HOW PATIENTS’ EXPERIENCES HELP INSTITUTIONS TO IMPROVE CARE IN ONCOLOGICAL PATHWAY

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Abstract

To improve services, institutions need to listen the patients voice. The patient experience through the health care pathway can help institutions to point out the problems and to learn to design the organization putting the patient at the center of the service.

Methods. Focus groups were performed on a group of patients affected by colon rectum neoplasia who had an operation during June-September 2003 in the hospitals located in three geographical districts. It was performed a focus group per district in the period between June and July 2004.

Results. Overall patient were interviewed in district A, B and C, respectively. District C included a University Hospital and a Community Hospital. We choose the focus group technics because of the peculiarity of the studied disease. By a crossed reading of patients’ experience we obtained two type of informations: how CORD is working (CORD is the structure which has the role of coordination of oncological pathway, according to the regional guidelines) and which are the strengthness and the weakness of the services delivered by each healthcare unit participating at the study.

The patient experience in benchmarking through out different institutions, has been useful for managers to start an internal process of reviewing critical points regarding above all humanization and care coordination along the health care pathway.

Particularly interesting is the case of the University Hospital of Pisa, where the patients indications allowed the institution to reengineering the process, to improve services and empower the communication skills of the physicians and nurses involved in the clinical pathway.

Conclusions. Patient point of view in oncological care was an easy tool for improving the health care pathway. It gives to health managers a simple method that allows the organization to evaluate services through the patients eyes.

JEL Classification: I10

Keywords: Focus group, Oncological pathway, Patients’ point of view
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Introduction

In the last years, Tuscany Region has focused its attention on the clinical pathways: according to regional organizational law of the 2000 (l.r 22/00) the healthcare pathway is the result of organizational roles and tools that guarantee coordination and integration of care and patient support throughout hospital and territorial services to the patient.

In a complex clinical pathway, no single function is able to provide a high quality service to patients but only multifunctional teams can be responsible for a total value delivery process.

In fact to be able really to focus each activity on the patient’s needs it’s necessary to manage the organization emphasizing the process approach, caring more about coordination and connections between different units rather than specific efficiency results of each individual unit. Often a team-based organization takes place to the traditional and functional one, having as main task the delivery of processes throughout the organization.

This is particularly true in long and complex health care processes that need to be controlled not only at the end, looking at final results, but also during the delivering of the service. It’s enough that only one phase of the delivering service process is not correctly conducted considering patient’s needs that all the service registers a loss. This happens because it is the same patient that goes trough all the service phases and he needs to have every step of the process to be perfectly connected and coordinate to be pleased of the total service delivered.

This means that in order to assure quality service it’s necessary to be aware of the patient experience along the clinical pathway, to work on the relationship between the departments involved in the process by creating cross-functional teams that can govern the critical links from phase to phase and be able to respond to the patient’s needs. The result in fact doesn’t often depend on the type of treatment but on the degree of continuity that can be assured by the multi-professional teams.

In our study we analysed the oncological pathway through the patients’ eyes.

In fact in the health services all the processes and activities are, and have to be, centered on the patient (Ford, Fottler 2000; Mc Laughlin Curtis, Kaluzny Arnold 2000).

In the following paragraphs is explained the methodology adopted in the oncological pathway of the colon rectum neoplasia and the process of reorganization applied by the University Hospital of Pisa.
**How to listen to the patient**

The focus group technique was chosen for collecting the patients’ point of view.

Focus groups consist of qualitative surveys with the involvement of a selected group of users in order to discuss opinions, assessments and perceptions regarding the health care received (Holloway B., Mobbs D., 1994; Krueger R.A, 1994; Mitchell K., Branigan P., 2000).

This method systematically collects the experiences of care followed by a group of patients who have similar characteristics. It is based on the dialog and the interactive comparison among participants; in this way the results are shared by the patients (Gandolfo A., Tamburini G., 2004).

The focus group is one of the qualitative tools most widely employed by health institutions on an international scale and also one of the most effective for the study of the behaviour of individuals as service users.

The characteristic that distinguishes focus groups from other types of interview is the importance given to the dialogue and interactive comparison between participants. Each focus session lasts for an average of about two and a half hours. Meetings involve a high level of participation by those selected, who are pleased to be able to contribute to the improvement of health service quality and efficiency.

The type of information and guidance obtained from focus groups is invaluable and is quite different from that obtainable by the health authorities through user satisfaction questionnaires. The information obtained from these questionnaires is undoubtedly useful because it tells the health authority about user satisfaction levels regarding services received, but they do not highlight judgement determiners. When an authority learns that its users have assessed a particular service as “quite satisfactory”, it cannot know what determined this result rather than “fully satisfactory”, or what could have been done better in order to obtain this judgement. It often follows, then, that having measured the level of user satisfaction, it is not possible to deduce the action needed to improve the service on offer. Furthermore, satisfaction levels are strongly linked to patient expectation: a patient might be satisfied even where a poor quality service is provided simply because he or she is not capable of giving an efficient judgement, or more simply because his or her expectations are very limited. Satisfaction levels are therefore no longer sufficient for management guidance: the health authorities need to be able to gather patient experiences and to learn from them in their organization. Patients have a surprising capacity to survey the way in which services are provided: a short stay in hospital is enough for a patient, through his or her own
experience, to be able to give a precise assessment of what goes on along the care pathway. The main player in this pathway, with direct experience of the service in question, can contribute to the identification of areas of service breakdown and areas where change is required.

In this respect, patient experience, gathered through the focus groups, becomes an extremely efficient means of assessing care pathways. It does not claim to have a statistical value in the representation of the user universe, but an account of a negative episode, which may have happened only to the person recounting it, is all the same emblematic and significant precisely because it happened at least once and because the system allowed a negative experience to arise. This single event, opportunely reported, forces the organization to question what it was that went wrong and why the episode was allowed to happen.

**Methodological aspects**

In methodological terms, focus group assessments were carried out in five phases:
1. Survey’s goals definition, that is the issue that has determined the need for an enquiry and what the research group aims to find out through the survey; pointing out specific aspects to be considered in the assessment process;
2. Intervention plan including: timetable, the modality to be adopted, the definition of expected findings, and finally the involvement of the person in charge of the service to be assessed. The support of the department manager is essential for the correct recruitment of those involved;
3. Survey conducted by a psychologist and a researcher;
4. Results - that is, the processing of the data received – and the drawing up of a summary report;
5. Quality indicators of a qualitative type.

Focus groups were performed on a pool of patients affected by colon rectum pathology who had had an operation during June-September 2003 in the hospitals located in three geographical districts. It was performed a focus group per district in the period between June and July 2004.

By a crossed reading of patients’ experience we obtained two type of information: how CORD\(^1\) is working (according to the regional guidelines, CORD is the structure which has the role of the oncological pathway coordination) and which are the strengthness and the

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\(^1\) Cord: Centro Oncologico di Riferimento Dipartimentale
weakness of the services delivered by each healthcare unit participating at the study.

These main objectives have been analyzed on the basis of six aspects:
1. Clinical quality in the different phases of the path;
2. Coordination by the CORD structure;
3. Psychological support;
4. Comfort;
5. Relationship with nurses and physicians;
6. Health communication and privacy.

**Patients’ voice : principal outputs**

The results of the study points out the main strengths and weaknesses in the four healthcare authorities analysed.

Starting from the strengths we report the main positive aspects of the service indicated by patients:

- The screening phase gives patients the first perception of quality of service and of personal attention. This phase represents the welcoming to the clinical healthcare path
- The surgery phase is generally considered of high quality
- The majority part of patients is satisfied by the relationship with physicians and staff
- Patients appreciate very much the role and the services delivered by the Cord in the healthcare authorities where this structure is really working

The main weaknesses complained by patients are:

- Lack of CORD coordination: according to the several regional guidelines on the oncological pathway, the patient should be driven by CORD in all phases, from the discovery of the disease to the post therapy and the follow up. This is not applied in every health authority and this makes patients uneasy;
- Sometimes there are also problems because the organizations are not aware of the patient’s needs and are not able to get correctly patients in charge;
- CORD doesn’t work because often it’s really difficult to coordinate different professionals not trained to work in team;
- Problems with communication: sometimes physicians put the patient in front of a critical decision about the therapy, but they did not give sufficient information and don’t support patient’s decision. There
were also problems in communicating the discovery of the disease that led traumatic emotions in patients.

- Problems with comfort location especially in the recovery phase.

**Re-engineering of the process: the experience of the university hospital of Pisa.**

The patients’ experiences, in benchmarking throughout different institutions, have been useful for managers to start an internal process of reviewing critical points regarding above all humanization and care coordination along the health care pathway.

Of particular interest is the case of the University Hospital of Pisa, where the patients’ indications allowed the institution to reengineer the process, to improve services and to empower the communication skills of the physicians and nurses involved in the healthcare pathway.

The results of focus group point out lots of patients’ needs disregarded by the U.H. of Pisa. They can be summarized in the following aspects:

1. the lack of CORD as the structure which guides oncological patient along his health pathway, patients have no point of reference;

2. the lack of management in the patient healthcare path: he has to manage his care by himself, from the booking of the appointment for visit to the payment of exams that should be free for oncological patients;

3. the organization focused not on the patient’s needs but on the physician’s ones: patients are called for medical examinations all at the same time so that they have to wait for hours before being seen by a doctor;

4. the inadequate communication and support to patient: no clear indications are given to the patients;

5. the insufficient organizational support: signals are scarce.
After the focus group, the U.H. made some internal audit within physicians and staff to face problems and to reduce gaps between patient’s needs and service provided.

The U.H. planned the following changes:

1. The activation of CORD: it has been created a fixed group of persons working with defined rules;

2. The newborn CORD has introduced rules and standards for the board of coordination, it has set up a multidisciplinary group of oncologists, it has established a fast track for reducing waiting time and booking appointments of specific exams, it has been activated electronically clinical history and welcoming activities to manage the pathway of the oncological patients;

3. the focus on the patient has improved starting from the easiest things such as the booking of appointments, CORD books exams at different times so that waiting time of patients is reduced;

4. It has planned periodic training courses for nurses and staff about relationship techniques and how to provide patient with information in order to improve staff and physicians’ communication skills;

5. Several changes are carried out as support to patient along his path, such as the creation of a dedicated phone number where patients may receive answer, open every morning from Monday to Friday; it has arranged two places for patients’ relax such as an outside garden and an inside music-book corner.

All these changes are introduced for an unique goal: to get patient in charge. Each patient has to be known and all aspects of organization from the hard ones (such as the comfort location) to the soft ones (such as the communication) have to be oriented to make it real.
References


Ford Robert C., Fottler Myron D.; (2000); Creating Customer-Focused Health Care Organizations; Health Care Management Review; Fall; 25; 4; page 18 - 33.


Mc Laughlin Curtis P., Kaluzny Arnold D.; (2000); Building client Centered Systems of Care; Health Care Management Review; Winter ; 25; 1.

Nuti S.; (2004); Colon retto, l’assistenza migliora se la voce dei pazienti è ascoltata - Sole 24 Ore Sanità Toscana n. 49/50.

Nuti S.; (2001); Creating process measures to monitor service delivery systems in the health sector; EIASM - Fifth International Seminar on Accounting Research; Pisa; June.

Nuti S., Miolo Vitali P.; (2004); Sperimentazione dell’activity based costing nella sanità pubblica: l’esperienza dell’azienda USL 3 di Pistoia - Franco Angeli.

Sasser W.E., Olsen R.P., Wickoff D.P.; (1978); Management of service operations, Allyn and Bacon; Boston.