Patient-Perceived Usefulness of Online Electronic Medical Records: Employing Grounded Theory in the Development of Information and Communication Technologies for Use by Patients Living with Chronic Illness

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Abstract

Objective: Patient use of online electronic medical records (EMR) holds the potential to improve health outcomes. The purpose of this study is to discover how patients living with chronic inflammatory bowel disease (IBD) value Internet-based patient access to electronic patient records.

Design: This was a qualitative, exploratory, descriptive study using in-depth interviews and focus groups of a total of 12 patients with IBD of at least one-year duration at University Health Network, a tertiary care center in Toronto, Ontario.

Results: Four themes have been elucidated that comprise a theoretical framework of patient-perceived information and communication technology usefulness: promotion of a sense of illness ownership, of patient-driven communication, of personalized support, and of mutual trust.

Conclusions: For patients with chronic IBD, simply providing access to electronic medical records has little usefulness on its own. Useful technology for patients with IBD is multifaceted, self-care promoting, and integrated into the patient’s already existing health and psychosocial support infrastructure. The four identified themes can serve as focal points for the evaluation of information technology designed for patient use, thus providing a patient-centered framework for developers seeking to adapt existing EMR systems to patient access and use for the purposes of improving health care quality and health outcomes. Further studies in other populations are needed to enhance generalizability of the emergent theory.

growth in the use of the Internet by the general populace for health information seeking. This apparent paradox exists because patients assess both the value of the Internet and their capacity to use the Internet from their own frames of reference and are motivated to use the Internet to meet their perceived needs. In other words, patient acceptance and use of the Internet for health information seeking is realizable because patients perceive that there is a seemingly good fit between the Internet and their perceived needs, wants, and capabilities.

Conversely, a lack of a definitive characterization of the patient’s point of view may be responsible in part for the uneven record of patient-directed ICT such as access to EMR and online peer-to-peer communities to demonstrate consistent, measurable impacts on health outcomes. Therefore, the onus is on the health informatics research community to develop sound theoretical models for the design and evaluation of patient-use ICT that take into consideration the unique challenges of being a patient.

Background and Rationale

More than 40% of patients have at least one chronic illness, accounting for nearly two thirds of all medical expenditures. Because of their long time frame and high attendant costs over time, chronic illnesses lend themselves to electronically mediated self-management tools. Prototypes of Web-based, patient-centered ICT have been demonstrated to support self-management of illness and enhance understanding of the complications of poorly controlled disease. Patients living with chronic illness are also more likely to use health information than their healthier counterparts, although each chronic illness has specific, recognizable challenges for affected patients in symptom comprehension, information management, task fulfillment, and social interaction.

A descriptive, exploratory research approach such as grounded theory is well suited to uncover the nature of chronically ill patients’ perceptions of reality, how these perceptions create meaning with regards to the specific phenomenon of access to medical records, and how the patients’ subjective meaning about this phenomenon contributes to their eventual acceptance and use of EMR. Iterative interplay between data collection and analysis allows for the “emergence” of concepts directly from the language and perspectives of the actual chronically ill patients. Subsequent integration of these concepts with the researchers’ interpretation of the literature results in a theoretical framework that is “grounded” in the realities of chronically ill patients. This “grounded theory” should then form the basis for the development of systems and evaluation tools that capture this subjective reality of potential patient-users. In contrast, development that is guided solely by information system designers’ and clinicians’ beliefs about patient-users may result in ICT that do not fit with the actual challenges and informational needs of patients living with chronic illness in the community.

Methods

Research Setting

The setting for this research was the “iChart” project at University Health Network (UHN) in Toronto, Ontario, a collaborative research initiative that partnered patients, clinicians, and technical specialists in the design and development of patient access to online EMR. The original intent was to study a group of patients affected by one chronic illness. Although many patient groups were initially considered, a strategic decision was made early on in the study to focus on inflammatory bowel disease (IBD) patients. Despite concerns over limits to the generalizability of eventual results, this proved to be the most fruitful choice because of ease of access for the research team to this particular patient population.

Inflammatory bowel disease is a prototypical chronic illness: complex origin and insidious onset followed by a trajectory of long duration with unpredictable exacerbations and remissions, psychosocial etiologies and ramifications, incurable or nonspecifically resolving with the potential for long-term functional or physical disability, with numerous strategies for direct and indirect treatment, and in which patients are active agents in management. Inflammatory bowel disease patients also tend to be of younger age groups, more technologically aware, and highly interested in self-management of their disease. The specific psychosocial (e.g., body image, loss of control, feeling dirty, isolated, fearful, lack of medical community information and support) and physical (e.g., bowel symptoms, energy loss) concerns of IBD strongly affect patients’ health perceptions and interpersonal relationships. Psychosocial stresses arising during daily living are an important etiologic factor in IBD exacerbations. The potential for discordance between patient and physician perceptions of IBD erodes communication, treatment adherence, and health outcomes.

What is already known about the perspective of the patient with IBD on the use of information in illness self-management appears contradictory. Generally, patients subjectively and objectively need more information than they already receive from their physicians and other resources. While there is high interest in online information, self-reported use of the Internet for information and support is low. Paradoxically, more information may cause either no impact on or worsening of health-related quality of life and psychosocial adjustment.

Sampling Procedure

The study used a systematic, nonprobabilistic sampling procedure. Informants were chosen if it was thought they were likely to possess experiential knowledge of living with chronic illness and personal medical information: Subjects were required to have lived with a long-term incurable illness for at least one year. There were no restrictions on age and gender, nor was computer, technology, or Internet experience a requirement for entry. Subjects were told that the interview was part of a hospital-based initiative to develop access to patient records over the Internet, but previous experience with medical records was not specified as a criterion for study entry. Subjects were reimbursed solely for personal expenses related to attending the interview.

The initial focus on patients with IBD was considered “convenience based” because one of the researchers (PGR), a practicing gastroenterologist, facilitated access to a subject population. However, remaining with patients with IBD was a purposeful sampling decision because, as described
above, IBD fit the characteristics of a prototypical chronic illness.17
Subsequently, our sampling strategy evolved into a theoreti-
cally driven sampling process: After the initial focus groups,
sampling selection identified patients with IBD with a variety
of personal attributes that could either substantiate or negate
previously observed findings,36 including experience with in-
formation systems, other comorbidities, health care–related
work experience, self-professed biases against the Internet
and computers in self-care, and technological “illiteracy.” In
total, 12 patients with chronic IBD of at least one-year dura-
tion were interviewed either in focus groups or individually
in depth (Table 1).

Data Collection Procedure
The UHN Research Ethics Board approved the study. A set of
open-ended questions about information, medical records,
and EMR access and use (Table 2) was employed in in-depth
interviews and focus groups limited in duration to 90 min-
utes. One facilitator assisted by one note taker conducted
each session. Each session was recorded and transcribed ver-
batim. The qualitative research software N-Vivo (Version 4,
QSR) was used to manage data and to provide a structure
for analysis.36
In addition, seven “mock pages” from an online medical
record were shown to participants during each session
(Fig. 1). These were nonfunctioning to avoid bias related to
a patient’s fascination with the particular technology. After
the first focus groups were completed, transcribed, and ana-
yzed, some patient-generated ideas were integrated into
the mock Web pages to stimulate more in-depth discussion
during subsequent interviews.

Data Analysis
A “responsive” approach to data collection and analysis in
which data extracted from earlier transcripts were compared
with more recent transcripts and the literature, termed the
“constant comparison method,” was employed throughout
the study. Data analysis took place both simultaneously
with and immediately following data collection (interviews
and focus groups). As concepts and apparent gaps emerged,
methods for sampling and data collection evolved to address
those gaps.37,38
The researchers employed a three-stage analysis of the
transcript data.39 In the first stage, termed “open” or “sub-
stantive” coding, transcripts were deconstructed into
component key words and phrases. These codes were then
grouped into a loose framework of ideas, a procedure known
as “axial” coding. These ideas were then grouped into a more
structured framework of higher level themes, a procedure
known as “selective” coding.17 Each subsequent transcript
was deconstructed in a similar manner, but the higher level
codes evolved to reflect the integration of newer ideas emerg-
ing from the transcripts into the overall coding structure.

Table 1 ■ Participant Demographics (N = 12)

<table>
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<tr>
<th>Gender</th>
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<td>8</td>
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<tr>
<td></td>
<td>Individual interview</td>
<td>4</td>
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Table 2 ■ Interview and Focus Group Questions

| Current health self-management strategies | Is there any aspect of your illness that you find challenging? What is the most difficult thing to deal with? How do you cope with it? How do you currently overcome these challenges? Are you aware of other things you could do to overcome the challenges? How does your illness affect what you can or cannot do?
| Do you have information resources that have helped you with your illness? Is it helpful? How? What are the sources of this information? Where did you get it? Was it easy to obtain? Did you record the information? Do you carry the information with you? Have you ever received information that was not helpful? Did you receive any information at the time of your diagnosis?
| Have you ever accessed your health record? Do you know whether you have access to your personal health record? What sort of information do you think is contained in your health record? How did/would you gain access? Do you think it would be easy to gain access? Do you think it was/would be useful? Would you like to be able to add information to your record?
| Have you ever used the Internet in relation to the management of your illness? If yes, how have you used it? Have you ever sought information on drugs, treatments, alternative therapies? Have you used communication tools such as chat rooms? How useful was the information to you? What did you do with that information?
| Attitude toward electronic health information | Do you think you would use an electronic health chart if it were available to you over the Internet? If yes, how do you see yourself using it? If no, why not? What are your concerns?
| If you had full control over the design of the perfect electronic health chart, what would it be like? What would be on it and why? How would you use it and why? What issues are important to you that you would like the developer to consider?
| Demonstration of Internet-based EMR, and iChart prototype | What are your thoughts? Did you think things are missing that should have been available? Did you see things you would not have expected? Do you think you would you use any of these? |
While actively immersed in the data collection and analysis, researchers frequently reflected on coding decisions. Researcher “reflexivity” was important because it allowed researchers to bracket their biases, knowledge, experience, and personal feelings to minimize their influence on the analysis process. For methodological rigor, it was important to create an account of these reflections as they occurred. Memos, or brief documents automatically generated and linked to lines of text in the working transcript by the N-Vivo software, were employed throughout the analysis to document not only this researcher reflexivity, but also researcher thinking, discussion, and decisions as well.

Two subsequent individual in-depth interviews were scheduled to address possible inconsistencies and gaps in the early codes and to confirm conceptual saturation. Conceptual saturation refers to the end point in the qualitative data collection and analysis process, when further data collection and analysis cease to generate any new or distinctive categories, high level concepts, or substantive codes. As opposed to quantitative analysis, in which an ideal sample size is calculated before data collection based on previous research and literature review, final sample size in qualitative research is determined before data collection based on the prospective discovery of concepts, and hence there is no specific number that represents an “ideal” sample size. In our study, conceptual saturation appeared relatively early, after ten subjects, and was subsequently confirmed by comparing our preliminary conceptual structure with one generated from the analysis of two transcripts by a second, independent researcher.

Results

Clinician researchers in e-health assert that useful Internet-based solutions for chronic illness self-management facilitate self-monitoring of clinical signs, provide ready access to explanatory information, personalize content, and enhance patient-driven communication, personalized support, and mutual trust between physicians and patients.

Illness Ownership

Useful information technology promotes and supports illness ownership or the capacity of a patient to act on his or her own behalf when appropriate to directly influence his or her illness trajectory. To own illness, patients must have the power to knowingly participate in their care. They must possess an awareness of their illness, the choice to decide whether they wish to create change, and be afforded the latitude and legitimation to act on their own intentions. If patients perceive ownership of their illness, they are more likely to use tools that facilitate the management and solving of their problems.

... And if you actually can see your past and see your test results and you know that you’ve cheated, you can kind of relate why, and take responsibility and make changes ... —Interview 2, Line 641

Table 3 illustrates a small part of the interpretative process taken to arrive at the concept of illness ownership. From several discussions and comments in the transcripts on the subject of patient diaries, words and short phrases have been extracted verbatim. The words and phrases are simplified, where possible, as single-word codes. Related codes are grouped into a set of early concepts or axes. For example, “writing,” “recording,” and “thinking” are all actions that patients do that result in the diary’s content. The fact that patients actively determine content gives them power, and having power over their illness is one aspect of ownership.
Illness ownership is also born of experiential knowledge: living with illness, amassing information, and administering treatments over time. For patients with IBD, useful EMR further promotes illness ownership through on-patient-demand access to historical data, physician’s notes, test results, and explanatory information about relevant laboratory and disease markers, including explanations about things that patients may consider important but clinicians may not.

Anything you can learn is helpful. When you have something, you want to know everything about it, the good and the bad. What can happen to you if you don’t eat properly or medicines don’t take? I want to know the worst and the best — Interview 3, Paragraph 71

A useful information technology also facilitates healthy practices that allow for the creation of change. For patients with IBD, the EMR could (or should) provide a template for arranging appointments and consultations; a workspace from which diet, exercise, and illness-related tasks can be managed; a diary to allow contribution to the medical record; an interface to encourage active participation in research; a resource for appropriately formatted information to accurately and expeditiously fill out disability and insurance forms; and information that piques the patient’s interest. Control over the creation of change in their lives is another aspect of illness ownership.

When a patient describes his or her illness experience, it may be quite structurally different from the physician’s report. The physician synthesizes the patient’s story into an efficient, objective, problem- or disease-focused medical record, and, as a result, many of the patient’s values and priorities are not documented. From the perspectives of patients with IBD, their reality is not captured in the medical record, making it somewhat difficult to recognize the illness experience described in the document. The record becomes less meaningful to the patients as a reflection of their lives and, as a result, less useful. In contrast, when patients bear the responsibility to record the facts of their illness experience from their own perspective, this promotes the patient’s sense of illness ownership.

… I would have the symptoms and the descriptions and then a chronology … other medical problems … my own treatments … self-help treatments did you do … that would sort of complement the doctors. — Focus Group 3, Subject 2, Paragraphs 101–117

Letting the patient’s voice and understanding guide EMR structure and content and letting the patient’s voice direct at least some care decisions that emanate directly from the patient’s documentation promote the sense of illness ownership that enhances the perceived usefulness of patient-accessible EMR. Patients can control who has access to and stewardship of their information. They can also monitor and verify medical record content, take an active role in managing disease exacerbations and complications, and perform some autonomous decision making.

[It] would be my responsibility to look up my test results and if it would be low maybe I would have to get in contact with the doctor; or at that point, you can even … read up on ways to improve your [problems]. — Interview 2, Paragraph 696

**Patient-Driven Communication**

Electronic communication offers opportunities for meaningful patient participation in illness management, decision making, and knowledge creation.

Let’s say I have an appointment with my doctor, I will look back to … what I have written … then I see my doctor, [and] the doctor says “how are you” … at least I have something to report. — Focus Group 3, Subject 2, Paragraph 211

For patients with IBD, useful EMR integrate such communication tools as e-mail links, online bulletin boards, chat rooms, and online consultation services that change the norms of patient communication with physicians, other care providers, other patients, and ancillary health personnel. This communication shift gives patients with IBD greater personal control over the course of their illness and how interactions with physicians are initiated.

A patient … [has] been in ER and is having surgery and says [to the doctor] “you didn’t look at the record” or “you didn’t take the effort to do it” … when the doctor is not necessarily prompted to review that record … the patient [should have] a little pop up [reminder] that says if your medical condition deteriorates, you must notify your physician right away … [it] puts the responsibility back in the in the hands of the patient. — Interview 1, Line 1,629

Therefore, for patients with IBD, patient-driven communication means real change in the dynamic of physician-patient interaction. They envisage a new type of partnership between physicians and patients for sharing of information and...
responsibilities, a real appreciation for what patients know, and taking some burden for the patient’s management off the shoulders of the physician.

I would probably [use the online chart] if I knew ... that the physician would access that prior to an appointment ... If the physician didn’t read it, if it was more of a personal thing [just for me to do], I don’t know if I would kind of follow through with that.—Focus Group 3, Subject 1, Paragraph 199

Ultimately, patient-driven communication affirms that the patient owns his or her illness and that the physician-patient with IBD relationship evolves from one of passive dependency and expectation to one of interdependency, mutual appreciation, mutual support, and shared problem solving.52

[The doctor] isn’t sitting at the desk opposite you [when you are entering information], grilling you and asking you the really pertinent questions to make sure that your facts are straight ... the risk is that the patient incorrectly puts data in and then your doctor may draw the wrong conclusions ... —Interview 1, Lines 1,580–1,604

**Personalized Support**

A patient’s adjustment to chronic illness is made positive by the perception of support.53 A chronic incurable illness such as IBD, as with other uncontrollable events, benefits from two types of support: nurturing (such as emotional, self-esteem, and network forms of support) and action facilitating (such as informational and tangible forms of support). Ideally, nurturing support is best provided throughout each individual patient.50 Informational requirements, emotional support needs, knowledge, and understanding vary and evolve over the trajectory of an illness. The scope and depth of this support should be adjustable to each individual patient as he or she acquires knowledge and experience. For example, such easily accessible support could help patients cope with the inevitable negativity that arises at times in the long trajectory of IBD (without making them feel they are wrong or “bad” to be experiencing such negativity), or if they come in contact with people who misunderstand or are misinformed about the illness.

I don’t want people to think that I’m contagious ... I want people to know that it affects other parts of your body and it does other things to you ... I want people to know what I have to go through and I want them to be able to understand me more ... I am not ashamed of what I have and I think that people should be educated on it ... —Interview 3, Paragraph 287

For patients with IBD, useful EMR would therefore have to be customizable to the abilities, interests, and technological familiarity each individual patient.

Because I don’t deal in this world every day it would be my main concern that [the patient’s chart page] is as clear and easy as possible.—Focus Group 3, Subject 3, Paragraph 528

**Mutual Trust between Physicians and Patients**

Trust is two-way interdependency built on mutual feelings of freedom and intimacy between one individual and another: in a trusting relationship, individuals feel secure enough in who they are so they can open themselves up to others and realize their goals.55 Trust is important in therapeutic relationships between patients, health care organizations, and professionals,56 and is requisite for the promotion of patient self-actualization and empowerment behaviors to improve patient health outcomes and quality of life.57

So you [and your doctor] are sort of on the same page, so to speak. That would be pretty helpful.—Focus Group 3, Subject 1, Paragraph 203

The distinction between a patient “looking at” and “using” his or her medical records to improve their health is grounded in the mutual trust between physicians and patients.58 The trust embodied in the relationship with their physicians is automatically transferred to a patient-accessible EMR system when trusted physicians support such a system.

I assume that my doctor will inform me regardless ... [not] just because I have access to this that I am going to be on it.—Interview 3, Paragraph 358

Patients with IBD expect that the doctor and the hospital that they trust have already ensured the privacy, security, and confidentiality of their personal information and the believability and quality of supportive health information. However, in another study, it was found that a lack of trust in physicians and the health care system is linked to a patient’s desire to look at his or her medical records but not necessarily to use the records positively toward health gains.59

I found it very difficult to access ... personal information about being misdiagnosed ... it was confrontational ... —Focus Group 3, Subject 1, Paragraph 73

Paradoxically, even in the presence of “empowering” EMR, relationships with providers still remain the patient’s “safety net”: supporting patient illness ownership only if the patient feels that he or she possesses the self-efficacy to do so, while always supporting patients with professional confirmation and empathy.48

I don’t want to look up and find out that there’s been an abnormality on my colonoscopy or my mammogram. I think I’d want to hear from the physician first, then I’d like to go on and read it myself.—Interview 4, Paragraph 315

Although patients with IBD are more likely to assess a new information technology as useful if it is implemented in an environment that they trust, they still welcome the opportunity to ensure the integrity and meaningfulness of their personal information.60

... Sending an email to the information system that would update ... and then of course they would have your e-mail as backup ... if something goes wrong down the road, they would say well where did you get that information from?—Interview 2, Paragraph 972
Ideally for patients with IBD, trusted relationships affirm their aptitude to exercise self-care intentions through the EMR, even if some of these intentions may appear counter to the traditional patient role: self-diagnosis, self-triage, self-referral for consultation with dietitians and other professionals and direct access to physicians and to a community of support on demand.

I’d rather [not] wait a couple of days for my doctor to call me ... If it has gone up, that means I have to take one iron pill a day. If it has gone down, I have to take two. A couple of days of feeling better, to me, is worth it ... A good day for me is very important.—Interview 3, Paragraph 187

**Discussion**

Patients in this study evaluate information, technology, and the monitoring of results in terms of their meaningfulness, impact, and usefulness in self-care. The vision of useful EMR of the patient with IBD is a comprehensive informational, emotional, and tangible support ICT that are more complex than an EMR access portal alone. This vision also transcends the original iChart project hypothesis that patient access to their EMR can be an important adjunct to the delivery of quality health care.62 In fact, patients think that it is inadequate just to provide access to test data, laboratory reports, and doctor’s notes.

Since patients manage most health problems without any direct participation from health care professionals,63 it makes sense that patients would define a useful information technology as one that supports self-care through the provision of timely access to services, interaction within the social context of health care, assistance in the interpretation of biomarkers, availability of relevant information, and the construction of healthy practices.16

**Implications for Research Transfer**

To design and evaluate a new generation of useful ICT for patient-users, researchers and system designers require sound theoretical models that adequately capture the determinants of a patient-user’s motivation to use such technologies.64 Theories of behavioral motivation can provide valid conceptual frameworks to assess the influence of individual, technical, organizational, and social network characteristics on a potential user’s likelihood to use an information technology, even before the technology is fully developed and implemented.65

Satisfactory patient-specific theoretical motivational models to predict ICT use behavior do not yet exist, so they have to be adapted from other fields and academic traditions. For example, in the organizational behavior literature, the Technology Acceptance Model (TAM) provides one possible theoretical framework for understanding information technology user behavioral motivation. The TAM has been employed extensively in the workplace context but has not been studied in patients.66,67 In this model, perceived usefulness is considered the strongest motivational predictor of information technology use. Davis68 has defined perceived usefulness of information technology as “the degree to which a person believes that using a particular system would enhance his or her job performance” and that “within an organizational context, people are generally reinforced for good performance by raises, promotions, bonuses and other rewards.” However, since patients with IBD are not employees of the health care organization, reinforcements for use of information technology by patients are much less obvious. Since a patient’s motivation, setting of actual use, and informational needs are different from employee-users or professional-users,69 a patient’s perception of ICT usefulness may be quite distinct as well.

For patients with IBD, tangible technology (e.g., structure, communication tools, and informational content) and its concomitant functionality (e.g., monitoring, management, and communication) are useful in the long term only if they are actively made meaningful. The patient is the owner of his or her life and illness, and the IBD illness experience is a highly personal and individual experience. Informational content and record structure should be adjustable to the comfort level, wishes, and abilities of each individual patient. Capacity for communication with care providers should be streamlined and integrated into the technology. Access to resources should be driven by patient-assessed need, facilitated during periods of stress or crisis when more immediate action is needed, but available throughout the longer quiescent periods of the illness trajectory, when nurturing forms of support are more appropriate. Integration into the existing relationship of trust between patients and physicians envelopes the ICT with characteristics of reassurance, security, and relevance that maximize the patient-perceived usefulness.

**Limitations of the Current Study**

Unlike a quantitative study, the “results” of a qualitative study are extracted largely from descriptions or texts.69 Results are presented in the form of an emergent theoretical framework grounded in the textual data and related to the literature, and the reader is asked to accept the researcher’s interpretation as truth. The interpretative nature of such inquiry limits the study’s generalizability, a limitation of most interpretive qualitative studies that makes many quantitative, positivist researchers uncomfortable. However, because the ultimate goal of patient-accessible EMR is to promote the kind of real patient behavioral changes that can positively influence health outcomes, having rich narrative data explicating the patient’s perspective on the technology is both crucial and necessary. Nevertheless, the research agenda must go further to validate the theory through study of other patients with IBD, as well as other groups of patients and even people unaffected by illness. It is hoped that the emergent theoretical framework of patient-perceived usefulness can then be applied in a more structured manner in the form of a validated questionnaire to guide the formative evaluation of personal health records to empower patients toward greater participation in illness management.

**Conclusion**

Health informatics researchers need to expand research strategies for patient accessible EMR if this technology is ever going to effect desirable patient behavioral changes and improve health outcomes. The patient-user’s perspective on what constitutes technology usefulness is both distinct from and complementary to that of physicians and developers. To build useful ICT tools for patients, direct patient participation must be made part of all steps in the design and development process and, most importantly, in the earliest conceptual stages. Therefore, interpretative analytic approaches such as grounded theory should become an integral part of an ICT research agenda.
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