Patients using open-source disease control software developed by other patients.

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Abstract

Healthcare information systems are traditionally developed within the R&D labs of medical instrumentation providers, software houses, technology consultancy firms, medical faculties and hospitals. Professionals with either medical or IT backgrounds are the perpetual analysts and developers of most health-care information systems on the market. However, we tackle an exceptional variance where patients are themselves creators of their own health-care information systems.

This user-innovation phenomenon was already addressed in academia but mostly by looking at the systems *per se* or their development. In this paper, we turn to the users by exploring the consumer behaviors of patients using such patient-innovated systems, i.e. we explore the consumer behaviors of patients using open-source disease control software developed by other patients.

In a Netnographic approach we screened the product pages and relevant Internet forums around three open-source projects providing disease control software: GNU Gluco Control, MySHI (My Self Health Information) and PumpDownload. A rich set of qualitative data was collected from Internet sites and analyzed with the Grounded Theory method. We developed a theory that unveil two key motivations for the use of disease control software: the patients desire for a more active role in managing their diseases, and the patients annoyance with defective by design vendor lock-in mechanisms from the most common products.

Our contributions increase the understanding on the symbolism, meaning, and consumption patterns of this niche consumer group by screening publicly available data on the Internet, with potential implications to the body of theoretical knowledge in healthcare information systems, chronic care management and practitioners within the industry of disease control.

Keyworks: E-Health, Chronic Care, Patient Empowerment, Open-source, User innovation

1 Introduction

Healthcare information systems are traditionally developed within the R&D labs of medical instrumentation providers, software houses, technology consultancy firms, medical faculties and hospitals. Professionals with either medical or IT backgrounds are the perpetual analysts and developers of most health-care information systems on the market. However, we are aware of a new phenomenon where patients are themselves creators of their own health-care information systems.

This user-innovation phenomenon was already addressed by academia [1], [2] but mostly by looking at the systems per se or their development. In this paper, we turn to the users by exploring the consumer behaviors of patients using such patient-innovated systems, i.e. we explore the consumer behaviors of patients using open-source disease control software developed by other patients.

Taking a Netnographic approach, a novel approach with roots in cultural anthropology, we screened the product pages and relevant Internet forums around three open-source projects providing disease control software: GNU Gluco Control, MySHI (My Self Health Information) and PumpDownload. A rich set of qualitative data was collected from Internet sites, capturing the users backgrounds, lifestyles, medical conditions and their reasons behind the usage of alternative open-source disease control software.

The Grounded Theory method was employed to analyze the data and the method theory-building functions used to propose a theory emphasizing two key motivations for the use of disease control software: the patients desire for a more active role in managing their diseases, and the patients annoyance with defective by design vendor lock-in mechanisms within the traditional and marked dominant disease-control products.

Our contributions increase the understanding on the symbolism, meaning, and consumption patterns of this niche consumer group by screening publicly available data on the Internet, with implication to the body of theoretical knowledge in healthcare information systems, chronic care management and practitioners within the industry of disease control.

In the following section we introduce our methodological approach unveiling the details of how we collected the data from the Internet and analyzed it in accordance to established guidelines on Netnography and Grounded theory. Presented our findings, we discuss its implications for scholars and practitioners and conclude with future oriented remarks.

2 Method

Data-collection

The research questions are *how* do patients use open-source disease control software developed by other patients and *why*. Given the novelty of the phenomenon being study, and given the nature of the research questions, adopted Netnography.

Netnography, also know as ethnography on the Internet, is new qualitative research method that adapts ethnographic research techniques to the study of cultures and communities emerging through computer-mediated communication [3], [4].With roots on the Marketing discipline, Netnography is now recognized as a methodological innovation with crescent legitimacy across disciplines, including Information Systems [5].

The Interned was our medium, and for addressing the research questions we screened and retrieved product pages and relevant Internet forums around three open-source projects providing disease control software. The retrieved data was natural occurring and neither provoked or influenced by the researchers. The researcher tried to learn as much as possible about the products, forums, groups and the individuals we seek to understand without interacting directly with them.

From earlier research [1], [2], we have identified GNU Gluco Control, MySHI (My Self Health Information) and PumpDownload as open-source disease control software developed by patient to patient. In a first phase, and given the software products, we screened their associated Internet pages maintained by the software developers. In a second phase, we searched for complementary electronic bulletin boards, newsgroups, usegroups, usenet groups, webpages, online forums, blogs, indexed e-mail mailing lists, etc where consumers/patients meet to discuss their use of such software products. We limited our research to Internet pages written in the English and Spanish language.

The following Table 1, lists the retrieved Internet sites that we subjected to our analysis. The first three sites are product web-pages maintained by software developers that in our case are also chronic patients. The remaining sites are patient virtual communities, i.e. Internet sites that gather together chronic patients with a particular chronic condition such as diabetes. Patients use such virtual communities to seek and provide medical advise, look for peer support, review new products and services, discuss treatment approaches, advertise products and services, etc.

Table 1: Retrived Internet sites

Internet page	Description	Link
GNU Gluco Control	Product webpage	http://ggc.sourceforge.net
My Self Health Information	Product webpage	http://sourceforge.net/projects/myshi
Pump Download	Product webpage	http://pumpdownload.sourceforge.net
Tudiabetes	Patients virtual community (International)	http://www.tudiabetes.org
Juvenation	Patients virtual community (International)	http://juvenation.org

Diabetesdaily	Patients virtual community (USA)	http://www.diabetesdaily.com
Diabetessupport	Patients virtual community (UK)	http://www.diabetessupport.co.uk
Shotuporputup	Patients virtual community (UK)	http://www.shootuporputup.co.uk
Midiabetes	Patients virtual community (Chile)	http://midiabetes.cl
Wordgnat blog	Patients virtual community (Canada)	http://worldgnat.wordpress.com

The authors neither provoked the research data neither influenced the research sites. In other words, the authors did not participate in the forums, but just read them. Moreover, the author did not use any of the chat-room features available in some of the virtual communities. Those facts have positive implication to the validity of this research as pointed out by [6]. The selection of the research sites, captured in Table 1, took in consideration the nature of the research question and the segment, topic and group being studied, i.e. chronic patients using open-source software developed by other chronic patients. All towards purposing sampling [1], [2] and in consideration with the established research sites evaluation principles as proposed in [3].

Data-analysis

As "netnographers", the authors benefit from the nearly automatic transcription of downloaded Internet sites using a simple Internet web-browser. Give the very special nature of the research topic, the authors did not suffer from information overload that many "netbgraphers" experience. As we addressed an emergent and novel phenomena, the size of the data was manageable for the data analysis, without need for sampling or filtering.

Before applying more sophisticated qualitative data-analysis techniques, the authors performed a first pass or "grand tour" interpretation of the collected textual data. Going back and forward with the data allowed the researchers to be more "familiar" with the data. Some initial categorizations were performed for organizing information regarding *how* patients use this kind software and *why* patients use it. Most of the collected patients/consumers collected textual data revels how they use those systems, but patients/consumers also reveal the motives and pre-conditions of their use of such software. On the esprit of grounded theorizing [6] the initial categorizations were open and did not seek a fit towards the established theoretical body of the knowledge[7], [8].

Given the manageable size of the semi-automatically collected data, we screened all the data as long as new insights on important topical areas were popping up [3], [7]. Regarding the nature of the screened Internet forums, the natural occurring sentences had sufficient descriptive richness depth for revealing the behaviors of patients/consumers using open-source software open-source disease control software developed by other patients. Many reflective textual field-notes were taken by the researchers white reading back and forward the retrieved textual data. Those field-notes were not subjected to coding for the theory-building phase, but they are a recommendable procedure [3] that increased our understanding of the data.

By adopting netnography over the traditional ethnography we lost track of the valuable personal emotions that could be revealed by taking a more face-to-face on-site research approach. But on other hand, we could expand our data-collection much faster by semi-automatic manners. Data-collection and data-analysis were not made in a sequential manner, a very common execution strategy in the traditional ethnographic studies. In this study, data-collecting was expanded several times during the data-analysis, as data linked us to new Internet sites that worthed being collected and analyzed. Given the manageable number of Internet sites, their content and messages, we did not use any qualitative software packages such as NVivo and Atlas.ti . Coding, linking, content analysis and theory building were performed with pen, paper, pencil and paper basket, the last as deposit of several coding and theory-building efforts that led to not so interesting findings.

In consistency with established guidelines on how to conduct behavioral consumer research [3], [9], [10] we searched for a rich, penetrating metaphoric and symbolic interpretation over meticulous classification. In other words, we were more interested in understanding the how and why of this particular phenomenon that on “putting on boxes” the studied consumers. Our approach relying on netnography [3]–[5] is better suited to the classical approach of studying the act [6] in which the ultimate unit of analysis is not the person, but the behavior or the act. In this last point our “netnographic” approach diverges from the established ethnographic approaches [2], [7]–[9] as the research data occur through computer- mediation, are publicly available, generated in written text form, and the identities of the informers being studied are much more difficult to discern [4].

Given the nature of Internet forums, some textual data was marked as “to not consider”. By common sense manners we did no consider for our coding analysis textual sentences revealing extremism, intense hate expressions, intense non-related publicity and apparently off-topic useless talk. We wanted to focus our analysis towards the central topic of the use of open-source disease control software developed by other patients. The employed the Glasserian Grounded Theory [10]–[12] as the core method of data-analysis and technique for theoretical building. We pursued ontological and epistemological consistency with established works in Information Systems Research [13]. The employed the Glasserian aproach to Grounded Theory is already established in Information Systems Research as evidenced in [13]–[16].

Within an qualitative interpretative paradigm and with open and non-strict initial research questions , we enter within the “Glaserian” coding phases employing open-coding, theoretical-coding and theoretical memos. We could identify two kind of main actors within the semi-automatically retrieved textual data: the developers of such software and chronic-patients that are potential-users of such software. In this special case, the software developers are themselves also potential-users of such software. However we could notice that most potential-users do not have the technological and engineering skills required to develop software.

Theory building

After coding line by line, sentence by sentence and paragraph by paragraph, in time-consuming multiple interactions, until reaching theoretical saturation. We finally proposed the following categories and selective codes that drove the inductive and deductive theory building process of grounded theorizing as outlined in Table 2.

Table 2: Theorizing selective codes and categories

Selective codes	Category
Call for the use of own mobile devices Call for involvement on the choice of medical device Call for access to own patient data Call for the control of own patient data Call for self-care Call for proximity care Call for multi-geographical care	More active role on the management of their own chronic disease.
Loss of patient data upon device change. Lack of chronic-care data standards Encrypted patient data. Dissatisfaction with the lack of export features.	Perceived defective by design vendor lock-in mechanisms within the established medical products.

Dissatisfaction with lack of device-change functionalities.

After multiple iterations where we sorted and grouped open-codes into selective codes, the author then proceeded to theoretical coding, where the relationships between selective codes were considered. From the emerging categories we propose the following two theoretical proposition for increasing our understanding on how and why patients use open-source disease control software developed by other patients:

Theoretical proposition 1 – Chronic patients use open-source disease control software developed by other patients for having a more active role on the management of their own chronic disease.

Theoretical proposition 2 – Chronic patients use open-source disease control software developed by other patients due their perceived defective by design vendor lock-in mechanisms within the established medical products.

3 Findings and Implications

After the detailed data-analysis process relying on the grounded theory method, we identified two key motivations for the use of disease control software: the patients desire for a more active role in managing their diseases, and the patients annoyance with defective by design vendor lock-in mechanisms within the traditional and marked dominant disease-control products.

This study ads on previous research on the same phenomena [17], [18]. If [17] raised the awareness on this new empirical trend where patients turn themselves in the creators of medical software and [18] aggregated users-feedback on such products; we addressed the behavioral motivation on the use of such systems. The potential implications to the theoretical body of knowledge in information systems, medicine, chronic care, patient behaviors, consumer behaviors, virtual communities, health-care policy and wellbeing is to be addressed in future research after an systematic multi-disciplinary literature review on IT and chronic-care.

Our contributions increase the understanding on the symbolism, meaning, and consumption patterns of this niche consumer group by screening publicly available data on the Internet, with potential implications to the body of theoretical knowledge in healthcare information systems, chronic care management and practitioners within the industry of disease control.

4 Conclusion and future oriented remarks

We took an ethnographic approach for understanding the behaviors and motivations of patients using open-source disease control software developed by other patients. Data was collected from three product websites and seven related virtual communities (i.e. Internet sites) that gather together chronic patients with a particular chronic condition such as diabetes. After intensive data-analysis, we propose two motives for explaining how and why patients use open-source disease control software developed by other patients: First, the patients desire for a more active role in managing their diseases, and second, the patient perceived defective by design vendor lock-in mechanisms within the market products.

For future, we aim at testing and validating our two proposed behavioral explanations by using complementarity research methods that could enable the triangulation of research results. Interviews or survey instruments could be employed directly with the patient/consumers. However, there are a set of ethical and methodological dilemmas that must be careful mitigated before studying chronic patients with more evasive methods, i.e. the self-awareness of chronic patients that realize that they are being studied due their medical condition can affect the collected data either in the for of interviews or surveys.

This qualitative grounded theory study did not review a-priori a lot of the established knowledge in information systems, medicine, chronic care, patient behaviors, consumer behaviors, virtual communities, health-care policy, wellbeing, etc. In the spirit of grounded theory [13], [19], [20] this is not necessary a disadvantage at the time of the data-analysis; the established knowledge did not affected the categorization or coding of the retrieved textual research data. Extracted two theoretical propositions regarding the patients desire for a more active role in managing their chronic diseases and the patients perception of defective by design vendor lock-in mechanisms within established medical products, the authors will further review multi-disciplinary literature on the subject towards the discovery of theoretical implications that should be reported.

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