# Patient involvement in quality management of healthcare services

Envolvimento dos pacientes no gerenciamento da qualidade dos serviços de saúde

Ana Maria Saut<sup>1</sup> Fernando Tobal Berssaneti<sup>1</sup>

#### **Keywords**

Quality of health care; Quality improvement; Patients; Quality management; Health managment

#### **Descritores**

Qualidade da assistência à saúde; Melhoria de qualidade; Pacientes; Gestão da qualidade; Gestão em saúde

### **Submitted**

July 28, 2016

## Accepted

November 27, 2016

### **Corresponding author**

Ana Maria Saut Prof. Almeida Prado Avenue, Cross 2, 128, 05508-900, São Paulo, SP, Brazil. ana.saut@usp.br

#### DOI

http://dx.doi.org/10.1590/1982-0194201600080



## **Abstract**

**Objective:** To identify the stage of patient involvement in quality and safety improvement programs in Brazilian healthcare institutions.

**Methods**: A quantitative approach with 141 institutions located in 18 states and the Federal District, using an assessment survey from February to May of 2016. Data collection occurred via a questionnaire on the Web, using the SurveyMonkeyÒ online survey & questionnaire software. The questionnaire included questions to characterize the institutions and respondents, and seven questions related to the participation of patients in the quality management process.

Results: The activities performed by most of the institutions were "patient satisfaction surveys" and "formal process for communication with patients regarding their questions, suggestions and complaints". The mean number of activities performed was 3.84 out of the seven activities evaluated.

**Conclusion:** Assuming a scale from 0 to 3, approximately 70% of the institutions were classified between stage 0 (patient is not involved) and 1 (participation in evaluation of the quality goals).

#### Resumo

**Objetivo:** Identificar o estágio de envolvimento dos pacientes nas Instituições de saúde brasileiras, nos programas de melhoria da qualidade e segurança.

**Métodos**: Abordagem quantitativa, através de uma pesquisa de avaliação com 141 Instituições, localizadas em 18 estados e no Distrito Federal, no período de fevereiro a maio de 2016. Para coleta dos dados foi aplicado um questionário pela web, utilizando o *software* de questionários e pesquisas *SurveyMonkeyÒ*. No questionário, além das perguntas para caracterização das Instituições e dos respondentes, sete perguntas foram relacionadas às atividades de participação dos pacientes nos processos de gerenciamento da qualidade. **Resultados**: As atividades realizadas pela maior parte das Instituições foram 'pesquisa de satisfação dos pacientes' e 'processo formal para comunicação com os pacientes em relação às suas dúvidas, sugestões e reclamações'. A média de atividades realizadas foi de 3,84 de um total de 7 atividades avaliadas.

Conclusão: Considerando uma escala de 0 a 3, aproximadamente 70% das Instituições foram classificadas entre os estágios 0 (paciente não é envolvido) e 1 (participação na avaliação das metas de qualidade).

**Conflicts of interest:** there are no conflicts of interest to declare.

<sup>&</sup>lt;sup>1</sup>Universidade de São Paulo, São Paulo, SP, Brazil.

# Introduction

Since "To Err is Human", published in 1999 by the Institute of Medicine of the United States of America, there has been a growing concern over the issue of patient safety. The scope of the patient safety movement has expanded, and among the new dimensions highlighted is 'patient involvement'. (1)

In a recent discussion on the progress of this issue, a patient-as-partner approach was proposed, which enhances participation from the patient-centered approach, especially for the treatment of chronic diseases. (2) The patient can participate in certain stages of the care process, effectively contributing to a better result. Among these stages are the learning practices, evaluation, and adaptation. (3) The patient is now admitted as an active agent in the health care process. (3)

The subject of patient involvement has been addressed in different ways, both conceptually, as well as in terminology. One approach is the discussion on the subject from three observed trends. The first is considered to be low impact, the emergence of small groups of patients advocating for safety, often led by patients or family members who had a personal experience with medical errors. The second trend, however, whose effectiveness remains unproven, is known as "What can patients do to prevent medical errors?". And finally, the third is the increase in the disclosure of major errors (*error disclosure*). (1)

Additionally, some European studies have discussed the involvement of patients as participants in quality management of the healthcare services. (4-6) Along this line of research, four development stages were proposed and evaluated: "stage 0 - patient is not involved"; "stage 1 - assessment of the quality goals"; "stage 2 - development of quality criteria"; and "stage 3 - committees and improvement projects". (5,6)

A recent literature review demonstrated that, although the subject "patient involvement" is still considered a new and open subject for trials, the effort of involving patients has an important contribution to quality improvement. (4) This review (4) showed that the development of qual-

ity criteria appeared as an ad hoc function and related to the preparation of quality guidelines. During the planning and organization of the processes, patient involvement is typical for the lean style of work, but it is still poorly applied. Involvement in quality committees appears to be the most frequent activity, with regular and formal participation of the patients in the meetings. Research demonstrated positive results for participation in quality improvement projects, in which the patient extends beyond the study subject and is part of the project team. Regarding discussion of the results of the quality improvement projects, no articles were found, and this type of action can occur by participating in quality committees or may be accomplished through surveys. Research on patient involvement in Quality Improvement Committees, developed in Australia, showed that this approach provided good results, but it depended on a good selection and training of patients. (7)

The Brazilian Ordinance MS/GM No. 529/2013 defines, as a specific objective of the National Patient Safety Program, the involvement of patients and families in the process, among other objectives. In addition, the national accreditation program (ONA - Organização Nacional de Acreditação), the leading quality certification adopted by Brazilian hospitals (although this continues to have a low representation - about 5%) has, among its objectives, the involvement of patients.

The purpose of this study was to answer the research question: What is the stage of patient involvement in the quality management of Brazilian health institutions? The result will estimate the stage of development, identifying key actions for implementation, and comparing it to the results of similar surveys conducted in other countries. This was an exploratory study.

## **Methods**

This was a quantitative approach to evaluate the stage of patient involvement in quality management, from the perspective of assessment research

(survey). The questionnaire was developed according to a literature review and empirical research. (4-6,8,9) The survey was conducted via the Web, using the SurveyMonkey® online survey & questionnaire software.

The questionnaire contained, in addition to questions to characterize institutions and respondents, seven questions related to patient participation in quality management process activities: (1) assessment of the quality goals; (2) development of quality criteria; (3) participation in committees and improvement projects; (4) development of quality guidelines; (5) involvement of patient relatives; (6) patient satisfaction survey; and (7) formal process for communication with patients regarding their questions, suggestions and complaints. The questions 1 to 4 were taken from a research survey conducted in hospitals in the Netherlands, Hungary and Finland (6) and later only in Hungary. (5) Question 5 is derived from the literature review, in which family involvement appeared as a trend. (1) Questions 6 and 7 resulted from the empirical research mentioned, (5,6) but were not in the group "patient involvement"; in addition, these questions appeared in the model of excellence of the European Foundation for Quality Management (EFQM) and in the ISO 9001 quality standard.

Based on previous studies, <sup>(5,6)</sup> a four-point scale were used for responses: (1) do not know/not applicable; (2) no; (3) partially (i.e., yes, but is not fully operationalized); and (4) yes.

A feature of the SurveyMonkey® software was used in the application of the questionnaire, which randomized the questions, that is, the order of questions within each group was not the same for all respondents. Additionally, the system was parameterized, namely, the questionnaire could not be finalized without answering all of the "must answer" questions, to prevent loss of data.

A convenience sample was used for data collection. Since a complete list with all contacts in the country was not available, participants were identified using the internet, personal contacts, and using local associations. Furthermore,

the researchers were supported by the National Accreditation Organization (ONA), which sent an invitation to all institutions registered in its database, both accredited and non-accredited. The questionnaire was directed toward the quality management area, preferably, or the administrative area. Respondents could involve other people, but only one answer per institution was requested. The sample was not probabilistic, but considered to be one of convenience, mainly due to the possibility of using a questionnaire.

The classification of the Institutions, at first, occurred based on four quality development stages, considering that the level of activity selected should be implemented, as well as most of the activities of the previous levels. (5,6) In this classification, the 'yes' answers were accepted, that is, when the activity is present and fully operationalized. In addition, the classification was performed considering two intermediate stages, contemplating three new issues in which questions 6 and 7 were evaluated together. According to the responses, the institutions were classified among the original stages 0 and 1; and question 5 was considered an evolution of stage 3. The Spearman correlation analysis, assuming a confidence level of 95%, was performed, between the sum of answers "yes" to all questions, and the institutional characteristics variables; the existence of a Quality Department (yes or no); size of the institution (small, medium, large, or extra capacity hospital, or not applicable/other type of establishment); and type of management (private or public). Correlation analysis was performed using the Statistical Package for the Social Sciences (SPSS) statistical software, version 17.0.2 (March 11th, 2009).

The questionnaire was administered from February to May of 2016. The project was approved by the Research Ethics Committee of the Faculty of Medicine, USP (CAEE 51230715.1.0000.0065 / Protocol Number 1540061), before the data collection phase. According to Resolution 196/96 of the National Health Council, which deals with ethical aspects of research involving human subjects, the partic-

ipants were informed about the objective, justification and study purposes. Finally, the participants signed the Terms of Free and Informed Consent Form.

## **Results**

A total of 161 responses were received, and 141 were complete and considered valid. Among the 20 invalid questionnaires, 12 were excluded due to lack of completeness, five due to duplication, and three due to presenting incomplete or unclear answers regarding the respondent and/or institution (e.g., using only a number or letter).

Institutions of 18 Brazilian states and the Federal District participated in the research, encompassing all regions of Brazil. Most of the institutions were located in the southeast (56.74%), south (21.99%) and northeast (10.74%) regions of the country. The states with the highest participation were: São Paulo (48 participants), Minas Gerais (23 participants), Santa Catarina (15 participants), Rio Grande do Sul (10 participants) and Bahia (eight participants). Regarding the distribution by cities, considering the valid responses, the research was administered in 68 municipalities; half of the responses were from institutions located in the capital cities, and the other half from states within the municipalities. The response rate was 17.67%.

In the classification by type of establishment, 74.47% were hospitals; 76 (53.90% of the 141) were general hospitals and 29 (20.57% of the 141) were specialty hospitals. It was found that 83.5% of hospitals were of medium (50-149 beds) or large (150 to 500 beds) size. According to the administration, most of the institutions were part of the private sector (67.38%).

Regarding the organizational structure dedicated to quality management, 117 institutions (82.98%) reported having a quality service, with 75% of these implemented for more than three years. Of the total, 99 institutions (70.21%) had at least one accreditation, 85 were accredited by the national program (ONA), four by Joint

Commission International (JCI) and ten by national - ONA and international (JCI or Canadian Council on Health Services Accreditation - CCHSA).

The sample was composed mainly of professionals in leadership or managerial positions, corresponding to 80.85% of the respondents. Most of the participants were female (81.56%) and mean age was 40 years. As for education, 87.94% had a graduate degree. The mean length of time of respondents in their current position was 6.3 years, and the time they had worked in the institution was, on average, 9.6 years. The length of experience after graduation, for 75% of respondents, was at least ten years.

Table 1 presents the descriptive analysis of the results. Among the seven activities evaluated with the objective of involving patients in quality management, the most common activities were: patient satisfaction survey (86.33%), and formal process for communication with patients regarding their doubts, suggestions and complaints (84.17%). The other evaluated activities (questions 1 to 5) had a lower percentage of implementation, but without evidence of significant difference between the percentages obtained from implementation for these activities, with 95% confidence level. The mean number of activities was 3.84, among seven activities evaluated.

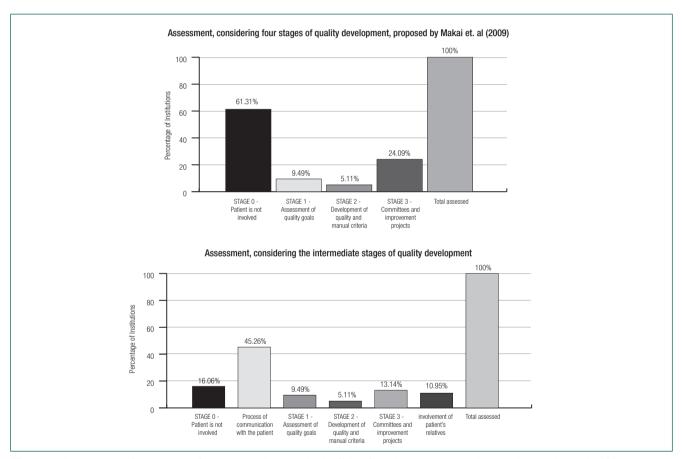
In the 'other' field of the questionnaire, respondents reported that, in addition to the assessed issues, also currently performed were: disclosure (in case of major events); availability of a communication process between the accrediting institutions and patients; use of information boards on the beds (points that indicated warnings about where the patient needed attention); and providing a "Patient's Guide".

Figure 1 presents the classification of the assessed institutions, according to two criteria: four stages of quality development versus intermediate stages (proposed by the authors). Considering the four stages, most of the institutions can be classified as stage 0 - Patient is not involved. However, if an intermediate stage "communication with the patient" (questions 6 and 7) is

**Table 1.** Descriptive analysis of the questions related to patient involvement

Activities	Total		Total	
	n	No (%)	Partial (%)	Yes (%)
1. Assessment of quality goals	137	43.07 [34.78;51.36]	18.25 [11.78; 24.72]	38.69 [30.53; 46.85]
2. Development of quality criteria	138	36.23 [28.21; 44.25]	16.67 [10.45; 22.89]	47.10 [38.77; 55.43]
3. Participation in committees and improvement projects	138	48.55 [40.21; 56.89]	10.87 [5.68; 16.06]	40.58 [32.39; 48.77]
4. Development of quality guidelines	139	40.29 [32.14; 48.44]	16.55 [10.37; 22.73]	43.17 [34.94; 51.40]
5. Involvement of patient relatives	132	20.45 [13.57; 27.33]	29.55 [21.77; 37.33]	50.00 [41.47; 58.53]
6. Patient satisfaction survey	139	0.72 [0.00; 2.13]	12.95 [7.37; 18.53]	86.33 [80.62; 92.04]
7. Formal process for communication	139	2.88 [0.10; 5.66]	12.95 [7.37; 18.53]	84.17 [78.10; 90.24]
Mean of activities by institution				
"Yes" answers	3.84 (of seven) (Standard deviation: 2.05)			
"Yes" and "Partial" answers	4.99 (of seven) (Standard deviation: 1.91)			

n - Number of valid responses, i.e., equal to the total (141) minus the "not known/not applicable" responses; Confidence interval with  $\alpha = 0.05$ 



**Figure 1.** Assessment of the stages of quality development in the field of "patient involvement", according to the scale of literature versus intermediate stages (n = 141)

considered, one can see that 45.26% of the institutions perform these activities and may have a source of patient information to continuously improve its processes. The institutions classified in the stage of "involvement of patient relatives" (10.95%) were those that performed the seven evaluated activities. It is noted that this remains a very small percentage.

An evidence of a statistically significant relationship, however weak, with 95% confidence existed in the correlation analysis (Table 2), between the results of the assessment of patient involvement and the existence of a quality service in the institution. In addition, the impact of the type of administration and its capacity was measured, demonstrating that no evidence of a statistically significant rela-

**Table 2.** Correlation analysis between patient engagement activities and institutional profiles ( $\alpha = 0.05$ )

Variable	Spearman's correlation analysis		
variable	Correlation coefficient	p-value	
Has a quality service (yes or no)	0.260	0.002	
Capacity (small, medium, large, extra capacity hospital or not applicable/other type of establishment)	0.152	0.072	
Type of facility (private or public)	0.035	0.679	

tionship existed, with 95% confidence, between the assessment of patient involvement results and these variables.

## **Discussion**

The main limitation of this study was the use of a non-probability sample and, therefore, the generalizability of results should be performed with caution. The simple translation of the instrument, without performing a cross-cultural adaptation and conducting a validation stage, before application, is highlighted as a limitation of this study. Other limitations included the subjectivity inherent in the method, and the establishment of one participant per institution. However, on this last aspect, the accuracy of the internal approval process involving several services (Administration, Education and Research area, and Ethics Committee) and the formalization of approving participation by signing the informed consent form reduced the impact of this limitation, and demonstrated that the person indicated from each institution to respond to the questionnaire was qualified for such activity. In addition, the profile of the respondents is evidence of their qualifications and experience. Moreover, in some cases, the respondents reported that they involved other people in the institution to respond to the questionnaire.

The contribution of the study was to identify that patient participation is still at an early stage, with little or no involvement of *patients*. On the other hand, some institutions, although with low representation in the sample (10.95%), showed that they were already in advanced stages and could serve as a reference for other institu-

tions, and for research on the subject. Another important aspect is that these results were not influenced by the existence of an organizational structure of quality management, the type of administration, or organization capacity/size. The lack of evidence of correlation between these variables may be related to the fact that the number of institutions with the implemented activities is still at an early stage, which therefore does not allow further analysis.

With the addition of two questions about communication with patients (formal communication process with patients and a satisfaction survey) in the questionnaire, an evolution of the institutions that initially were classified in stage "0" by the criterion proposed in the literature was observed. (3) Establishing a formal communication process with patients may be the first stage to receiving feedback and having an information base for promoting improvements in internal processes and support for strategic planning. These two activities characterize one of the mechanisms, referred to as "voice" in research conducted in Europe, applied to engage the patient to establish communication with health service providers. The customer satisfaction survey is used in several countries, for example in Denmark, England, Poland and Slovenia; in some cases the surveys are conducted at national level. (10-12)

The result of the stage of patient involvement in this study was similar to research conducted in Europe<sup>(4-6)</sup> and the United States.<sup>(8)</sup> In a research conducted with 102 hospitals in Austria, patient participation was treated as a subject within the quality activities, and it was observed that the obtained percentages were also low for the evaluated activities.<sup>(5)</sup>

In a more recent study, conducted with seven European countries, the average of the hospitals was found to be between stages 0 and 1.<sup>(13)</sup> The researchers concluded there was an absence of and/or large variations in the relationship between the institutionalization of quality management systems and the strategies to engage patients in the management of quality strategies programs. These strategies aim to improve care centered on the patient in the hospitals.

# Conclusion

This study identified that the stage of patient involvement in quality programs remains low in Brazilian hospitals, and can be considered to be in an early stage. Only 10.95% of the institutions fulfill the seven questions assessed. These results show that this subject in Brazil is still in development, similar to results found in studies conducted in the United States and Europe, in recent years. Two activities were found to be strengths, and were performed by more than 80% of institutions for patient involvement in quality management processes: the customer satisfaction survey, and the existence of a formal process of communication with patients regarding their doubts, suggestions and complaints. The inclusion of these questions in the questionnaire allowed us to observe that some institutions obtain information from their patients, which enables them to make improvements in their processes and to evaluate their projects. Therefore, these institutions are not considered to be at Stage 0, in which the patient is not involved.

## **Acknowledgements**

We thank the health institutions, the National Accreditation Organization (ONA- Organização Nacional de Acreditação), and the Higher Education Personnel Improvement Coordination (Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES); master's scholarship for Ana Maria Saut).

## **Collaborations**

Saut AM and Berssaneti FT contributed to the study design, analysis and data interpretation, article writing, relevant critical review of the intellectual content, and final approval of the version to be published.

# References

- 1. Wachter RM. Patient safety at ten: Unmistakable progress, troubling gaps. Health Aff. 2010; 29(1):165-73.
- Karazivan P, Dumez V, Flora L, Pomey M-P, Del Grande C, Ghadiri DP, et al. The patient-as-partner approach in health care. Acad Med. 2015; 90(4):437-41.
- Pomey M-P, Ghadiri DP, Karazivan P, Fernandez N, Clavel N. Patients as partners: a qualitative study of patients' engagement in their health care. PLoS One. 2015; 10(4):19.
- Groene O, Sunol R. Patient involvement in quality management: rationale and current status. J Health Organ Manag. 2015;29(5):556-69.
- 5. Makai P, Klazinga N, Wagner C, Boncz I, Gulacsi L. Quality management and patient safety: Survey results from 102 Hungarian hospitals. Health Policy (New York). 2009;90(2-3):175-80.
- Wagner C, Gulácsi L, Takacs E, Outinen M. The implementation of quality management systems in hospitals: a comparison between three countries. BMC Health Serv Res. 2006; 6(1):50.
- Pomey M-P, Hihat H, Khalifa M, Lebel P. Patient partnership in quality improvement of healthcare services: Patients' inputs and challenges faced. Patient Exp J. 2015; 2(1):29-42.
- 8. Han E, Scholle SH, Morton S, Bechtel C, Kessler R. Survey shows that fewer than a third of patient-centered medical home practices engage patients in quality improvement. Health Aff. 2013; 32(2):368-75.
- European Foundation for Quality Management. Introducing the EFQM excellence model [Internet]. 2010 [cited 2013 Jan 13]. Available from: www.efqm.orgen/PdfResources/EFQMModel\_ Presentation.pdf.
- Pestana MH, Gagieiro JN. Análise de dados para Ciências Sociais A complementariedade do SPSS. 5th ed. Lisboa: Edições Sílabo; 2008. 692 p.
- 11. Vrangbaek K. Patient involvement in Danish health care. J Health Organ Manag. 2015; 29(5):611-24.
- 12. Lichon M, Kavcic M, Masterson D. A comparative study of contemporary user involvement within healthcare systems across England, Poland and Slovenia. J Health Organ Manag. 2015; 29(5):625-36.
- Groene O, Arah OA, Klazinga NS, Wagner C, Bartels PD, Kristensen S, et al. Patient Experience shows little relationship with hospital quality management strategies. PLoS One. 2015; 10(7):e0131805.