

Children's Privacy in Pediatric Wards in Teaching Hospitals Affiliated to Shahid Beheshti University of Medical Sciences: 2014 - 2015

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Abstract

Background: Patients' privacy is an important ethical responsibility in medicine and an inseparable part of treatment. Children's privacy is no exception. Children's rights to privacy are recognized under the Children's Rights Convention as part of good medical practice.

Objectives: Few studies have examined children's privacy in Iran or in other countries. Thus, the present study was designed to investigate views expressed by relatives who accompanied sick children to the hospital about various aspects of the children's privacy.

Methods: In this descriptive cross-sectional study, data on two dimensions of privacy (informational privacy and physical privacy) of children in pediatric wards were collected using a researcher-made questionnaire from 90 individuals who accompanied children (90 children, 57.8% boys and 38.9% girls) to hospitals (Imam Hossein and Mofid) affiliated to Shahid Beheshti University of Medical Sciences. The data were analyzed using SPSS-18 software. Pearson's correlation coefficients were calculated, and t-tests and ANOVAs were performed.

Results: With regard to the two dimensions of privacy, informational privacy was respected more than physical privacy. No significant relationship was observed between the observance of privacy and duration of the hospital stay or admission ward, but there was significant linear correlation between the number of beds in a room and informational and physical privacy. The mean score for respecting privacy increased in accordance with the child's age, with the overall mean score significantly higher in the 11-14-y age group than the other age groups. Information disclosure occurred mainly through conversations with parents (52.2%) and during rounds (30%). Very little information disclosure (1.1%) occurred via discussions between personnel and discussions with parents. Hospital authorities investigated 40% of complaints about privacy violations or disclosure of a sick child's information.

Conclusions: The results showed that the level of respect for informational privacy was relatively acceptable. However, the level of respect for physical privacy was poor. Therefore, it is essential to provide appropriate training on the issue of children's privacy, especially physical privacy (e.g., using separate rooms and ensuring that medical staff knock before entering a room), and to ensure that rules governing children's privacy are followed.

Keywords: Privacy, Confidentiality, Hospitalized Children

1. Background

Privacy is a basic human right, which provides a sense of safety against intrusion of a person's personal life (i.e., their thoughts, feelings, and body). Privacy refers to personal issues that people do not wish to disclose to others and have control over (1,2). In Iran, one of the five articles in the charter of patients' rights is assigned to patients' privacy (3). Privacy is also emphasized in other texts on patients' rights in various countries (4). According to a report by the American College of Emergency Physicians, privacy and confidentiality are essential in the patient-physician relationship (5). Sometimes, hospital personnel may have to invade a patient's privacy because of the need to perform particular procedures or administer specific care. They should be aware that neglecting the patient's privacy while performing their duties can cause the patient discomfort

and stress and that paying attention to the patient's' privacy can strengthen the patient's sense that he/she is respected (6,7).

The following have been put forward as the basis for people's right to privacy: human dignity and respect for people's liberty or their personal autonomy (8), the establishment of trust and confidence in clinical interactions, and the establishment of a high quality physician-patient relationship (9,10).

On the issue of privacy and medicine, the Stanford Encyclopedia of Philosophy proposes the following dimensions of privacy in the relationship between the clinical team and patient:

1- Informational: In medicine, informational privacy is often expressed as confidentiality. The majority of medical professionals acknowledge privacy of patients' medical in-

formation as their ethical duty.

2- Physical: Physical privacy refers to private spaces. Patients have the right to be examined alone by the clinical team and the right of privacy in physicians' surgeries, hospitals, and other healthcare settings.

3- Associational: This refers to the ability to express empathy with patients experiencing pain, childbirth, or impending death or recovering. Associational privacy involves ethical treatment and is vital for social exchange.

4- Decision making: This is related to personal choices and respecting the privacy of patients in decision making associated with care and treatment.

5- Proprietary: This refers to the importance of paying attention to the unique attributes of patients when performing diagnostic and medical procedures (2).

In medical procedures, less attention has been paid to physical privacy than informational privacy. According to the literature, clinical teams appear to have little knowledge about the importance of human rights and state laws regarding patient's privacy (11). In a U.K. study, almost a quarter of patients admitted to hospitals stated that they believed their privacy was violated during the course of their admission (2). The results of a study in Iran suggested that the privacy of almost one-third of patients was violated (12). Like adults, children have equal rights to privacy. Unfortunately, although the privacy of older children is usually respected, it is neglected in cases of younger ones, especially infants (13, 14). Previous research showed that a child's need for privacy was associated with the development of a sense of independent identity (15). It also demonstrated that children's awareness of their environment and privacy and the need to have control over their own private space increased with age and cognitive development (15). Thus, a child's independence and separate identity from the parent deserves respect. For physicians, a child should be considered the first point of reference and the parents the second. The aim is to establish a direct physician-child relationship, regardless of the child's age. However, in practice, it may not be easy to engage with a child, and only a limited relationship may be possible (16). In addition, children are vulnerable, both mentally and physically, and they may lack the understanding and power to express physical and mental problems. Thus, the constant presence of parents or other family members is essential during medical procedures involving a sick child. A previous study showed that the presence of parents or other family members created the phenomenon of "overhearing," which made observing privacy much more difficult, especially in the area of confidentiality (11). Among various aspects of privacy, violation of confidentiality (usually defined as deliberate disclosure of information to a third party) is the most common. Previous studies showed

that privacy of information (confidentiality) was of vital importance for hospitalized adolescents. Other aspects of privacy, including psychological, social, and physical, were also shown to be important to this vulnerable group. According to previous studies, concern about confidentiality of information was one of the main reasons underlying adolescents' unwillingness to receive medical care (17). The maintenance of the aforementioned aspects of privacy by the medical team and hospital personnel is very important for patients, especially sick children.

2. Objectives

As no study has been conducted in the area of pediatric patients' privacy in Iran, the main goal of the present study was to assess whether medical teams respected various dimensions of the privacy of hospitalized children of different ages in pediatric wards based on the views of those who accompanied the patients. An additional goal was to determine ways to eliminate deficiencies in this area according to the results obtained.

3. Methods

This descriptive cross-sectional questionnaire study involved children admitted to various pediatric specialty or subspecialty wards in hospitals (Mofid and Imam Hosein) affiliated to Shahid Beheshti University of Medical Sciences (ranked second in Iran) during 2014 - 2015. The study population consisted of those who accompanied the hospitalized children. The inclusion criteria were the willingness of the person who accompanied the child (admitted to a specialty or subspecialty ward for a minimum of 48 hours) to take part in the questionnaire and the mental ability to answer the questions. Those unwilling to take part were excluded, as well as those who provided incomplete information. According to a preliminary study, a sample size of 96 people was required. The sample size was calculated using Cochran's formula presented below, where P was 0.5, α was 0.05, and d was 0.1:

$$n = \frac{\left(Z_{1-\frac{\alpha}{2}}\right)^2 P(1-P)}{d^2} \quad (1)$$

In total, 110 questionnaires were distributed to parents/guardians. Of those, 90 questionnaires were completed and assessed. (given incomplete answers). The sample was randomly selected through a random-number generator. The objectives of the study were first explained to the parents/guardians willing to take part. After obtaining informed verbal consent, the questionnaires were completed anonymously. This research project was approved

by the ethics committee of Shahid Beheshti University of Medical Sciences (no: 12045; date: 9.2.2014).

The data were collected using a researcher-made questionnaire based on available resources, such as books, guidelines, and research papers. It consisted of three sections. Section one contained questions on demographic details, including the age of the child, gender, relation of the respondent to the child, admission ward, number of beds in the room, and duration of the hospital stay. Section two dealt with two dimensions of privacy: physical and informational. After an extensive review of the literature and according to sociocultural conditions in Iranian society, 15 questions were included on these dimensions, with eight questions on physical aspects of privacy and seven questions on informational aspects of privacy. The questions were scored as follows using a 5-point Likert scale: always (a score of 5); in most cases, yes (a score of 4); sometimes (a score of 3); in most cases, no (a score of 2); and never (a score of 1).

Next, the mean and standard deviation (SD) for each question and mean score for the two dimensions of privacy were computed. The mean score for each dimension (based on a 5-point Likert scale) was classified as inappropriate (1-2), relatively appropriate (3-4), and appropriate (> 4). Section three contained a four-option question about the patient information disclosure method and a two-option question about violations of the privacy of the sick child or disclosure of information about the child. The content validity index of the questionnaire was determined based on assessments by 15 professors in medicine and experts in medical and nursing ethics. After two rounds of validation, the questionnaire was accepted, with an inter-rater agreement of 0.87. Some questions were omitted, added, or modified according to comments made by the assessors. The reliability of the questionnaire was determined based on 20 completed questionnaires, which produced a Cronbach's alpha of 0.8.

SPSS-18 software was used for the data analysis. An ANOVA was performed to determine the association between the "scores for the dimensions of privacy in different admission wards." Pearson's correlation coefficients were calculated to determine the correlation "between the number of beds in a room and physical privacy" and "between the number of beds per room and informational or physical privacy." Descriptive data are presented as the mean, with SDs and distribution indices.

4. Results

Most of the patients were aged 6 - 12 month (48.9%). Children aged 11 - 14 years (3.3%) accounted for the smallest number of the sample. In this study, 57.8% were boys,

and 38.9% were girls. Most children were accompanied by mothers (87.8%), followed by fathers (5.6%), sisters (4.4%), brothers, and members of welfare organizations (1.1%). The duration of the hospital stay was 4 - 7 days in most cases (45.6%), followed by 2 - 3 days (35.6%). Only a few children (6.7%) had a hospital stay of more than 2 weeks. The mean number of beds in each room was 6 ± 2 . The majority of rooms (27.8%) had eight beds, and only a few (4.4%) had two to three beds.

Physical privacy was less favorable, with the mean score of 12.2 (group overall mean of 14.72). The scores for informational privacy were relatively appropriate, with a mean of 3.86 (group overall mean of 20.02). There was a statistically significant linear correlation between the number of beds in a room and physical privacy ($r = 0.31$, $P < 0.001$) and between the number of beds per room and informational/physical privacy ($r = 0.4$, $P < 0.001$). The frequency of information disclosure was 52.2%, and most information disclosure occurred through parents' conversations. Conversations between medical personnel and conversations between the personnel and parents were responsible for the least information disclosure, with a frequency of 1.1%. According to the results of the study, hospital authorities investigated 40% of complaints about privacy violations or disclosure of a sick child's information.

The overall mean score for the dimensions of privacy was 38.24 ($SD = 7.4$) and it was not significantly associated with the type of admission ward ($PV = 0.65$), length of hospital stay ($PV = 0.137$), or number of beds per room ($PV = 0.312$). However, it was significantly associated with the child's age group ($PV = 0.013$). The mean score for privacy in the 11 - 14-years age group was significantly higher than that of the other age groups (Table 1). Physical and informational privacy scores increased with increasing age. The questions and mean scores for privacy based on the views of those who accompanied the patients are shown in Table 2.

5. Discussion

Overall, the minimum score for observing children's privacy was 16, and the maximum score was 51. The mean score was 35.02, and the median was 35 ($SD =$). Given the scores in the study (inappropriate, 17-32; relatively appropriate, 32 - 47; and appropriate, 46 - 62) the level of observing children's privacy was relatively good in these teaching hospitals. In a study conducted in Tehran University of Medical Sciences, satisfaction with patients' privacy in the emergency department of affiliated hospitals was 50.6% in 2007, and patients described their satisfaction with privacy as poor to medium. Satisfaction with privacy for patients younger than 30 y and older than 60 y was poor (1).

Table 1. The Relationship Between Privacy and the Children's Age Groups

Age	Informational Privacy	Physical Privacy
6 mon to 1 y		
Mean	13.2667	14.4000
SD	1.97023	1.89195
1 - 5 y		
Mean	13.1429	14.9130
SD	1.93820	2.13015
6 - 10 y		
Mean	12.9091	14.4444
SD	2.07145	2.55495
11 - 14 y		
Mean	15.0000	20.5000
SD	0.00000	2.12132

In a study conducted by Borhani et al. (18) in Kerman, Iran in 2010, the observation of the privacy rights of pregnant women, as well as confidentiality, was reported to be good, which disagrees with the findings of the present study (17). In a study in Turkey (19), observing patients' privacy was reported to be 86.1%, which strongly disagrees with the findings of the present study. In a study conducted in a teaching hospital in Zanjan, Iran in 2010, the mean score for respect of patients' privacy was 51.23 ± 14 , which was higher than that found for children in the present study (35.02 ± 12) (20). Despite the higher respect for privacy reported in the teaching hospital in Zanjan compared to that found in the present study, more than 50% of patients complained about a lack of examination curtains and blamed authorities for poor planning regarding patients' privacy. Hence, the physical privacy of patients was poorly observed. The higher level of privacy in hospitals in smaller cities compared to that in larger cities, such as Tehran, may be because most people in these cities (patients and medical teams) tend to know each other. In addition, fewer patients attend hospitals in less populated cities due to limited diagnostic and treatment facilities. Instead, the majority of patients are referred to better equipped hospitals, which are mainly located in Tehran. The results of a study that compared the perceptions of nurses and hospitalized adolescents of the observance of privacy in various hospitals affiliated to Tehran University of Medical Sciences showed that privacy was not observed in 59.4% of cases (21), which was lower than that in the present study. In the present study, due to the children's ages, lack of understanding of privacy, and lack of decision-making competence, children's privacy was less observed than that of the adoles-

cents and adults in the other studies. In a study conducted in emergency departments of hospitals affiliated to Tehran University of Medical Sciences in 2007, the observance of physical privacy was similar (36.1%) to that found in the present study (36.48%) (1). The same study reported that psychosocial privacy was observed in 31.9% of cases and that informational privacy was observed in 30.6% of cases, which was lower than that (41.58%) found in the present study. In a study conducted in Lahore, only 10.8% of public hospitals maintained patient data confidentiality (22), which was lower than that in the present study. The poor level of confidentiality was attributed to the large number of patients in the hospitals making it difficult for physicians to observe all confidentiality protocols, in addition to large numbers of beds in rooms, examinations without curtains, and physicians observing and examining patients in the presence of others. Thus, the physical environment (limited rooms and beds) of teaching hospitals, low cost of teaching hospitals, huge workload of clinical teams, and large numbers of desperate patients referred from remote areas requiring medical attention, with low expectations regarding their rights and privacy seem to lead to no significant differences between these hospitals in terms of observing privacy. Multiple-bed rooms (as opposed to single-patient rooms) and lack of training of clinical teams can be blamed for poor patient privacy in teaching hospitals. The significant difference in the level of observance of informational privacy between the present study, Tehran University study, and Lahore study may be due to the personnel undertaking the following: performing training rounds in hospitals affiliated to Shahid Beheshti University regarding patient examinations, taking the patient's his-

Table 2. Questions and Mean Scores for Privacy Based on the Views of the Patients' Parents/Guardians (N = 90)

Dimensions of Privacy	Questions	Mean	Never (%)	Mostly No (%)	Sometimes (%)	Mostly Yes (%)	Always (%)
Informational	Have you heard any information about other patients from personnel?	4.5	69 (76.7)	5 (5.6)	12 (13.3)	0.0 (0.0)	2 (2.2)
	Have your relatives been given any information about your child without your permission?	4.9	84 (93.3)	4 (4.4)	1 (1.1)	0.0 (0.0)	0.0 (0.0)
	Has confidential information about your child been disclosed during rounds (collective visits by physicians and students) by physicians or nurses?	3.6	44 (48.9)	5 (5.6)	17 (18.9)	9 (10)	12 (13.3)
	Has your permission been sought to disclose information to relatives?	1.15	81 (90.0)	6 (6.7)	0.0 (0.0)	0.0 (0.0)	2 (2.2)
	Has your permission been sought to disclose personal information when introducing your child?	1.89	59 (65.6)	4 (4.4)	8 (8.9)	3 (3.3)	12 (13.3)
	Has your permission been sought to disclose medical information when introducing your patient?	1.77	63 (70.0)	4 (4.4)	7 (7.8)	3 (3.3)	10 (11.1)
	Has your child's physician sought your permission to discuss pertinent medical information with other physicians?	1.94	58 (64.4)	6 (6.7)	10 (11.1)	2 (2.2)	13 (14.4)
Physical	Has hospitalization in a room with four or more beds affected the disclosure of information?	4.08	10 (11.1)	2 (2.2)	10 (11.1)	14 (15.6)	51 (56.7)
	Does your physician ask permission to enter the patient's room ?	1.24	74 (87.6)	5 (5.6)	3 (3.4)	1 (1.1)	2 (2.2)
	Do nurses ask permission to enter the patient's room?	1.11	73 (81.1)	1 (1.1)	2 (2.2)	0.0 (0.0)	1 (1.1)
	Before an examination, does your physician ask you or your child whether you would like a curtain or cover?	1.18	77 (85.6)	7 (7.8)	1 (1.1)	1 (1.1)	1 (1.1)
	Before an examination, do nurses ask you or your child whether you would like a curtain or cover?	1.18	68 (75.6)	4 (4.4)	1 (1.1)	0.0 (0.0)	2 (2.2)
	Is a curtain or cover normally used during examinations?	1.33	73 (81.1)	10 (11.1)	2 (2.2)	0.0 (0.0)	4 (4.4)
	During examinations, are areas of the body other than the examination area covered?	4.28	10 (11.1)	2 (2.2)	3 (3.3)	10 (11.1)	62 (68.9)
	In your opinion, is the room large enough to accommodate the number of beds?	1.70	63 (70.0)	13 (14.4)	1 (1.1)	4 (4.4)	9 (10.0)

tory in English and using medical terminology, and conducting the case interpretation and assessment in separate rooms and in the absence of the child's parents/guardians. The aforementioned factors may ensure better observance of privacy of patient information. Studies conducted in India clearly showed that privacy was poorer in public medical centers than private medical centers (23). A study of teaching hospitals in Nepal also showed that lack of patient privacy was a problem in these hospitals. The same study also showed that privacy and confidentiality were a major concern for people, especially younger patients. There are similar concerns about patient privacy and confidentiality in South-East Asia and the Middle East, but no

studies have been conducted in this area (24).

According to a 1989 study of adults' perceptions of privacy in terms of physician-patient relationships based on the Burgeon model, despite the importance of social, psychological, and physical privacy, the majority of studies on privacy and confidentiality were simply based on answers derived from anonymous questionnaires (25). Some were based on more comprehensive data obtained from focus group discussions with adolescent groups. They highlighted the need for changes in communication, such as obtaining permission to talk about sensitive issues, describing the importance of personal questions asked, and increased privacy in physical examinations of adolescents

in the course of clinical care (25). Interviews with patients in a qualitative study conducted in an outpatient clinic in Egypt showed that privacy in consultation rooms was considered unsatisfactory (26). In a study conducted in a general hospital in Italy, physical privacy was better observed during physicians' and nurses' interactions with patients than informational and verbal communication privacy (27). The results of the present study differed from those obtained in the Italian study because the types of questions and settings were different. The present study was conducted in teaching hospitals with multiple-bed rooms and a huge amount of movement, leading to doors being left open, and no one knocking or asking permission to enter. Furthermore, the numbers of patients in these rooms exceeded their capacity, and the beds had no curtains for examination purposes. In addition, it is not general practice in those hospitals to obtain permission or consult the child or child's parents about using a cover during an examination because the clinical teams have received no training in these areas. In the present study, other than the lack of training, another noteworthy point was that the clinical team did not feel obliged to use curtains or obtain the permission of the children or the parents/guardians due to the children's ages and their perceptions of privacy. However, in the present study, except for the examination area, other areas of the body were adequately covered in 68% of cases.

Judgment about the level of observing the various dimensions of privacy in hospitals should be reserved until patients are asked a range of questions relating to privacy, and each answer is assessed and compared in clinical emergency or nonemergency situations (similar to other countries). Conclusions can then be drawn about observance of the different dimensions of privacy. In a study conducted in emergency departments of selected hospitals of Tehran University of Medical Sciences in 2007, 50% of participants expressed poor satisfaction with the observance of physical privacy (1), which agrees with the results of the present study and disagrees with the findings of the Italian study (27). It seems that maintaining privacy in emergency departments is much more difficult due to the urgent nature of the patient's condition and movements by family members. The agreement between the results of the present study and those obtained in emergency department of Tehran university hospitals is incidental and cannot be interpreted. Furthermore, the findings cannot be directly compared with those of the Italian study because the latter was conducted in internal medicine and surgery departments.

A study in the pediatrics department of Liverpool hospital in London, U.K. showed that reports by the medical team in the morning rounds to parents about their

child's condition were overheard in 86% of cases (11). In another study investigating the bedside presence of relatives during training rounds, 100% of relatives preferred to be present during rounds (28). In the present study, information was mostly disclosed by parents' conversations (52.2%) and patients during rounds (30%), which was very different from the results of the U.K. study. In a study conducted in Birmingham Hospital in 1998, 300 parents of children aged 3 mo to 16 years who were hospitalized for a minimum of 36 hours were asked about privacy, dignity, and confidentiality experienced during their hospital stays (29), and the results of various aspects of privacy were assessed according to the number of beds per room. In that study, 90% of the participants were < 5 y, and 96% of parents overheard private information on three or more issues in the ward or through contact with other parents in rooms with four beds. The figure was 88% in rooms with two beds, and none in single rooms. Furthermore, 86% of parents revealed that ward rounds were the source of over-hearing information.

In the present study, questions about physical privacy were associated with nurses requesting permission before entering a patient's room. According to the responses, this did not happen in rooms with four beds, and it occurred in only 22% of cases in single rooms. In the present study, permission to enter a patient's room was not requested in 81.1% of cases. With regard to decision-making privacy, the question asked was "Was permission to share information about your child with other relatives obtained from you?" The results showed that decision-making privacy was observed in 65% of single rooms, 30% of two-bed rooms, and 22% of four-bed rooms. In the present study, considering that the mean number of beds per room was 6 ± 2 , 90% of parents answered "never" to this question, which showed a significant difference between the two studies. With regard to the question: "Are other areas covered during the examination?" this was observed in 50% of cases in rooms with two beds and 40% of cases in rooms with four beds. In the present study, this was "always" observed in 68.9% of cases. Due to the difference in the numbers of beds in the rooms in the Birmingham hospital study (two and four) vs. those in the present study (a mean of 6 ± 2), the results of the two studies cannot be compared. However, the observance of physical privacy in Iran seems to be appropriate compared to that reported in the Birmingham Hospital study.

5.1. Conclusion

The results of the present study suggested that privacy was poorly to relatively well respected in teaching hospitals. However, the level of observance of the physical dimension of privacy was particularly poor. Thus, the pri-

vacuity of a sick child in teaching hospitals was relatively less respected but that the autonomy and physical privacy of older sick children was relatively well respected. The privacy of children can be better observed through a series of strategies. These include the development of guidelines on observing various dimensions of privacy in pediatric wards of teaching hospital and the development of a patient's rights charter to make them aware of their rights in hospitals and in clinical relationships with physicians and the clinical team. In addition, training is needed to teach physicians and clinical teams how to respect the privacy of children and establish appropriate relationships with patients, as well as strengthen supervision of managers in relation to clinical ethics. Furthermore, parents should be briefed about nondisclosure of patients' information, and patients' records should be discussed and interpreted away from the patient's bedside (i.e., in designated rooms) rather than during rounds. Resolving problems in teaching hospitals, such as a lack of adequate space and equipment and staff shortages on wards, may be helpful in establishing clinical relationships that employ basic principles of medical ethics, which will lead to improved quality of care and increased patient satisfaction.

The limitations of the present study included the non-cooperation of some of the hospitals in sampling and the noncooperation of some relatives who accompanied the patients in completing the questionnaires for various reasons. In addition, the patients' answers probably did not reflect their true feelings, especially regarding unpleasant experiences, for many reasons. Given the small number of studies in this area in other countries and in Iran, further studies are required.

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Footnote

Authors' Contribution: Mina Foroozadeh: contributed to the conception of the study, participated in conducting the study, revised the draft, approved the final version of the manuscript, and agreed to all aspects of the study; Mehrzad Kiani: contributed to the conception of the study, approved the final version of the manuscript, and agreed to all aspects of the study; Leila Afshar: contributed to the conception of the study, approved the final version of the

manuscript, and agreed to all aspects of the study; Shabnam Bazmi: contributed to the conception of the study, participated in conducting the study, revised the draft, approved the final version of the manuscript, and agreed to all aspects of the study.

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