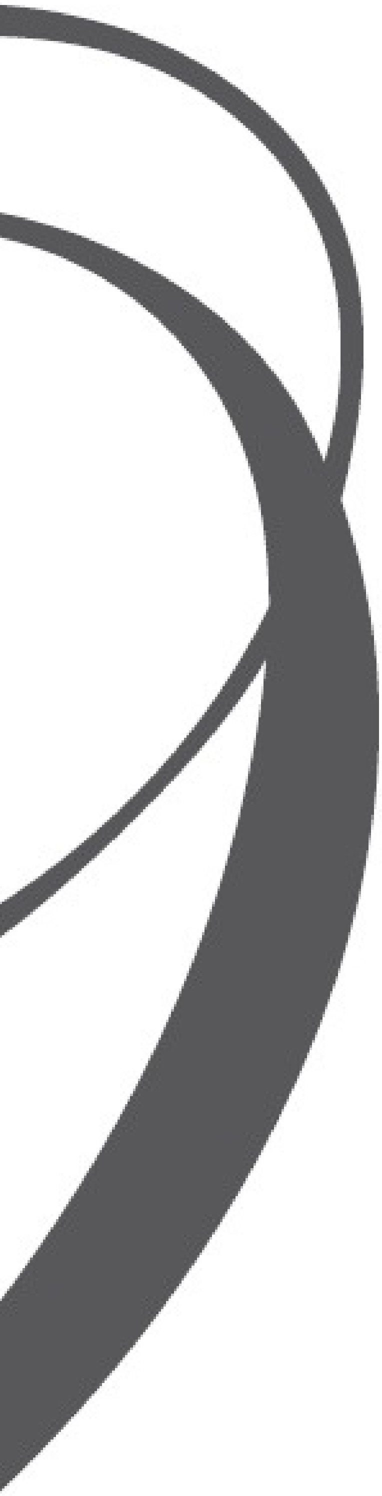

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The Filter Bubble: How to Control Democracy in the Information Society Era

Ewa Milczarek*
University of Szczecin, Faculty of Law and Administration, Narutowicza 17a, 70-240, Szczecin, Poland
ewa.milczarek@usz.edu.pl

Abstract

Research Question: The research lead to answer the question: Do filter bubbles distort the electoral process in such a way that it violates the right to free elections?
Purpose: The main research objective is to show that information bubbles violate decisional privacy, which in consequence leads to a violation of the correctness of the election process.
Method: : The research methodology includes a systematic review of scientific papers and studies developed by international organizations and of reports.
Results: The research shows the effects of filter bubbles on election process. Thanks to this, we can see that not all information is distributed evenly on the Internet and some of the information does not reach the recipients. The main research objective is to show that filter bubbles violate decisional privacy, which in consequence leads to a violation of the correctness of the election process. The author presents why states should regulate social media in the field of filter bubbles and what steps should be taken.
Organization: The development of the information society poses new challenges for the legislator. One of them is the problem of regulating social media and related tools - including filter bubbles. The article presents the influence of filter bubbles on the electoral process. The article reviews the current research on this problem- both empirical and doctrinal.
Society: The article deals with a socially relevant topic, which is the manipulation of the electoral process. The examples studied in the work on the cases of recent elections in the USA, Great Britain or Brazil show that the problem affects practically every corner of the world. The result of the study is to show that filter bubbles pose a threat to democracy.
Originality: The problem of filter bubbles and their impact on the electoral process is still an unexplored phenomenon. The work analyzes examples of the impact and indicates the steps that should be taken to start work on regulating this phenomenon. This research is based on the concept of social control over the social media algorithm.
Limitations / further research: The purpose of this article is to identify problems and review solutions. Research on the problem should be further established on the basis of legal and factual analysis

Keywords: information bubble, internet law, democracy, decisional privacy, social media.

1 Introduction

The development of the Internet and new technologies has led to fundamental social changes, resulting in the development of the information society. This society is characterized by the

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* Korespondenčni avtor / Correspondence author

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growing dependence of the economic, political, social, psychological and ecological spheres on information (Kreft, 2012, p. 755). These permanent and significant changes in socio-economic relations should be reflected in the legal order, including due to their impact on fundamental rights. Technological advances are opening up the possibility of highly sophisticated surveillance and espionage in ways that the older rules of the game may not be enough to keep in check (Strümholm, 1967, p. 19). Technology has had the biggest impact on how we transmit and receive information. Also, the role of social media in providing information on current affairs is growing. Furthermore, for the young people social media is the main source of information (Schwaiger et al., 2022, p. 609). Through social media public debate takes place and thus the right to freedom of expression is exercised. However, information on social media is distorted by filter bubbles.

The main research objective is to show that filter bubbles violate decisional privacy, which in consequence leads to a violation of the correctness of the election process. The research lead to answer the question: Do filter bubbles distort the electoral process in such a way that it violates the right to free elections? The article is a starting point of the research. The aim of the work is to outline the issues and indicate further directions of research.

2 Theoretical framework

The changes initiated by the information revolution affect the constitutional balance, understood as an ideal state created by the application of constitutional law norms in a given legal order, in the context of the protection of fundamental rights and the balance of power in the individual/state/enterprise relationship (Celeste, 2018, p. 88). This balance is disturbed primarily by the dominant role of enterprises in the digital environment, which negatively affects the position of both the individual and the state. The positions of the individual are further weakened by the increased surveillance capabilities of citizens. This control is exercised by the state authorities, but also by private corporations, which is a novelty in the protection of individual rights. This interference, although it has occurred so far, has not been so intense and profound. This phenomenon is exacerbated by the pervasive presence of technology among individuals and the dominant role that private corporations play in the digital environment. Existing legal mechanisms to protect civil and political rights are not adequate to abuses generated by platforms (Suzor, 2018, p. 9). In the social aspect, it is also worth paying attention to the discrepancies between the assessment of identical online and offline behaviors, which result in differences in their social acceptance (Milczarek, 2020, s. 56). One of the aspects of changing the balance of power in the individual/state/enterprise relationship is the problem of access to information. Internet companies (such as Google and Facebook) create the space where public debate is created. They have control over the flow of information and access to it. One of the disturbances in the flow of information are filter bubbles.

The term filter bubble was coined by Eli Pariser in 2011 (Pariser 2011). “Filter bubble” (also called “information bubble”) is situation in which someone only hears or sees news and information that supports what they already believe and like, especially a situation created on the internet as a result of algorithms (McIntosh, 2020).

Due to the algorithmic personalization of search results (in social media and search engines) people receives different search results (»personalized universe of information« (Pariser, 2015) consistent with their previous activity on the Internet, and that in effect each search engine user exists in a filter bubble. Thats create echo chambers: we assume that everyone thinks like us, and we forget that other perspectives exist.

Privacy is of key importance in election processes, because access to the attention of an individual leads to sophisticated ways of promotion, primarily the use of profiling, and thus violates decision-making privacy, especially in the field of making decisions (Wójcik, 2018, p, 127). In the attention economy, winning means getting as many people as possible to devote as much time and attention as possible to the product (election candidate, political party, some idea), because in the attention economy it is really "the user is the product". Privacy is therefore an ontic, necessary dimension of man and thus an inalienable right of his personal nature (Pniewski, 1994, p. 110). Bruns suggests that search engines and social media, together with their recommendation and personalisation algorithms, are centrally culpable for the societal and ideological polarisation experienced in many countries (Bruns, 2019).

That lead us to main research question (RQ1): do filter bubbles distort the electoral process in such a way that it violates the right to free elections? To check how the system of filtering bubbles and information personalization works, we can use the data provided by Facebook Help Centre: Posts that we see higher in Feed are influenced by our connections and activity on Facebook. The number of comments, likes and reactions a post receives and what kind of post it is (e.g. photo, video, status update) can also make it more likely to appear higher up in our Feed. Filter bubbles are therefore not just a state in time, but also a process that evolves into increasingly more personalised information, which ultimately makes it impossible to find challenging information (Dahlgren, 2021, p. 15).

Posts that you might see higher in Feed include:

- A friend or family member commenting on or liking another friend's photo or status update.
- A person reacting to a post from a publisher that a friend has shared.
- Multiple people replying to each other's comments on a video they watched or an article they read in Feed.
- The EdgeRank algorithm used by Facebook is based on three components:
- Affinity Score- expressing the intensity of the relationship between users.
- Edge Weight- specifying the value of a specific action.

- Time Decay - how long the message has been active on the site.

As a result of the operation of an algorithm, the person using the network will receive selected information. Algorithmic filtering may also constrain further exposure to a narrower, more closely aligned range of content. This, in turn, may foster the adoption of more extreme opinions (Kitchens, Johnson, Gray, 2020, p. 1620) and foster populism. Current research shows that the negative effects of filter bubbles are stronger for younger people and those with low interest in news (Fletcher & Nielsen, 2018, p. 2450).

Violating information freedom by filter bubbles undoubtedly have a potentially negative impact on democracy (Vīķe-Freiberga et al, 2013). Using filter bubbles and microtargeting, you can influence voter preferences and voter turnout. The analysis of several examples makes it possible to determine the scale of the negative impact of filter bubbles on electoral processes. An experiment in which Facebook persuaded its users to vote in the US election demonstrates the power of new opinion influencers well. The results suggest that the Facebook social message increased turnout directly by about 60,000 voters and indirectly through social contagion by another 280,000 voters, for a total of 340,000 additional votes. That represents about 0.14 % of the voting age population of about 236 million in 2010 (Bond et al., 2012, p. 297). In the UK, filter bubbles have distorted the public debate during the Brexit campaign (Bastos, Mercea, Baronchelli, 2018, passim). In presidential campaign in Brazil in 2022 the social media was very polarized, with two big groups of nodes that share similar content and almost no connections between these groups (Recuero et al., 2022, p. 161). In another study, the researchers claimed that differences in Google search results were capable of shifting voting preferences of undecided voters by 20 % (Zuiderveen Borgesius et al., 2016). As you can see, even such a small intervention in the algorithm made it possible to influence the behavior of users. That create a space for fake news and misinformation campaigns, with are the core threats to a transparent and fair electoral process.

3 Method

The research methodology includes a systematic review of scientific papers and studies developed by international organizations and of reports. I used the following databases to gather relevant articles to which we had full access: Scopus, Pr, Web of Science, Google Scholar, JSTOR, Wiley Online. Additional articles from other sources were also identified by examining the reference lists of the studies located through the database search. The search term consisted of three sets of keywords –filter bubbles, democracy and elections.

The analyzed literature was divided into 5 thematic groups: (1) devoted to the way filter bubbles work; (2) the impact of filter bubbles on access to information; (3) the impact of filter bubbles on the right to privacy; (4) cases of negative impact of filter bubbles on the electoral process; (5) behavioral research.

The article only presents selected views seen in the literature that shed light on the themes that legal scholars and commentators address.

An important part of the work was the analysis of the functioning of filter bubbles in practical terms. For this purpose, the Edge Rank algorithm provided by the Meta corporation was analyzed.

The conducted research allowed for the creation of an article based on four key issues:

1. The concept and operation of filter bubbles.
2. Examples of the negative impact of filter bubbles on election processes.
3. The tail wagging the dog - The problem of control over the social media.
4. How to protect democracy in the information society era.

The research lead to answer the question (RQ1): Do filter bubbles distort the electoral process in such a way that it violates the right to free elections?

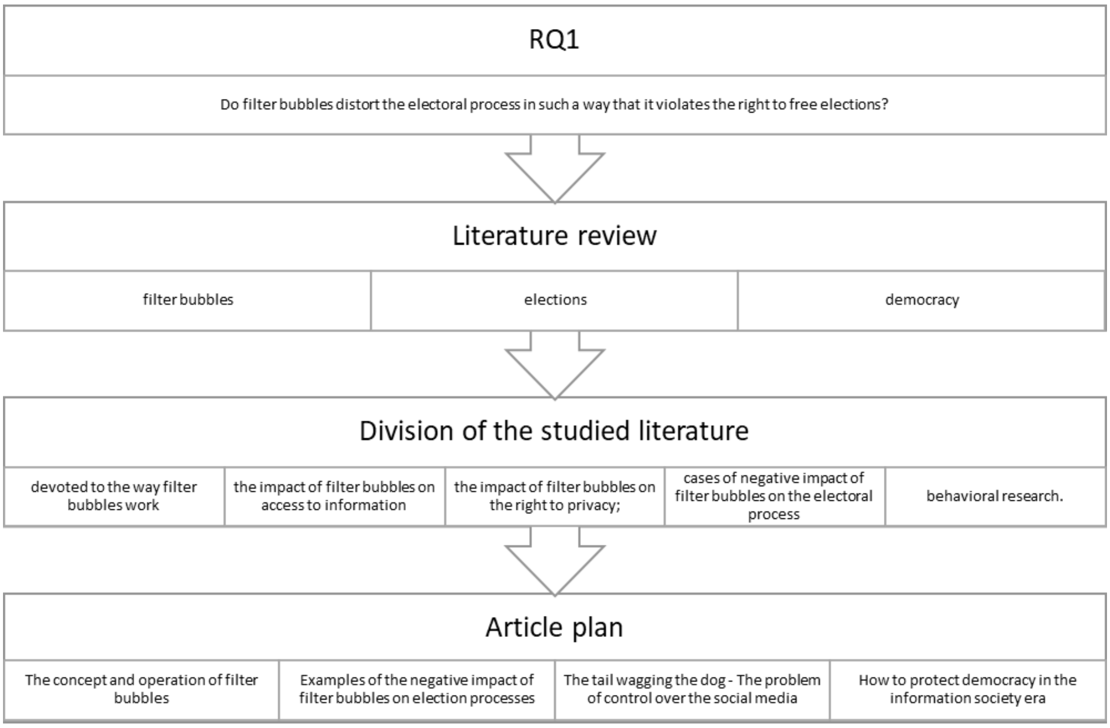

Figure 1. Research model

4 Results

4.1 Decisional privacy and democracy

The sort of classical model of democracy is one where it's we are making sure the peaple has information to make good decisions. Article 3 of Protocol I to the European Convention of

Human Rights guarantees everyone a right to free election. Freedom, fairness and transparency are recognized as key principles of democratic elections. Free elections are those where candidates can compete without any obstacles erected by the authorities, where the electorate has genuine options and a free access to information concerning those options. Fairness of elections can be prejudiced if there is a interference resulting in inequality of chances for the runners in the electoral race. The principle of electoral transparency is not met if the voters have no freedom to seek, receive and impart information about the process and the candidates, including about the source and spending of financial support received by a candidate or a party (The Report of the Kofi Annan Commission, 2020). Filter bubbles create opportunity to manipulation of society and could have influence their voting behaviour.

Each individual should be able to independently shape his personality and his destiny according to his own will and demand (Kopff, 1971, p. 38). The scope of the right to privacy includes the individual-general relationship, in terms of the individual's control over information about himself, but also in the general-individual context - that is, what information an individual receives in the context of shaping his personality and fate.

Privacy protection is related to access control (Bok, 1983, pp. 10-11). The preservation or disruption of privacy through filter bubbles affects spheres of privacy functioning, including information privacy, i.e. the ability to regulate the disclosure of sensitive or confidential information; physical privacy relating to being able to define private space and setting boundaries, and decision-making privacy relating to being able to choose a particular course of action without interference or interference from others (Fleczer, 2015). Restricting access to information is a source of distortions in decisional privacy, because we make decisions based on a distorted picture of reality (based on incomplete, biased, false, emotional information).

Sunstein points out two other basic risks of filter bubbles. First, in a democratic society people need to come across opinions that differ from their own opinions, to develop themselves fully. Otherwise, people might enter a spiral of attitudinal reinforcement and drift towards more extreme viewpoints. Second, if people locked themselves in their own information cocoons, they might have fewer common experiences. Sunstein says a diverse democratic society needs shared experiences as ‘social glue’ (Sunstein, 2001, p. 191).

When affective polarization becomes severe, »people increasingly perceive and describe politics and society in terms of ‘us’ versus ‘them’« (Somer, McCoy, 2018 p. 2). In effect society stops to believe that political opponents are legitimate and deserve equal respect, or are even acceptable as family and friends, they become less likely to adhere to democratic rules in the struggle for power (Lührmann et al., 2019, p. 904).

Currently, the protection of privacy of attention is solely in the hands of network users, who can defend themselves against unwanted interference in a limited way. Facebook provide the ways to customise Feed by changing the view and adjust Feed preferences; hiding a story that appears in Feed (also from a specific person, Page or group); and by reporting violates Community Standard. However, this protection is negligible and insufficient. The main problem with control of social media is that we don't really know how the algorithms works. Thus we cannot measure the real negative impact of filter buble.

4.2 Algorythm problem

Until recently, traditional media played the role of the so-called gatekeepers, i.e. the authority deciding what information should be made available to the public and in what form. The role of the gatekeeper was inextricably linked with consistent journalistic ethics, which requires not only objectivity and reliability, but also the presentation of different points of view and information that is often inconvenient, undesirable, and yet necessary. In a situation where the role of the information medium is taken over primarily by social media, with Facebook at the forefront, the role of gatekeepers is taken over by algorithms, i.e. de facto machines. Their biggest limitation is their lack of ethics. Algorithms sort according to rigid rules of importance, but they do not have the soft ability to subjectively distinguish what is really important from what is irrelevant or harmful from the perspective of the broader public good (Malinowski, 2006, p.20). Algorithms are not neutral technologies (Gillespie, 2014, p. 182), they are infrastructures of advertising and persuasion, designed to maximize user attention, and subsequently, advertising revenue (Wu, 2016). Digital information environment is 'mutually shaped' by algorithms that sort, rank, prioritize, and deliver content, and users (Schroeder, 2014, p. 145-157). Food for algorithms is the data generated by online interactions. People's attention is drawn to emotional, drastic and controversial information, including hate speech and fake news. That is why that kind of information is most often found on the social media feed. Howard et al. found that Twitter users in the United States shared as much "junk news"—or content that was conspiratorial, hyper-partisan, and lacked professional journalism standards—as professionally produced news in the two weeks leading up to the 2016 Presidential Election (Bradshaw et al., 2019, p. 188-189). The purpose of social media is not to provide good, reliable information (this is the idea of journalists). Their goal is to attract attention to get income from the sale of advertising. Hence, the debate via social media is aggressive, polarizing, full of misinformation, hate speech and fake news- because it attracts attention. As Fishkin points out, contemporary critiques about the poverty of deliberation in our democracy predate the rise of the Internet. The quality of democratic deliberation have declined in some democracies (Fishkin, 1991).

Also, social-media corporation could in theory make it easier for a political party which their business or ideological interests align with to reach their supporters or blocking information and views that are inconsistent with their ideology or interests (such practices have also been noted) (Committee of experts on Media Pluralism, 2016).

The examples presented above clearly indicate that filter bubbles have a real impact on the implementation of electoral processes. However, we only learn about the scale and extent of the damage after the elections, this information is selective and perfunctory. They do not give a complete picture of the situation.

4.3 Social media- out of control

Despite the theoretical pluralism of the choice of social media, it is de facto dominated by several websites (Facebook, Twitter, Instagram), which impose their conditions on all users and develop standards that are often a model for other enterprises of this type. In addition to the monopoly position, several additional factors left the activity of social media practically out of control. Among them, one can point out the international nature, which makes it difficult to supervise the enterprise; innovativeness, causing state authorities to have little awareness of how they operate; monetization of personal data that has led to the massive use of social media for business and political activities. The system therefore offered broad benefits. So, the system is in favor of big companies and political forces.

Social media play an important role in the implementation of public debate (and, consequently, are an important element of the electoral process). Social media are a public place (Bruns & Highfield 2016, pp. 56-73), (Shirky, 2011, pp. 28-41), (Cela, 2015, pp. 195-200), which implies the need to apply the Habermas model of the public sphere (Ochman 2015, p. 148). The situation we are currently dealing with, i.e., arbitrary decisions on the shape of public debate by corporations managing social media, is incompatible with the axiology of liberal societies. This creates a real (and realizing) threat of limiting the freedom of speech inconsistent with the accepted standards and top-down management of the public debate. There is a precedent-setting creation of a kind of lex specialis to national (or international) law, where private companies are the legislators, and not authorized bodies acting on behalf of the sovereign.

In my opinion we can't fall all responsibility on technology companies to design algorithms that encourage “fake news” and “filter bubbles.” States are responsible for the legal regulation of social, political and economic life. Leaving the social media out of control is a violation of the positive obligations of the state. The establishment and strengthening of democratic processes and institutions is the common responsibility of governments. States are responsible for protecting human rights to free elections in the information society. Therefore, they must adjust the law on an ongoing basis so that it meets the current threats and challenges.

5 Discussion

As I mentioned in this paper, as a society we have a little awarness about the way the algorithm works. The algorithm literacy is key to to determine the actual effect of the filter bubble on the distortion of the information we receive. As a Milan and Agosti points out: “algorithmic sovereignty tool should be open source, in order to promote transparency in its functioning and enable others to check its functioning, evolve its functions, modify or customize it.” (Milan & Agosti, 2019). Other researchs points out the importance of research on micro-targeting, specifically on its effects on citizens, including a normative component and debate about online political micro-targeting (Zuiderveen Borgesius et al., 2018). Its impact is especially significant not only because of how quickly fake news spreads, but also because identifying the authors of such campaigns and digital material is very difficult (Doublet, 2019). For governments and other actors that seek to legitimize undemocratic elections and delegitimize democratic elections or undermine specific candidates or parties, the use of on-line disinformation is a low-cost strategy with a potentially high impact (Bader, 2018, p.34).

Voices about increasing control over the operation of filter bubbles appear with increasing intensity. As Elizabeth Denham, the British Information Commissioner investigating the Cambridge Analytica case, points out, "it is important that the public is fully aware of how information is used and shared in contemporary political campaigns and the potential impact on their privacy". Users' privacy is being used against them.

To prevent election manipulation, national data protection officers have issued guidelines for political parties. In March 2014, the Italian data protection authority adopted rules on the processing of personal data by political parties. The legislation underlines the general prohibition of using personal data that is publicly available on the Internet, such as social networking sites or forums, for political communication purposes if the data has been collected for other purposes (Provvedimento in materia, 2014).

European Commission High Level Group on Media Freedom and Pluralism (HLG) points to the importance of harmonization of the existing national legislations, covering cross-border media activities on areas such as libel laws or data protection. HLG calls to adapting regulatory frameworks and codes of self-regulation to the fluid media environment (Vīķe-Freiberga st al., 2013). The European Data Protection Superviso is of the view that the problem of online manipulation is only likely to worsen, that no single regulatory approach will be sufficient on its own, and that regulators therefore need to collaborate urgently to tackle not only localized abuses but also both the structural distortions caused by excessive market concentration (Opinion 3/2018).

Dependence on providing information from one source favors the negative effects of filter bubbles (Dubois, Blank, 2018, p. 732). Hence, the young generation using social media as the main (sometimes the only) source of information is the most vulnerable. Due to the increasing participation of young people in elections, the tendency of filter bubbles to damage the electoral process will increase.

6 Conclusion

The analysis carried out in the study allows to answer the research question (RQ1) that filter bubbles distort the electoral process in such a way that it violates the right to free elections.

Based on the research, it was found that:

- The filter bubble combined with the manipulation of the algorithm allows you to control access to information.
- Filter bubbles can (and are) controlled by algorithms programmed by Internet companies (Google, Facebook).
- The public has no access to information on how the algorithm works.
- Analysis of past elections (such as Great Britain, Brazil, United States), in which the negative impact of filter bubbles on the electoral process was found.

Filter bubbles pose a threat to the right to privacy by analyzing our every digital footprint and by using algorithm feed by collected data to distort their access to information, and thus interfere with decision-making relating to being able to choose a particular point of view. As this and other studies have shown, filter bubbles, in conjunction with microtargeting and fake news, are conducive to manipulation that negatively affects the correctness of the electoral process.

The user bubble is not voluntary. It is a kind of censorship. While, by appropriately adjusting the browser settings, you can -partially-adjust the effects of the filter bubble in terms of the content provided (which, however, is rarely the case due to the poor awareness of the use of algorithms), the very fact of analyzing user behavior remains beyond any control.

The experience gained so far shows that the social media as information environment generates problems and threats different, more intensified, than those occurring in the analog world. This therefore requires other protection tools. Currently, no institutional framework has been created to strike the right balance between the interests of information providers and users. We need to applicate the human rights standards and normative frameworks to the challenges that social media pose to elections. States must fulfill their positive obligations related to the protection of individual rights, including the right to privacy, freedom of information and freedom of elections. Leaving filter bubbles out of control is a violation of these obligations.

Social media as public places are burdened with certain obligations related to conducting a public debate. As a society, we should have insight into how these responsibilities are met. Main responsibility for maintaining media freedom and pluralism lies with the states, yet it also points out that the EU is competent to intervene on media freedom and pluralism in order to guarantee to representative democracy. Developing legal solutions is difficult because lawmakers do not know how social media algorithms are constructed. We can only guess based on scanty data and observations. Key data is not made available, despite promises, even to scientists. It is crucial to subject the algorithm to social control in the spirit of transparency and to limit micro-targeting (which makes it difficult to verify the information provided by candidates). This will be a first step to answer the question: how to regulate social media during elections.

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Ewa Milczarek. Juris Doctor, PhD thesis: EU Standards of Protection of the Right to Privacy on the Internet Author of several articles and scientific papers; area of research: Constitutional law, European Union law, international law, Internet law. Professor (Assistant) at University of Szczecin Faculty of Law and Administration).

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Povzetek:
Filtrirni mehurček: kako nadzorovati demokracijo v dobi informacijske družbe

Raziskovalno vprašanje: Raziskava vodi k odgovoru na vprašanje: Ali filtrirni mehurčki izkrivljajo volilni proces tako, da kršijo pravico do svobodnih volitev?

Namen: Glavni cilj raziskave je pokazati, da informacijski mehurčki kršijo odločanje o zasebnosti, kar posledično vodi v kršitev pravilnosti volilnega postopka.
Metoda: Raziskovalna metodologija vključuje sistematičen pregled znanstvenih člankov in študij mednarodnih organizacij ter poročil.
Rezultati: Raziskava prikazuje učinke filtrskih mehurčkov na volilni proces. Zahvaljujoč temu lahko opazimo, da niso vse informacije enakomerno porazdeljene po internetu in nekatere informacije ne dosežejo prejemnikov. Glavni cilj raziskave je pokazati, da filtrirni mehurčki kršijo odločanje o zasebnosti, kar posledično vodi v kršitev pravilnosti volilnega postopka. Avtorica predstavi, zakaj bi morale države regulirati družbene medije na področju filtrskih mehurčkov in kakšne korake je treba sprejeti.
Organizacija: Razvoj informacijske družbe postavlja pred zakonodajalca nove izzive. Eden od njih je problem regulacije družbenih medijev in sorodnih orodij – vključno s filtrirnimi mehurčki. Članek predstavlja vpliv filtrirnih mehurčkov na volilni proces. Članek pregleduje dosedanje raziskave tega izziva – tako empirične kot doktrinarne.
Družba: Članek obravnava družbeno aktualno temo, to je manipulacija volilnega procesa. Primeri, preučeni na primerih nedavnih volitev v ZDA, Veliki Britaniji ali Braziliji, kažejo, da problem zadeva praktično vsak kotiček sveta. Rezultat študije je pokazati, da filtrirni mehurčki predstavljajo grožnjo demokraciji.
Izvirnost: Problem filtrirnih mehurčkov in njihov vpliv na volilni proces je še vedno neraziskan fenomen. V delu so analizirani primeri vpliva in nakazani koraki, ki jih je treba narediti, da se začne delo na področju urejanja tega pojava. Ta raziskava temelji na konceptu družbenega nadzora nad algoritmom družbenih medijev.
Omejitve/nadaljnje raziskave: Namen tega članka je prepoznati težave in pregledati rešitve. Raziskavo problema je treba dodatno utemeljiti na podlagi pravne in dejanske analize.

Ključne besede: filtrirni mehurček, internetno pravo, demokracija, zasebnost pri odločanju, družbeni mediji.

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Health Literacy of Nurses and Patients with Disabilities

Andreja Vovk*
University Medical Centre Ljubljana, Division of Obstetrics and Gynaecology,
Šlajmerjeva ulica 3, 1000 Ljubljana
andreja.vovk@fos-unm.si

Abstract

Research Question (RQ): How do the nurses master to work with patients with disabilities according to the knowledge they gain during formal and informal education?

Purpose: Special needs of people with disabilities are an essential part of life. Persons with disabilities face numerous obstacles, therefore the attitude towards them is of great importance. The awareness of the significance of health literacy gives healthcare workers an opportunity to support patients and their families to surmount obstacles in the areas of health and welfare. The purpose of the research was to establish the amount of knowledge on working with patients with disabilities gained by nurses during their formal education, to establish their need to acquire additional knowledge, to establish the impact of their personal experiences on their point of view and attitude towards patients with disabilities and to determine what kind of experiences they have with relatives of patients with disabilities.

Method: A qualitative research design was employed; data were collected with a survey. Data were collected with a structured questionnaire. For the interpretation of the data and the text written by respondents, a multi-phase approach of qualitative context text analysis was used. Context analysis of respondents' answers yielded three main topics: (1) experiences on nursing patients with disabilities, (2) experiences with the relatives of patients with disabilities, and (3) the importance of knowledge on working with patients with disabilities. Collected data were coded and the interpretation of findings was made.

Results: Our results revealed that nurses require formal education in the area of disabilities in their undergraduate and postgraduate curricula. They gain knowledge for working with patients with disabilities during the working process and by attending additional training and education. Nurses have both personal and professional experiences in the area and describe their relations with patients with disabilities and their relatives positively.

Organization: The research was focused on the health literacy of nurses and patients with disabilities. The focus research primarily addresses the importance of health institutions and their workforce, which are required to ensure the safe and inclusive environment for vulnerable groups (in our case patients with disabilities).

Society: Nursing has a long and important history of adjusting to changes in the society and its health needs and responds to demands of the society. Nurses play an important role in health care, so the necessary changes need to start with them. Nurses have an impact at personal and individual level and at organizational level. They are the most important when it comes down to promotion of health literacy as they are the ones working closest to patients and have contacts with patients on daily bases.

Originality: The originality of the article can be seen in the study of a very current social issue, which affects the so far under-researched health literacy of nurses and patients with disabilities in Slovenia. The research is the first one of the kind in Slovenia.

Limitations / further research: First, the number of respondents was too low. Second, this was the first research of this kind in Slovenia, so there are no other Slovene research data to compare our results with. Third, the instrument was made for the purpose of the research as the foreign instrument

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* Korespondenčni avtor / Correspondence author

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was out-of-date and unsuitable. The research also gives an idea for further research in the area as it is an important part of work of nurses.

Keywords: disabilities, patient, nurse, health literacy, knowledge.

1 Introduction

The phenomenom of disabilities in the society is as old as the history of mankind is. Wars, terorist attacks, natural disasters like earthquakes, fires, floods, accidents, poisoning, drug addictions and numerous other factors of a modern lifestyle are known as the cause of a steep rise in the number of persons with special needs, especially in the developing countries. Nowadays society is a subject of constant changes. So us, humans, are changing in it and together with it. Constant changes put people in front of new, smaller or bigger challenges and problems and they solve all of those more or less successful. In the society there are also people with disablities who have (at least) the same if not bigger or worse problems in overcoming those obstacles. People with disabilities are still treated as an exception of a rule and as a deviation, deflection from »normal« (Zaviršek, 2014a, p. 4). Due to better conditions in the society, better access to healthcare and advances in medicine life expectancy is prolonging and by this, life expectancy of people with disabilities is also prolonging.

There are more than 15 % of people with some kind of a disability or handicap in the European Union, and the data about Slovenia give us the number of 12 – 13 %. It is an important group whose capabilities to contribute to the success of the society do not differ from the rest of the population. We have to stress out that due to different obstacles, barriers and reduced accessibility to their potentials they often can not show all of those potentials. These people do not represent a unique group, they are defined as persons with different functional limitations as mental retardation, visual impairment, hearing impairment, mobility impairment etc. There are also other persons that have encountered different obstacles in their lifetime. As the numbers of older and old population is increasing rapidly, the need for long-term care is rising proportionately (Ministrstvo za delo, družino, socialne zadeve in enake možnosti, 2014, p. 4). Each kind of disability has specific health, educational, rehabilitational, social and support needs. Despite all these the response to the needs has to be different easc time they arise – two persons with the same disability can have totally different experiences and needs. People with disabilities, in comparison with other population, face health care differencies and have basic needs unmet. States should try to eliminate those differencies and create health care systems that already exist more accessible to people with disabilities (World Health Organization, 2011 in Vovk, 2020, p. 2). Life expectancy of people with disabilities is prolonged nowadays and so the attention that they receive is bigger. The attention is oriented towards meeting their basic needs and towards creating health care systems that respond to those obstacles (Ervin et al., 2014, p. 83). People with disabilities face numerous obstacles and attitude towards them is of great importance (Khan et al., 2016, p. 18).

With the purpose of encouraging, protecting and ensuring full and equal human needs and basic rights and encouraging respect of their inborn dignity the United Nations Convention on the rights of Persons with Disabilities was adopted (United Nations, 2006). The title of the Convention is not properly translated into Slovene language, argues Zaviršek (2018a, p. 143), as the term »disabilities« is not equal with the Slovene translation »invalid«.) The term »invalidus« in Latin stands for dependent and weak Zaviršek (2014a, p. 124). Gosenca et al. (2016, p. 59) warn about the fact that in Slovene legislation and also in other public sources and establishments, among which there are health care facilities, the term »invalid« is still being used. Its use implies that those persons are weak, frail, helpless, uncapable of work performance. The authors suggest the use of a term handicapped persons respectively persons with different kinds of disabilities. The concept of handicap stresses that mental crises and distress, intelectual, sensory and physical disabilities limit an individual in normal functioning but become a problem when the individual faces society respectively the environment where they are seen as a deviation from normal (Zaviršek et al., 2014b, p. 134). A handicap is always connected with the suffering of a person; sooner or later a person suffers due to his handicap (Rutar, 2018, p. 23). The Constitution of the Republic of Slovenia (Official Gazette, no. 33/91-I, 42/97, 66/2000 and 24/03) in its Chapter II – Human Rights and Fundamental Freedom, Article 14, speaks about equality before the Law. Human rights and fundamental freedoms shall be quaranteed to everyone irrespective of national origin, race, sex, language, religion, political or other conviction, material standing, birth, education, social status, disability or any other personal circumstance. All are equal before the law. The right to equality of people with disabilities is explicitly enlightened. Special needs of people with disabilities have to be considered and all human rights taken into account. By having this in its Constitution, the state is obliged to accept the ammendments which will allow people with disabilities to reach and keep the most possible independence, physical, mental, social and occupational capability and full participation in all areas of life. Also, The Patients' Rights Act of Slovenia (ZpacP, 2008) in its chapter on Patients' Rights, Article 7, Discrimination ban, speaks about »the right to equal treatment in medical treatment regardless of their sex, nationality, racial or ethnic origin, religion or belief, disability, sexual orientation or any other personal circumstance«.

Primary goal of public health – health improvement of the entire population – encounters health inequities. There are several definitions of health inequities and there is a general agreement that health inequities refer to health results on the population level. Historically, they are associated with social, economical or environmental inequalities that could have been avoided. The health care system can have a large impact on decreasing health inequities that are associated with accessibility and use of health care services (Krahn et al., 2015, p. 198).

A man is one of a kind and has to be seen as that (Rutar, 2018, p. 23-26). He has got two roles – his own and the role of a group respectively groups that he belongs to – and this duality is extremely important as the relationship among group members is diverse. It is why it is unacceptable that health care workers are stereotypical or very stiff in their behaviour. Every individual has to be treated according to his cultural and social background and his individual needs (Jelenc et al., 2016, p. 21). To be able to become friends with someone, especially someone with a disability, a person has to be open-minded and accept his differences (Rutar, 2018, p. 23-26).

Nurses deal with health care information in different areas so it is urgent that they are ready to face everyday challenges while working with patients that have limited capabilities and literacy (Torres & Nichols, 2014, p. 84).

The purpose of the research was to explore the area of health literacy of nurses, that is to explore the attitudes, knowledge and values of nurses to work with patients with disabilities. The term disability refers to any kind of physical or mental disability in the observed population. The value of the research lays in a fact that the area in not highlighted enough in Slovenia.

2 Theoretical framework

2.1 Health literacy

Early definitions of health literacy primary focused on the ability of a person to have basic reading and calculating abilities. It is a rising phenomenom that tends to be a priority lately and overcomes all of the boundaries with the purpose of ensuring safety and quality in health care (Parnell, 2014, p. 50; Pleasant et al., 2016, p. 1). Health literacy is a term, first mentioned by the World Health Organization in its document in 1998. It states that »health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment. Health literacy is itself dependent upon more general levels of literacy. Poor literacy can affect people's health directly by limiting their personal, social and cultural development, as well as hindering the development of health literacy.« (World Health Organization, 1998, p. 357). Unique to health literacy is an emphasis on interactive communication between an individual and health care professional as a way of gaining information and understanding information (Lawles et al., 2016, p. 144). The amount of health literacy that a person has impacts his reaction in a new situation, connected with his health. The same can be said for nurses and their professional performance.

Low health literacy was meant to be the responsibility of an individual, his own deficit and his own health risk. But in time researchers have discovered that health care systems and individuals share the same responsibility for low health literacy (Hayran & Özer, 2018, p. 24; Lloyd et al., 2018, p. 1). Babnik et al. (2013, p. 68) reviewed existing models of health literacy and discovered that health literacy is a complex phenomenom, defined by 2 characteristics: the characteristics of an individual (demographic variables, kognitive, social and physical abilities, general literacy and experiences with good respectively bad health and health care system) and the characteristics of a society (culture, education of health care workers, helath and health care contents, health care system). The changes in the level of health care literacy of individuals have positive effects in the society and in the health care system (eg. the improvement of health status of population, improvement in quality and costs of health care services etc).

It is important that nurses are knowledgeable in health literacy. They are the ones that use words to teach, inform and explain, support and comfort and are advocates for patients and their families. Due to all of these nurses need to have good knowledge about the prevalence of low health literacy and its impacts on patients, and they also need to be well informed in useful communication strategies in health care. The results of treatment are partly dependent on quality of communication between the patient and the health care personnel. Patients typically do not follow instructions they do not understand or do not accept (Scott, 2016, p. 153). The awareness of importance of health literacy gives health care workers an opportunity to support patients and their families overcoming the obstacles, related to health and well-being, and allows patients to take control over their health needs (Eadie, 2014, p. 9-10). The skills in health literacy are dynamic and can improve or diminish upon content, individual abilities and experiences or changes in the health care system (Parnell, 2014, p. 50).

Low health literacy has an enormous impact on health care system. The responsibility to teach patients is on nurses, and Kennard (2016, p. 118) reports that nursing is a discipline where the biggest gap in knowledge and awareness of health literacy exists. Macabasco – O'Connell & Fry – Bowers (2011, p. 300) say that empowerment of nurses to become health literate means a big step forward. They state that research showed that 80 % of nurses had already heard about health literacy, less than half of them received formal education in the area and as much as 56 % of them see health literacy as unimportant. Drake (2016, p. iii) found out in her research that 48, 3 % of nurses did not receive any knowledge of health literacy during formal education whilst 90 % did not receive any additional education in the area of health literacy during their professional performance. Cafiero (2013, p. 70) states that the knowledge about health literacy, their experience with health literacy strategies and their willingness to use those strategies affect not only the relationship between those involved, but also on the overall health care system. This impact is especially felt in the areas of communication and patient safety. Kennard (2016, p. 119) and Mosley & Taylor (2017, p. 109) believe that nursing students should be tought about the importance of health literacy for the patient and about the use of appropriate teaching techniques during their educational period. To be able to achieve this, nursing curricula would have to change. Nursing students should be aware of the importance of health literacy. Traditionally, literacy includes the knowledge of reading and writing, so one can assume that health care workers are highly health literate. The growing recognition of multidimensional nature of health literacy can discard the upper statement (Mullan et al., 2017, p. 2). Nurses have an important role in the community, in health care facilities and in nursing education, so they support the development of health literacy as a concept (Lawles et al., 2016, p. 144).

Individual skills and abilities and the demands and complexities of health care systems have impact on health literacy. One important aspect of efforts to improve health literacy of health care systems is the organizational health literacy, which is also an important aspect of patient satisfaction (Hayran & Özer, 2018, p. 20). The need for a systemic change in a way of patient-centered-care and health literate health care systems has become more and more relevant (Altin & Stock, 2015, p. 1). Health literate helath care organizations facilitate cooperation and transition of patients and their families in the health care system with the purpose of promoting understanding and useage of health care informations and services, which have the goal of imnproving health (Kripalani et al., 2014, p. 2). Decades of development of health literacy concept have gone by, and people with disablities have been overlooked (Geukes et al., 2019, p. 1).

Brach et al. (2012, p. 3-19) describe ten attributes of a health literate organization. The health literate organization:

- Sees health literacy as an important part of its mission, structure, and operations.
- Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
- Prepares the workforce to be health literate and monitors progress.
- Includes populations served in the design, implementation, and evaluation of health information and services.
- Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
- Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
- Provides easy access to health information and services and navigation assistance.
- Designs and distributes printed, audiovisual, and social media content that is easy to understand and act on.
- Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
- Communicates clearly what health plans cover and what individuals will have to pay for services.

The purpose of those attributes for an organization is to establish its status regarding those attributes and to prepair a correction plan where there are irregularities or disadvantages (Johnson, 2016, p. 25).

Zaviršek (2018b, p. 125) describes that relatives often report of health personnel avoiding people with disabilities whilst health care organizations do not have specialized equipment to make the health check-up possible (e.g. gynaecological chair, dentist chair…). Details like patient respect, service availability, simplicity of information shared, appropriate orientation boards and questions of patients answered are equally efficient as health literacy of individuals (Koh et al., 2013, 359; Brach, 2017, p. 203).

2.2 People with disabilities

People with disabilities have always been treated differently than the rest of the population. Their position in the society determines laws and other regulations. Stereotypes play an important role here. Stereotypes are a reflection of unequal power of relations, and they derive form culturally accepted norms and values of human body. Stereotype views see people with disabilities as unable of independent life, as mentally disabled and genderless. Stereotypes which hurt and cause discrimination, suppression and violence against people with disabilities are those that put people with disabilities in the position of physically and intellectually less capable, emotionally unstable and untrustworthy. In everyday speech there are negative, disrespectful labels of people with disabilities, and they themselves and the organizations that represent their interests see term "people with disabilities" as the most appropriate one (Krasniqi, 2014, pp. 25-28).

As Veronique Dasen (cited in Zaviršek, 2000, pp. 187-188) states the first documents about handicapped come from ancient Egypt. The Ebers Papyrus, dated in 1550 B. C. E., contains descriptions of diseases, mental retardation, epilepsy, blindness and the first known description of deafness. The papers reveal that the blind was treated nicely as the priests taught them about music, art and massage. The vision loss was seen as being a positive religious sign. The bling was part of religious rituals, in temples and on funerals, they were also harpists and singers in aristocratic housekeepings as they seemed harmless for their women. People with mental retardation were supposed to be obsessed with the souls of dead people and were not allowed to enter the temples. People with bodily malfunctions were shown as children and together with them. Novljan (1997) states that there are no relevant data about the relations with the handicapped in the ancient age, but different sources tell that people, who were not capable to take care of themselves, were executed. The data of the relations towards them in Sparta, Athens and Rome are known for the 4th and 5th century B.C. E. The educational systems in Sparta and Athens forbid education and training of handicapped as they were not seen as being able to reach the goals of their educational systems. In Sparta those children were thrown into the Taygetos mountains, in Athens they were left by the roads, in Rome they were thrown into the Tiber River. Winzer (cited in Zaviršek, 2000, p. 192) describes that in the 2nd century A.D. the Romas started to value the handicapped as the subject of their own entertainment (being negative in the sense of humanity, of course). On the special markets one could buy a handicapped person and have him as a pet fool. Natural scientists studied different pathological appearances in the ancient age and had proved that the disease is not a consequence of transcendent forces but rather a consequence of a disorder in the development of an organism.

They also alerted about the specific development of the handicapped. The church had and extremely negative approach to people with disabilities; the disorder was supposed to be the sign of an evil mind. The Inquisition requested all handicapped children to be withdrawn from the social life, regardless to their origin and class affiliation. The Renaissance changed the mindset of people about the goals and meaning of life. A human with his mind and power became important and the position of people with disabilities started to change. It was then that the first education and training of people with disabilities started (Novljan, 1997).

Currently, World Health Organization (2014, p. 1) defines health as »a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity«. According to World Health Organization (2011 in Vovk, 2020, p. 15) more than one billion of people across the world live with some kind of disability and almost 200 million of them experience some kind of problems in functioning. In the future there will be numerous other problems as the prevalence of disabilities is on the rise. The cause of that is the ageing population and the increase of the risk for developing chronical health conditions such as diabetes, kardiovascular diseases, cancer and mental health issues. Many people with disabilities do not have access to health care, education and employment, they do not benefit from from services they are and people with disabilities entitled to and they experience exclusion from everyday life activities. Looking at the United Nations Convention on the rights of Persons with disabilities and its Article 25, »persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability« (United Nations, 2006, p. 18) and no country in the world is excluded from following the Article. People with disabilities have, due to different deficits, developmental delay, unfavourablje financial situation and social circumstances, problems with communication, detection, mobility, responding to stimulus an communication with the environment (Bervar, 2017, p. 6).

In Slovenia there are the criteria for children, and they are: children with mental disorders, blind and partially sighted children and children with limited sight function, deaf and hard of hearing, children wih speech and language disorders, children with physical disability, long-term ill children, children with deficits in specific learning areas, children with emotional and behavioural disorders and children with autism spectrum disorders (Zavod Republike Slovenije za šolstvo, 2015, p. 4). There are no specific criteria for adults in Slovenia, but accoring to my knowledge in the area, similar criteria are suitable for adults. Here a definition of handicap by Zaviršek (2014b, p. 135) is suitable. Handicap is a social category which conceptualizes the interlinking of material, emotional and social and reflects socially marked responses on physical features like physical disablity (muscular dystrophy, paraplegia, quadriplegia etc.), sensory impairment (problems with vision and hearing), intelectual impairment (difficulties with understanding the world, difficulties with learning, reacting to specific stimuli etc.) and mental health problems (psychiatric diagnoses, psychiatric hospitalization). Among above mentioned some are visible and some are not (multiple sclerosis, cancer, dyslexia, mental distress etc.). Zaviršek (2000, p. 289) also states that handicap is a cultural trauma, transmitted by language.

People with disabilities are a special group of people, each different in his or her own way, but with a common experience of life with certain limitations in functioning. Consequently, they are often excluded from the society (Krahn et al., 2015, p. 198).

2.3 Nurses and work with patients with disabilities

Communication and interpersonal relations are an essential part of everyday life and all through the lifetime. Daily we meet and face different people and start communication with them. In nursing relations and communication are needed za make contact with patients. The patient uses communication to express his feelings. A nurse helps the patient to meet his needs and that is possible only if she understands him (Zamolo, 2014, p. iii). Communication in nursing is characterized by new processes of communication that start with each patient. Communication is always different and absolutely not a routine. It is an essential part of active so-sensing and an integrative part between the health care worker and the patient. It influences the process of patient discharge, his self-disclosure and empathetic communication (Zamolo, 2014, p. iii; Rampre, 2016, p. i; Železnik, 2016, p. 2). Good communication skills are an important part of core competencies of nurses and are essential for the nursing practice and patient-centered care (Boykins, 2014, p. 40). Nurses are oblighed to consider the needs and concerns of individuals with any kind of disability (Brown & Kalaitzidis, 2013, p. 937).

The admittance to the hospital, no matter of the cause for it, is a stressful event. A person finds himself in an unfalimilar environment, with unknown people, speaking unknown language, around. Also the person might be seriouslay ill and/or in pain, so he or she is vulnerable. In cases like these people with disabilities are even more vulnerable due to communication problems, problems with expressing discomfort or pain or problems with self – management. Several other factors may also have impact in the process (Guidelines and Audit Implementation Network, 2010 in Vovk, 2020, p. 18).

There are several obstacles that impact the quality of health care (Ilkhani, 2013, p. 7-8):

- lack of relevant knowledge and clinical capabilities,
- disrespectful relations and accusations abouth the health situation is a consequence of health care professionals,
- inappropriate nursing plan,
- lack of empathy and understanding from hospital staff that can lead to mistrust and negative feelings of patients and their families,
- dependence from the caregivers,
- insufficient equipment and compensations,
- negative attitude to persons with disabilities,

- lack of knowledge for successful communication and reassurance of nurses,
- nurses' lack of time for patients,
- calls to cut down the high expenses of care of patients with disabilities,
- quality of care reduction,
- lack of information exchange,
- problems at admittance of the patient,
- inadequate coordination between different services,
- inaccessibility of health care services,
- unwillingness to help and to support.

Iacono et al. (2014, p. 327) report that despite 20 years of research and government initiatives, people with disabilities continue to have poor hospital experiences. Ilkhani (2013, p. 2015), Aston et al. (2014a, p. 301-302; 2014b, p. 221) and Sharkey et al. (2014, p. 748) state that nurses' communication with disabled children and their parents needs to improve as the nurses find communication with patients with disabilities as problematic due to communication barriers and general lack of experiences and knowledge to work with this population. They also report aboust discomfort and frustrations. Effective therapeutic relationship between nursing staff and clients je crucial for the positive results of treatment (Aston et al., 2014 b, p. 221) and information, gained during communication with patients, are crucial for the success of the nursing process. How we act when communicating with a person with a disability depends of beliefs that were formed in the early childhood (Bervar, 2017, p. 11) with the help of parents and educators.

Based on reading the literature we formulated the fundamental research question: »How do the nurses master to work with patients with disabilities according to the knowledge they gain during formal and informal education?«. The research focused on knowledge about disabilities, gained during formal and informal education and on personal and professional experiences both with those patients and with their relatives.

3 Method

A qualitative research design was employed; data were collected with a survey. The reason for this type of approach is rooted in the fact that in Slovenia there is no relevant instrument to evaluate health literacy of nurses and their attitude towards working with patients with disabilities. The research was of an explorative nature and a pioneer work in the area.

The review of the literature was made from September 2018 to September 2018, using databases CINAHL, PubMed, Springerlink, COBISS, Digital Library of University of Ljubljana, Digital Library of University in Maribor, Science Direct, SAGE Publications webpage and Slovenian Nursing Review. The key words used were literacy, nursing AND health literacy, nurses AND health literacy, disability, patients with disabilities, communication in nursing, mental health.

The survey method was used. Data were collected with a structured questionnaire. First the pilot research was made on the sample of 30 nurses, employed at University Medical Centre Ljubljana, Division of Obstetrics and Gynaecology. For the research itself the same questionnaire was later on sent by an e-mail link to a thousand members of The Nurse and Midwifery Organization of Ljubljana. The data were processed in Excel. The first part of the questionnaire contained questions about how nurses actually know people with disabilities; the translation of a questionnaire *Disability Awareness Quiz 1* (ProProfs Quizzes, 2022) was used. The second part contained questions about education and training for working with people with disabilities, the third contained questions about personal and professional experiences and working with patients with special needs. The last, fourth part contained six demographic questions (sex, age, education, workplace, years of work). The demographic data were statistically interpreted with the help of SPSS 24.0 Statistics for Windows and data were displayed with the descriptive statistics method for frequency and percentage distributions. At the end of the questionnaire there was some space for possible additional comments, suggestions and opinions.

For the interpretation of the data and the text written by respondents, a multi-phase approach of qualitative context text analysis was used. Context analysis of respondents' answers yielded three main topics: (1) experiences on nursing patients with disabilities, (2) experiences with the relatives of patients with disabilities, and (3) the importance of knowledge on working with patients with disabilities. Collected data were coded and the interpretation of findings was made.

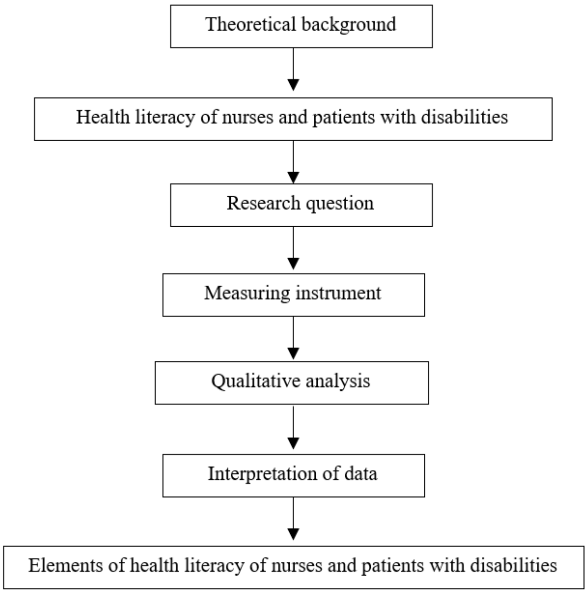

Figure 1. Research model

4 Results

Hereafter the results of the research are shown, and they give a general overview of the health literacy of nurses and their attitude towards patients with disabilities. The results also show what kind of disabilities the patients had and what kind of personal experiences nurses had with people with disabilities and with their relatives. At the end remarks and suggestions of nurses are shown.

In December 2018 there were 5028 members at The Nurse and Midwifery Organization of Ljubljana, so our sample represented 19,9 % of all members. There were 276 entries into the questionnaire on the webpage, and 212 completed questionnaires (21,2 %) were used in the statistical analysis. Between the respondents there were 194 (91,5 %) women and 18 (8,5 %) men, aged from 21 to more than 50 years. Their age was put into the appropriate age range, so we were not able to calculate their mean age. Most of the respondents were aged from 41 to 50 years (76 respondents – 35,8 %), 34 % were older than 50 years, 22,2 % were aged 21 to 40 years. In the age group from 21 to 30 years there were only 8 % of the respondents. None of the respondents was younger than 20 years. Most of the respondents have 1st Bologna cycle educational level (130 respondents – 61,3 %), 53 respondents (25 %) have a university degree respectively 2nd Bologna cycle education, 16 respondents (7,5 %) have post – graduate degree respectively 3rd Bologna cycle education and 13 (6,1 %) finished secondary school. Half of the respondents, 108 (50,9 %) are registered midwives, 88 (41,5 %) are registered nurses and 16 (7,5 %) are nurse assistants. More than half of the respondents, 130 (61,3 %), have been working in nursing care more than 21 years, 30 (14,2 %) 11 – 15 years, 26 respondents (12,3 %) 16 – 20 years, and the same number, 13 (6,1 %) up to 5 years and 6 – 10 years.

We prepared a Cronbach’s Alpha coefficient calculation and factor analysis in order to test the reliability and validity of our survey questionnaire.

Table 1. Reliability analysis

Cronbach's Alpha	N of Items
0.860	17

Construct: Knowledge of the field of disabilities has excellent reliability since the value of the Cronbach's alpha is equal to 0,860.

Table 2. KMO and Barlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		0.876
Bartlett's Test of Sphericity	Approx. Chi-Square	1361.007
	df	136
	Sig.	0.000

The KMO measure (0,876) and the Bartlett Test of Sphericity (sig. < 0,05) confirm the data is appropriate for factor analysis. We used the Principal Axis Factoring method and Varimax rotation with Kaiser Normalization.

Table 3. Communalities

	Initial	Extraction
It is always obvious if someone has a disability.	0.126	0.532
Most people with disabilities cannot work.	0.563	0.644
Words such as wheelchair-bound, handicapped or special needs are acceptable to use.	0.288	0.253
People with disabilities always need help to accomplish everyday activities.	0.413	0.548
People with disabilities want to be respected and have the same opportunities as people without disabilities.	0.402	0.400
Developmental irregularities are chronical conditions, caused by a mental or physical irregularity.	0.239	0.243
Some people who are deaf do not use sign language.	0.351	0.287
Shouting at a person who is deaf will enable them to hear you better.	0.818	0.848
Hearing impairment is a physical disability.	0.324	0.394
It is better to speak with a companion or sign language interpreter rather than directly with the person with a disability.	0.435	0.354
When you do not understand someone who has problems with communication, you politely ask him to repeat everything he said and by doing so, make sure if the undesrstood everything correctly.	0.485	0.490

»to be continued«

»continued«

Autism, bipolar disorder and ADHD are hidden disabilities.	0.241	0.275
The words “retard” and “crazy” are harmless words.	0.535	0.410
You don’t have to introduce yourself to someone who is blind because they have awesome memories and hearing ability and will remember your voice.	0.606	0.682
You should not pet a service or guide dog while they are working because petting them will distract them from working.	0.316	0.281
It is appropriate to help a person in a wheelchair and not to ask if the person actually needs help.	0.518	0.560
The Paralympics are for people with disabilities.	0.403	0.373

All communalities are higher than 0,2, which means the variables define our phenomenon, there is also no need to exclude any of the variables.

Table 4. Total Variance Explained

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	6.053	35.609	35.609	5.557	32.689	32.689	2.860	16.821	16.821
2	1.387	8.158	43.767	0.830	4.882	37.571	2.671	15.711	32.531
3	1.251	7.360	51.127	0.688	4.044	41.615	1.544	9.084	41.615
4	0.988	6.695	57.822						
5	0.983	5.781	63.604						
6	0.816	4.803	68.407						
7	0.767	4.513	72.920						
8	0.678	3.990	76.910						
9	0.655	3.855	80.765						

»to be continued«

»continued«

10	0.624	3.671	84.435
11	0.573	3.369	87.804
12	0.489	2.874	90.677
13	0.444	2.611	93.289
14	0.410	2.414	95.703
15	0.309	1.815	97.518
16	0.278	1.633	99.150
17	0.144	0.850	100.000

SPSS suggests the exclusion of three factors, since their eigenvalue is higher than 1, likewise four of the factors can explain 51,127 % of the common variance.

Table 5. Rotated Factor Matrix

	Factor		
	1	2	3
It is always obvious if someone has a disability.	0.412		
Most people with disabilities cannot work.			0.648
Words such as wheelchair-bound, handicapped or special needs are acceptable to use.			0.434
People with disabilities always need help to accomplish everyday activities.			0.674
People with disabilities want to be respected and have the same opportunities as people without disabilities.			0.503
Developmental irregularities are chronical conditions, caused by a mental or physical irregularity.		0.449	
Some people who are deaf do not use sign language.		0.449	
Shouting at a person who is deaf will enable them to hear you better.		0.634	
Hearing impairment is a physical disability.		0.615	

»to be continued«

»continued«

It is better to speak with a companion or sign language interpreter rather than directly with the person with a disability.		0.466
When you do not understand someone who has problems with communication, you politely ask him to repeat everything he said and by doing so, make sure if the undesrstood everything correctly.		0.563
Autism, bipolar disorder and ADHD are hidden disabilities.		0.497
The words “retard” and “crazy” are harmless words.	0.520	
You don’t have to introduce yourself to someone who is blind because they have awesome memories and hearing ability and will remember your voice.	0.782	
You should not pet a service or guide dog while they are working because petting them will distract them from working.	0.435	
It is appropriate to help a person in a wheelchair and not to ask if the person actually needs help.	0.721	
The Paralympics are for people with disabilities.	0.537	

We can observe which variables were sorted within a certain factor inside of the factor matrix. We can conclude that our questionnaire is valid, therefore suitable for use.

4.1 Knowledge of the field of disabilities

In this section the respondents were asked about their knowledge of the field of disabilities (Table 6).

Table 6. Knowledge of the field of disabilities

KNOWLEDGE OF THE FIELD OF DISABILITIES						
Questions		Answers			Correct answers	Incorrect answers
		True	False	Sum		
Q1	It is always obvious if someone has a disability.	16 (7,5 %)	196 (92,5 %)	212 (100,0 %)	196 (92,0 %)	16 (7,5 %)
Q2	Most people with disabilities cannot work.	4 (1,9 %)	208 (98,1 %)	212 (100,0 %)	208 (98,1 %)	4 (1,9 %)
Q3	Words such as wheelchair-bound, handicapped or special needs are acceptable to use.	195 (91,9 %)	17 (8,1 %)	212 (100,0 %)	195 (91,9 %)	17 (8, 1 %)

»to be continued«

»continued«

Q4	People with disabilities always need help to accomplish everyday activities.	15 (7,0 %)	197 (93,0 %)	212 (100,0 %)	197 (13,0 %)	15 (7,0 %)
Q5	People with disabilities want to be respected and have the same opportunities as people without disabilities.	202 (95,3 %)	10 (4,7 %)	212 (100,0 %)	202 (95,3 %)	10 (4,7 %)
Q6	Developmental irregularities are chronical conditions, caused by a mental or physical irregularity.	144 (68,0 %)	68 (32,0 %)	212 (100,0 %)	144 (68,0 %)	68 (32,0 %)
Q7	Some people who are deaf do not use sign language.	175 (82,5 %)	37 (17,7 %)	212 (100,0 %)	175 (82,5 %)	37 (17,5 %)
Q8	Shouting at a person who is deaf will enable them to hear you better.	0 (0,0 %)	212 (100,0 %)	212 (100,0 %)	212 (100,0 %)	0 (0,0 %)
Q9	Hearing impairment is a physical disability.	166 (78,3 %)	46 (21,7 %)	212 (100 %)	166 (78,3 %)	46 (21,7 %)
Q10	It is better to speak with a companion or sign language interpreter rather than directly with the person with a disability.	35 (16,5 %)	177 (83,5 %)	212 (100 %)	177 (83,5 %)	35 (16,5 %)
Q11	When you do not understand someone who has problems with communication, you politely ask him to repeat everything he said and by doing so, make sure if the undesrstood everything correctly.	202 (95,3 %)	10 (4,7 %)	212 (100 %)	202 (95,3 %)	10 (4,7 %)
Q12	Autism, bipolar disorder and ADHD are hidden disabilities.	128 (60,4 %)	84 (39,6 %)	212 (100 %)	128 (60,4 %)	84 (39,6 %)
Q13	The words “retard” and “crazy” are harmless words.	11 (5,2 %)	201 (95 %)	212 (100 %)	201 (94,8 %)	11 (5,2 %)
Q14	You don’t have to introduce yourself to someone who is blind because they have awesome memories and hearing ability and will remember your voice.	11 (5,2 %)	201 (94,8 %)	212 (100 %)	201 (94,8 %)	11 (5,2 %)
Q15	You should not pet a service or guide dog while they are working because petting them will distract them from working.	156 (73,6 %)	56 (26,4 %)	212 (100 %)	156 (73,6 %)	56 (26,4 %)
Q16	It is appropriate to help a person in a wheelchair and not to ask if the person actually needs help.	28 (13,2 %)	184 (88,8 %)	212 (100 %)	184 (86,8 %)	28 (13,2 %)
Q17	The Paralympics are for people with disabilities.	176 (83 %)	36 (17 %)	212 (100 %)	176 (83 %)	36 (17 %)

4.2 Training for working with patients with disabilities

The respondents were asked about the training for working with patients with disabilities during their formal education in nursing. The results were as follows:

- During formal educational programme 26 respondents (12,2 %) acquired special knowledge for work with patients with disabilities.
- During formal educational programme 54 respondents (25,5 %) did not acquire special knowledge for work with patients with disabilities, but had written materials/literature available.
- During formal educational programme 132 respondents (62,3 %) did not acquire any special knowledge for work with patients with disabilities.

Further on the respondents were asked to express their feelings about training in the area of patients with disabilities.

- 10 respondents (4,7 %) have the feeling they received enough training to work with patients with disabilities during formal educational programme.
- 202 respondents (95,3 %) do not have the feeling they received enough training to work with patients with disabilities during formal educational programme.

4.3 Experiences with relatives of patients with disabilities

The respondents were asked about personal experiences with people with disabilities. 40 respondents (18,9 %) have a person with a disability in the family, 20 respondents (9,4 %) have a good friend with some kind of disability, 82 (38,7 %) have a neighbour or an acquaintance with some kind of disability, 65 (30,7 %) have no personal experiences with people with disabilities, 31 (14,6 %) met a person with disability at work and 26 (12,3 %) worked with people with disabilities (one respondent (05, %) during studies), one respondent (0,5 %) has a brother-in-law who is a paraplegic, 2 respondents (0,94 %) have relatives that work with people with disability. One respondent (0,5 %) wrote that each person has special needs - some kind of disability.

The respondents were also asked about the type of disability the patients they cared for had (Table 7).

Table 7. The type of disability of the patients

HAVE YOU EVER CARED FOR A PATIENT WITH THE FOLLOWING DIAGNOSES? WHAT TYPE WAS THE DISABILITY?	Number (N)		Share (%)	
	YES	**NO**	**YES**	**NO**
physical handicap	194	18	91,5 %	8,5 %
hearing loss (hard of hearing, deafness)	185	27	87,3 %	12,7 %
sight loss (partial sight, blindness)	191	21	90,1 %	9,9 %
speech problems	190	22	89,6 %	10,4 %
mental retardation (eg. Down syndrome, cognitive impairment)	179	33	84,4 %	15,6 %
mental health problems (mental illness – schizofernia, depression, anorexia)	186	26	97,7 %	12,3 %
longterm illness (eg. diabetes, epilepsy)	197	15	92,9 %	7,1 %
HIV/AIDS	117	95	55,2 %	44,8 %
addiction	163	49	76,9 %	23,1 %
alcoholism	157	55	74,1 %	25,9 %
other, what: Autism spectrum disorders, Coeliac Disease, mental deficiency, brain trauma, dyslexia, Scotopic anchor, dementia, all of the above	9	203	4,2 %	95,8 %

We also analysed the answers about experiences of respondents while working with patients with disabilities and their relatives. With the analysis of the answers two main themes emerged:

- experiences with care of patients with disabilities (Table 8),
- experiences with relatives of patients with disabilities (Table 9).

The theme "experiences with care of patients with disabilities" consists of 13 codes from which we then derived 5 categories (Table 8).

Table 8. Caring for a patient with disabilities during professional practice and the experience

CODE	**CATEGORY**	**TOPIC**
Positive experience of working with a patient with disabilities (n=22)	Experience of working with patients with disabilities	Experience of caring for patients with disabilities
Negative, unpleasant experience of working with a patient with disabilities (n=3)		
Work experience gained working with a patient with disabilities (n=5)		
Importance of knowledge and experience for working with patients with disabilities (n=6)	Knowledge required for working with patients with disabilities	
Lack of knowledge, uncertainty to work with patients with disabilities (n=14)		
Working with a person with disabilities is challenging (n=5)	Working with patients with disabilities is challenging	
Challenging, tiring to work with patients with disabilities (n=7)		
Individual approach to patients with disabilities (n=1)	Individual treatment of patients with disabilities	
Understanding, respect, patience at work, time component (n=18)		
Equality in treatment of patients (n=8)		
Adaptation to the situation (n=18)	Communication and cooperation	
Communication with the person with disabilities (n=1)		
Establishing appropriate communication between participants (n=2)		

In the category "Experience of working with patients with disabilities", there are three codes, with the majority of respondents (n=22) indicating that they have had a positive experience of working with patients with disabilities, 5 indicating that they have had experience of working with patients with disabilities in the course of their work, and 3 describing their experience of working with patients with deisabilities as negative and unpleasant.

In the category "Knowledge needed to work with patients with disabilities" we find two codes, 14 respondents indicated that they lacked this kind of knowledge, that they felt insecure; the importance of knowledge and experience in working with these patients was important to 6 respondents.

In the category "Working with patients with disabilities is challenging", we find two codes: 7 respondents indicated that working with patients is challenging, tiring; 5 respondents indicated that working with these patients is particularly challenging.

There are three codes in the category "Individual treatment of patients with disabilties". The majority of respondents (n=18) wrote that understanding, respect, patience and time are needed when dealing with patients with disabilities. 8 respondents stated that equal treatment is needed at work. An individual approach to patients with disabilties was mentioned by 1 respondent.

The last category, the fifth, contains three codes. 18 respondents indicated that the situation needs to be adapted to; two respondents indicated that there needs to be adequate communication between the participants and one respondent indicated that communication with the person with disabilities is important.

The theme "Experiences with relatives of patients with disabilities" consists of nine codes, from which we then derived two categories (Table 9).

Table 9. Experience with relatives of patients with disabilities

CODE	**CATEGORY**	**TOPIC**
Positive experiences with relatives (n=28)	Establishing a relationship with relatives	Experiences with relatives of patients with disabilties
Relatives are very demanding (n=12)		
No contact with relatives (n=3)		
Relatives are helpful to staff (n=19)		
Establishing a relationship with relatives (n=5)		
Adapting to the situation (n=5)		
Relatives' protective attitude towards a patient with disabilties (n=8)	Relatives' protective attitude towards a patient with disabilities	
Relatives' attitude towards the patient with disabilities (n=1)		
Relatives forget about the patient (n=1)		

Six codes are found in the category "Establishing a relationship with relatives". The majority of respondents (n=28) indicated that they had good experiences with relatives of patients with disabilities. Furthermore, respondents (n=19) indicated that relatives of patients with disabilities are helpful to them,12 respondents found the relatives of these patients to be demanding. This is followed by respondents (n=5) stating that it is necessary to build a relationship with relatives and that it is necessary to adapt in the situation. Three respondents have not had any contact with relatives of patients with disabilities.

In the category "Relatives in relation to a patient with disabilities", 8 respondents consider that relatives have a protective attitude towards a patient with disabilities, one respondent thinks that the relatives have not yet accepted the patient and another one that the relatives forget about the patient.

4.4 The suggestions and comments from respondents

At the end of the survey, respondents were given the opportunity to make suggestions and comments. Here, we analysed the responses to identify a third main theme - "The importance of knowledge for working with patients with disabilities" (Table 5).

The theme “Importance of knowledge for working with patients with disabilities” consists of eight codes from which we then derived four categories.

In the first category "Expressing the need for knowledge", 15 respondents expressed the need for additional training and 6 for formal training. However, one respondent indicated a need for formal education and one for formal and additional education.

The next category "Lack of knowledge to work with patients with disabilities" contains the indication that respondents lack knowledge (8 respondents feel this way).

Table 10. Suggestions and comments from respondents

CODE	**CATEGORY**	**TOPIC**
Need for formal education (n=6)	Expressed need for knowledge gaining	Importance of knowledge for working with patients with disabilities
Need for additional education (n=15)		
Need for formal and additional education (n=1)		
Need for training (n=1)		
Lack of knowledge (n=8)	Lack of knowledge to work with patients with disabilities	
Equality of treatment, acceptance of differences (n=26)	Acceptance of difference	
Detabuing the area of disabilities (n=3)		
No experience of working with patients with disabilities (n=3)	No experience of working with patients with disabilities	

The third category "Acceptance of difference" consists of two codes, 26 respondents indicated that there is a need for equality of treatment and acceptance of difference, and 3 indicated that there is a need to detaboo the area of disabilities.

In the last category "No experience of working with patients with disabilities" there were 3 respondents.

5 Discussion

Special needs or disabilities are part of human life. Practically everyone will be temporarily or permanently impaired at some point in their lives, and those who live to old age will face increasing difficulties (World Health Organization, 2011 in Vovk, 2020, p. 37). According to Zaviršek (2014b, p. 133; 2018b, p. 127), people are only temporarily non-disabled in the course of life, i.e., we do not have any particular handicaps or special needs. For most people, the handicap occurs later in life; they are not born with a handicap and it is not inherited. A child born with a congenital condition such as cerebral palsy, a young soldier who loses his leg in a minefield, a middle-aged lady with severe arthritis and even an elderly person with dementia are all handicapped. And the list goes on and on. Such health conditions can be outwardly visible or not, temporary or long-lasting, static, episodic or degenerative, painful or without consequences (World Health Organization, 2011 in Vovk, 2020, p. 38). In our research, we found that nurses have a relatively good knowledge of the special needs of people with disabilities, with more than 60 % of nurses answering all questions correctly. We can therefore conclude that the nurses surveyed have a relatively good health literacy in terms of their knowledge of people with disabilities.

We were also interested in the amount of knowledge nurses acquire for working with patients with disabilities during their formal education. We found that 87.8 % of the respondents had not received any specific training in working with patients with disabilities during their formal education, and 25.5 % of them had access to additional material/literature in this area. The survey also found that 95 % of respondents had not received sufficient training in working with patients with disabilities during their formal education. The nurses surveyed draw on experience gained during the course of their work to support them in their work. Given that nurses spend much more time with patients than any other health professionals (Beauchamp & Sparkes, 2014, p. 49), any interaction, intervention or contact with the user, i.e. the patient, requires some form of communication, and it is this communication that has a consequent impact on the quality of care (Espinoza & Heaton, 2016, p. 693). It does not take much to make a patient feel better; just a warm look, a kind word or a reassuring touch can help. Scott (2016, p. 153) says that nurses use words to educate, inform and explain, to support and comfort, but also to act as advocates for patients and their families. As Kunšič (2016, p. 38) states, nurses need to be good communicators, they need to know the codes of ethics and, of course, the Patients' Rights Act, because only in this way can they treat patients with respect and preserve their dignity.

Effective therapeutic relationships between healthcare providers and users are important determinants of positive health outcomes (Aston et al., 2014a, p. 302). Castell & Stenfert Kroese (2016, p. 41) explored midwives' experiences when working with women with disabilities while pregnant and after birth. Both midwives who do outreach work and those who work in hospitals reported that they did not have enough time or were not trained enough to care for these women adequately. They stated that they felt that they were not supported and that they were on their own in their efforts to provide adequate midifery care despite their lack of knowledge in the area of disabilities. They expressed the need for training and information in this area. Höglund et al (2013, p. 950) discovered that almost half of the Swedish midwives had not received any training in pregnancy and childbirth for women with disabilities during their training. However, the majority of respondents expressed a need to receive evidence-based knowledge about women with disabilities in relation to childbirth. McCauley et al. (2011, p. 1) discovered that midwives, despite their many years of experience (10 years or more), need additional education and training in mental health, as they are the ones who can contribute to better outcomes for both mother and newborn, because they can continuously care for this vulnerable group during this sensitive period. It is important to note here that midwives are viewed positively by women and can develop a close, trusting relationship. In a trauma ward of one of the general hospitals in Slovenia, Čremošnik (2010, p. 67) conducted a survey among 26 nurses and found out that more than half of the respondents (73 %) felt that they did not have enough knowledge about communication with patients with disabilities. He also states that 98 %

of the respondents would like further education in the area of communication with patients with disabilities.

Uysal et al. (2013, p. 456) suggest that nursing students need to develop and maintain positive attitudes towards children with disabilities. In their study they showed that Turkish nursing students' attitudes towards people with disabilities are much lower compared to those of students from Western countries. They suggest that the nursing education curriculum should be adapted accordingly, which is also agreed by Culp et al. (2017, p. 48). Shakespeare & Kleine (2013, p. 33) suggest that in order for nursing students to develop a holistic understanding of patients with disabilities, they should encounter healthy persons with disabilities as well as the elderly. By doing it this way, these people would be the experts who would teach the students.

Further on, the respondents were asked about their personal experiences of working with people with disabilities. From the answers of the respondents it can be seen that in addition to professional experiences, the respondents also have personal experiences with people with disabilities.

The vast majority of respondents in our research had already cared for a patient with a disability, namely a patient with a physical/motor disability, a patient with a hearing loss (hard of hearing or deaf), a patient with a visual impairment (visual impairment or blindness), a patient with a speech impairment, a patient with a mental disability (e.g. Down's syndrome, cognitive disability), a patient with mental health problems (e.g. mental illness - schizophrenia, depression, anorexia), a patient with a long-term illness (e.g. diabetes, epilepsy). Slightly smaller number of respondents had already cared for a patient with an addiction and a patient with alcoholism problems, while the lowest number of respondents had cared for a patient with a diagnosis of HIV/AIDS. Other types of disabilities of patients included Autism spectrum disorders, coeliac disease, mental retardation, brain injury, dyslexia, Scotopic syndrome, dementia. One respondent stated that he had cared for all of the above.

Most respondents described their experience of working with a patient with a disability as positive. Some respondents had gained experience for working with this type of patient while working in nursing profession. Only a few respondents described their experiences as negative, unpleasant. A common statement was that respondents lacked the knowledge to work with patients with disabilities because the work is demanding and challenging. They also stated that working with these patients requires understanding, respect, patience and time. They believe that patients with disabilities should be treated on an equal basis with other patients and, where necessary, an individualised approach should be used. It is necessary to adapt to the situation on an ongoing basis and to establish appropriate communication between the participants.

Van der Kluit et al. (2013, p. 129) and Cremonini et al. (2018, p. 28) state that holistic care, support and age have a positive impact on positive attitudes, while workload has a negative impact. A qualitative study, conducted by Crowe & Averett (2015, p. 57-58), looked at the impact of educational programmes and professional experience in relation to the attitudes of healthcare professionals working with patients with mental illness. They found that education has no impact, but on the other hand, it has a critical impact on the deconstruction of the concept of mental illness. Other influences include increased knowledge, increased tolerance and empathy, consideration of the patient's strengths and putting the patient first. Their results are similar to those of previous research, but of course it is up to each individual to decide how to react and act. Mårtensson et al. (2014, p. 782-783) found in their study that personal and professional experience with people with mental illness, knowledge, the work environment and its subcultures, and sociodemographic characteristics influence nurses' attitudes towards people with mental illness. Nurses report uncertainty, and often fear, when dealing with a psychiatric patient, especially when they do not know the patient, as such situations can be completely unpredictable. This unpredictability may be due to lack of knowledge, stereotypes, prejudices, rather than ontological or intrinsic factors of the patient, as noted by Appelgren et al. (2018, p. 18). Health professionals, like the general population, have negative attitudes towards people with disabilities (Ghai et al., 2013, p. 293; Clarke et al., 2014, p. 273; Khan et al., 2016, p. 16; Iftikar et al., 2019, p. 152). In a survey of Slovenian paramedics, Rant & Bregar (2014, p. 183) found that it does not make sense to view paramedics' attitudes towards patients who have attempted suicide as positive or negative, because attitudes change and are negative at one time and positive at another, depending on factors that originate from each individual paramedic or from the physical or social environment. Brglez et al. (2015, p. 55) state that there is no general guidance in the nursing profession on how to choose an appropriate form of communication with a patient with intellectual disability, so it is up to each individual and their experience in practice to decide how they will cope. Noblett & Henderson (2015, p. 25) found that staff who do not specialise in mental health consistently have more negative attitudes towards people who use illicit substances, alcoholics or schizophrenics, for example. However, they also found that health professionals perceive these people in a less stigmatised way than students of the same profession.

In our survey we also wanted to find out about nurses' experiences with relatives of patients with disabilities. Most of the respondents said that they had a good experience with relatives of patients with disabilities, and that relatives were often helpful. They state that the relatives of these patients are demanding, stressing the importance of establishing a relationship with them and the importance of adapting to the situation. A few respondents feel that relatives have a protective attitude towards patients with disabilities, but it also happens that relatives simply forget about the patient once they have brought him/her to the health facility for treatment. Some respondents have not had any contact with relatives of patients with disabilities.

If we talk about children with disabilities and their parents, they face unique challenges when trying to establish a relationship with health care providers, mainly due to the social and institutional stigma and stereotypes associated with children with disabilities. In their study, Aston et al. (2014a, 291-304) presented examples of nurses and mothers of children in the health care system experiencing frustration, and sometimes positive enthusiasm, about a relationship that had become supportive. The same authors mention several studies where staff relied on the parents of children in care, leading to tension and discomfort; sometimes going so far as to treat parents as part of the team, with no agreement on this, but with staff taking it for granted that this was the case. As a result, there was discomfort and tension between parents and health staff. Ilkhani (2013, p. 215) found in her research that nurses were enthusiastic about working with children with disabilities and their families, but felt that they lacked training in this type of work. They would need more training to develop their skills and knowledge to do their job well. In the studies conducted by Aston et al. (2014a, p. 296-301) and Sharkey et al. (2014, p. 748), the nurses and mothers interviewed talked about the importance of knowing how to communicate with children with different disabilities. The examples given by the nurses spoke of the importance of establishing the connection and communication that is the foundation of effective care. This includes listening carefully to the patient when they talk about their values and beliefs, as this is part of providing appropriate care. Uncertainty about one's own abilities to work with children with disabilities has led to ineffective communication as a result. Parental interaction is of great importance here. The authors highlighted time as a very important challenge that affects both the initiation of the relationship of all those involved and the continuous provision of care. Some of the participating nurses stated that they had no problem working with children with disabilities, either because they had their own experience of working with this population or because they had sought out the information they needed to work with. They stressed the need for additional training and learning workshops.

Based on the analysis of the data and comments of the respondents we can answer our fundamental question and say that nurses master their everyday work with patients with disabilities with the help of their own experiences, professional experiences and with the help of patients' relatives. They certainly do need additional and formal training to work with this population of patients.

6 Conclusion

Our survey revealed that nurses have a fairly good understanding of the special needs of people with disabilities. During their formal education, the vast majority of them have not received specific education and training in working with patients with disabilities. In addition to their personal experience with these persons, they have a lot of professional experience, most of which is positive. In most cases, they also have good experiences with relatives of patients with disabilities. The interviewees would like to receive both additional and formal training in this field. They stress the importance of equal treatment, acceptance of difference and detabuisation the field.

Nurses need to provide quality care to patients with disabilities as well as to all other patients.

Therefore, education about the special needs of people with disabilities should be included in the nursing curriculum at undergraduate and postgraduate levels. Nurses should also be motivated to undertake education and training outside their working area. People with disabilities should be included as providers of education and training whenever possible, which would certainly help with detabuisation of the field and to accept difference. Evidence-based guidelines for identification of needs and treatment should be developed, with an emphasis on patient-centred care. Health literate organisations should provide not only equal, but also special medical treatment (e.g. adapted gynaecological chair, adapted dentist chair).

According to Parnell (2014, p. 50) nurses play a critical, central role in healthcare and believe that this is where change needs to start. Nurses can influence what happens in healthcare at both the individual and the organisational level. They play a key role in promoting health literacy. Nursing has an important role to play in direct patient care and in the delivery of health care. Educating nurses in health literacy and improving communication with patients can significantly improve treatment outcomes.

The findings of the survey we conducted among members of The Nurse and Midwifery Organization of Ljubljana have certain limitations, but also a certain advantage and implication for further research.

We consider the following limitations and an advantage of the conducted research:

- the participation of insufficient number of members of the The Nurse and Midwifery Organization of Ljubljana,
- this is the first study of this kind in Slovenia, so it is not possible to make appropriate comparisons with the findings of other national authors,
- the measuring instrument used was partly self-developed, as the existing foreign measuring instrument is outdated and inappropriate,
- the research carried out provides an idea for further work in this very sensitive but increasingly important area of nurses' work.

Our suggestions for decision-makers for further work in the area are:

- Include education on the subject of special needs of people with disabilities in the nursing curriculum at undergraduate and postgraduate levels.
- Motivate nurses to pursue education and training outside their field of work.
- Include persons with disabilities as providers of education and training, which would certainly help to detabooise the field and to accept differences.
- Develop evidence-based guidelines for identification of needs and healthcare with an emphasis on the patient-centred care.
- Ensure that health literate organisations provide not only equal but also specialised medical treatment (e.g. adapted gynaecological chair, adapted dentist chair).

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Andreja Vovk, registered nurse, master of advanced nursing care, quality systems manager, has been employed at University Medical Centre Ljubljana, Division of Obstetrics and Gynaecology, since 1996. Currently she works as a consultant in nursing and midwifery in the area of quality and research and as a coordinator of the quality management system. She is an external and internal auditor according to ISO 9001, lecturer on quality and safety topics and head of the module Quality and Safety in Health Care at The Nurse and Midwifery Organization of Ljubljana. She is a doctoral student at the Faculty of Organisation Studies in Novo mesto.

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Povzetek:
Zdravstvena pismenost medicinskih sester in pacienti z oviranostmi

Raziskovalno vprašanje (RQ): Kako medicinske sestre obvladajo delo z invalidnimi bolniki glede na znanja, ki jih pridobijo na formalnem in neformalnem izobraževanju?
Namen: Posebne potrebe oseb z ovirami so del človeškega življenja. Osebe z ovirami se soočajo z mnogimi preprekami in odnos do njih sodi med najpomembnejše. Zavedanje pomembnosti zdravstvene pismenosti daje zdravstvenim delavcem priložnost za podporo pacientom in njihovim družinam pri premagovanju ovir. Namen raziskave je bil ugotoviti, koliko znanja za delu s pacienti s posebnimi potrebami so medicinske sestre pridobile med formalnim izobraževanjem, ugotoviti

njihove potrebe po pridobivanju dodatnega znanja, ugotoviti vpliv osebnih izkušenj na njihovo stališče in odnos do pacientov s posebnimi potrebami ter ugotoviti, kakšne izkušnje imajo s svojci pacientov s posebnimi potrebami
Metoda: Uporabljena je bila kvalitativna paradigma raziskovanja, podatke smo zbirali z anketiranjem. Podatke smo zbirali s pomočjo strukturiranega vprašalnika. Pri interpretaciji podatkov oz. besednih zapisov anketirancev smo uporabili večfazni postopek kvalitativne analize vsebine. Z analizo vsebine odgovorov anketirancev smo oblikovali tri glavne teme: (1) izkušnje z negovanjem pacientov z ovirami, (2) izkušnje s svojci pacientov z ovirami ter (3) pomembnost znanja za delo s pacienti z ovirami. Zbrane podatke smo kodirali in na koncu pripravili pojasnila ugotovitev.
Rezultati: Ugotovitve raziskave med medicinskimi sestrami kažejo na potrebo po vključitvi izobraževanja s področja posebnih potreb oseb z ovirami v izobraževalni kurikulum medicinskih sester na dodiplomskem in na podiplomskem izobraževanju. Medicinske sestre svoje znanje za delo z osebami z ovirami pridobivajo tekom delovnega procesa, pa tudi z dodatnim usposabljanjem in izobraževanjem. Medicinske sestre imajo osebne in profesionalne izkušnje s tega področja, pri čemer imajo tako s pacienti z ovirami kot tudi z njihovimi svojci pozitivne izkušnje.
Organizacija: Raziskava je bila osredotočena na zdravstveno pismenost medicinskih sester in pacientov z ovirami. Fokus raziskave naslavlja predvsem pomen zdravstvenih ustanov in njihove delovne sile, ki so dolžni zagotavljati varno in inkluzivno okolje za ranljive skupine (v našem primeru paciente z ovirami).
Družba: Zdravstvena nega ima dolgo in pomembno zgodovino prilagajanja spremembam v družbi in njenim zdravstvenim potrebam ter se odziva na zahteve družbe. Medicinske sestre imajo pomembno vlogo pri zdravstveni oskrbi, zato je treba potrebne spremembe začeti pri njih. Medicinske sestre imajo vpliv tako na osebni in individualni ravni kot na ravni organizacije. Pri spodbujanju zdravstvene pismenosti so najpomembnejše, saj so tiste, ki delajo najbližje pacientom in imajo vsakodnevne stike z njimi.
Izvirnost: Izvirnost prispevka se kaže v proučevanju zelo aktualne družbene problematike, ki posega v doslej premalo raziskano zdravstveno pismenost medicinskih sester in pacientov z ovirami v Sloveniji. Raziskava je prva tovrstna raziskava v Sloveniji.
Omejitve/nadaljnje raziskovanje: V raziskavi je sodelovalo premajhno število medicinskih sester. To je prva tovrstna raziskava v slovenskem prostoru, zato ni možno izvesti ustrezne primerjave z ugotovitvami drugih domačih avtorjev. Uporabljen merski instrument smo delno izdelali sami, kajti obstoječi tuji merski instrument je zastarel in neustrezen. Izvedena raziskava podaja idejo za nadaljnje delo na tem tako zelo občutljivem, a vse bolj pomembnem področju dela medicinskih sester.

Ključne besede: oviranost, pacient, medicinska sestra, zdravstvena pismenost, znanje.