The influence of the Web on the decision-making process during the pregnancy-puerperal cycle: Literature review and proposal for a research project

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Abstract

In the context of the existing paradigms of communication and health, this paper explores the influence that the web may have on the decision-making processes of women who are either pregnant or in the six weeks following the delivery — the pregnancy-puerperal cycle. For this, the processes of 'autonomy' and 'mediation' will be analyzed, considering their importance to understand how search practices and procedures are carried out on the web.

The aim is therefore to assess whether the decision-making process of pregnant and postpartum women – in first and subsequent pregnancies – is influenced by the search for information provided by institutional and/or commercial websites, and if the nature, quantity and quality of information is taken into account when choosing a source of information.

Moreover, we want to understand whether the participation of pregnant and postpartum women in social networks improves their decision-making ability and if the views and stories shared by other pregnant women can influence decisions.

Finally, we are assessing whether the decision-making process of pregnant and postpartum women is supported by the opinion expressed by health professionals or by independent web searches.

This research is being supported by data collected through an exploratory survey applied to pregnant and postpartum women. To complement and better understand the data collected during the survey, we are also conducting in-depth interviews with pregnant women, postpartum women and health professionals. We are also studying the case of an online community specifically developed to support pregnant and postpartum women.

Key Words: Decision-making process; Web; Pregnant; Postpartum woman; Autonomy; Mediation

Introduction

The web plays an increasingly significant part in the decision-making process of ordinary citizens.

Nowadays, this interest in the web as an effective agent in the choices made by individuals is even more obvious when it comes to health issues, perhaps because this area of knowledge has been beyond the sphere of ordinary decision-making for so many centuries, even though it is such a vital aspect of people's lives (Espanha, Mendes, Fonseca, & Correia, 2012). Therefore, cyberspace has provided an excellent medium for exercises of identity construction to take place and develop. In fact, several studies (Katz, Rice, & Aspden, 2001; Murray et al., 2003; Nettleton, Burrows, & O'Malley, 2005 cited in Espanha & Lupiáńez-Villanueva, 2009, p. 3) have noted that the greatest developments in the role of information in the health system and, in particular, in the doctor-patient relationship, concern the enormous flow of medical or health information in the Internet.

It is important to understand the influence that the web has on decision-making processes during the pregnancy and puerperal cycle. This task is even more significant due to the specificity of pregnancy and to the multitude of options that it entails.

Healthcare professionals should recognize the

importance of this new reality and take it into account when caring for pregnant women. The processes of autonomy and mediation must be analyzed, therefore, with special heed paid to how they can influence the information search on the web, to ascertain the way that women make decisions regarding their pregnancy in the digital era.

The aim is therefore to understand if the decision-making process of pregnant and postpartum women – in first and subsequent pregnancies – is influenced by the search for information provided by institutional and/or commercial websites, and if the nature, quantity and quality of information is taken into account when choosing a source of information.

Moreover, we want to understand whether the participation of pregnant and postpartum women in social networks improves their decision-making ability and if the views and stories shared by other pregnant women can influence decisions.

Literature review

a) Lagan, B. M., Sinclair, M., & Kernohan, W. G. (2010). Internet Use in Pregnancy Informs Women's Decision Making: A Web-Based Survey. [Article]. Birth-Issues in Perinatal Care, 37(2), 106-115.

"Internet Use in Pregnancy Informs Women's Decision Making: A Web-Based Survey", Lagan *et al.* (*B. M. Lagan et al., 2010*), used an exploratory descriptive design method through an online questionnaire survey answered by

613 women from 24 countries over a period of 12 weeks, and yielded the following results: 97% of the respondents use search engines (especially Google) as a means for identifying web pages with information related to pregnancy (1), finding support groups (2) and shopping online (3). Moreover, about 94% of the women in the sample said that that they had searched the web to supplement information previously provided by their health care professional, whereas 83% stated that the research was done to help the process of decision making; in fact, about half of the respondents mentioned the lack of time spent with and limited information provided by the health professional as reasons for searching online.

From the statistical point of view, the self-confidence levels of pregnant women increased significantly after searching the web. This alerts us to the growing need for health professionals to help pregnant women to search, interpret and use information on the Internet about their condition. Above all, this article reveals the possibility of searching the Internet as a way to complement information previously provided by the health professional, which is considered insufficient by nearly half of the respondents. Therefore, it is worth highlighting the importance of teamwork between the pregnant woman and her doctor, which may be of benefit to both. Of particular interest to our research, this study also emphasizes the increased confidence of the mother as the result of the search on the web.

b) Lagan, B. M., Sinclair, M., & Kernohan, W. G. (2011). What is the impact of the internet on decision-making in pregnancy? A global study. Birth (Berkeley, Calif.), 38(4), 336-345. doi: 10.1111/j.1523-536X.2011.00488.x

Having previously investigated Internet use by pregnant women and the effect of their searches on the decision-making process (B. M. Lagan, 2006; B. M. Lagan et al., 2010), Lagan et al. (Briege M. Lagan, Sinclair, & Kernohan, 2011) undertook a new study, electing to use the interpretive tradition of qualitative research. Pregnant women's experiences and representations while using the Internet as a research tool for information on their condition were explored in depth, together with the influence of this medium on their decision making. The authors analyzed 13 online focus groups, asynchronous, from 5 countries (Australia, Canada, New Zealand, United Kingdom and United States), with 92 women using online research for a period of 3 months.

The central theme identified was related to "the need for information" in order to "validate information," and for "empowerment," "sharing experiences" and "assisted decision-making". The reasons given for preferring this type of research included the ease of obtaining knowledge, the possibility of anonymity, social support and security stemming from it, satisfaction, interactivity, clarity, control and possibility of choice.

This study suggests that the pregnant woman is becoming an increasingly informed consumer, demanding more control over decisions that are related to motherhood. Thus, not only should the research carried out by pregnant women be discussed at follow-up appointments but also the health professional should provide some guidance on the most appropriate websites to visit.

This article also enumerates the reasons given by the sample for searching for information on the web, which clearly indicate a desire to have greater confidence and control regarding the decision-making process. Additionally, we consider the association made between individual research carried out by pregnant women and the intervention of the health professional of utmost relevance.

c) Larsson, M. (2009). A descriptive study of the use of the Internet by women seeking pregnancy-related information. Midwifery, 25(1), 14-20. doi: 10.1016/j.midw.2007.01.010

Within Europe it is important to look at Sweden, where prenatal care is provided mainly by the public health system, meaning that patients bear no financial burden during pregnancy, childbirth and the postpartum period. In this country, midwives have the responsibility and authority to monitor uncomplicated pregnancies and births (Larsson, 2009).

Larsson's (2009) goal was to ascertain whether pregnant Swedish women used the Internet to search for pregnancy-related information, how they perceived the trustworthiness of the information, and if they discussed this information with their midwife during antenatal care visits.

Methodologically, this was a descriptive study based on questionnaires handed out in the waiting rooms of 11 antenatal clinics. A total of 182 women, with an average age of 31 and at least 32 weeks pregnant, participated in the study.

91% of the women surveyed had access to the Internet and 84% used it to search for information related to their condition, especially in the early stages of gestation. Fetal development and stages of childbirth were the two topics of interest mentioned most often. Most participants considered the information found to be reliable, according to the following main criteria: if the data collected were consistent with information from other websites or sources, and if there was a list of references. However, 70% of the women did not discuss the information from the Internet with their midwife, even though 55% had searched for information on topics she/he suggested.

The author advises the health professionals in this area to take this opportunity to discuss web-based information with pregnant women.

This study is very relevant to our research, not only because of the similarity of the context portrayed with the Portuguese health sector (National Health Service) but also in terms of the method used and the conclusions reached. Indeed, waiting-room questionnaires might be a useful tool in future research work. Moreover, it should be noted that most of the women had searched for online information related to the phases of pregnancy and childbirth, especially in the first months of gestation.

d) Usui, N., Kamiyama, M., Tani, G., Kanagawa, T., & Fukuzawa, M. (2011). Use of the medical information on the internet by pregnant patients with a prenatal diagnosis of neonatal disease requiring surgery. Pediatr Surg Int, 27(12), 1289-1293. doi: DOI 10.1007/s00383-011-2965-6

The topic of decision-making by pregnant women has also been analyzed in Japan, specifically concerning risk pregnancies. Usui et al. (Usui, Kamiyama, Tani, Kanagawa, & Fukuzawa, 2011) wanted to clarify the problems associated with the use of medical information online during pregnancy in patients diagnosed with fetal anomalies. A survey was conducted at a single Japanese healthcare institution by means of an anonymous questionnaire given to 155 pregnant women in the circumstances mentioned above, between 2000 and 2009.

Participants were asked several questions: the diagnosis of fetal complications; the gestational age when the complication had been detected; if they had searched the Internet for information related to the problem and what information they had found; their opinion regarding the reliability of the web-based data and if they had compared the information collected online with that provided by their doctor. They were also asked whether they would use the researched information and what information they would specifically like to have, should they face a similar situation again.

It was found that 57.3% of the respondents collected information online during pregnancy. In 60% of the cases, a different impression was gained when the information from the web was compared with that provided by health professionals: the respondents considered the web information more frightening and negative than what their doctor told them.

The authors concluded that the number of pregnant patients who search the Internet has greatly increased in recent years and that these women experienced a greater feeling of anxiety and negativity concerning the severity of the disorder that affected their babies.

This Japanese study highlights an issue we also intend to analyze in our research: pregnant women diagnosed with fetal pathology. We believe that this is a matter of crucial importance, as in this situation parents are urged to make very serious decisions. Therefore, we aim to assess whether parents are influenced by their research of information on the Internet. Also worthy of note is the conclusion regarding increased anxiety and negativity experienced by pregnant women who examine information taken from the Internet, compared with that provided by their healthcare professional.

e) Lima-Pereira, P., Bermudez-Tamayo, C., & Jasienska, G. (2012). Use of the Internet as a source of health information amongst participants of antenatal classes. Journal of Clinical Nursing, 21(3-4), 322-330. doi: 10.1111/j.1365-2702.2011.03910.x

We should also take into account the article by Lima Pereira (Lima-Pereira, Bermudez-Tamayo, & Jasienska, 2012), who consider that there is a large information gap regarding the online research habits of couples who attend childbirth preparation courses.

Their data was collected through direct administration of a questionnaire. 114 women and 21 men in Granada (Spain) answered questions related to Internet use and frequency of web searches, the sources of information about pregnancy, their preference for some online sources rather than others, positive and negative feelings fostered by the webbased information and their willingness to receive instruction on how to access and search the web.

In relation to the results of this research it must be stressed that 93.5% of the respondents mentioned daily use of the Internet and that 97.7% researched information about pregnancy at any given time. However, doctors were the first choice when it came to information (54. 8% of the women and 53. 3% of the men), while the web remained in second place. The most searched topics were related to stages of childbirth and baby names, mainly consulted on commercial websites, since 90% of respondents had no knowledge of non-profit organizations' websites.

The authors highlight the need not to ignore

this new reality – the use of the Internet as a source of information about pregnancy – suggesting that health professionals should advise their patients about which sites to access.

The main input of this article for our study is the introduction of a new concept: the involvement of the father in the decision-making process. Another relevant point is that its findings reveal the future parents' broad lack of knowledge about non-commercial websites.

f) J. H., & Raymond, J. M. (2011). How The Internet Is Giving Birth (To) A New Social Order. [Article]. Information Communication & Society, 14(6), 937-957. doi: 10.1080/1369118x.2011.582132

The Internet has also some influence on public policies regarding pregnancy. On this topic, Cohen & Raymond (Cohen & Raymond, 2011) analyzed the *modus operandi* of three online public forums dedicated to the sharing of pregnancy experiences.

According to these authors, pregnancy is at the borderline between health and disease, for although the pregnant woman is not ill or injured she may suffer from some disorders related to pregnancy. Moreover, most pregnant women carry the burden of the uncertainty regarding the possibility of spontaneous abortions, of harming their fetus or of their own death. In this context, the online forums for pregnant women may contribute to their empowerment by sharing information, encouraging constant questioning, demanding accurate data and challenging health professionals.

This study used the technique of participant observation to explore the communication in 3 online forums: CafeMom: "Talk to Other Moms about Pregnant Pregnancy Who Are Just Like You" (www.cafemom.com/group/pregnancy/); I-Am-Pregnant: "I-am-pregnant.com is your first source of pregnancy and baby information. It's a forum based community of other pregnant women and new mothers" (http://www.i-am- pregnant.com / encyclopedia /) and JustMommies: "JustMommies is the friendliest message board for moms and moms-to-be! Discuss getting pregnant, pregnancy and prenatal care, parenting, and more" (www.justmommies.com/forums/).

From the point of view of our research, this article is relevant for its analysis of online communities and their contribution to the empowerment of the pregnant woman.

g) Tucker Edmonds, B., Krasny, S., Srinivas, S., & Shea, J. (2012). Obstetric decision-making and counseling at the limits of viability. [; Research Support, Non-U.S. Gov't]. American journal of obstetrics and gynecology, 206(3), 248.e241-245.

Finally, we would like to draw attention to one last article that focuses on a rather different point of view. In "Obstetric decision-making and counseling at the limits of viability", Tucker Edmonds *et al.* (Tucker Edmonds, Krasny, Srinivas, & Shea, 2012) studied the factors that influence the process of obstetric decision-making in situations of preterm delivery from the perspective of the healthcare professionals. According to these authors, doctors are influenced largely by the preferences of the patients and by their own opinion regarding patient autonomy. In their view, pregnant women want "everything done" or "nothing done" (Tucker Edmonds et al., 2012, p. 248), as their position tends to be extreme in that stage of gestation.

The same study mentions that while some obstetricians see their role as providing the necessary information so that the patient can make a decision rather than them, others considered that they should not simply present the options available because "empowering patients"

with information does not mean that patients are empowered to make decisions" (Tucker Edmonds et al., 2012, p. 248).

Another factor to take into account is the socio-demographic profile of the pregnant woman. According to the obstetricians interviewed, these factors per se were not taken into account in the process of clinical decision making. However, "such factors did influence patient preferences and their approach to counseling" (Tucker Edmonds et al., 2012, p. 248). Consequently, these professionals felt it was harder to give advice to patients whose education level is poor, and admitted they allowed greater autonomy to those with a higher level of education.

Research Project Proposal

Scope and context

The literature review may lead to the conclusion that in most developed countries pregnant women and those in the puerperium stage do in fact use the web to research information related to their condition (e. g. Lima-Pereira et al., 2012). Some studies state that the web-based information influences the decision-making process of those women (e. g. Lagan, 2006).

There is no information about any national (Portuguese) scientific research on this subject. The investigation of the real impact of online research from the angle of such issues as autonomy and mediation becomes extremely relevant in the context of the new communication paradigms.

Given the present state of the art in this area, it is essential to investigate the Portuguese context, particularly with respect to the decision-making process during the pregnancy-puerperal cycle.

We need to know if the decision-making process of pregnant and postpartum women in their first and subsequent pregnancies is influenced by information they find on institutional and/or commercial websites, and if the type, quantity and quality of the information retrieved is a decisive factor in the selection of websites. It is also important to ascertain whether the participation of pregnant and postpartum women in social networks increases their decision-making capacity and whether the opinions of other pregnant women work as a source of information and influence the decision-making process.

Furthermore, it is essential to understand and compare the impact of both (i) autonomous research on the web, and (ii) the opinions of healthcare professionals on the decision-making process of pregnant and postpartum women.

Methodological approach

From a methodological point of view and bearing in mind the three major paradigms that guide research in the social sciences field (Bisquerra, 1989; LaTorre, 2003; Morin, 1973), our research project is based principally on the qualitative or interpretive paradigm, as it aims to understand how subjects "interpret different situations and the meaning that these have for them" (Latorre, Del Rincon, & Arnal, 1996) in order to be able to "understand the complex world of lived experience from the point of view of those who live it." (Mertens, 1998, p. 11)

However, we must acknowledge the possibility

of an epistemological unity which does not give rise to a paradigmatic confrontation (Walker & Evers, 1997), and therefore advocate combining methods that supplement one another through methodological integration/triangulation (Howe, 1992). Quantitative methods can be used in conjunction with qualitative methods (Pérez Serrano, 1998), including the use of a survey, which is the most often recurring method employed in social research (Landsheere, 1993), as well as a case study, to achieve a wider view of reality.

Therefore, as we need specific information about various behaviors in order to understand the use of the web by pregnant and postpartum women, and the effect of web-based research on the decision-making process, from an operational point of view we would go for a survey, a tool that can be defined as a "question about a particular situation encompassing individuals in order to generalize it" (Ghiglione & Matalon, 2001, pp. 7, 8). This will prove enlightening about the attitudes, opinions, preferences and representations of a given society, in all their complexity (Pereira Coutinho, 2011, p. 276).

Considering that a survey "aims to assess the incidence and distribution of and relationships between variables that are studied as they exist in their natural context, without manipulation" (Miller, 1991; Bravo, 1992b, Wiersma, 1995; Kalof & Stern, 1996; Meltzoff, 1998 cited in (Pereira Coutinho, 2011, p. 277), as researchers we are aware that the answers are not neutral, since they are not produced in a vacuum but in an environment of social interaction.

Thus, our project will analyze the existence (or not) of a relationship between the Internet search for health information and the decision-making process of pregnant and postpartum women in the three different contexts of ambulatory primary care, ambulatory hospital care and inpatient hospital care. We will choose an exploratory survey (Babbie, 1997) to serve as an initial basis for collecting information, and this is being refined and deepened through a case study. It is a transverse survey since the data is being collected on a single occasion, with a representative sample of the group we want to understand.

We believe that this method serves the aim of defining the appropriate research topics comprehensively, considering the influence of the context in which the phenomenon under study occurs and using multiple sources of evidence (Yin, 2001, p. xi).

In our research we are using a convenience sample selected deliberately (Bravo & Eisman, 1998). It is precisely in this complexity that the interest of qualitative research lies. Stake, in fact, warns that we forget that the "case study is not an investigation based on sampling. One does not make a case study to understand other cases but to understand the case itself" (Stake, 1995, p. 5).

According to the categorization of Brewer & Hunter (1989), our case study focuses on behavioral acts, actions and interactions, trying to determine "the 'how' and 'why' of present events over which the researcher has little or no control" (Yin, 2001, p. 9).

In order to study the current practices of web usage by pregnant and postpartum women, we decided to study the case of the online community "Rede Măe". The choice of this community is justified mainly by the fact that it is a project related to our subject of research, with many similarities to our approach, and certified by HON - Health on the Net Foundation.

Data collection methods

We are collecting data by means of a set of printed questionnaires given to: pregnant women in the aforementioned situations; postpartum mothers; fathers, and nurses and obstetric and general medicine doctors of the three services involved. In-depth interviews are also being conducted with selected respondents, with interview scripts developed for audio recording.

Aiming to "prove or disprove effects and relations in the case" (Guba & Lincoln, 1994, p. 111), we compare / contrast the existence of a relationship between a first or a subsequent pregnancy and the researched information, as well as the nature, quantity and quality of information and its selection. The purpose is to assess whether the decision-making process of pregnant and postpartum women in the first and in subsequent pregnancies is influenced by institutional and/or commercial website information research, and if the nature, quantity and quality of the information thus obtained influence their selection.

Moreover, to ascertain whether the participation of pregnant and postpartum women in social networks increases their ability (competence) to make decisions and if the opinions shared by other pregnant women work as a source of information and influence their decision-making, we compare/contrast the existence of a relationship between participation in social networks and the capacity to make a decision, as well as between decision-making and taking into account the shared opinions.

Finally, to analyze the relative influence of (i) the opinions of health professionals and (ii) the online research carried out independently on the decision-making process of pregnant and postpartum women, we compare / contrast the existence of a relationship between the decision-making process and the opinion of healthcare professionals, as well as between the decision and the autonomous web-based research.

Case study classification

This research is being supported by data collected through an exploratory survey applied to pregnant and postpartum women. To complement and better understand the data collected during the survey, we are also conducting in-depth interviews with pregnant women, postpartum women and health professionals. We are also studying the case of an online community specifically developed to support pregnant and postpartum women.

We are also conducting a case study about the online community "Rede Măe" aiming to better understand the current on line behaviours and practices of pregnant and postpartum women.

Our case study also fits into the analytical method of induction (Gomez, Flores, & Jimčnez, 1996), since it is a multiple case, as noted above, aiming to be able to generalize to a broader context.

Conclusion

A number of international studies have shown that information on health is being increasingly researched on the Internet (Espanha et al., 2012). In fact, regarding health policy, increasingly informed citizens, knowledgeable about their rights, are pressuring policy makers to find prompter and better quality answers (Simőes, 2004).

However, if it is true that the Internet, like no other medium, can empower users/patients to act in the prevention and treatment of their condition, it is undeniable that the potential of this virtual interface can also involve great dangers in terms of the protection of privacy and individual rights, as well as the trustworthiness of the conveyed information.

Health professionals must be increasingly aware of this new reality that is reshaping the concepts of patient, doctor and care provider in both the virtual and the real world. However, this new world still needs in-depth studies to understand it and to derive the best benefit from it. That is why we believe that our study could provide an important contribution to this new reality, particularly with regard to the Portuguese context.

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