our outcomes is the phenomenon of internet, which conforms to the finding of the Czech Statistics Office that the number of individuals using internet again increased in 2014; 41% of the total population and 56.3% of internet users used internet to look up this information (Czech Statistics Office 2012).

It needs to be mentioned that most of the participants look up additional information on internet after leaving their doctor's office. Most of the respondents do not know about the opportunity of an internet connection with their doctor.

In this association, the data collected were visualized by means of Pareto diagram where it can be seen that the strong point which can help to increase the health literacy is supporting the influence of internet counselling and healthcare professionals. Here, attention needs to be drawn to the potential of telemedicine, which is based on the use of electronic information and communication technologies in the area of healthcare. Telemedicine penetrates into individual medical and healthcare specializations and also interferes in the area of social care and education. Among others, it offers the possibility of a distant approach in the area of therapy, e-learning of both doctors and nurses (Středa and Panýrek 2011). An example of this approach to patients with a cardiovascular disease, particularly in the area of prevention of thrombo-embolism in patients with an implant of mechanical heart valve, is presented in the study called *Telemedicine-guided very low-dose international ratio self-control in patients with mechanical heart valve implants* (Koertke *et al.* 2014).

One of the possibilities of how to help a passive care recipient to become an active recipient is to increase health literacy of the population outside the doctor's office, i.e. to shift the educational activity into the community area. This opens the space for the establishment of a particular centre where both nurses and doctors would be used in the role of educators. It would enable the improvement of the adult population's health literacy in the required area of primary, secondary or tertiary education. Our opinion is in accordance with Johnson (2015), who regards the patient education in health problems as an important tool by means of which nurses in cooperation with doctors can help the general public to take a more effective care of their health and improve their general health condition.

CONCLUSION

This study dealt with the problem of the adult individual's proportion of decision making in the process of healthcare and the adult patients' availability of information concerning their health condition. As a contribution of the study, the fact can be regarded that the areas have been identified where the adult population's health literacy needs to be supported and developed, which, therefore, need a deeper exploration. One of these areas is internet counselling and telemedicine. Further studies of this phenomenon should be focused on these topics.

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