


 HAUTE AUTORITÉ DE SANTÉ


Patients' experience of hospital care : a qualitative study

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Starting point


- **Patients' rights law in 2002 – principles upheld and promoted by hospital accreditation**
- **Context of this study : renewal of hospital accreditation standards in 2007-2008 by the HAS (French National Authority for Health)**
- **Recognition of a gap between hospital accreditation's reports or satisfaction surveys results and people' accounts on their experience of hospital care**
 - Complaints and testimonies seem to offer a quite different image of hospitals and shed a light on dimensions of the quality of care that are sometimes underestimated

➔ **A need to listen without « filters » to what patients have to say about hospitals**

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Objectives of the study

- **Main objective :**
 - Investigate « real life »/ordinary patients' experiences of hospital care
- **Secondary objective :**
 - Investigate the health care professionals perceptions :
 - research if and to what extent the patients' perceptions of the dysfunctions are shared by health care professionals
 - Ask why, in their view, things are going wrong and what they do to improve it

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Material and methodology

- **The material used for the patients' part :**
 - 59 written statements (personal accounts, complaint letters...)
 - 22 indepth interviews of patients who have been hospitalized, and patients' family and relatives
- **The material used for the health care professionals' part :**
 - 16 indepth interviews of health care professionals, experts and « opinion leaders »
- **Data analysis through qualitative methods**

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Results : the global picture

- **Despite the positive changes triggered by patients' rights movement and laws, patients and families often feel they have not been sufficiently « cared » for even if the patient is « cured »**
 - Hospitals still tends to be perceived by patients as dysfunctional, unresponsive organizations
 - Disruptive behaviours from health care professionals are described
 - ➔ A common, invisible and « institutional » type of abuse or mistreatment is denounced
- **Health care professionals acknowledge this phenomenon**
 - They identify some factors, especially their own difficulties due to growing pressure on health care professions
 - They emphasize ways to counteract this phenomenon and promote a type of care more « human » and respectful to the person

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Results : examples and extracts from the study - Patients and families' accounts


- **Identification of two types of mistreatments :**
 - 1. Inappropriate individual behaviours of professionals**

Examples :

 - When the professionals talk with each others without acknowledging the presence of the patient
 - When the professionals complain about working conditions in front of the patient...
 - 2. Improper organisation that leads to abuse :**

Examples :

 - The noise in hospitals : described as a constant nuisance, disrupting rest and sleep, day and night
 - Anguishing and unexplained waits, for a consult, for exams results, and for explanations

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Results : examples and extracts from the study Patients and families' accounts

- **Three major patients' rights issues :**
 1. **The right to information**
 2. **The right to be relieved from pain**
 3. **The respect of dignity**
 - Viewed from the patients' perspective, dignity is not a lofty but a very concrete concept...
 - Too often, the patients and the families underline that the response to basic needs are lacking or are inappropriate :
 1. - Old but self-sufficient people forced to put diapers
 2. - Unbearable delays to get some relief
 3. - Humiliating remarks when a patient cannot control his sphincters

Results : examples and extracts from the study Patients and families' accounts

- **Three critical areas of care :**
 1. Intensive care unit
 2. Emergency room
 3. End-of life care

Examples :

 - How an inflexible organisation and avoidant behaviours from professionals reinforce the grief of a daughter :

- the visiting hours in this unit were 12.15 pm to 8 pm. (...) During the first times, one evening, an nurse's aide came trumpeting with acrimony that it was 8.03pm and time to go. But it is obvious that the most difficult moments for hospitalized people is the approach of dusk, night itself and wake-up time. It would have been crucial to be allowed, at least during the first times, to reassure my mother and help her get accustomed by assisting her until she fell asleep and when she woke up at dawn (...) Considered as an « obstacle » to care, I tried to carefully respect the visiting hours. (...) During the last times, I was allowed to stay as long as I wanted and come at 6.45 am (...). It never disturbed anyone, nor health care workers, nor patients. But it was too late for my mother (...) I asked you one day if my mother slept and if the nights were going well, and you reply that there was nothing remarkable about them. But one of the night nurses, at the end, told me that my mother had always « called for her daughter ». This point will remain unbearable and impossible to obliterate ».

Results : Health care professionals' accounts

- **Recognition of the existence of an « everyday life » mistreatment of the patients and their relatives**
 - Some differences from patients' views :
 - Although testimonies from patients and families concerned patients of all type and age, professionals tend to consider that the risk of bad treatment concerns mainly, even exclusively, aged people
 - The health care professionals underestimate the importance of patient information in the process of care
- **Factors contributing to patients' mistreatment, as identified by the professionals :**
 - The difficulty of facing death and suffering : avoidance, burn-out...
 - The lack of appropriate management support
 - The conflicting messages issued by the health care institutions :
 - asking for more quality in a context felt as one of constant deterioration of working conditions (cost control policies, shortage and turn-over of health care professionals...)
 - asking for standardization and individualized care at the same time

Conclusions : What can we do about it as accreditors ?

- **Introduction of a new requirement in hospital accreditation standards regarding hospital policy for « bientraitance » (« human care-giving »)**
 - « Bientraitance » : a notion largely used in french services for elderly or/and disabled persons
 - Reshaping organisations to make them more responsive to individual needs, rights and expectations implies :
 - *Commitment by leadership to promote a culture of human care-giving*
 - *Training of health care professionals (communication with patients...)*
 - *Active prevention of abuse*
 - *Concrete quality improvement initiatives targeting everyday life in hospital and based on « ordinary » experience*
- **Reinforcement of previous requirements :**
 1. Palliative care
 2. Management of patients' complaints