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SOCIAL MEDIA IN PATIENTS' SELF-MANAGEMENT OF CHRONIC DISEASE: THE ROLE OF NURSES AS BOUNDARY SPANNERS

Research-in-Progress

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Abstract

This paper presents research-in-progress of the adoption and use of social media as part of patients' self-management of their chronic disease. The purpose is to investigate the social and organizational challenges that social media bring to the healthcare setting. We focus on how nurses can act as mediators between the formal healthcare institution and the informal setting in which patients engage via social media. We discuss how the use of social media influences nurses' professional identity, roles and responsibilities. Preliminary findings and existing literature point to two issues of interest: 1) The inclusion of the informal system of self-management and use of social media into the formal healthcare system and 2) The development of the role of nurses as boundary spanners. We wish to pursue these issues in a three-year research project, conducting in-depth case studies in 10 General Practices to investigate the collaborative partnership between patients and nurses.

Keywords: Social media, health information systems, online communities, chronic disease, collaboration

Introduction

The use of social media in healthcare is gaining momentum (Alpay et al. 2009). An increasing number of patients are becoming active users of health related information provided on the Internet through online patient communities and other types of social networking sites (Honey and North 2009; Rasmussen et al. 2009). We define social media broadly as a group of Internet-based applications that allow the creation and exchange of dynamic, peer-to-peer, and user-generated content (Kaplan and Haenlein 2010; Scott and Orlikowski 2009). Social media provide patients with a broader understanding of their condition and the possibility to engage in social conversation online, relating personal experiences and needs with others (Rodgers and Chen 2005). Moreover, social media provide a wide range of links between items and quality ratings from peers (Agichtein et al. 2008) which can be helpful for patients in making better decisions about their health.

Contrary to clinical electronic record systems that are professionally generated and approved, social media represent more informal and interactive connections among patients who need support in dealing with their disease (Kimby 2006). For example, on Facebook, topics appear such as adverse medication effects, recommendations on medication, and advice on different treatments. Various e-communities also exist, often in relation to patient associations, where patients share opinions, insights, and experiences regarding treatment of specific diseases (Fox and Purcell 2010).

The increased use of social media means that many patients are well-informed about their health condition and take on a new role with respect to self-management outside the realm of formal healthcare institutions (Winthereik and Langstrup 2009). Self-management refers to patients who play an active role in managing their condition and its treatments, side effects, and resulting lifestyle changes. Self-management means that patients make the day-to-day decisions about medication, life-style changes, or undertake preventive actions (Alpay et al. 2009). The focus in this study is on patients who suffer from chronic diseases. For these patients, support for self-management is important as treatment of chronic disease is strongly related to patients' lifestyle e.g. smoking habits, choice of food and level of physical exercise – issues which cannot be managed by medical treatment (Fox and Purcell 2010).

While patients to a large extent benefit from the information they get from peers through social media, some patients experience uncertainty and anxiety when they are confronted with this extensive flow of (sometimes contradictory) information (Kelly et al. 2002). As a result they seek professional guidance which may generate an increased number of inquiries to the professionals in the practice sector[1] (Eysenbach et al. 2004) often related to support for searching and processing information (Steenberger 2009) rather than to traditional medical skills (Petersen et al. 2005).

An example of this is patients diagnosed with diabetes, who can find information using one of the many Internet communities on how to put together various food articles in order to delay glucose absorption or lower the impact of the glycemic load. However, as every diabetic responds differently to different amounts of carbohydrates, or might suffer from other conditions that are affected by what they consume, patients become unsure about what advice to follow and what symptoms to be aware of if they experiment with lifestyle changes. This example shows that social media have great potential in empowering patients by giving them an important role in their own treatment (Rodgers and Chen 2005; Rubunelli et al. 2008); however, it also shows the limitations of social media, particularly in situations where information provided is ambiguous.

While patients suffering from chronic conditions seek online information which is comprehensible and tailored to their health situation, they need skills, tools and support to manage their health (Alpay et al. 2009). A survey conducted by Fox and Purcell (2010) on Chronic Disease and the Internet shows that people living with chronic diseases increasingly use online health services but remain strongly connected to offline sources of medical assistance and advice (p. 2). Support for patients' self-management requests new competences of healthcare professionals involving both provision of information and a collaborative partnership between professional and patient. Where the healthcare professional in traditional care of chronic disease was the expert, whose role was to solve the patient's problems by telling the (passive) patient what to do, the roles of both the professional and the patient are different in a collaborative approach (Bodenheimer et al. 2002). Professionals are still the experts about the disease, but the patients are the experts of their life, and therefore share the responsibility for solving problems and for the outcomes of the treatment. The role of the professional is to help the patient set goals and make informed

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[1]The practice sector refers to the first line of contact with healthcare professionals that a patient encounters such as general practitioners.

choices. Patients are not told what to do, but are taught by professionals how to use social media to support the management of their disease. Although medical knowledge is part of the competences needed for facilitating self-management, new competences related to dialogue, support and care giving become central rather than peripheral as patients become more active in self-management.

The new competences that are required are traditionally held by nurses, and studies show that nurses in General Practices (GPs) are beginning to take on a more active role in the collaborative partnership with patients (Goodrick and Reay 2010). From primarily being doctors' assistants, nurses are becoming independent professionals (nurse practitioners) with an upgrade of existing competences. They are becoming interested and willing to take on new roles and responsibilities (Horrocks et al. 2002; Kaasalainen et al. 2010), including learning how to use social media (Wolf 2009). They come to act as facilitators or boundary spanners (Levina and Vaast 2005) between the patient on the one side and the professional healthcare institution on the other.

In this study we focus on the interaction between patients and nurses when engaging in social media. We study how this interaction is constructed and maintained in practice, and how it develops over time. We are particularly interested in exploring what activities are required to engage patients in social network sites related to healthcare and how to prepare nurses to partner with patients to support their use of social media. We aim to identify potential mediating mechanisms (Olivera et al. 2008) that can be invoked by the nurses and support patients' technology use. To do this we look at what kind of activities nurses can and should initiate to facilitate information exchange between the informal and the formal systems, acting as boundary spanners. This also implies a discussion of how the use of social media influences nurses' professional identity, roles and responsibilities. This will offer new insights into ways of effectively using available social media sources and the possible benefits for the health situation and quality of life for patients.

This leads to the overall research question:

How can nurses in GPs facilitate and support patients' use of social media in the self-management of chronic disease to ensure better quality and coherence of the treatment?

We pursue this research question through in-depth case studies in 10 GPs over a period of three years. Here we want to study the use of social media in the treatment of patients and to follow the nurses to explore the construction of their role as boundary spanners and how this role develops in an interaction with patients, technology, and other healthcare professionals. Our primary focus is on the nurses and their interaction with patients and social media; however, we also include doctors as obvious key players in the construction process.

The remainder of this paper is organized as follows: Next we present the theoretical basis of this study. We then present the research design and methodology, including a pilot study that we conducted in one GP. Based on the findings from the pilot study and existing theoretical knowledge, we conclude this research-in-progress paper by outlining its potential theoretical and practical contributions.

Existing Literature

We draw from existing literature on healthcare resources through social media, identity construction, and boundary spanning to theorize about the mechanisms at play in the interaction between the nurses and patients in collaborative treatment through social media. We argue that nurses come to act as boundary spanners between formal healthcare institutions on the one hand and the informal settings in which patients engage on the other. This interaction has implications for the professional identity and role of the nurses as well as on the expected outcome of a more integrated patient treatment.

Online Health Information and Services through Social Media

Information technology in healthcare, often referred to as eHealth (Lefebvre et al. 2010), spans a broad array of applications ranging from electronic patient records (EPRs), health information web sites, healthcare portals, eLearning programs, and online communities and networks. Some of these applications are designed and managed by healthcare professionals as e.g. EPRs and health decision support systems, whereas others are created by special interest groups of patients or relatives with little or no professional involvement (Kreps and Neuhauser 2010). In this study we are interested in applications that are characterized by engaging people with a common interest or concern in communicating and sharing experience and knowledge about their chronic disease on a blog or contribute to an

online discussion, a listserver or other online group forums on social media such as Facebook, Twitter, MySpace and YouTube as well as dedicated online web-communities as e.g. PatientsLikeMe.com and HealthCentral.com.

To study social media networks and communities, we draw from the notion of electronic networks of practice (ENoP), which emanates from the literature on communities of practice (CoP) (Wenger 1998; Wenger et al. 2002) and which has gained significant focus in IS research in recent years (see e.g. Hara and Hew 2007; Silva et al. 2008; Whelan 2007). CoPs are defined as "…groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis" (Hara and Hew 2007, p. 236). A CoP consists of a tightly knit group of people engaged in a shared practice who continuously communicate, negotiate and coordinate to reify the practice they share (Wenger 1998). CoPs thereby provide a context in which knowledge can be created, shared and sustained. Specific to our study, we have seen an increase in the number of patients and relatives who engage in communities of various sorts to cope with their disease through social support (Leimeister and Krcmar 2005).

ENoPs are special cases of CoPs where the sharing of practice-related knowledge occurs through computer-based communication technologies (Whelan 2007). Wasko and Faraj (2005) define an ENoP as a "self-organizing, open activity system focused on a shared practice that exists primarily through computer-mediated communication" (p. 37). The network is generally self-organized and made up of individuals who voluntarily choose to participate. It is a network open to those who are interested in engaging with others in similar situations. In ENoPs the participants engage in a shared practice through social media such as online communities, blogs, Internet websites, etc. but the group is not as tightly knit and may be larger than in the case of CoPs (Wasko and Faraj 2005). In this context, individuals may never get to know one another or meet face to face.

ENoPs are of particular interest to our study as they may help us describe the context in which patients engage in the self-management of their chronic conditions (Fox and Purcell 2010). With the increased use of social media among patients, healthcare professionals can no longer rely exclusively on traditional and formal medical care but need to engage with patients in these more informal networks (Leimeister et al. 2008; Whelan 2007).

Existing literature has shown that social media can be difficult to reconcile into the traditional organizational and social structures that exist in healthcare (Campbell et al. 2009). These media cannot be controlled by the formal healthcare institution which means that they have primarily been perceived by professionals as a private matter, not directly related to the medical treatment and have accordingly not been part of the curriculum in the education of nursing (Whitehead 2000). However, as the use of e.g. Facebook, Twitter, and other Internet communities have become more widespread amongst patients, research indicates that it becomes vital for professionals to be familiar with the information and the facilities provided by these tools (Wolf 2009).

To enable this change and facilitate effective use of social media, we must focus on the social structure within the health institutions along with the technology capabilities. Social structure is defined by Barley (1986, p. 79) as "patterned action, interaction, behaviors, and cognition" and are aspects of social life which are taken for granted (Davidson and Chismar 2007, p. 741). We draw from the literature which emphasizes the alignment of technology with social structure (e.g. Orlikowski et al. 1995; Vaast and Walsham 2005) to explore how social media can become an integrated part of patients' treatment facilitated by nurses.

Nurses' Role as Boundary Spanners between Formal Healthcare Institution and Informal Patient Communities

In this new constellation of collaborative treatment involving health information and services online, nurses come to play an important role as boundary spanners between the formal healthcare institution and the informal patient communities. This role has implications on the professional identity and role of the nurses. Identity is acknowledged as an important dimension of how individuals, groups and organizations think about themselves and act accordingly (Alvesson et al. 2008; Cornelissen et al. 2007). Although identity theory has not been used extensively in IS research (Gal and Kjærgaard 2009), the concept is gaining momentum and has shown its value in e.g. the study by Lamb and Davidson (2005) who describe the transformations in the professional identities of groups of scientists associated with the introduction of new IT. Similarly, Gal et al. (2008) have studied the transformations in the identity of an organization as it adopted new IS suggesting that IS help to form organizational identities and enable cross-organizational change. And in the studies by Walsham (1998) and Barrett and Walsham (1999) the link between the

introduction of new IT and changes in the identities of groups of professionals in the London insurance market sheds light on the impact of IT on self-identity.

Identity work is the ongoing mental processes that people continuously engage in to construct an understanding of the self that is coherent and distinct. Although the understanding of identity work is that of a continuous process of becoming, this process can be intensified when triggered by uncertainty, anxiety, questioning or self-doubt (Collinson 2003; Knights and Willmott 1989), as well as during crises (Elsbach and Kramer 1996; Martins 2005). We see the new role of nurses as information facilitators as a trigger for engaging in concentrated identity work, thus reconstructing their self-identity as professional nurses.

Previous research on nurses' identity construction has focused on discursive processes and how a more professional role has been legitimized rhetorically over time (Goodrick and Reay 2010), how micro-processes have gradually initiated new roles (Sandelowski 2000), and how the occupational identities of nurses have been manifested and developed (Kirpal 2004). Apker (2004) suggests in a study of managed care that sensemaking among nurses generates interpretations of change that are deeply rooted in their care giving role.

Along with the concept of identity, we draw on the notion of boundary spanners (Wenger 1998) to investigate how nurses can act in their new role as facilitators in building a new joint field between the groups that they span, i.e. patients and healthcare professionals. Nurses are supposed to "...facilitate the sharing of expertise by linking two or more groups of people separated by location, hierarchy, or function" and "...span inter- and intra-organizational boundaries" (Levina and Vaast 2005, p. 338). The concept of boundary spanning is particularly relevant for understanding the role of nurses, as they are often perceived as "the glue" that holds the healthcare delivery system together (Sandelowski 2000; Strauss et al. 1997).

As formal structures may not support the actual practice that involves diverse interests and in which actions may have unexpected consequences, we need to improve our understanding of the actual practices through which nurses engage as boundary spanners which is referred to as "boundary spanners-in-practice" by Levina and Vaast (2005).

By combining the literature of electronic networks of practice with that of identity and boundary spanning, we want to explore the role of nurses as boundary spanners between the professional healthcare institution, characterized by being highly formalized, based on strict professional standards, clearly defined authority and a high degree of control on the one hand and the patients' private use of social media, characterized by informal communication and information exchange, based on ordinary people's experience and highly incontrollable on the other hand.

Research Design and Methodology

To address our research question we adopt a contextualized, interpretive research approach (Pettigrew 1987; Walsham 2006), building on in-depth case studies to answer our explorative "how" question (Silverman 2000; Yin 1994). Interpretive research focuses on understanding phenomena through the meanings that people assign to them (Myers and Avison 2002), and access to reality is through social constructions such as language, consciousness and shared meanings (Berger and Luckmann 1966). In this study we will mainly follow the work of nurses in GPs to explore how they can facilitate and support patients' use of social media in the self-management of their chronic disease to ensure better quality and coherence of the treatment. We are particularly interested in the way the collaborative partnership between nurses and patients develops over time through the use of social media and how this partnership is facilitated by nurses as mediators.

Empirical Setting

The data collection aims at gaining in-depth insight into the attitudes, perceptions, actions, and interactions of the participants in their everyday context. We base our empirical study on 10 Danish GPs that will be selected based on their engagement in social media and interest in participation. We choose to conduct our study in medium-sized and large GPs where six to ten doctors and two to four nurses are employed.[2] In this way we can engage as many healthcare professionals and patients as possible and get different views on the use of social media. The size of the GPs is also important as medium-sized and large practices will have a higher number of patients with chronic

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[2] In Denmark 78% of GPs have from one to three doctors and on average one nurse to every three doctors (Hansen et al, 2008).

diseases and thus may wish to support those patients' self-management of their condition. Our ambition is to gain access to two GPs in each of the five Danish regions in both urban and rural areas to ensure geographical diversity and possible divergent views on the subject matter.

So far we have gained access to two GPs in the capital region. We have conducted a pilot study in one of these practices where we observed the work procedures and interviewed three nurses and seven doctors about their daily work. We were interested in knowing how doctors and nurses divide tasks and responsibilities between them and discuss the new role of nurse practitioners. We did not interview patients in the pilot study but in the (coming) second data collection round, the primary focus will be on the patient-provider consultations and on the different types of social media that are used in consultations.

Data Collection

The ambition is to collect data over a period of three years based on observation studies, semi-structured interviews, data from online conversations on social media websites among patients and between patients and nurses, group interviews, and written documents. We will conduct **observation studies** of the interaction between nurse practitioners, patients, and doctors during consultations. The purpose is to investigate how daily work practices are conducted in GPs, i.e., what tasks nurses perform, how they communicate with patients, which tasks doctors and other personnel perform, and the interrelationship between the personnel. We will also focus on the different types of social media that are used in patient consultations. Furthermore, observation studies will be conducted outside the GPs to observe how patients interact online and how nurses engage in this online conversation.

The primary data collection technique will be based on **individual semi-structured interviews** (Kvale 1996) with relevant stakeholders. We will interview 20-25 nurse practitioners from the GPs about their perceptions of, and experiences with, their work. We are primarily interested in understanding the roles that the nurses take on in relation to prevention, care, treatment, support, and counseling with respect to patients suffering from chronic conditions. The interviews aim at identifying how the nurses perceive their duties and roles, how social media affect their work, and what their visions are. We will also interview patients about their perceptions of the treatment and care they receive in the GPs as well as their use of social media in relation to their chronic disease and we inquire into patients' perceptions and experiences of self-management of their treatment by the use of social media combined with support from the formal healthcare system. Finally, we will conduct semi-structured interviews with doctors (approximately 20) from the same practices to examine their perceptions of the organization and management of the work. We will investigate how the doctors perceive the use of social media and the nurses' roles and responsibilities in this respect. The interviews will be repeated each year, resulting in a large amount of interview data throughout the three years in which the project takes place.

An important part of the empirical material includes **data from social media websites** to analyze the online communication taking place in the collaborative partnership between professional and patient. In this respect, we will investigate how patients engage in social conversations online that reflect peer-to-peer relations. We will also investigate how nurse practitioners become part of this dialogue.

A number of **group interviews** will be conducted with nurse practitioners to open up discussions of the possibilities and limitations of their tasks and roles. The group interviews are creative, reflective, and visionary in nature, and aim at creating new ideas and understandings of the nurse practitioners' work and perceptions of social media. Other stakeholders, primarily patients and doctors, will be invited to participate in the group interviews to discuss the current situation as well as future developments and trends with respect to the collaborative partnership between healthcare professionals, patients, and technologies such as social media.

Documents, reports and other written material will also be collected. This data will provide an overview of the empirical field by looking at the historical development of nurses' work, and the development in primary care, primarily with a focus on the use of social media. Furthermore, written material about related areas, such as municipal health centers and home care, will be included.

Data Analysis

The data analysis will be inductive in nature (Locke 2001; Strauss and Corbin 1998) and based on field notes, interview transcripts, and written material. We plan to use a three step model of coding, categorizing and conceptualizing the data to help us interpret the empirical findings and to find dominant themes that can help us

address our research question. Throughout the analysis process, existing theories will inform our findings and enable us to construct new theoretical insights.

Preliminary Findings and Discussions

In the pursuit of our research question we see several opportunities for discussions which will contribute to existing research on the use of social media in healthcare and which will have practical implications for patients' self-management of their chronic conditions. Although our research is still in progress, based on the findings from our pilot study and existing literature, we center the discussion on two issues: 1) Inclusion of the informal system of self-management and use of social media into the formal healthcare system and 2) The development of the role of nurses as boundary spanners.

Inclusion of the Informal System of Self-Management and Use of Social Media into the Formal Healthcare System

Patients' engagement in healthcare applications on social media is characterized by informal communication and information exchange among peers rather than between professionals and patients. It may be difficult to reconcile these two worlds and the first issue we would like to raise is how the informal system of patients' self-management outside the realm of professional healthcare can become part of an integrated patient treatment. Findings from our pilot study show that doctors are reluctant to discuss information from social media with patients and tend to consider it as private and sometimes irrelevant or untrustworthy. At the same time, however, they are well aware that support from other patients is an important source of encouragement to changes in lifestyle. One doctor mentions:

> "Many patients get motivated to lose weight by reading on the Internet about others who have managed to do so; however, they often pick up the negative stories and get so worried that they ask for more consultations. This of course means money for us but also longer waiting lists."

The increased use of alternative sources of information has implications for the relation between patients and healthcare professionals. In particular doctors have had the authority to provide patients with the medical information that they need and should follow; other sources of information have been considered by doctors as lacking evidence-based data and have been disregarded as valid sources of information. However, the growing awareness that patients need to play an active role in the treatment of their disease creates a need for reconsidering the relation between health professionals and the formal system on the one hand and the patients' use of other more informal sources of information on the other. As stated by another doctor:

> "If patients do not change their way of living, our possibilities for helping them are very limited. And we cannot provide them with a pill to make them do this."

This context is relatively new and may be difficult to reconcile with the traditional, professional healthcare institutions as they are highly formalized and based on a set of standards and regulations that may be difficult to change. We argue that this development represents new challenges for healthcare institutions, which implies organizing, managing, and thinking about the patient treatment in new ways. We will address issues on how to organize the relations between the formal and the informal system in our study including issues of division of responsibilities, and need for as well as lack of control.

The Development of the Role of Nurses as Boundary Spanners

Deriving from the need to include patients' self-treatment into the formal treatment by healthcare professionals, we want to address a second dimension about the opportunities for reorganizing responsibilities within the formal system, i.e. exploring the role of nurses as boundary spanners. From our preliminary findings we see that doctors recognize that nurses play an important role in the long-term support of patients who suffer from chronic illness and other lifestyle related diseases. One doctor mentions:

> "…if the patient tells me that he is not motivated, you know if he is a smoker, a diabetic or a heart patient, I always tell him to talk to the nurse to make a plan."

This is supported by another doctor:

"Nurses are very caring, friendly and cordial … they are better at informing the patients and spend the time they need to provide the necessary information. I think they are better at using a language that patients understand compared to the doctors."

Nurses agree that they should be responsible for the long-term support and consultation of patients:

"We are better skilled in taking care of patients who suffer from chronic conditions, diabetes patients and patients with high blood pressure. We make sure that the patients experience a better coherence in their treatment and we collaborate with healthcare professionals in hospitals. And the patients, at least the chronic patients, are often happy to be consulted by a nurse as we follow more stringent procedures."

Studies show that nurses start to engage in online communities (Danish Nurses' Organization 2008; Wolf 2009), and that they consider the use of social media as a natural part of patients' self-management of their chronic disease. The nurses we talked to are aware of patients' use of social media:

"It is normal that patients have looked up information on the Internet before they come here for consultation. Some of them participate in online communities and get vital support from others who are in similar situations."

However, our findings show that doctors are reluctant to delegate too much authority and control to nurses. They argue that the existing structures, regulations and procedures do not enable new ways of organizing the formal system and they argue that nurses in practice do not wish to take on too much responsibility:

"Although they [nurses] are good at talking to patients, they don't like to make decisions and therefore they often leave it up to us [doctors]."

"Some patients get offended if they realize that they are going to be consulted by a nurse and not a doctor."

We pursue the discussion of how the division of roles and responsibilities between nurses and doctors can be (re)organized to construct a new role for nurses as boundary spanners and how this new role influences the everyday practice of patient treatment in GPs. Based on further empirical data collection, we hope to be able to discuss whether the nurses as boundary spanners should be interpreters, controllers, facilitators, communicators, and/or a collaborators and whether they should break with inherent beliefs and social rules that exist in the social structures of health institutions today in order to create new understandings of patient treatment (Davidson and Chismar 2007).

Contributions

We conclude this research-in-progress paper with some reflections about the theoretical and practical contributions of the project.

Theoretically, this study contributes to our understanding of the adoption and use of social media in patients' self-management of chronic diseases. By exploring critical issues in patients' perceptions and use of social media, the project elicits how the quality of patient treatment in the area of chronic disease can be improved. In line with this we will be able to discuss how ambiguity and uncertainty can be reduced by having a human mediator to support the use of health information systems/ehealth applications.

A second theoretical contribution relates to how the new role as boundary spanners, through the use of social media, influences nurses' identity (re)construction. In this respect, we will discuss what organizational and managerial implications this entails in the existing healthcare practices that are characterized by a long history and well-established traditions.

As a practical contribution, we provide guidelines to GPs and nurse practitioners about organizational and managerial issues that need to be addressed in order to integrate social media in the treatment of patients. We expect to provide new knowledge about how nurses can improve their support of the chronically ill in self-managing their disease in order to improve the treatment of patients and increase their satisfaction with the healthcare system. This entails guidelines of the competences that nurses need as mediators but also what it requires from patients to engage in a collaborative partnership.

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