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PRESERVATION OF THE RIGHT TO PRIVACY: PERCEPTION OF HOSPITALIZED PATIENT INTEGRATIVE REVIEW

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ABSTRACT

Introduction: Privacy as a fundamental human right must be preserved in all dimensions. In hospitalization the two dimensions of privacy most affected are physical and information privacy. Preserving patient privacy is essential in establishing a relationship between the patient and the health care team and is currently an important indicator of the quality of care.

Objectives: Knowing perspectives of hospitalized patients about their right to privacy.

Methods: An integrative review was based on research studies in databases B-on, SciELO and EBSCO in the last 12 years (2005-2016).

Results: We selected 9 articles, 4 of which are quantitative approach and 5 qualitative. The articles suggest that the dimensions of privacy that are most often violated are the physical and informational dimension. Aspects of physical space are referred to as factors that negatively influence the preservation of privacy.

Conclusion: Patients' perception of their privacy predicts their satisfaction about care. The lack of privacy conditions in the patient feelings of stress and affects the relationship between these and the health professionals.

Keywords: Privacy; confidentiality; hospitalized patient; nursing care; integrative review.

INTRODUCTION

Privacy is recognized as a fundamental human right that must be preserved in all dimensions. The Universal Declaration of Human Rights provides in article 12 that "no one shall be subjected to arbitrary interference with his privacy, family, home or correspondence"[1]. In Portugal, the right to privacy is established in the Constitution of the Portuguese Republic since 1976, specifically in the chapter "Personal rights, freedoms and guarantees", article 33, which guarantees the right to privacy of private and family life[2].

The right to privacy assumes specific and quite relevant aspects in health care contexts. The Basic Health Law No. 48/90 of 21 August, in its Base XIV, no. 1, paragraph (c) defines the right users have to be "treated by adequate means, with humanity, promptness, technical accuracy, privacy and respect"[3].

The hospital is an environment hostile to human nature as it enhances the physical fragility and vulnerability of patients[4]. For many years, the respect for privacy and confidentiality of patients has been an obligation of health professionals. Nowadays, this issue is

still essential in nursing practices[5]. In Portugal, this requirement is explicit in the Code of Ethics for Nurses, especially in article 106, which reports to the Duty of Confidentiality, and article 107, which focuses on Respect for Intimacy[6].

During hospitalization, physical and information are the two most affected dimensions of privacy.

Preservation of privacy is essential in establishing a relationship between patients and the health care team. It is important to consider that the intrusion of privacy can include multiple approaches such as the physical presence of an unwelcome person, examination by an unauthorized person, misleading information or decision making by inpatients themselves without their consent[7].

The lack of privacy and confidentiality impedes communication between patients and health professionals, especially when discussing sensitive issues and important treatment options[8].

Over the last years, patient satisfaction levels have been identified as one of the biggest indicators of quality in health care, being influenced by many factors. The protection of privacy in health care is taken as an important quality indicator[7].

METHODS

We have developed an integrative review considering the principles of evidence-based research. According to Ercole et al.[9], an integrative review of literature allows combining research results of a given topic in a systematic, orderly and comprehensive way. This method allows the simultaneous inclusion of quasi-experimental and experimental research, joining theoretical and empirical literature data and thus providing a more complete understanding of the subject matter.

During this study, we asked the following research question: *What is the perception of inpatients about their right to privacy?* We formulated the research question according to the PICOD methodology (Participants, Intervention, Comparisons, Outcomes, Design).

Considering the research question, we outlined the inclusion criteria to select the different studies:

- *Population*: hospitalized adults;
- *Phenomena of interest*: the analyzed studies must consider the perspective of inpatients regarding their right to privacy;
- *Outcomes*: results must include the patient's perception and satisfaction concerning their privacy during hospitalization;
- *Design*: The review will consider studies that focus on both qualitative and quantitative data.

Similarly, we defined as exclusion criteria studies not indexed to electronic research bases, articles whose full text were unavailable and that were not published in one of the following languages: Portuguese, English or Spanish.

We carried out the research in journals indexed in various databases, individually by the elements of the Working Group, including B-on, SciELO and EBSCO, using 2005 as the lower limit and 2016 as the upper limit. We used the following keywords: *privacy*, *confidentiality*, *patient*, *nursing care*, and satisfaction, with the following Boolean combinations: *patient privacy* AND *nursing care*; *patient privacy*; *patient confidentiality*; *patient privacy* AND *satisfaction*.

In a first phase we analyzed the titles of the articles found to identify those that met the objectives of this integrative review. Afterwards, we continued the process of inclusion/exclusion of articles by reading the abstracts. Those whose abstracts were in line with the objectives of this review and met the defined inclusion criteria were analyzed in full.

RESULTS

Considering the defined strategy, the literature search in the databases mentioned resulted in 237 articles. This was followed by reading the titles and later the abstracts. We analyzed 38 articles in full. Afterwards, in accordance with the objectives and the inclusion and exclusion criteria previously defined, we selected nine studies to be part of this review.

The methodological quality of the studies was independently assessed by two authors using the critical assessment tools of the *Joanna Briggs Institute*[10].

We used tables to carry out the data systematization process to facilitate the analysis of the studies. Tables covered the following aspects: identification of the study, country and date, purpose of study, study design, number and type of participants, outcomes, intervention

or phenomenon of interest, results and main conclusions. According to the Joanna Briggs Institute[10], the evidence levels found were level 2[8], level 3[5,7,11] and level 4[4,12,13,16,17].

The studies analyzed were developed in several countries and are distributed in the following way: Brazil (2 studies), Taiwan (2 studies), Turkey, England, New Zealand, Australia and Iran (1 study each).

We grouped the results of the studies included in this review according to the methodological approach used to better understand and visualize them. Thus, four out of the nine studies analyzed had a quantitative methodology and five had a qualitative methodology. We should also emphasize that within the quantitative studies, one is quasi-experimental and three are descriptive. Table 1 shows the selected studies to systematize and compare results.

The study sample is mostly constituted by patients admitted to emergency services (4 studies) or wards (5 studies). However, there are two studies that simultaneously consider patients and nurses, thus allowing to know the perspectives of this professional group concerning the issue.

Table 1 - Methodological aspects of the selected studies and main results.

Author/year	Country	Sample	Research methods	Intervention/Phenomena of interest
Qualitative studies				
Soares, V. & Dall'Agnol, C. (2011)[17]	Brazil	12 patients	Semi-structured interviews Simple observation	Patients' perception regarding the respect to their privacy.
Results	Exposing their body to another person and the inappropriate attitude of nursing professionals can create anxiety, embarrassment and stress, affecting the health and well-being of patients.			
Pupulim, J. & Sawada, N., (2012)[4]	Brazil	34 patients	Semi-structured interviews	Patients' perception regarding their privacy.
Results	Patients mentioned the behavioral factors that contribute to the protection and maintenance of privacy in hospital contexts, highlighting respect as the most important one, followed by personal control over situations that can violate this privacy.			
Woogara, J. (2005)[16]	England	73 patients 34 nurses	Non-participatory observation, unstructured interviews and semi-structured interviews	Behavior and perceptions of patients and professionals about privacy.
Results	*Patients:* constant interruption by the routines of the professionals; the hospital environment do not encompasses their individual values, beliefs and relationships; they have little control and choice over the aspects of their private life; greater limitation on choices about themselves when the level of dependency is high. *Health professionals:* the younger ones are more aware of the documents that safeguard the right to privacy; they do not promote patient personal space; they often sit in the beds of patients without their consent and do not generally communicate with patients in a way that respects their individuality; the patient's personal information is shared without their consent; overall, the health team failed to protect patients' dignity and privacy; in addition, patients are not treated in a place that effectively ensures their privacy.			
Akyüz, E. & Erdemir, F. (2013)[12]	Turkey	102 patients 47 nurses	Semi-structured interview	Perception of patients who underwent surgery and nurses about how care affects the maintenance of privacy as well as suggestions for improvement.
Results	52.9% of patients and 70.2% of nurses define privacy as "confidentiality of private life"; 75.5% of patients referred to never have had an unpleasant experience related to sharing their personal information, while 24.5% refer otherwise; 85.1% of nurses said to protect patients' information during shift change; nurses claim to be careful to prevent third parties from hearing or accessing patients' information; nurses are determined to respect and protect patients' autonomy; 80% of patients consider that the hospital rules respect and protect their privacy; 95.7% of nurses and 80.4% of patients report that the physical space should be improved to respect the privacy of patients (individual rooms, closed doors during procedures, curtains); patients highlighted the importance of privacy during elimination activities.			

Table 1 - Methodological aspects of the selected studies and main results.

Author/year	Country	Sample	Research methods	Intervention/Phenomena of interest
Qualitative studies				
Malcolm, H. (2005)[13]	New Zealand	12 former patients	Semi-structured interview	To identify problems encountered by previously hospitalized people regarding privacy maintenance since they stayed in a shared room. To verify how former patients perceived their own privacy in previous hospitalizations.
Results	Lack of privacy is a given: effective privacy is lower than expected. Physical constraints, desire for a private place where to discuss private matters; curtains do not promote informational privacy, only a visual barrier. Patients are aware of being heard as well as hearing information from other patients with families and professionals (healthcare professionals should keep their voice down); choosing the aspects concerning privacy would keep personal information under control: patients tend to restrict the information given to health professionals as a way of protecting private matters from other people.			
Karro, J. et al. (2005)[11]	Australia	235 patients	Questionnaire	To identify environmental factors and their relationship to patients' perceptions of privacy violations. To notice how privacy violations affected healthcare developments.
Results	Privacy is more important for women than for men. Patients who stay in spaces divided only by curtains report more privacy violations. The higher the stay in healthcare facilities, the larger is the patient perception of privacy violations. Patients tend to withdraw information or to refuse examination when they notice previous privacy violations.			
Lin, Y. et al. (2013)[8]	Taiwan	313 pre-intervention patients 341 post-intervention patients	Questionnaire	The intervention in the ER included: Organization of space and working procedures; access control; training and exercises in Bioethics; ethics consultation performed by professionals who allow patients to express their concerns.
Results	The post-intervention group had significantly higher values of satisfaction and general perception of privacy; they also had better levels of satisfaction in the "personal information heard by third parties," "be seen by irrelevant people," "inappropriate conversations intentionally heard by health professionals," and "respect for privacy" categories. There was no difference between the two groups in the "room privacy for physical examination" category. The overall analysis shows that the intervention improved the perception of privacy and patient satisfaction.			

Table 1 - Methodological aspects of the selected studies and main results.

Author/year	Country	Sample	Research methods	Intervention/Phenomena of interest
Estudos qualitativos				
Nayeri, N. & Aghajani, M. (2010)[7]	Iran	360 patients	Questionnaire	Considering three dimensions of privacy – physical, informational, and psychosocial – the authors sought to understand how ER professionals respect patient privacy, which is related to patient satisfaction.
Results	There is a strong and meaningful relationship between privacy and satisfaction as well as privacy and placement of patients' beds (they referred to privacy as "weak" in public areas without curtains and "better" in rooms with curtains); there is also a relationship between patient age and privacy; older patients report more privacy violations; informational privacy respect was considered "weak" by 30% of patients and as "pretty good" by the same percentage; about 30% of patients said "weak" regarding psychosocial privacy; the longer the hospitalization period, the more likely are privacy violations; patients that said their privacy has been preserved indicate higher levels of satisfaction.			
Lin, -Y. & Lin, C. (2010)[5]	Taiwan	313 patients	Questionnaire	Predict the patient's perception of privacy and whether this perception is associated with their degree of satisfaction.
Results	A large percentage of patients are satisfied with the care received at the ER (41.2% considered to be good), showed good general perception of privacy (40.3% considered to have a good level and 10% a very good level); 21% of patients said to withdraw information for feeling that their information may be inappropriately disclosed; 19% claim to be reluctant to be physically examined for feeling that their body may be inappropriately exposed; 75% believe that privacy is very important in the ER; older patients and with longer stays have lower levels of general perception of privacy; patients who are treated in hallways also have lower levels of general perception of privacy.			

DISCUSSION OF RESULTS

As result of the analysis of the selected studies, we can see that patients who had their privacy respected had higher levels of satisfaction[5,7,8]. We found that the length of stay and patient age are related to the perception of privacy: the longer the stay and the older the patient, the greater the number of privacy violations reported[5,7,11].

Physical space was referred several times as a factor that hinders the preservation of privacy. Patients report that spaces divided only by hospital curtains have less privacy[7,11,12,13]. Authors such as Downey & Lloyd[14] and Guimarães & Dourado[15] also support these findings, stating the essential role of strategic measures such as the use of folding screens and curtains as well as the carefulness when undressing patients as ways of protecting their privacy.

As result of the disregard for privacy as perceived by patients, some refuse to be examined given previous observations of violation[5,11].

Information privacy is also a very present dimension in the studies analyzed[7]. Most patients said to withdraw personal information for feeling that their privacy could be inappropriately disclosed[5,11,13]. These findings reflect the results in Soares[18], who points out that professional comments are often voiced about patients' personal information in places that go beyond the care practice.

Hospitalization is most often seen as a time of depersonalization. Patients view their limitations when choosing the aspects related to their private life during hospitalization as a decrease in privacy[4,16].

In studies that include the nurses' perception, these professionals consider adopting measures to promote the patient privacy[12]. However, in two qualitative and non-participatory observation studies there is an overall inappropriate attitude concerning nurses, which can cause failure in patient privacy protection[16,17]. Backes et al.[19] states that this aspect reveals the disruption of values in which the oversight by ethical principles seem to be a part of the everyday of these professionals.

Regarding the methodology used by the different studies analyzed, there are aspects which we believe can hinder the reliability of results. The most common are: the use of reduced samples, the sample type used and the use of recall strategies in the clearing of the data. One of the studies analyzed[13], which had interviews with patients after their hospitalization period, focused on the analysis of a subjective perception, the perception of privacy, using recall strategies, which could cause information bias.

Convenience sampling was used in three of the quantitative studies analyzed[5,7,11]. This aspect can restrict the study because since this type of sample includes subjects available on site at the time of data collection, these people can have different characteristics of the target population, which prevents the generalization of results[20]. In addition, the sample in the analyzed quasi-experimental study[8] was not randomized, which according to Eccles et al.[21] can hinder and interfere with results, since it is difficult to obtain samples with similar characteristics in the two periods of the study. The number of patients and the type of pathology in two periods of the study may have been different, which can affect the perception of privacy.

We also understand the reduced number of samples as a limiting factor, since it implies studying a group of people who may not be representative of the issue. Out of the studies analyzed, the largest sample consisted of 360 people[7] and the smallest sample consisted of 12 people[13,17]. According to Fortin[20] large samples usually lead to better approximations to population parameters. However, in studies whose goal is to explore and describe phenomena, the sample size can be reduced.

Finally, we think that is necessary to reflect on the different socio-cultural contexts where data collection happen. The analysis of a dimension as subjective and culturally dependent as privacy, evaluated in countries with social and cultural conditions as different as those that integrate this review, can also influence the generalization of results.

CONCLUSIONS

This integrative review concluded that inpatients' perception regarding privacy is related to their satisfaction with the care provided. Most patients perceived physical or informational violations regarding their own privacy or the privacy of others. According to them, the lack of privacy is related to their dignity, respect and guarantee of autonomy. The lack of privacy can create stress and affects the relationship between patients and health professionals.

The results presented by the several studies included in this review allow us to infer some implications for clinical practice. One of the points made was the importance of professional development of health teams in ethics and patients' rights, since the increase of knowledge in this area can improve the privacy given to patients. The studies reviewed show the need to improve the physical space of health facilities as constraints of physical space are related to multiple privacy violations.

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