BMJ Open

# How do hospitals engage patients and family members in quality management? A grounded theory study of hospitals in Brazil

Ana Maria Saut , Fernando Tobal Berssaneti, Linda Lee Ho, Simone Berger

**To cite:** Saut AM, Berssaneti FT, Ho LL, *et al*. How do hospitals engage patients and family members in quality management? A grounded theory study of hospitals in Brazil. *BMJ Open* 2022;**12**:e055926. doi:10.1136/bmjopen-2021-055926

► Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2021-055926).

Received 28 July 2021
Accepted 20 July 2022



Polytechnic School, Production Engineering Department, University of Sao Paulo, Sao Paulo, Brazil

**Correspondence to**
Dr Ana Maria Saut;
ana.saut@usp.br

## ABSTRACT

**Background** Patient and family engagement (PFE) is considered an essential element of the transformation of the healthcare system. However, it is characterised by its complexity and a small number of institutions that have implemented the mechanisms of engagement.

**Objective** To understand PFE in quality management (QM) in the hospital environment.

**Design** A qualitative approach was guided by the grounded theory based in Straussian perspective. Data were gathered using semistructured interviews. The coding was performed by excerpts, using an inductive approach and the constant comparison technique.

**Setting and participants** A total of seven Brazilian hospitals were selected based on the theoretical sampling technique.

**Results** A total of five categories emerged, namely: patient partner, mechanisms of engagement, internal structure for engagement, maturity of the QM system and openness to change. Externally, three contextual factors can impact the engagement: the local health system, the profile of the community and the change in access to the information. At the centre of the change is the balance in power relations between patients and professionals, the sharing of information from the hospital and a proactive attitude towards improving services.

**Conclusions** The PFE involves a cultural and process change. Cultural change is represented by 'openness', that is, openness to learn, to listen and to consider new perspectives. The change in processes is in turn characterised by the phrase 'test and venture' because the model to be adopted may be different between hospitals. The patient's perspective allows actions to be driven towards what really matters to them, ensuring quality of service and safety, obtaining a new perspective to understand and solve problems, and stimulating a sense of urgency, more empathy and compassion in professionals.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ The hospitals were selected based on the theoretical sampling technique.
⇒ All respondents behaved in an open and safe way to discuss issues of power and culture, so the investigation did not remain at the superficial levels.
⇒ The use of grounded theory allowed to achieve a broad, novel and original finding.
⇒ No institutions were found to have the level of engagement known as 'partnership and shared leadership', which restricted the observation of the patients and family members' coleadership practices.
⇒ A limitation to the study was the sample restricted to hospitals located in Brazil and only one participant per hospital.

## INTRODUCTION

Berwick describes three eras in the evolution of quality in healthcare: Era 1 of 'professional heroism'. Era 2 is characterised by accountability, payment by performance and measurement. Era 3 emphasises the importance of the science of improvement, and the active voice of patients and community, in addition to reduce the complexity of incentives.[1] Rethinking health as a coproduced service with patient participation adds depth to the understanding of how to design and create better services, to improve them and ultimately to increase its contribution to improve health.[2]

Patients and family members (P/F) have perceptions based on their experiences of care through the health system, from a perspective that only they can have as users of the system.[3] This reasoning establishes patients as 'specialists by experience'.[4] Patient and family engagement (PFE) can catalyse quality improvement through 'influential histories', 'different perspectives' or 'experiential knowledge'.[5]

PFE is considered an essential element of the transformation of the healthcare system.[6] Although there is recognition of the importance of PFE to improve the quality and safety of healthcare services, a fairly low number of institutions has implemented the mechanisms to engage them.[7–9] There is uncertainty about the best way to work with P/F to improve quality.[5 10 11] This uncertainty was

considered as one of the greatest challenges to establish a partnership with patients,[5] intensified by the fact that there is few studies referring to the hospital context.[10] In Brazil, this theme is still little explored, and caution must be exercised when considering theoretical models developed in other regions, as regional factors of the external context may exert an influence. PFE is characterised by its complexity and difficulty in demonstrating the obtained results.[10 12–14]

In addition, knowledge gaps in this field of research could be mentioned as the theoretical limitation as the studies do not address the forms of power and capital that occur in the relationships between the professionals and patients in the engagement process.[15]

In summary, this research is guided, on the one hand, by the context of recognising the pressing need for PFE in the quality management (QM) system as an important strategy to improve the service and, on the other hand, the knowledge gaps. Based on these, the objective is to understand PFE in QM in the hospital environment.

## METHODS

This study was based on the grounded theory methodology based on Straussian perspective,[16] which is a theoretical framework for understanding the interactions between patients and healthcare professionals.

Throughout this research, the term 'family' was used to represent those whom the patient chooses to call, those they trust and with whom they have a good relationship.[17 18] In addition, QM encompasses the three basic management processes described by Juran: quality planning, control and improvement.[19]

### Setting

According to the Brazilian National Register of Health Establishments, in March 2021, there were around 7000 hospitals (426 000 beds) in the country. Of these, 38% are public with 165 000 beds (39% of total), 36% are private with 99 000 beds (23%) and 26% non-profit with 161 000 beds (38%). Approximately 5% have at least one accreditation and most are accredited by the National Accreditation Organization. Most non-accredited institutions have not implemented the standardisation of processes and indicators for process management.[20]

The Brazilian constitution establishes that health is a right of all and a duty of the Government. One of the basic principles of the healthcare system is participatory management involving the community. However, a survey carried out with healthcare institutions in Brazil showed that participation still occurs at the 'consultation' engagement level and the mechanisms of 'involvement' level can be further explored.[20]

### Theoretical sampling and data collection

To support the selection of hospitals, the institutions were previously invited to answer a questionnaire containing questions about their profile, organisational culture,[19] QM activities and mechanisms of PFE.[6 9 10 21–24] Based on this questionnaire, it was possible to identify the level of PFE ('consultation', 'involvement' or 'partnership and shared leadership')[21 23] of each hospital. There was also a question about the respondents' interest in participating in the interview. Additionally, it was gathered information about the hospital profile on the institutional website.

A total of seven hospitals were selected based on the theoretical sampling technique (see table 1). The sample was considered sufficient when most categories showed specificity, were dense in terms of their properties, showed variation in size and were well integrated.[16] To allow the theoretical sampling, the interviews were analysed soon after their completion using the constant comparison technique. Table 1 shows that, in hospitals H6 and H7, no new concepts were identified (column 3) and, consequently, no new questions arose (column 4).

In the hospitals, the criteria for inclusion/selection of professionals considered their participation in planning or managing the QM system of the selected institutions. As an inclusion criterion, in addition to the professional's function, a minimum time of 6 months in the current position was considered. The seven professionals interviewed (one representative per hospital) were appointed by the administration and/or research and teaching department of the institution during the first contact made with the institution to invite them to participate. It is noteworthy that all participants were from the QM or related areas, had a postgraduate-level qualification (two of them have concluded a specialisation course, three with a master degree and two with a PhD), and professional experience of at least eleven years. Concerning the professionals gradutation, four of them are nursing (H1, H2, H5 and H7) and three are physicians (H3, H4 and H6).

Data were gathered using semistructured interviews, following a guide developed in accordance with the study aim, literature review[25 26] and new questions that emerged during the data analysis (table 1—column 4). The interviews were conducted between October and December 2019, with an average duration of 60 min. They were recorded, transcribed and sent to respondents for validation.

### Data analysis

Data collection was followed by analysis, using a circular process: analysis led to concepts, concepts generate questions and questions lead to more data collection. For instance, the question 'What is the difference in the QM processes in the Head Office (located in a large city) and in a Unit (located in a small city)?' that emerged during the analysis of the interview performed in H2 led the selection of H3 (see table 1).

NVivo V.12 software was used to assist the data analysis. The first step of analysis was a complete reading of the interview. After reading, the coding was performed by excerpts, using an inductive approach and the constant comparison technique. The results of the analysis were

**Table 1** Theoretical sampling

| # | Selection criteria and main characteristics considered | Findings | Emerging questions for the next interviews |
|---|---|---|---|
| H1<br>Purposeful sampling | ► Transition between 'involvement' and 'partnership and shared leadership' levels<br>► Private sector<br>► General hospital | 21 concepts emerged from the data | How can the historical of foundation and/or the culture of founders impact the QM system?<br>What is the impact of the profile of the community served and the relationship with it?<br>Why do the hospitals decide to implement different mechanisms? |
| H2<br>Purposeful sampling | ► 'Consultation' level<br>► Philanthropic sector<br>► General hospital | 9 existing concepts<br>9 new concepts emerged | What is the difference in the QM processes in the head office (located in a large city) and in a unit (located in a small city) considering the<br>► Decision-making process<br>► Relationship with the community<br>To explore the use of the terms 'customer' and/or 'consumer' to refer to patients.<br>To understand the importance of financial resources in the PFE process. |
| H3<br>Selected to discuss the questions that emerged | ► Located in a small city (<10 000 citizens)<br>► Organisational culture: Clan<br>► Small size | 9 existing concepts<br>5 new concepts emerged | What is the relationship between P/F engagement and<br>► The size of the city?<br>► The relationship with the community?<br>What is the influence of the patient's length of stay or the intensity of contact for the engagement of patients treated in general (non-chronic) services? |
| H4<br>Selected to discuss the questions that emerged | ► Private sector | 9 existing concepts<br>2 new concepts emerged | What is the relationship between the use of different mechanisms and<br>► The objectives of their implementation?<br>► The maturity of the institution? |
| H5<br>Selected to discuss the questions that emerged | ► 'Involvement' level | 12 existing concepts<br>1 new concept emerged | What is the meaning of the maturity of the QM system?<br>To deep the discussion on what is the patient 'consumer'. |
| H6<br>Selected to discuss the questions that emerged | ► Public sector<br>► University hospital | 9 existing concepts | No new questions emerged. |
| H7<br>Purposeful sampling | ► Specialised hospital—maternity | 9 existing concepts | No new questions emerged. |

Source: The authors.
P/F, patient and family members; PFE, patient and family members engagement; QM, quality management.

registered in memos. Similar data were grouped under the same conceptual titles, using words to represent the meaning of the interpretation (concepts). The concepts vary according to the level of abstraction, from basic level concepts to the formation of categories and the integration around a core category. The relationships between the categories were represented in the theoretical diagram.[16]

## Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

## RESULTS

The objective of theoretical sampling was looking for hospitals to sample that will demonstrate different properties of concepts and show variation in the PFE. The final sample comprised private (H1 and H4), philanthropic (H2, H3 and H5) and public hospitals ((H6 ad H7). The dominant organisational culture was hierarchy (H1, H2, H4, H6 and H7) and clan (H3 and H5). Concerning the engagement level,[21 23] the hospitals were classified as consultation (H2, H3 and H7), involvement (H4, H5 and H6) and in transition between 'involvement' and 'partnership and shared leadership' levels (H1). The QM activities and mechanisms of engagement implemented by the participating hospitals are given in table 2.

**Table 2** Profile of selected hospitals regarding quality management activities and mechanisms of engagement implemented

| Activities | Hospitals | | | | | | |
|---|---|---|---|---|---|---|---|
| | H1 | H2 | H3 | H4 | H5 | H6 | H7 |
| Quality management activities | | | | | | | |
| 1. Definition of mission, vision and values | 3 | 3 | 3 | | 3 | 3 | 3 |
| 2. Strategic planning | 3 | 3 | 3 | | 3 | 2 | 2 |
| 3. Deployment and goal management | 3 | 3 | 3 | 2 | 3 | 2 | 2 |
| 4. Standardisation of processes | 3 | 3 | 2 | 2 | 3 | 2 | |
| 5. Definition and use of indicators for process management | 3 | 2 | 2 | 3 | 3 | 2 | |
| 6. Six Sigma improvement projects | 3 | | | | | | |
| 7. Application of Lean Service or Lean Healthcare methodology | 3 | 2 | 2 | 2 | 2 | | |
| 8. 5S Programme | 3 | 3 | 2 | | | | |
| Mechanisms of engagement | | | | | | | |
| 1. Surveys of patient satisfaction—carried out continuously | 3 | 3 | 3 | 3 | 3 | 2 | 3 |
| 2. Surveys or patient satisfaction—conducted annually, by sampling | 3 | 3 | | | 3 | 2 | 3 |
| 3. Survey of patient experience—carried out continuously | 3 | 3 | 3 | 1 | 1 | | |
| 4. Survey of patient experience—conducted annually, by sampling | 3 | 3 | | 1 | | | |
| 5. Ad hoc survey | 3 | | | | 2 | | |
| 6. Formal process of communication with patients regarding questions, suggestions, complaints and compliments | 3 | 3 | 3 | 3 | 3 | 3 | 3 |
| 7. Suggestion box | 3 | 3 | 3 | 3 | 3 | | 3 |
| 8. Interview with patients during root cause analysis of a problem | 2 | 2 | | 2 | 2 | | |
| 9. Panel or focus groups with patients (event to discuss an in-depth topic with selected participants) | 3 | | | 1 | 1 | 1 | |
| 10. Patient participation as a member of an improvement project team | 2 | | | | 2 | | |
| 11. Patient participation as a member of a research project team | 2 | | | | | | |
| 12. Patient participation as a member of the root cause analysis team | 1 | | | | | | |
| 13. Participation of the patient as a member of the quality or management committee of the hospital | 1 | | | 1 | | | |
| 14. Patient participation as a member of an advisory committee | 3 | | | 1 | 3 | 3 | |
| 15. Participation of the patient as a member of the Board of Administration | 1 | | | | | 3 | |
| 16. Patients share the leadership of safety and quality improvement committees | 1 | | | | | | |
| Patient participates in the elaboration of process standards, tasks or protocols | 2 | | | | 2 | | |
| 17. Patient participates in the development of booklets or other materials for communication with patients | 3 | | | | 2 | | |
| 18. Patients participate in the evaluation of quality goals and/or objectives | 1 | | | 2 | | | |
| 19. Patients participate in the development of quality criteria | 1 | | | | | | |
| 20. Patients participate in the development of content for training other patients | 1 | | | | 2 | | |
| 21. Patients participate as educators in the training of other patients | 1 | | | | 2 | | |
| 22. Patients participate in the development of the content for the training of professionals | 1 | | | | | | |
| 23. Patients participate as educators in the training of professionals | 1 | | | | | | |

1=In the structuring phase, but not yet implemented; 2=Implemented only on one or a few units; 3=Implemented.
H, hospital.

**Table 3** Categories and concepts emerged from data analysis

| Categories | | Concepts |
|---|---|---|
| Enablers of process and structure of PFE | Partner patient | Patient selection as a strategy to increase participation |
| | | The patient's feeling of ownership by the hospital facilitates their engagement |
| | | Importance of the patient's willingness and availability to participate |
| | | Change in the behaviour of the patient who becomes coresponsible for their care |
| | | The length of stay in the hospital interferes with the patient's experience |
| | | Difficulty in engaging family members |
| | Mechanisms of engagement | All actions begin with the direction of senior management |
| | | No direct relationship is observed between PFE activities in QM and accreditation programmes |
| | | The process is facilitated by targeting topics of common interest with the P/F |
| | | There are different levels and ways of engaging the P/F according to the objective and the context; the hospital needs to experiment |
| | | Unilateral communication brings information. On the other hand, dialogue allows the team to build the solution together with patients |
| | | Technology can improve communication because it increases the response/ participation rate and reduces the time for all interested parties to have access to information |
| | | Concept of PFE and how to do it are not clear |
| | | Involvement in actions to improve processes at the routine level is easier than at the strategic level |
| Enablers of success for effective PFE | Internal structure for P/F engagement | The culture of the institution and its founders has an impact on the structure of the QM programme |
| | | Think differently about how the patient can be a partner |
| | | The care model can direct the appreciation of interdisciplinary work and the appreciation of different perspectives, including professionals and patients |
| | | Within the institution, there are differences that can impact the level of PFE in QM |
| | | Lack of financial resources for improvements generates frustration in the team |
| | | Transparency of information about processes facilitates P/F participation |
| | Maturity of QM system | Accreditation and regional quality programmes assist in structuring the QM system |
| | | Change starts with a pilot and then expands to other areas |
| | | Quality programmes are reinvented |
| | | Having a person who can interact with different areas to implement the improvements facilitates the process; horizontal and wide action |
| | Openness to change | Engagement requires a cultural change of professionals and P/F, so it is a slow process |
| | | Power relationship between healthcare professionals and patients |
| | | Patient experience is of personal importance to professionals |
| | | Risks involved in the engagement process |
| Definition and contributions of PFE | | Quality is creating value for the patient |
| | | The patient experience is a source of information for improving quality |
| | | The contribution of PFE is to plan improvements considering the perspective of P/F |
| | | Generate more empathy and compassion in healthcare professionals |
| | | Quality and patient safety are treated together |
| | | Face-to-face participation of the P/F generates a sense of urgency and commitment to change |
| Contextual factors | | Patients and professionals are changing, so communication can no longer be one sided; change begins at 'home' (hospital) |
| | | Patient as customer |
| | | Culture of the region impacts the way of working and the relationship between professionals within the institution; collaboration |

Source: the authors.
P/F, patient and family members; PFE, patient and family members engagement; QM, quality management.

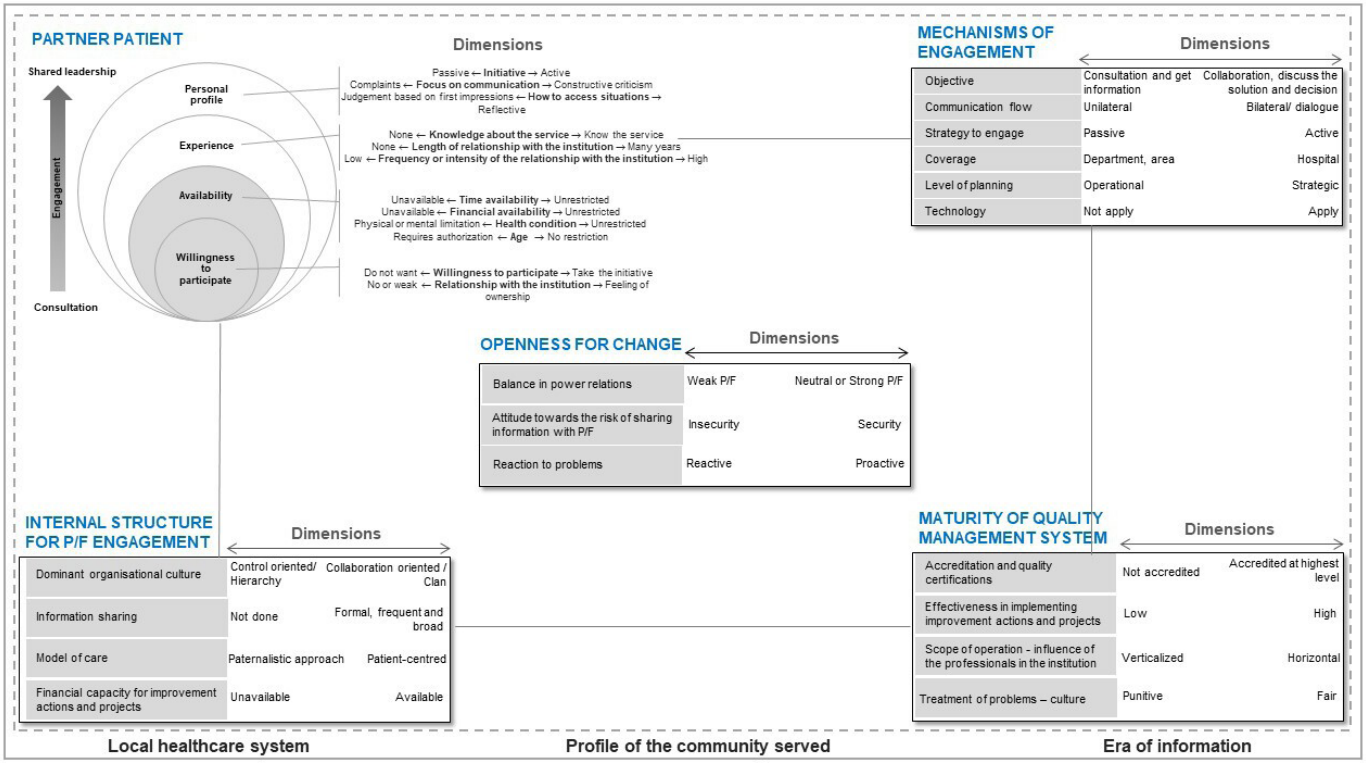


**Figure 1** Openness to cultural and process change: a theory based on the engagement of P/F in quality management. Source: the authors. Notes: categories are represented with rectangles within dotted lines. Contextual factors can be observed outside dotted lines. P/F, patient and family member.

The analysis identified a total of 37 concepts, with most classified at the basic level (see table 3). The concepts were grouped into five categories considering the interrelation between themes. The first category was named 'partner patient' that grouped all the concepts related to the patient, their profile, characteristics and requirements for participation. The second one 'mechanisms of engagement' addressed concepts related to planning and implementation of processes, methods, techniques and tools used to involve P/F. The other one was 'internal structure for PFE' grouped issues related to organisational aspects, both structural and financial. The fourth category addressed the issues of the maturity of the hospital QM system both to support engagement mechanisms and to enable the implementation of improvement actions. Finally, the last one was named 'openness to change' and it was about cultural and human issues. In addition, six concepts are related to definition and contributions of PFE, and three were classified as contextual factors that can influence engagement.

Based on the evidence collected in the interviews, the definition, dimensions and properties of PFE, categories and contextual factors were described. The analysis of the categories and how they are related allowed the central category of 'cultural and process change' to be identified. Figure 1 illustrates the grounded theory for PFE in QM in hospitals referred to as 'openness to cultural and process change'. Categories along with some quotations from respondents are included in table 4.

Following the definition and contributions of engagement, external contextual factors and a conceptual description of the five categories that integrated the concepts emerged from the data analysis are provided.

## Definition and contributions of engagement

The PFE in QM allowed them to focus the service improvement actions on what really matters to the patients, considering their points of view, opinions, needs and wishes. The patient could contribute with an 'outside view', suggesting solutions different from those identified strictly by the hospital's professionals. The patient's participation promoted a change in thinking and the paradigms 'I (professional) decide, and you (patient) obey' and 'my doctor is the only one who knows' to 'let us discuss the matter'.

> […] what we are proposing to the patient is not always what they need or the way we are proposing to the patient makes difference to them. We already have to adapt so many things in the best language, structure, and best way that is important to them. (H1)

The mechanisms that promote the patient's face-to-face participation could stimulate a greater commitment in hospital professionals to the deadline for implementing the improvements ('sense of urgency'), more empathy and compassion. Internally, quality and patient safety are strongly related, so PFE also covered safety-related issues.

Table 4 Categories and some related quotations

| Categories | Quotations from respondents |
|---|---|
| Patient partner | Having a dedicated time for people outside of hospital time is also not an easy task. While they are in the hospital, inviting them to participate is easy, when they leave here this involvement is not so simple. (H1)<br>We have patients from other municipalities who have difficulty. So, if you are going to bring them after admission or at another time, they are not going to come.(…)So, we should make use of the time while they are in hospital. (H3)<br>Here, I cannot perceive (a movement on the part of the patient to participate), for example, in my institution I still do not experience this. It is still low, people have little interest in wanting to collaborate, in helping to improve the process. The result is important to them and that is it, maybe the process is not so important. (H2)<br>People adopt the [hospital name] as their hospital, so this is a facilitator. There are people who were born here and spend their whole lives being cared for here and feel that the [hospital name] is their hospital. So, when we invite them to participate in something, they are participating in 'their' hospital. (H1)<br>If we do not have a balance in the group, there may be times when there are feelings of 'them' and 'us'. You cannot obtain integration anymore. So, we need people who can take a more reflective look at this and not just be passionate.(…)If we say, 'he has a certain characteristic and has had a relationship over a certain period of time, this I imagine could guarantee. (H5) |
| Mechanisms of engagement | When we bring the patient to a committee, we are saying that, along with us, they can be responsible for some things. It is different, when they complete a survey, when they respond to a satisfaction survey, the NPS (Net promoter score), or something else that we have sent to patients, because in this case, they are giving us information to do differently, that is, how to do things better. (H1)<br>We stopped focusing only on passive research (for instance, satisfaction survey) and began to act more with active research. We keep the passive channel, where people go there, fill out the questionnaire, and leave it in the box. There is a little box that is for suggestions. But there are people in the hospital who go into the room and try to find out, exchange an idea with family members, exchange an idea with patients, for example by asking 'how is your experience here?'. (H3)<br>The committee is a level of involvement; it is an institutional level of involvement. It is a level that involves people who are making themselves available to come too, because you are inviting people to join the committee. (H1)<br>In my opinion, I think we have two ways of contributing. I will call it committee, sometimes it does not have this name.(…). What I think that often arises is that the ideal, that the patient can also bring contributions from the viewpoint of some decisions that are a little more strategic, which is to define some paths for the institution itself such as where invest. (H5)<br>In the past, the questionnaire was in paper format and people did not want to complete it, or did not have time, and after that this form should be transcribed and entered in the system, something that took longer. Today, this information is already registered in the system and immediately sent to the people who are responsible via email. Today, when a form comes with a complaint or suggestion, the manager responsible for the area receives it 24 hours after the registration. (H2) |
| Internal structure for P/F engagement | A hierarchical culture(…)is quite common in hospitals. So, the nurse just comes into contact with their area, the physiotherapist only their area, and the doctor in their area. Everyone has the expectation that the other will perform their function and it will be all right in the end. But in practice, the process or the result is not as expected from the sum of the various small processes. So, in this sense I think that makes it difficult. However, within that hierarchy you have obedience in terms of following the processes. (H4)<br>We can bring people closer when we share as much information as possible.(…)access to information on the performance of the service, of each of the flows, of each of the processes. (H3)<br>The [assistance] model placed all professions on the same level of care.(…)We are revisiting the model to make it clear that while all professionals are extremely important, the patient remains the driver of our actions. (H1)<br>To be restricted (do not treat a patient's complaint) for financial reasons is frustrating.(…)From the moment you put a customer to be part of this process and they sense this and also sees no solution for financial matters, I find this quite complicated. Maybe we have a lot of such barriers. (H2) |

Continued

Table 4 Continued

| Categories | Quotations from respondents |
|---|---|
| Maturity of the QM system | I understand maturity, how to make the most of what you have (mechanisms implemented) to achieve your purpose. (H6)<br>There is a guide to be followed that in a way the institutions that are accredited by the [name of accreditation] following. (H1)<br>So, when I talk about process, it is a matter of process maturity even with a view of what problem is in the process and not in person. So, I think it is an evolution that we still must pursue in that we are still looking at people and we need to look more at the processes. At some point, it involves people, but not with a punitive view. I think there is still some maturing to occur in this sense. (H4)<br>We have a very lean and small team. I am the care manager of the hospital, so I coordinate the entire nursing sector, but at the same time, I coordinate the pharmacy, nutrition services, and cleaning services as well. So, all these processes go through me. I end up following this very closely, triggering the changes that need to be done and I follow all of them. (H3)<br>We usually do it just for one unit, after that we move on to a second unit with patients of different characteristics. We started (a project we developed on patient education) with elective surgery patients, which is an easier patient, we move on to another unit, Neuro, which is a slightly more difficult area, and we are now expanding because now we go to the whole unit, the whole ICU. (H5) |
| Openness to change | I still think there is a cultural issue of both the professionals and the patients, which represents a barrier. I think it has been a process of learning and an opening for both of us. It is a barrier that comes back, and we must take a little time, rethink, and talk because it is one of the things that can have an impact. (H1)<br>There is the question of hierarchy, distance, and the culture that is like 'I decide, and you (patient) obey'. (H6) |

Source: The authors.
P/F, patient and family members; QM, quality management.

> I think we learn more empathy; we learn more compassion; we learn more about how we behave with the patient. It has several gains in contact (with the patient), to open this official channel within the institution. (H1)

### Patient partner

The patient's involvement in QM made them a partner in the objective of improving services. Initially, their involvement was linked to their availability (health condition, age, time and financial resources) and willingness to participate. Participation was considered easier while the patient was at the institution.

Not all patients wanted to participate in activities other than those related to their care. A long relationship with the institution or a high frequency of visits in a shorter period could provoke a feeling of ownership. In addition, this feeling could also be awakened in patients who started to participate in forums, suggesting this to be a cycle, that is, the feeling of ownership encourages patients to participate in QM, while their participation further reinforces the feeling of ownership.

Willingness and availability were requirements for participation at any level of engagement. However, for participation in levels such as 'involvement' and 'partnership and shared leadership', other requirements should be considered. The first was the experience, which was related to the knowledge of the service and allowed the patient to have a reference to assess its quality.

Another requirement for the patient to participate in higher levels of engagement was their profile. Depending on the type of engagement mechanism to be implemented, there could be some important requirements for creating a collaborative environment. Most institutions had specific channels for patients to report complaints, which corresponded to the level 'consultation'. For this reason, when implementing mechanisms of the 'involvement' level, such as committees, councils or working groups, it was expected that these forums would not become 'another place for the complaints'. Patients were expected to be participatory, to have an active and more reflective position, and to make a constructive criticism to contribute to the solution of problems and the improvement of services; otherwise, it was felt that the new engagement mechanisms may not add value. The partner patient could become coresponsible for the results.

### Mechanisms of engagement

The definition of the engagement strategy should begin with the recognition that there were different mechanisms to involve patients and their choice should consider the objectives of the institution in terms of this action. In QM, there was no relationship between the accreditation programmes and the motivation and direction of actions for PFE. Respondents used the terms 'test' and 'venture' when referring to the planning and implementation of the mechanisms.

The mechanisms of the 'consultation' level allowed the hospitals to know the viewpoint and opinion of patients

to direct improvement actions. In contrast, the mechanisms of the 'involvement' level inserted the patient in the discussion and decision process for the resolution of problems in terms of partnership.

As for the format, there was a change in the way the mechanisms were applied, with the aim of seeking greater participation. The research with P/F and the format for recording suggestions, which were previously most frequently applied passively, were also being actively carried out at the time of data collection.

As for the scope, the mechanisms could involve different levels within the institution. For example, the committee was considered an institutional level. On the other hand, education actions could be specific to a sector or unit of the hospital.

As for the planning level, the mechanisms could address issues related to routine processes or at the strategic level. Involvement in actions to improve routine processes was considered easier than at the strategic level, as this level required the patient to have a longer relationship and better understand the processes of the institution. In discussions to improve routine processes, day to day, patients contributed and effectively participated in the discussion in search of solutions.

The use of information technology to capture information (eg, surveys of patient experience or satisfaction) could increase the rate of patient participation and reduce the time to send the information internally to the areas involved.

### Internal structure for P/F engagement

In this research, the concept of internal structure considered organisational aspects of management, that was, organisational culture, shared information and model of care, as well as financial resources.

Most hospitals were characterised by the dominant organisational culture of either 'hierarchy' (oriented by controlling) or 'clan' (oriented by collaboration). The first type, hierarchical dominant culture, created a more favourable environment for the change of issues related to processes (because they are clearly established and standardised), but did not promote a good communication and collaboration between the areas. On the other hand, the clan dominant culture, characterised by the collaboration between areas, could facilitate to change issues that involve people. The identification of the dominant organisational culture could help in the planning of actions for PFE, recognising the strengths and weaknesses of the institution to carry out the change.

> […] within that hierarchy, there is an obedience to the processes. Another example is a question that involves communication between sectors or professionals within the same sector who responds hierarchically to different departments, like nursing and administrative departments. The one from the administrative department only does what the administrative manager allows, he cannot talk to someone from the other area […]. He waits for a decision, an endorsement from above, so he will execute something. So, in this sense, I think it [culture of hierarchy] does interfere negatively. (H4—hierarchical dominant culture)

> We have a structure here that is very collaborative, the areas and the people who come in here. The people who work here feel this very strongly, that when you have a new activity to do […] many people want to participate, so it just doesn't more people because we have to take care of the assistance too. (H5—dominant clan culture)

The sharing and transparency of information about the process and the results were considered important issues for patient participation. It was also important to highlight that the patient-centred model created an internal environment that facilitated the institution's openness to listen to patients and to consider their perspective in decisions.

The institution needed financial resources for the execution of improvement actions. The resources were mainly needed to implement the improvements, because the expenses for the implementation and maintenance of the mechanisms were not considered as significant. The issue of financial availability was more discussed as a point of attention by public and philanthropic hospitals than by private hospitals.

### Maturity of the QM system

Maturity of the QM system was related to the capacity and internal structure of the hospital to improve the process, based on the problems and opportunities identified with patients. The mechanisms of engagement started the improvement process, but hospitals needed a QM system that supports the planning and execution of actions internally, effectively solving problems and/or promoting the improvement of services.

National or regional quality programmes, quality certification and accreditation supported the structuring of the QM system. It was observed that institutions that had some certification, accreditation or participated in quality award programmes had processes to identify stakeholders and communicate with them, as well as standardised processes and people trained in problem-solving methodologies. This context created an environment to get closer to patients and gave agility in the implementation of improvements in services.

The punitive culture could also influence the maturity of the QM system. When a problem has occurred, the team could direct the focus of actions on people (looking for blame) and not on processes (solving problems).

The people designated by the institution as responsible for implementing the improvement actions/projects needed to have influence to involve and interact with all the necessary areas, autonomy and scope for execution. In more complex projects that involved several areas, it was necessary to have a manager with a horizontal and

broad role. The actions were most effective when a person was able to closely monitor their implementation, interacting with different sectors and acting directly in terms of the processes. Hospitals with small capacity seemed to be able to better execute projects involving many areas (horizontal scope of action).

One successful strategy in the implementation of the improvement actions/projects adopted by the institutions was to start on a pilot scale (eg, in one area, process or work shift) and, after evaluating the results, expand its implementation to the other areas/units. This strategy was observed mainly in large hospitals, as this reduces the impact of the difficulty of these institutions having projects that need to have a horizontal scope of action covering many areas.

### Openness to change

All respondents mentioned 'cultural change', and the term 'openness' was often used to represent the necessary transformation, that was, openness to learn, to listen and accept other points of view. The change encompassed both the healthcare professionals and patients and it was a slow and time-consuming process. In the institution, the issues to be addressed were: (A) the power relationship between professionals and P/F created by the symbolic power of knowledge, (B) the fear of sharing with the P/F the information and exposing the existing problems in internal processes, due to the risk of generating judicial proceedings and (C) active position in the face of problems.

Regarding physicians, cultural change was strongly impacted by their technical education and the difficulty arising from the structures adopted by hospitals with open clinical staff. Technical education made openness to listen to the patients difficult, there was a culture of 'I decide, and you (patient) obey'. There should be a meaningful change in interpersonal relationships between patients and physicians, with a new balance in power relations. The symbolic power of the knowledge attributed to the health professionals generated a distance between them and the patients.

Regarding the attitude towards the risk of sharing information with the P/F, from the perspective of the institutions, critical situations were those that involved 'care risk, legal risk or even image risk' (participant H4). These risks could become a barrier to involvement as they imply a restriction on the sharing of information with the P/F.

Related to the reactive culture, it was observed that it could interfere in the time of carrying out the improvement actions, as the professionals started to act only after the problems occurrence.

### External contextual factors

In the external context, in the planning of PFE in QM, it was necessary to consider the model of the local health system, the community served and the changed in access to information.

The structure of the health system, public or private, could influence the patient's willingness to be in the institution. The public health system, which did not allow the patient to choose the institution for their care, might represent a first barrier to their engagement.

> I am talking about that our health structure, the health structure of Brazil, does not allow the patient to choose where they want to go. So how are you going to engage a person who might not want to be in there? So, it is a barrier for you to talk about experience. You are going to talk about experience, and they are going to say 'no, I do not even want to be here'.(H6)

The culture of the community served could contribute to know both patients and professionals. Professionals brought this culture into institutions. Especially in small cities, the relationship and social interaction could strengthen a collaborative environment within the institutions, which could have an impact on the way of working and on the results of services. Knowing the profile of the community, such as age, chronic diseases, among others, could also help in planning the mechanisms.

> I think we only have achieved the results due to this modus operandi that we have, but this is perhaps a particularity of the place where we are inserted, the profile that we have. […] we live in a city of [number] inhabitants, everyone knows each other, families live together. So, our relationship goes way beyond the hospital. […]. We have a bond of friendship that permeates the work. (H3)

Related to access to information, it was currently easier to access and there was a lot of information available, making it difficult for patients to identify reliable sources. This movement had changed the communication between professionals and patients, as patients had become more questioning. Institutions could have initiatives aimed at patient's education. The communication flow was no longer one-sided also between professionals.

> You know that we go through a challenge to deal with the Google generation, anything that you present within the service, that you propose as a therapeutic goal, care plan, people already search Google, already see if this is the best alternative or if it is not. (H3)

## DISCUSSION

The main objective of this study was to understand PFE in QM in the hospital environment. It was observed that PFE requires cultural and process changes, which are interrelated. These findings add to grow evidence that argues cultural change is important and disregarding it can lead to conceptual and theoretically limited research.[15]

A change in processes and culture in hospitals implicitly refers to the need for top management support. The

support and direction of top management are key factors cited by the gurus of quality, for instance, to provide the resources for quality improvement is part of the basic management process known as 'quality improvement' in Juran's[19] quality trilogy. Top management needs to support and be committed to the strategy of engaging patients in QM,[10 27 28] defining guidelines and objectives,[5 6 14 22] approving the planning of financial resources, and enabling training for all involved.[5 6 12 14]

The literature suggests that institutions have been adopting a multimodal strategy,[6 8 11 29 30] which provides a comprehensive strategy that can be adapted to address patient experience, satisfaction and outcomes.[24] Different mechanisms of engagement may be necessary, since involvement can take many forms, in different situations (contexts), with different types of participants, requirements and objectives[31] and there is no single strategy or method that can be considered to reflect the best practices of P/F engagement.[32] The research findings can contribute to an understanding of these variations and deepen the knowledge about the mechanisms. The mechanisms of engagement must be planned according to the objective of the institution, which need to be clearly defined. Mechanisms of the 'consultation' or 'involvement' level bring different contributions. Hospitals are experimenting and testing the mechanisms (to understand which best meet the different needs).

The results indicate that the PFE practices stimulate a change in professionals (sense of urgency, empathy and compassion). These findings corroborate the literature, which highlights empathy and compassion, strongly referring to the concept of centred care,[12] which favours engagement more broadly. However, no studies have been found that present a stimulus of the sense of urgency in professionals to solve problems as a result promoted by the engagement of P/F in QM.

Berwick *et al*[33] discuss the importance of considering contextual factors in the design of care systems and adapting them. Our findings lead to three main propositions for intervening factors in the external context: the local health system, the profile of the community served and the local culture, and the current changed in access to information. Cahill[34] identified the first two factors.

Our findings expand the previous works exploring the importance of the maturity of the QM system to improve the services and the hospital internal structure and solve problems.[34]

The limitations of the study are mainly related to the contemporary nature of the theme. No institutions were found to have the level of engagement known as 'partnership and shared leadership', which restricted the observation of the P/F's coleadership practices in initiatives and forums with the participation of patients. Another limitation resulting from the contemporary nature is that there may be results and intervening factors that need more time to be captured or perceived. Finally, a limitation to the study was the sample restricted to the hospitals located in Brazil and only one participant per hospital.

The risks associated with studies that addresses issues of power and culture in healthcare organisations could be highlighted. The investigation can remain at the superficial levels of manifest behaviours and verbalised opinions.[35] However, in this study, all respondents behaved in an open and safe way to discuss these issues, so we believed that the risk was low.

A priority for further research is to investigate, in the context of the COVID-19 pandemic, how the social distancing measures can impact on the mechanisms of PFE which, at first, were performed in person, such as committees. Furthermore, the limitations related to data collection mean that further research is needed to investigate specific issues around 'partnership and shared leadership'.

## CONCLUSION

Based on the experience of hospitals, PFE in QM requires a profound change in the institutions, both cultural and process. Cultural change is represented by the term 'openness', that is, openness to learn, to listen and to consider new perspectives. The change in processes is characterised by the term 'test and venture' because the model to be adopted may be different according to the objectives, profile of those involved, maturity of the QM system to implement improvements in services, internal structure of the institution and external factors. Cultural change is not only a 'change in the way of thinking', but also requires a 'change in the way of doing' and should therefore be based on a change of process in the hospitals.

Hospitals know the patient's perspective allows to take improvement actions driven towards what really matters to them, ensuring quality of service and safety, obtaining a new perspective to understand and solve problems, and stimulate a sense of urgency, more empathy and compassion in professionals.

The result of this research shows that to effectively engage P/F in QM in hospitals, the theme needs to be addressed in a more comprehensive and integrated way, considering all the essential elements related to processes and culture. The main theoretical contribution of this research is to develop an integrated model based on five categories to PFE: (1) to invite and make the 'patient a partner' in hospital services improving; (2) to plan and implement the 'mechanisms to patient engagement'; (3) to identify and consider in the implementation plan the issues related to the 'internal structure' with emphasis in organisational culture, shared information, model of care and available financial resources; (4) to connect the PFE with hospital 'QM system' considering its capacity to support the processes improvement and (5) to promote an environment in the organisation that is 'openness to change' the power relation between professionals and P/F, the fear of sharing information and the initiative to solve problems.

The results may be relevant to hospital administrators and QM professionals. To understand the variables of the

theoretical model and how they are integrated can help in targeting objectives, defining internal policies, recognising the importance of cultural aspects and planning resources and training necessary to carry out the activities. The results can allow them to identify the characteristics of the institutions' profile can facilitate or hinder the PFE.

For the society and patients or family members who participate or will be involved in the activities, the results can contribute by enabling knowledge and understanding about what is expected from them, what should be encouraged and what should be avoided to facilitate working in partnership, contribute based on your point of view and ensure the achievement of the expected results. The results of this study show that people who want to contribute to quality improvement do not need to be healthcare service specialists, but rather that their contribution must be based on their experience. It is also noteworthy that the results can contribute to all those involved in the associations formed by P/F, which can contribute to the improvement of quality in hospitals with the experience of their associates.

**Acknowledgements** The authors would like to express their gratitude towards the participating institutions and respondents for their contribution, and to the National Accreditation Organisation (ONA) for supporting this research. The authors also would like to thank the editor and the reviewers for their valuable and helpful comments and suggestions.

**Contributors** AMS was responsible for planning, conduct and reporting of the work. FTB, LLH and SB contributed to the planning phase and analysis of the data; and revised and edited the manuscript. All authors read and approved the final manuscript. AMS is acting as guarantor.

**Funding** This work was supported by the Coordination for the Improvement of Higher Education Personnel (CAPES) and National Council for Scientific and Technological Development (CNPq).

**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by Universidade de São Paulo—CAAE 16783419.7.0000.0068Hospital Universitário da Universidade de São Paulo—CAAE 16783419.7.3001.0076Hospital do Trabalhador/SES/PR—CAAE 16783419.7.3003.5225Universidade Federal de Santa Catarina—CAAE 16783419.7.3002.0121Universidade Federal de São Carlos—CAAE 16783419.7.3004.5504Hospital Geral do Grajaú—Associação Congregação de Santa Catarina—CAAE 16783419.7.3007.5447. Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** All data relevant to the study are included in the article or uploaded as online supplemental information.



**ORCID iDs**
Ana Maria Saut http://orcid.org/0000-0002-8775-7385
Simone Berger http://orcid.org/0000-0003-0131-3749

## REFERENCES

1 Berwick DM. Era 3 for medicine and health care. *JAMA* 2016;315:1329–30.
2 Batalden P. Getting more health from healthcare: quality improvement must acknowledge patient coproduction—an essay by Paul Batalden. *BMJ* 2018;1:k3617.
3 Bate P, Robert G. Experience-Based design: from redesigning the system around the patient to co-designing services with the patient. *Qual Saf Health Care* 2006;15:307–10.
4 Baker GR, Fancott C, Judd M, *et al*. Expanding patient engagement in quality improvement and health system redesign: three Canadian case studies. *Healthc Manage Forum* 2016;29:176–82.
5 Johnson KE, Mroz TM, Abraham M, *et al*. Promoting patient and family partnerships in ambulatory care improvement: a narrative review and focus group findings. *Adv Ther* 2016;33:1417–39.
6 Herrin J, Harris KG, Kenward K, *et al*. Patient and family engagement: a survey of US Hospital practices. *BMJ Qual Saf* 2016;25:182–9.
7 Groene O, Sunol R, Klazinga NS, *et al*. Involvement of patients or their representatives in quality management functions in EU hospitals: implementation and impact on patient-centred care strategies. *International Journal for Quality in Health Care* 2014;26:81–91.
8 Groene O, Lombarts MJMH, Klazinga N, *et al*. Is patient-centredness in European hospitals related to existing quality improvement strategies? analysis of a cross-sectional survey (Marquis study). *Qual Saf Health Care* 2009;18 Suppl 1:i44–50.
9 Saut AM, Berssaneti FT. Patient involvement in quality management of healthcare services. *Acta Paulista de Enfermagem* 2016;290194201600080:579–85.
10 Liang L, Cako A, Urquhart R, *et al*. Patient engagement in hospital health service planning and improvement: a scoping review. *BMJ Open* 2018;8:e018263.
11 Han E, Hudson Scholle S, Morton S, *et al*. Survey shows that fewer than a third of patient-centered medical home practices engage patients in quality improvement. *Health Aff* 2013;32:368–75.
12 Castro EM, Van Regenmortel T, Vanhaecht K, *et al*. Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. *Patient Educ Couns* 2016;99:1923–39.
13 Mockford C, Staniszewska S, Griffiths F, *et al*. The impact of patient and public involvement on UK NHS health care: a systematic review. *Int J Qual Health Care* 2012;24:28–38.
14 Bombard Y, Baker GR, Orlando E, *et al*. Engaging patients to improve quality of care: a systematic review. *Implement Sci* 2018;13:98.
15 Locock L, Boylan A-M, Snow R, *et al*. The power of symbolic capital in patient and public involvement in health research. *Health Expect* 2017;20:836–44.
16 Corbin J, Strauss A. *Basics of qualitative research: techniques and procedures for developing grounded theory*. 4th edn. California: SAGE Publications, 2015.
17 Balik B, Conway J, Zipperer L. Achieving an exceptional patient and family experience of inpatient hospital care. In: *Innovation series 2011*. Cambridge, Massachusetts: Institute for Healthcare Improvement, 2011.
18 Frampton SB, Wahl C, Cappiello G. Putting patients first: partnering with patients' families. *Am J Nurs* 2010;110:53–6.
19 Juran JM, Gryna FM. *Juran's quality control handbook*. 4th ed. McGraw-Hill, 1988.
20 Saut AM, Berssaneti FT, Moreno MC. Evaluating the impact of accreditation on Brazilian healthcare organizations: a quantitative study. *Int J Qual Health Care* 2017;29:713–21.
21 Carman KL, Dardess P, Maurer M, *et al*. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff* 2013;32:223–31.
22 Kohler G, Sampalli T, Ryer A, *et al*. Bringing value-based perspectives to care: including patient and family members in decision-making processes. *Int J Health Policy Manag* 2017;6:661–8.
23 Carman KL, Workman TA. Engaging patients and consumers in research evidence: applying the conceptual model of patient and family engagement. *Patient Educ Couns* 2017;100:25–9.
24 Berger S, Saut AM, Berssaneti FT. Using patient feedback to drive quality improvement in hospitals: a qualitative study. *BMJ Open* 2020;10:e037641.
25 Snow ME, Tweedie K, Pederson A. Heard and valued: the development of a model to meaningfully engage marginalized populations in health services planning. *BMC Health Serv Res* 2018;18:181.
26 Joint Commission Resources. *Engage and activate your patients! joint Commission resources*, 2014: 1–2. https://www.jcrinc.com/engage-and-activate-your-patients/

27 Batalden M, Batalden P, Margolis P, *et al*. Coproduction of healthcare service. *BMJ Qual Saf* 2016;25:509–17.
28 Palumbo R. Contextualizing co-production of health care: a systematic literature review. *International Journal of Public Sector Management* 2016;29:72–90.
29 Makai P, Klazinga N, Wagner C, *et al*. Quality management and patient safety: survey results from 102 Hungarian hospitals. *Health Policy* 2009;90:175–80.
30 Groene O, Sunol R, Klazinga NS, *et al*. Involvement of patients or their representatives in quality management functions in EU hospitals: implementation and impact on patient-centred care strategies. *Int J Qual Health Care* 2014;26 Suppl 1:81–91.
31 Rowe G, Frewer LJ. A typology of public engagement mechanisms. *Sci Technol Human Values* 2005;30:251–90.
32 Groene O, Sunol R. Patient involvement in quality management: rationale and current status. *J Health Organ Manag* 2015;29:556–69.
33 Berwick DM, Feeley D, Loehrer S. Change from the inside out: health care leaders taking the helm. *JAMA* 2015;313:1707–8.
34 Cahill J. Patient participation--a review of the literature. *J Clin Nurs* 1998;7:119–28.
35 Kurcgant P. PESQUISA, PODER E SAÚDE. *Rev Esc Enferm USP* 1992;26:167–70.