

Internet as a source of patient information – Patient Targeted Googling

Internet jako źródło informacji o pacjentach – Patient targeted googling

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STRESZCZENIE

INTERNET JAKO ŹRÓDŁO INFORMACJI O PACJENTACH – PATIENT TARGETED GOOGLING

Wprowadzenie. Dostęp do zasobów Internetu spowodował zmiany w postrzeganiu zasad komunikacji międzyludzkiej, prywatności i dzielenia się informacjami osobistymi. Dla personelu medycznego pozyskane z Internetu dane mogą stanowić uzupełnienie informacji zebranych podczas wywiadu z pacjentem lub ukazać inny obraz jego funkcjonowania. W poszukiwaniu w Internecie informacji o pacjentach (*Patient Targeted Googling – PTG*) kluczowa jest ocena motywacji do takiego działania, poszanowanie praw pacjenta i uzyskanie jego zgody, przestrzeganie zasad etyki medycznej, a także ocena przydatności takiego postępowania dla procesu terapeutycznego. Pojawiają się jednak pytania, czy podawane przez pacjenta informacje są prawdziwe, a w odniesieniu do osób z zaburzeniami psychicznymi na ile są one zmienione przez zaburzenia poznawcze lub zaburzenia nastroju.

Cel pracy. Celem pracy jest przedstawienie wybranych zagadnień dotyczących poszukiwania w Internecie informacji o pacjentach przez członków zespołu terapeutycznego.

Metoda. Artykuł powstał w oparciu o analizę dostępnych badań i opracowań naukowych, dostępnych w bazach danych Medline oraz PubMed.

Podsumowanie. Opracowania naukowe potwierdzają obecność zjawiska PTG, odnoszą się do kwestii zasad etycznych, pozyskiwania zgody od pacjenta, wiarygodności umieszczanych treści i prawdziwej tożsamości pacjenta, umieszczania uzyskanych informacji w jego dokumentacji medycznej oraz ich znaczenia w kształtowaniu relacji pacjent - zespół terapeutyczny.

Słowa kluczowe: poszukiwanie w Internecie informacji o pacjentach

ABSTRACT

INTERNET AS A SOURCE OF PATIENT INFORMATION – PATIENT TARGETED GOOGLING

Introduction. Access to Internet resources has resulted in changes in the perception of principles related to interpersonal communication, privacy and sharing of personal information. Medical personnel may use data obtained from the Internet to supplement information gathered during the patient interview or to reveal a different picture of the patient's health status. In PTG, it is crucial to assess the motivation for such an action, respect the patient's rights and obtain his consent, comply with the rules of medical ethics, as well as assess the usefulness of such an action for the therapeutic process. There are questions as to whether the information provided is true, and to what extent it is altered by cognitive or mood disorders.

Aim. The aim is to present selected issues related to the search for information about patients on the Internet by the therapeutic team.

Method. Analysis of research and scientific studies in the Medline and PubMed databases.

Summary. Scientific studies confirming the occurrence of PTG phenomenon, refer to the issue of ethical principles, obtaining patient's consent, reliability of recorded data and true identity of patients, inclusion of obtained information in their medical records and its importance in shaping the relationship between the patient and the therapeutic team.

Key words: patient targeted googling

INTRODUCTION

The evolution in access and use of the Internet has caused a change in the perception of communication between people, in privacy, anonymity and rules for sharing personal information [1]. The widespread use of social networks, creating blogs, publishing videos or photos causes a kind of blurring of the line between private, professional and social life [2-6]. The Internet and social media have an undeniably important role in healthcare today [5, 7-10]. However, the easy availability of patient information can raise numerous concerns, including those of an ethical nature [1,10,11] and related to occupational professionalism [4, 10]. The possibility of obtaining private patient information from the web does not mean that medical personnel are entitled to use this data source in an unlimited way [12]. These activities are not against the law, but they raise numerous ethical concerns [6,13]. Searching the Internet for patient information may involve numerous risks, including violations of privacy and trust in the therapeutic relationship, but in some circumstances it may be legitimate and beneficial [3,11,14].

Searching data posted on the Internet to obtain private information regarding patients is referred to as Patient Targeted Googling (PTG). The word “googling” which refers to the name of one of the web browsers, has become synonymous with the activity of searching for information on the Internet [4,13,15]. The continuing development of Internet technology, the transformation of modern society (information society) and healthcare, may result in PTG becoming a new source of data used in daily medical practice [3,4,16-18].

AIM

The aim of this paper is to present selected issues related to searching the Internet resources for private information on patients by medical personnel as well as to determine their usefulness in clinical practice.

METHODS

A literature review was carried out using the electronic bibliographic databases Medline, ProQuest, Scopus, CINAHL and a search of Google Scholar resources. The databases were searched using keyword terms: „patient-targeted googling,” „patient-targeted googling,” „PTG”.

RESULTS

Patient targeted googling

The widespread availability of the Internet and search capabilities have enabled easy and rapid access to information. In the context of medical care, these possibilities can raise numerous concerns related to ensuring privacy, confidentiality, therapeutic relationship, and standards of patient communication and protection [18-19]. Each person using the Internet and social media leaves

a record of their activity that constitutes a kind of digital phenotype [16]. Therefore, browsing the Internet for information about a patient provides a variety of data on: statements, photos, videos, messages, interpersonal interactions undertaken, social activities, information relating to lifestyle, alcohol or other substance abuse, engaging in activities described as risky, property status and personal information, health information, and data on sexual activity and preferences [4,14].

For medical personnel, information from the Internet can complement the data provided directly by the patient. Data obtained from web resources, often reveal different aspects of the patient’s life than those addressed during a face-to-face conversation [11], allowing for a holistic understanding of the person, across multiple dimensions of functioning [16]. However, often the information posted by a patient can, intentionally or unintentionally, mislead those who seek information about them [16].

When analyzing content posted on the Internet, it is important to remember that it will not always be accurate and fully reflect the patient’s condition. Therefore, it is important to interpret the obtained data in the context of situation in which the person is, the patient’s medical history and the symptoms or disorders present [11,16,20]. In addition, it is important to take into account that the resulting content posted by the patient on Internet resources may differ significantly from the information derived from the patient interview [13,16]. In view of the apparent anonymity of the network, which leads its users to a kind of online disinhibition [2,18], it is necessary to maintain a distance, in relation to the posted content. In addition to analyzing the information posted by the patient, it is also possible to study data that was not posted intentionally by the patient – i.e., actions taken online. This kind of information (metadata) is, e.g., automatic marking of a person’s location or time of undertaking a particular online activity (e.g., date of logging into an application, automatic marking of a visited location or place where a photo was taken) [16].

Health care professionals may suggest patients to analyze their content posted in Internet resources or social media as a complement to their medical history [11]. Analysis of information posted by a patient on the Web may also be undertaken when a patient’s overall clinical assessment of his condition indicates that the patient is at high risk of engaging in actions that are harmful to himself or others [11,14], and when it is necessary to identify the patient or obtain contact with his loved ones (if no other means of obtaining contact are available) [4,13,19,21]. The rationale for PTG may also be the need to warn the patient of danger, to verify the information provided by the patient (when there are inconsistencies between the interview and medical records or examination and observation results, and when evasive answers are given), when the patient is suspected of being a victim of violence or substance abuse [14] and when the patient is observed to be in a crisis situation [19].

Searching for information about patients with mental disorders

Due to numerous controversies, the issues of obtaining publicly available online information about patients suffering from mental disorders (patients under psychiatric care, mentally ill) require special attention [3,4,11,17,19]. Social media, as well as other information resources made available online, can be a rich source of additional data to help show a complete picture of the patient's disorder, diagnosis, treatment, and functioning [4,22]. Analysis of the content posted by the patient can be helpful in terms of identifying disorders or causes of an existing condition (e.g., detecting content indicative of suicidal intentions, depressive disorders, addictions) [2,4,11,16]. It is important to remember that information obtained this way cannot be the only source of data nor replace a direct interview with the patient [3].

Almost unlimited access to the possibility of monitoring patient activity on the Web is associated with the risk of violating boundaries in the professional relationship between medical personnel and the patient [3,16]. There is a widely held belief that data uploaded to publicly available resources does not require consent for its use. This belief is based on the assumption that when a person posts information in Internet resources (social media, blogs, by publishing photos or videos), he or she is aware of the extent to which the data is available to the general users of the Web. However, treating this type of data as public property may lead to the misconception that searching for patient information on the Web does not require their consent [4,7,12].

Information can be searched according to several possible options: without obtaining the patient's consent, with the patient's consent, and with the patient's consent and presence [3-4]. Failure to obtain the patient's consent to make a PTG reduces trust in the therapeutic relationship and remains ethically questionable [12,16,22] as well as is a sign of paternalism [3]. It is advisable to obtain informed consent from the patient to explore the content posted by him on Internet resources [2,11], this affects mutual trust and credibility in the therapeutic relationship [4,19]. Obtaining consent should be preceded by providing the patient with information about the purpose, benefits, and risks of conducting PTG and the planned subsequent handling of data obtained through this means (e.g., informing about the possibility of inclusion in records, modification of therapeutic management, etc.) [4,19]. It may be difficult in some cases to obtain informed consent from a person with mental disorder to conduct PTG, due to current psychopathology and limitations of competence and discernment in a given situation [3].

Conducting PTG is considered appropriate when implemented at the patient's request, in situations of danger to the patient and others (need to ensure safety), and in the lack of other available sources of information. The use of PTG in clinical practice is supported by the possibility of better understanding the patient due to information obtained from a different perspective than the interview and physical examination, the acquisition of data relevant to the therapeutic process not disclosed by

the patient, and the possibility of confirming the veracity of statements or identifying lies [1,13,14,17,19]. Another consideration is protection of patients from harm and abuse (e.g., when a patient in mania publishes sensitive data about themselves) [1,3].

Violation of trust in the therapeutic relationship, the patient's right to privacy, questionable reliability of the information obtained by this means, the risk of countertransference in the relationship with the psychotherapist are most often identified as arguments against conducting PTG. In addition, the risk of violation of impartiality and objectivity in the therapeutic relationship and the use of PTG for purposes that do not serve the patient's good [2,12,14,16,17,21], as well as the occurrence of problems with the identity of patients on the Internet (similar or the same personalities, use of pseudonyms, impersonation) [3,13] have been indicated. This type of risk can be minimized if, after consenting to PTG, the patients actively participate in it or if they verify that the information obtained applies to them [3]. The reliability of information obtained and its usefulness in the therapeutic process, the risk of taking inadequate or harmful actions in relation to the actual condition and the patient's needs on the basis of information obtained in this way may also be questionable [1]. In addition, there is also the risk of misinterpretation of the information posted by the patient [13].

In health care (particularly in psychiatric care), maintaining confidentiality and respecting patient privacy is at the core of therapeutic relationship. Technological advances that facilitate patient interactions may also carry risks associated with violating these basic principles of medical care [5,13]. However, it is easy to obtain information about an individual via the Internet, which may lead health care providers to initiate and conduct PTG without the required ethical consideration [4,19]. Therefore, before undertaking such a practice, it is crucial to balance the potential benefits and risks of being able to obtain information via this channel. It is also important to take into account the patient's rights, principles of medical ethics and applicable legal standards [4,13].

The ethical aspect of obtaining patient information online should first of all consist in assessing the motivation and purposes of conducting such a search [16]. The purpose should be dictated by a concern to help the patient and not by considerations of another kind, such as satisfying curiosity or looking out for own interests [3,10,16,22]. Ethical considerations for conducting PTG should be focused primarily on the pragmatic consequences of undertaking such an activity for a particular patient, not just on general moral principles. The issues to be considered in the ethical conduct of PTG focus on respect for rights, minimizing the risk of harm to the patient, and the practical outcomes of such a search – its relevance to the therapeutic process [4]. The first priority is to answer the question of why PTG is planned – reasons other than patient welfare should not be the basis for conducting such a search. The next step is to assess whether the results of PTG will affect the ongoing medical care – the key issue is to assess whether the information obtained from online sources can be used for the patient's benefit in the

ongoing therapeutic process and will not negatively affect the ongoing treatment and relationship with the patient, as well as whether it is not possible to obtain this information from other sources (e.g., family or relatives of the patient). This is particularly important in the context of patient treatment for psychiatric disorders. The next stage of consideration is the issue of obtaining informed consent from the patient before undertaking PTG. If the decision is made to undertake PTG without the patient's consent, the potential benefits of such a search must be assessed against the risks associated with compromising the patient's privacy and the therapeutic relationship (trust). By its very nature, conducting PTG involves the collection of information, and therefore, a determination must be made as to whether the data obtained in this manner should be shared with the patient. If the patient agrees to PTG, he should be informed about the scope of data to be analyzed and what information will be searched. If PTG is conducted without patient consent, the benefits and risks of disclosing the information obtained during the search should be carefully evaluated. If a decision is made not to disclose the retrieved data, it is also important to consider how this will affect the subsequent therapeutic relationship (especially in the context of psychotherapy practice and the phenomenon of countertransference). Inclusion of results from conducted PTG in patient records also requires caution. If the search was conducted with the patient's consent and the results are clinically relevant, such information may be entered into the patient's record. On the other hand, if the PTG was conducted without consent, inclusion of the information in a record that is also accessible to other health care professionals is inappropriate due to the violation of individual privacy. A final recommended practice element is ongoing reflection by professionals related to the conduct of PTG and the motivations behind it [1,4,18]. It is important to consider that the inclusion of information obtained through PTG in the patient record, certainly requires acknowledgement of its source. This minimizes the risks associated with liability for posting misinformation [13].

To date, there has not been much research on the issue of patient targeted googling by medical personnel [22], but the results of these available reports confirm the existence of this phenomenon [1,4,13,16,17,21,23,24].

The first significant paper on PTG was published in 2010 [4] and initiated discussions related to the practical, as well as ethical, aspects of searching for patient information online. Issues related to PTG are evolving with the emergence of new options offered by the Internet, including accessibility to its resources, new applications, and use of the Internet in healthcare. This evolution creates many new dilemmas and controversies.

Also, the COVID-19 pandemic, which contributed to the partial transfer of some areas of medical care to the Internet, may significantly affect the functioning and perception of PTG phenomenon [24].

The widespread availability to information posted on the Web requires the inclusion of PTG-related content in both undergraduate and postgraduate education in health sciences and medical sciences [1,13]. However, in our

country there is no guidance relating to the principles of obtaining private patient information from Internet resources and further handling of the knowledge obtained this way. The mere fact that the acquisition of publicly available data is not illegal does not mean that medical personnel should unreflectively undertake such activity. Both professionals and medical students are obliged to respect patients' rights and maintain professional secrecy, and the lack of guidelines for conducting PTG requires reflection and introduction of obligatory guidelines and recommendations of good practice in this area.

SUMMARY

Due to the rapid development of possibilities offered by the Internet, the perception of privacy and confidentiality has evolved.

In the era of information society, the sense of anonymity on the Web is only apparent, and the data posted online can be relatively easily and quickly found in the Internet resources. This possibility can be used by everyone, but the acquisition of information on patients by medical personnel (PTG) can generate a lot of ambiguity associated mainly with the risk of violation of current ethical and legal principles and overstepping the boundaries of professionalism in providing care. Therefore, it is necessary to sensitize health care professionals (as well as medical students) in the area of importance and consequences of carrying out PTG, and to direct them to the prudent use of this possibility for obtaining information and using it in the therapeutic process. It is also important to reflect on the role that the Internet plays in the relationships between medical professionals (physicians, nurses, psychologists, paramedics, students) and patients as well as their loved ones.

The decision to conduct PTG should be made wisely, with an assessment of purpose and motivation of the action taken, respecting the patient's consent and applicable ethical and legal principles. The potential impact of PTG on subsequent stages in the therapeutic process should also be assessed, and consideration should be given to issues related to informing patients on the results of search, recording data collected in this way in their medical records. Prudence and caution are crucial to the safety of this process in view of the widespread use of the Internet to obtain patient information.

Patients expect medical professionals to respect their rights, maintain confidentiality and trust, and exercise professionalism in the broadest sense. Browsing through patient information published online or in social media may have an impact on further therapeutic relationships, especially in relation to building trust and respecting privacy, taking into account the fact that many people posting information online do not assume that it can be used by health care professionals. In the era of widespread and easy ability to obtain patient information from Internet resources, both medical personnel and medical students should be sensitized to the ethical aspects of conducting PTG, while also drawing attention to the potential benefits as well as risks of this way of seeking information.

Due to the lack of extensive research in this field and, to the authors' knowledge, the lack of studies in Poland, it is advisable to conduct a study to assess the scale of PTG phenomenon carried out by medical personnel and future health care students.

CONCLUSIONS

1. Patient information obtained by medical personnel from publicly available Internet resources may be an additional source of data. However, it should be taken into account that PTG, apart from its potential benefits, is subject to numerous risks and should not be a routine procedure for the personnel.
2. There is a need for recommendations or guidelines regarding patient targeted googling for health care professionals (and medical students) that sensitize them to its potential benefits and risks.
3. Available databases confirm few works related to Internet search for patient information, and therefore, it seems appropriate to deepen the existing area of research related to PTG issues.

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