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# What Can TA Learn from Patient Narratives

## Using Narrative Methodology to Assess the Role of Patients in Dutch Hospitals

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### Abstract

Using narrative methodology, we assess the feasibility of the active and independent patient, an image portrayed in Dutch government papers and contested by patient organizations, medical occupational groups and political parties. 109 stories about hospital care from 103 patients were collected online. Storyline analysis resulted in nine experience types that describe prototypical situations in which patients find themselves in the hospital. These nine types offer a rich picture of patient perspectives on quality and safety of hospital care. Being in the hospital creates a tension for the patient. On the one hand, many patients are scared and become silent. On the other hand, many patients feel the need to speak out, and to be involved in their own care trajectory. We argue that this tension cannot be taken away, as it is a part of being a patient in a hospital. Instead, we propose that the hospital system should be designed in such a way that sensitivity for this tension is taken into account. Patient narratives could be fruitfully deployed for this purpose. Our study shows that narrative research is a promising method for TA as it offers a tool for identifying contextualised dilemma's experienced by stakeholders and users of large socio-technical systems.

### Introduction

#### *Changing role of patients – towards an independent and active patient in Dutch healthcare*

Dutch patients have become more independent and active. That is, at least, how patients are often portrayed in Dutch governmental papers. Patients have gained more say in the health-care system with the effectuation of the Medical Treatment Contracts Act (WGBO) in 1996. This law has given patients the right to actively take part in decisions concerning their own illness and treatments by means of informed consent, accompanied by official complaint

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procedures. In an environment of marketization, ever-increasing care budgets and the long-standing political wish to control health expenditures while maintaining quality, an active and independent patient has become the key solution to many problems in health care, at least rhetorically. At the same time, the image of the active and independent patient has been criticized by Dutch patient organizations, medical occupational groups and some political parties because such a patient does not exist. This tension raises the question of how real this independent patient is.

In this project, we explore a novel method of Technology Assessment which is derived from the field of narrative health research (Sools 2012; Murray & Sools in press). In this article, we explore how this methodology can enhance TA, mainly to assess the feasibility of the active and independent patient. We use the hospital as the location for investigation. The hospital as the complex socio-technical system is characterized by a highly hierarchical structure in which the patient has the lowest rank. We use narrative methodology to explore the perspective of the patient as one of the users of this complex system. The research questions in this article is: How feasible is the independent, active patient in hospital care, viewed from patient perspectives?

### **The Narrative Method**

In our online study, we used a mixed-method design consisting of a qualitative part (online written narratives and focus groups) and a quantitative part (questionnaire).

#### ***Data Collection***

We collected written patient narratives on hospital care by means of a website. We used the format of a written letter with a heading, an addressee and a sender to collect the experiences. The letters could be between 200 and 2 000 words. Furthermore, we asked the patients to formulate a wish at the end and to propose a solution for how to make this wish come true.

This limited pre-structuring of the form enabled easier processing and comparing of large quantities of letters while retaining the exploratory, open nature of the content of the stories. Openness to the patient perspective and their own words is a central feature of narrative research. After posting the story, participants were asked to answer a few questions related to the interpretation of the story, for instance if they felt it was a positive, ambivalent or negative experience and for what reasons. This was done to gain insight into the themes that were important to participants while in the hospital and to identify the main lessons to be learned from their perspective. This was used to find out what issues contribute to good or bad hospital care for patients. Furthermore, to see how representative the stories were of the general population, we asked some background questions related to the writer: about the kind of their illness, the length of their stay, the location and type of the hospital and socio-economic variables such as gender, age, educational level and income of the writer.

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We chose an online tool for its known advantages, such as easy accessibility and availability for anyone with access to the Internet. The threshold to participate was lowered not only with regard to location but also temporally because participants can choose their own best moment to write the story. Moreover, physical presence is no longer necessary, and the Internet provides a high degree of anonymity (Gerhards et al. 2011). The downsides are that the method of written narratives selects people who feel capable of writing and people with access to computers and the Internet.

In order to engage patients to share their stories, we drew attention to our website in several ways. First, we contacted over a 100 Dutch patients organizations with information about the project and asked them to spread the information about the project. Many responded to our request by placing some information on their website or in their paper magazines. We contacted all 109 Dutch hospitals and asked them to place posters and flyers. About one third of the hospitals replied positively and received posters and flyers. We engaged the ambassadors of the project - a group of ex-political representatives, doctors and patients - to help bring the project to public attention. Furthermore, we posted banners on online medical and health fora and posted calls to participate in the project on more than 100 of these websites. We placed some ads and advertorials in free local and national newspapers. By these means we tried to reach both patients who were already active on Internet fora and in patient organizations as well as patients who were not.

Over the course of one year we received 109 narratives by 103 unique authors. Writers of the stories were a heterogeneous group of varying gender, age, education level, income and experience with hospital care. We received more stories from female writers (77%), from people with a higher education (53%) and native Dutch writers (94%). We received a comparable amount of exclusively positive (25%) and negative stories (26%). However, most stories (43%) were classified as ambivalent, containing both positive and negative elements. A minority of the stories (6%) were classified as neutral. Experiences addressed both academic (24%) and local hospitals (73%) or both (3%) and covered much of the Netherlands and described more than 50 different illnesses. The majority of the stories (64%) concerned a longer stay in the hospital, other stories concerned visits to outpatient clinics (36%). In most stories, the patient was also the writer (76%), but a minority of the stories were written by a family member or a friend of the main character (the patient) in the story (24%).

## **Narrative Analysis**

We analysed the narratives in two different ways: 1) storyline analysis of the patient experience of the hospital system, their perception of the patient role, and patients' reflections on good and bad quality of care, and 2) thematic analysis of tensions in these storylines.

Storyline analysis is a narrative method of analysis based on the pentad (Burke 1969; Bruner 1990; Sools 2010) consisting of five interconnected elements which together form

a storyline: 1) The setting or location of the story, 2) the Agent, 3) the acts or events, 4) the goals or intentions and 5) the means or helpers. The storyline is defined by a tension that is generated by a deviation from the expected order of things. First, thirty narratives were analysed in an iterative process combining in-depth analysis of single stories and broad analysis of all stories in order to find patterns of differences and similarities in the stories. This resulted in nine experience types, which have been checked intersubjectively by the research team. These nine types were subsequently used as an analytical framework for the remainder of the collected stories and refined and adjusted accordingly. Eventually, nine well-described experience types remained that captured the diversity of the whole sample. These were then summarised in four themes, which each indicate a particular dilemma or tension related to our research question regarding the feasibility of the active and independent patient.

## Results

### *Nine types of stories*

The storyline analysis resulted in nine experience types that described prototypical situations in which patients found themselves in hospitals. These were:

1. *'The patient wants to be involved as 'co-professional', seeks recognition of medical expertise within the setting of the hospital.'* This type of story can be understood as a negotiation of the boundaries of the patients' expert role. It calls attention to ambivalence and dilemmas of acting out the expert role for patients.
2. *'The attentive and articulate patient is forced to act as guard or "Centre" of good care.'* In contrast to storytype one, patients are endowed with a larger and different role than desired. In this storytype, patients are forced to pay attention and alert caregivers on errors in a situation of sub-optimal care, which arises as a result of failing cooperation and communication between caregivers and between hospital departments.
3. *'The patient who listens to his/her body indicates that something is not right, but "vague complaint" is not taken seriously.'* This storytype draws attention to the role of embodied knowledge, and whether this knowledge is considered a viable source for medical diagnosis and treatment, or subjected to objective scientific validation. How health care professionals take body signals into account, is not only a medical matter, but as these stories show also of consequence for patient autonomy.
4. *'Patient with initial trust in healthcare feels powerless to counteract failing care.'* Storytype four can be regarded as a from-bad-to-worse story in which initial patient trust in the hospital turns into distrust and despair. This storytype focuses on how (failing) quality of care at an earlier stage influences trust in hospital safety in later stages.
5. *'The patient who is not well informed about what awaits her, dares say nothing of the unpleasant treatment.'* This storytype locates what, how, when, where and by

whom patients need to be informed. The story draws attention to possible differences in perception between health care providers and patients about what counts as (un) wanted intimacy.

6. *'The medical ignorant patient wants to be informed in an involved manner; to let fear and uncertainty decrease.'* Similar to type five this storytype locates patients' need to be informed. Specific to type six is the need for information in a situation where the patient feels left to his fate by the doctor who sees him/her primarily as an interesting object of study. Another similarity between type 5 and 6 is that both stories warn of objectifying the patient instead of attending to their personal concerns, fears and desires.
7. *'The patient who expects "extra care": healing and practical support from A to Z.'* Central to this storytype is the negotiation of what is considered standard care and what counts as additional care. What can patients reasonably expect and who decides what is standard care and what not?
8. *'The patient who is prepared for the worst, has and unexpected positive experience.'* This storytype is the mirror of storytype 4 in the sense that now the patient has low expectations of the hospital and in fact fears the worse. When, unexpectedly, the hospital visit turns into a positive experience, this could result in increased trust in the hospital system. This storytype shows that good care can make a difference.
9. *'The patient with serious illness experiences uncertainty and despair about life due to illness.'* This final storytype calls attention to the way in which medical interventions also have social consequences and psychological effects on patients. This storytype calls for attending to patients existential questions in the context of healthcare.

#### Four Themes

To understand what we can learn from personal stories about the feasibility of the active and independent patient in hospital care, we identified the following four themes.

1. *Insecurity or anxiety in an unfamiliar situation.* This theme challenges the notion of the patient as an independent, active consumer or citizen in a healthy situation. Illness, disease or an acute admission to a hospital causes people to feel insecure and anxious or frightened. This can be caused by pain, the fear of (possible) death or physical weakening or the unknown prospect of living with an illness. In many stories, people first dealt with the anxiety and insecurity caused by a diagnosis or their hospitalization and then with other elements of visiting the hospital. Considerations of the active and independent role of patients should take this unfamiliar situation into account, instead of assessing patients and their capacities to act independently and actively in a decontextualized fashion.
2. *Appreciating the active independent patient, a challenge?* In contrast to theme 1, we have learned from the stories that there also are many patients who indeed want to

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play an active part in their own care trajectory. Patients want this for several reasons: because they feel jointly responsible, because they have a great amount of knowledge concerning their illness or because they feel they cannot leave the responsibility for good care to the hospital and are afraid of mistakes. Others see a lack of efficiency or wastage and want to report it. Many patients feel that active involvement is not always appreciated by caregivers.

3. *(Dis)empowered by the hospital.* Many patients feel disempowered in a hospital –even people who, under normal circumstances, feel empowered – the hospital system facilitates this feeling. Patients experience that they are badly informed about procedures, diagnosis or treatment. Patients feel doctors and nurses have little time and empathy for their emotions and feelings. In some stories, patients who expressed complaints were simply ignored. Patients subsequently did not communicate this out of fear of being seen as troublesome .
4. *Unknown expectations.* Patients’ expectations of hospital care do not always match the reality of hospitals. Some people enter hospitals with low expectancies and are positively surprised. In other cases, the care does not live up to expectations, which might result in a bad experience or even complaints. Health care professionals also have, often implicit, expectations of patients. Patients and healthcare professionals’ expectations often do not match. This may contribute to positive, but more often to negative patient experience.

## Conclusions

Our study shows that listening to patient stories about their own experiences and to their own words has a lot of potential for gaining insights into the quality and safety of hospital care.

### *How being in a hospital creates a tension that affects the feasibility of an active patient role*

What narrative technology assessment offers is the recognition that health care is a practice with high moral and emotional stakes (Kleinman and Seeman 2000). It may come as no surprise that being in a hospital is not a pleasant, emotionally neutral experience. However, the narrative approach teaches us how this personal truth is enmeshed in a relational and systemic practice. Patient experiences and professional care experiences meet with system requirements and result in dilemmas for all involved. These dilemmas are considered very real by patients on the individual level, and, at the same time, have implications on the organizational and policy levels.

In summary, the four dilemmas that were most prevalent in our study share a common feature relevant to the discussion on patient activity and independence. On the one hand, many patients are afraid and become silent. On the other hand, many patients feel the need to speak out and be involved in their own care trajectory, for valid reasons. This tension between becoming silent and wishing to be active and independent is present in many of

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the contacts between patients and care professionals and often defines the kind of contact patients have with care professionals, as we have seen in many of the stories. A hospital is a complex socio-technical environment in which social and technical processes are intertwined and need to be managed. Moreover, care trajectories of a single patient often involve many disciplines for diagnosis, radiology, treatment, the daily care, et cetera. This distribution of actions and care requires good integration and the sharing of information with the patient throughout the process. This makes hospitals hard to grasp for patients and contributes to both becoming silent and the need to be active and pay attention.

***The patient and their well-being as political aim***

Moreover, this tension defines many political and societal discussions about the role of the patient in the health-care sector. Political parties and many patient organizations wish to strengthen the position of patients. Others wish to leave patients alone and instead increase the authority of medical professionals. Both of these wishes can be seen as the sides of the same coin. The active and independent patient, as it is now presented by the government, seems to offer a way to support silent patients in hospitals. But the same goes for opposing views that argue that patients are not capable of taking an active part in their own care trajectory. Proponents of both directions have patients and their well-being as their objective.

However, we would argue that this tension cannot be taken away, as it is a part of being a patient in a hospital. The taking of sides pro or against active and independent patients does not take away the tension, nor does it solve it. The hospital system itself could become more aware of this tension and could develop a sensitivity for this tension. The use of patient narratives could be useful for this purpose.

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