

Patient Education as an Information System, Healthcare Tool and Interaction

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ABSTRACT

Patient education (PE) has a crucial role in the function of a healthcare organisation. For the care process of a patient, it is essential to get the right information at the right moment and in the right form. This paper analyses PE as the primary mode of interaction between a patient and a healthcare organisation. The approach is illustrated with a study among nurses based on their conceptions about PE. Practical implications and the potential of ICT in PE in particular are discussed.

Keywords: Health care, Scenario-based design, Ethics

1. INTRODUCTION

Patient education (PE) is commonly conceptualised as a discrete session in a hospital environment in which only the patient, or sometimes the patient's friend or relative, and the healthcare practitioner, commonly a nurse are present. During the PE session, the patient is provided with important information about, for example, an approaching operation, treatment plan, or nutrition instructions concerning a particular disease or condition such as diabetes or severe obesity.

Getting adequate information about the care plan is of course not only the right of the patient, but also a cornerstone of good life and wellbeing. There is, however, a clear need for a broader view of PE than just the one way delivery of information from the healthcare practitioner (nurse or a doctor) to the patient. In PE, more attention should be paid to the individual needs and resources of the patient. The focus in the development of PE should be the information delivery process as well as managing PE in an optimal way from the patients' perspective. One of the known success factors in PE is that a sound basis for the communication and trust

between the patient and the healthcare organisation is to be created. The patient-practitioner relationship is known to be one of the key factors in the process of building trust between the patient and the healthcare organisation (FitzPatrick et al., 2005; Leske et al., 2012).

In the current paper we approach PE with the help of group discussions with PE experienced nurses. Although we were not able to collect data from patients themselves, the discussions with the nurses provided important insights about the need to develop PE from the point of view of patients.

2. NURSES' ROLE AND CONCEPTIONS ABOUT PE

New healthcare regulations demand that patients and families assume greater responsibility for their own healthcare and take a more active role in decision making. In the UK this has been summarized as the "no decision about me without me" approach. This shift in responsibility should mean that PE plays a more important and central role in the delivery of care; however, there is an evident lack of appreciation of PE in health care which according to Redman

(2004), results from its non-prioritisation. The old understanding of PE implies simply giving orders and instructions to patients which Redman refers to as calls “compliance to medical regimen”, the provider’s approach. This should be replaced by the new approach which highlights the patients themselves as an influential factor affecting their treatment decisions. However this new ideology requires that PE is established as a more central role in the work of healthcare professionals.

Today the television, movies and the internet are an important influence on patients’ conceptions of medical care and this information overflow is constant (Lewis, 2003). The role of the practitioners as educators becomes increasingly important while the patients need help in finding the sources of relevant information. The internet is a powerful resource for patients seeking health information and advice. But the quality and variability of online content means that, unguided, patients are exposed to information that is sometimes misleading, frightening or simply irrelevant. Healthcare organisations are in a position to offer relevant information to their patients in an easily accessible and understandable form. Indeed time pressures on initial appointments with general practitioners mean that GPs are now starting to direct patients towards trusted reliable sources of information online (NHS Choices, Patient UK) for further reading. It is a known challenge that only a small amount of the information provided in traditional PE counselling sessions is understood by the patient and solutions are needed for optimising this delivery. It is also known that patients do not always follow the “doctor’s orders” and that this is dependent on, *inter alia*, the practitioners interpersonal skills or the patient’s level of education (Smith et al., 2009). However it is also recognized that if an appropriate level of trust and confidence are gained during the patient education sessions, then the greater the patients’ intention to follow the prescribed plan of care. (Hayes, 2007). The content of the sessions then whilst of course important is perhaps equaled by the manner in which it is delivered. Indeed a central aspect of role of nurses in the delivery of PE is actually to reduce patient anxiety (Swindale, 1989).

Technological applications for PE have been developed for a number of purposes including, as teaching material, as decision aids, and as a method for acquiring informed consent. They are seen as an opportunity to lower costs as well as facilitating easier retrieval and storage of information (Stoop et al., 2004). However there are both failures and success of these technological PE systems. The inclusion of audio and video clips of patient stories, for example, to enhance decision aids and thus improve decision making itself remains controversial (Bekker et al., 2013). The educational systems should offer patients a high level of information and strive towards better comprehension, enabling them to be more involved in decision making and dialogue with the healthcare professionals. Prior to any design process patients’ needs should be explicated in detail. There is no requirement to try and design systems that replace traditional face-to-face PE as these are likely to fail. We know that face-to-face communication has been proven to increase trust and therefore technology should only be

used as an additional element to supplement more traditional means of PE (Stoop et al., 2004).

In the current study we explored the opportunities of information and communication technology (ICT) in PE and counselling. Since we were equally interested in the perspective of the patient and the healthcare organisation (in this case, a hospital), we chose to use nurses with experience about PE as our informants. The purpose of this strategy was to provide a direct view of the life of the nurses, as well as a mediated view of the patient. The experience of the nurses chosen to take part in the study actually meant we were able to explore a wide range of mediated patient perspectives.

The study was conducted in the department of gastroenterological surgery and the research context was pre-operative PE session.

We gathered PE related ideas using a so called Rich Use Scenario (RUS) method (Pirhonen et al., 2007). RUS was originally created for the purpose of user-interface design. In particular, the design of non-speech user-interface sounds was in focus when the method took shape. In its original usage, the idea was to encourage design panellists to identify themselves with a character in a story. This story, typically about some every day situation, allowed the character or characters at some point to use the application whose user-interface was the subject of the design process.

In some cases the story has been implemented as a live ‘radio play’, (just reading the story aloud, see Pirhonen et al. 2006) and in some case studies as a recording (e.g., Pirhonen et al. 2007). When the primary interest was the user-interface sounds, the recorded version enabled the implementation of those sounds.

The core idea of RUS is to identify oneself with a real person and understand that person in a real life situation. This is a starting point for the creation of something new which would promote the construction of something genuinely valuable for the imaginary – but credible – character. The strategy focuses on just one or a couple of fictional characters and this is very different from the typical implementation of use- scenarios, which usually tries to cover as many user types and contexts as possible. In RUS, however, rather than striving for maximum coverage the primary aim is to understand the human being. Empathizing with the character of the story is supposed to result in a different kind of design above and beyond a more mechanical approach. The strategy is appropriate whenever the intention is to design something for human beings, whether a physical item, computer application, or a service.

The application of RUS started in the case of PE by creating a vivid story about a patient and his experience in hospital including PE. The story was suggested by a panel of five experienced nurses. After some initial instruction and an overview of the general framework for the method the rest of the session focused on the creation of the story – starting with the creation of the characters and the patient character in particular. The creation of the actual story proceeded as a form of collaborative story telling – one participant narrated a section of the story and then handed over to another nurse to continue. There was no strict order in terms of turn taking; anyone who had an idea continued the story from where the previous participant had finished. In the next stage, the researchers finalised the story manuscript. Then another

panel session was organised. This consisted of a different set of experienced nurses from the same department. There was no overlap between the participants in the first and second panels. The second session started with a brief introduction before one of the researchers read out the story. This was followed by a free flowing discussion in which the researchers used a series of open-ended questions to promote discussion. Initially the researchers were interested to know whether the panellists had found the story credible and realistic. Then the discussion proceeded to the details of the story. The only explicit theme that the moderators explored was whether the panellists had any ideas about how contemporary ICT could be applied in PE. The overall duration of both sessions was approx. 75 minutes. The sessions were recorded and transcribed.

In the analysis of the transcription our aim was to find themes that could form a thread throughout the discussions. One theme was quite evident in the discussions: that of trust. For instance, when the researcher asked the nurses what was important for the characters of the story, one of the nurses replied: "Probably that trust was created from the beginning. They had a lot of sort of insecurity, and some kind of prejudices, which then faded away". Trust emerged as something that should be pursued in the development of healthcare i.e., the patients' trust in healthcare is a self-evident objective. In order to enhance and develop trust there appeared to be two complimentary strategies: to promote practices that strengthen trust and to avoid practices that weaken it.

1) Strengthening trust: Getting comprehensible information; getting relevant answers to specific questions; being able to share information and experiences; access to peer support; timely information, for example, patients having access to clear instructions about next steps immediately after receiving news of their diagnosis; access to emotional and psychological support in addition to practical information; being able to receive information from a trustworthy source; the importance of the primary nurse; being able to have a dedicated point of contact at all stages of the process as this generates a feeling of familiarity and safety.

2) Weakening trust: Impenetrable information; overwhelming volume of information may cause anxiety and diffidence; a shortage of resources - there are not necessarily the resources to organise primary nurse or adequate amount of PE.

3. TRUST AND E-HEALTH

Human contacts and direct interaction between healthcare professionals and patients appear to be one key factor when striving towards trust and avoiding anxiety. In our study, trust emerged from the discussions amongst experienced nurses, but indeed, trust has previously been found to be a key factor in the actual recovery of a patient (Lee and Lin, 2008). Patient trust in their practitioner is known to lead to empowering outcomes such as activating patients to create their own goals and commit to their treatment plans (Leske et al., 2012). Ongoing, trusting relationships are vital in the health domain and when the patient is committed to

following the plan of care it is also likely that healthcare costs will be reduced (Hayes, 2007).

In terms of information systems, this could suggest the application of the primary nurse principle in providing care and support as well as PE. With the help of appropriate information systems, patient centred practices could be promoted. In an example provided by Graf et al. (2003), a productivity and benchmarking system provides comprehensive workload, staffing, and productivity data daily in real time for the effective management of nursing resources which classifies patients according to their needs for care, not according to the amount of nursing staff working hours available. The authors argue that safe, quality patient care, needs staffing and resource allocation decisions made on the basis of patients' needs for nursing care. Likewise being able to signpost patients to appropriate PE resources requires a sensitive understanding of his or her specific information needs. In some cases these needs are relatively straightforward and of a practical nature. Practitioners can direct patients to ICT resources that allow them to navigate to a 'comfortable' level of information, i.e. the right amount of information given, for example, the stage of their medical condition and their preferences in terms of medical literacy. In other cases practitioners might identify that the patient would value information and advice from peers and welcome the opportunity to share experiences. Reading or listening to other patients' personal accounts may help people to feel supported or may assist them in learning to tell the story of their own illness or condition (Ziebland and Wyke, 2012). In this case the practitioner must recognize that patients often value experiences that provide a good match in terms of condition severity, age, gender and outlook (Sillence et al., 2013) and as such direct patients to relevant websites. The development and deployment of ICT within PE also needs to recognize the patient's information needs in addition to their level of competence with and acceptance of ICT. Technological obstacles have proved to be unanticipated barriers to using purpose built technology to support healthcare needs (Maitland and Chalmers, 2009).

At a general level, we propose that gaining and maintaining trust towards a healthcare organisation should be taken as a primary criterion in the development of healthcare, including applied information systems. The starting point for PE-applications, for example, should not be cost savings alone, but increased quality of information delivery and interaction; if the development of such a system weakens trust, it undermines its whole function. For instance, Andreassen et al. (2006) found that technology mediated communication between a patient and GP has an impact on trust. Factors such as careful listening, responsive feedback, and whether the patients feel that the doctor is able to understand their distress or vulnerability were clearly affected by the presence of communication technology. It cannot be concluded, however, that the effect is always negative; for instance there is some evidence suggesting the appropriateness of e-mail communication between patients and GPs (Roter et al., 2008).

Instead of seeing ICT only as a tool for mediating doctor-patient communication, technology's potential might be in the efficient gathering and provision of information. Following up on information imparted during discussions

with the doctor is one of the main drivers of internet use for health purposes. Patients who have spent some time online sifting and sorting information may also feel better prepared for consultations with their healthcare professionals (Sillence et al., 2007) These kinds of systems could save time that could be better spent in, for example, face-to-face communication (Andreassen et al., 2006).

Besides the importance of trust, another central conclusion from our study was that PE can no longer be conceptualised as a discrete function, only existing within the realms of a traditional, dedicated face-to-face PE-session.

A patient wants to trust in the expertise of the healthcare professionals around them and therefore takes all their comments seriously regardless of the context. For instance, medical doctors do not usually regard PE as being part of their job. We argue, however, that for a patient, all interaction with a doctor or with any other healthcare professional has fundamentally the same significance as dedicated PE-sessions. PE should not be thought of as being easily packaged into separate elements rather as a process that begins often before the first consultation and continues throughout the health episode. During this time patients both actively seek and passively receive PE from leaflets, medical discussions and incidental comments, other patients, family and friends and a range of media sources. Therefore the elements enhancing trust should be acknowledged in all patient-healthcare practitioner interaction situations as well as in all situations when information is delivered from the healthcare organisation to the patient. This will mean recognizing situations which may not at first appear to be about PE. Sessions, for example, that are arranged within the healthcare organisation for groups of patients about to encounter the same treatment are often viewed solely as support opportunities for patients. These sessions, however will provide patients with the opportunity to exchange experiences, overhear information and ask questions of each other and the medical staff. Patients may often be looking to draw comparisons and to gain any additional information about what the treatment procedure will be like for them as an individual. Healthcare practitioners will need to be aware of these opportunities and respond appropriately enhancing the potential for the development of a trusting environment. Such encounters within the healthcare organisation also allow professionals to become aware of PE that patients are exposed to outside of that setting and consider how best to manage any issues arising from those other sources.

In terms of PE-applications, this can put pressure on the development of ICT for healthcare. How can patients be given the impression that they are important? How can they be assured that we as human beings and healthcare professionals care for them and will use all available means to promote their health and well-being?

4. DISCUSSION

The utilisation of contemporary information and communication technology in patient education is frequently handled as a straight forward solution to the existing needs. The setting is familiar from numerous other contexts in which the technology experts believe that they already understand the needs. When ICT-based solutions are then

implemented, they inevitably have an impact on the functions they deal with. i.e. it is a question of the classic argument about the inseparability of the form and the content (McLuhan, 1964)).

In PE, the intentions to apply ICT are typically based on oversimplifications about the needs and nature of PE. When handling PE as an information system, we should be aware of the changes that the application of ICT causes. When ICT is introduced as a new opportunity in PE, we should take care that it remains an opportunity; if the introduction of a new ICT based process implies the rundown of existing practices then ICT is no more an opportunity but rather a necessity. Too often, we do not allow different options a chance to exist in parallel and let time show which one best meets the real needs. Financial arguments are often presented to justify the construction of one single form of service, but if this results in the decline of the quality of PE, it has a cost as well.

We have dealt with concepts at different conceptual levels. First, we found that trust is a key issue. Second, we concluded that interpersonal communication which indicates caring and expertise is essential in the creation and maintenance of trust. Thirdly, we argued that all these forms of communication can be conceptualized within the framework of patient education. Finally, at the most practical level, we argue that whatever technology is used to enhance communication it has to be applied in terms of trust and ultimately the objectives of patient education. The relationships between these concepts are illustrated in Figure 1. The illustration stresses that PE can be seen as the overarching theme – it is the big picture within which, for example, the applied technology (ICT) has mostly an instrumental value.

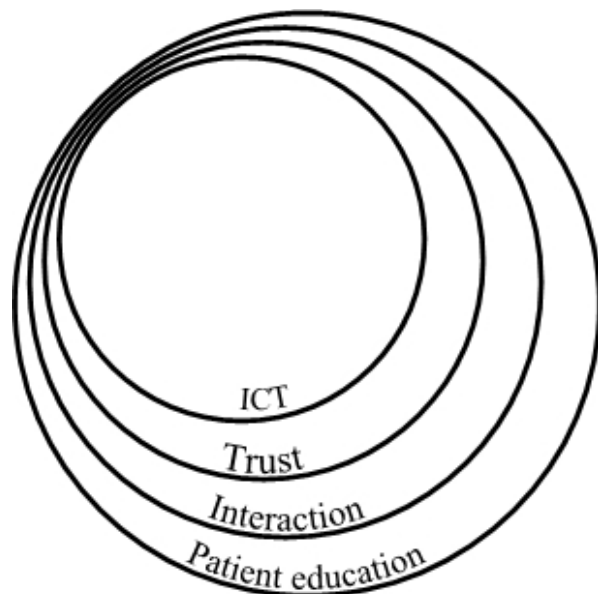


Figure 1. Conceptual framework

In the current paper, we propose a broad definition of PE. In addition, we derive arguments about the utilisation of ICT in PE from the actual objectives of PE. The chosen strategy brings PE to the very core of the whole healthcare

system. Rather than being patient (or even customer) centric, we propose that the development of our healthcare systems should be PE-centric. This is justified by the fact that interaction between the patient and the representatives of healthcare organisation is what healthcare is fundamentally all about. We argue that if the communication between a patient and a healthcare organisation works, it results in benefits in:

- the recovery of the patient or improved self-management of the health condition
- cost savings
- well-being of the care-givers

As can be seen, the potential benefits are so central to the whole healthcare system that the development of healthcare could indeed be built around the concept of PE. The proposed approach would help to see practical implementations, like the utilisation of ICT, from an appropriate perspective. In other words, once we have formulated the objectives for PE, we could apply them as criteria in individual ICT-projects.

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