Communicating health decisions: An analysis of messages posted to online prostate cancer forums

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Abstract

Background: Experiential websites such as message forums and blogs allow Prostate Cancer (PCa) patients to communicate their health decisions to peers. The issues surrounding this form of indirect involvement in public health are little understood. Objective: This paper explores the types of decision making processes that people are exposed to on PCa online message boards. The kinds of treatment choices patients are making and the reports of their decision making processes to peers through an online environment are examined in the context of the Heuristic Systematic Model (HSM).

Method: Messages about treatment decision making were collected from four PCa websites. In total 137 messages were selected from blogs and online forums and their decision making processes coded.

Results: Men looking online for information about treatment options for PCa are exposed to a range of decision making processes. Just under half (49.6%) of the messages reported non-systematic decision processes, with deferral to the doctor and proof of cancer removal being the most common. For systematic processing (36.5%) messages most commonly considered treatment outcomes and side effects. Processes did not vary between the blogs and online forums.

Discussion and conclusion: Compared to previous studies far fewer messages reported non-systematic decision processes and only a small number of messages reflected lay beliefs or mis-beliefs about PCa treatment. Implications for men and their clinicians of seeking health information online are discussed.

Keywords: Decision making; narratives; patient experience; Internet; Prostate cancer

1. Introduction

Health websites allow patients and their carers to communicate information and exchange experiential advice. Studies have documented the social and emotional support these websites offer their members across a range of conditions including sports injuries [1], irritable bowel syndrome [2], infertility [3] and HIV/AIDS [4]. There has been relatively little attention given to the influence such health websites exert in terms of decision making. In a notable exception Ziebland & Herxheimer [5] observe that patients' experiences are an important part of the evidence that people use when making decisions about health care and should be viewed as such rather than as an alternative to traditional sources of information and advice.

Health blogs and forums are examples of the online landscape which are rich with discourse or narratives on patient experiences with a particular disease. This material can be highly variable in terms of its opinion and purpose and in addition to social and emotional support can include reports of treatment decision making processes. Health blogs allow people to communicate a diary like account of their disease experiences whilst message boards are typically more interactive containing queries and responses about, for example, treatment decisions. Similarly, patients accessing these discourses about experience with disease may choose simply to read about other people's experiences [6] or to actively seek advice and information. Visitors to online message forums seek advice both directly and indirectly and their requests often result in advice that is offered rather indirectly through the form of personal experience [7]. A response, for example, might begin 'I can't tell you what to do but this is the decision I made and why'.

Access to experiential Internet based information has shown to be valued amongst prostate cancer (PCa) patients in reducing fear and isolation and assisting with treatment

decisions [6]. Previous research into decision making processes in men with a diagnosis of PCa suggests that in general they do not use medical information in a comprehensive or systematic manner and that their processing can be biased by previous beliefs [8]. These earlier studies were based on data collected through verbal protocols or 'think aloud' techniques from newly diagnosed men in face-to-face settings and it may be that in an anonymous online environment patients feel able to report on a wider range of treatment decision processes free from the pressures of social desirability. Given the concerns expressed over the quality and accuracy of information available to PCa patients online [9] it would seem timely to explore what kinds of decision making processes are being communicated in such forums. Are readers encountering 'advice messages' that are predominantly non-systematic? Given the research highlighting the importance of PEx in decision making what are the implications of this indirect form of involvement on health care. This is the focus of the current study which explores the types of decision making processes posted on PCa websites. The objectives of this study are therefore: a) to describe the treatment decision making processes of men posting messages to online prostate cancer forums; b) to examine whether the medium affects the type of processes reported and finally c) to consider the implications for prostate cancer patients looking online for advice about treatment decisions.

In the UK prostate cancer is now the most common cancer in men excluding non melanoma skin cancer [10]. Worldwide, more than 670,000 men are diagnosed with PCa each year [11]. After diagnosis men are faced with decisions concerning their treatment options. These include active surveillance (no active treatment), radiotherapy and hormone therapy and surgery. Many of the treatments have comparable efficacy but differing side effects e.g. impotence and urinary incontinence [12] making decisions difficult. The fact that the cancer has a relatively slow growth rate makes it difficult to quantify the risk of mortality. Research so far on decision making for PCa patients has shown that men do not tend to use information

about medical treatments in a comprehensive or systematic manner. When asked to talk about their treatment decision making, a large proportion of men newly diagnosed with PCa reported non-systematic decision making processes i.e. deferral to the doctor or pre-existing beliefs about cancer and treatment options [8]. Indeed non-systematic processes are common when people reason about health [13] and systematic and non-systematic (or heuristic) processing modes have been shown to co-occur and interact in terms of PCa decision making [14]. Motivation for systematic processing should be high given the importance of the decision outcome but the uncertainty regarding ideal treatment could cue non-systematic processing to help resolve the issue.

Will men discussing their treatment options with other PCa patients on a health website display different decision making processes to those encountered by researchers in previous studies? As already highlighted previous research has employed verbal protocols as a technique for collecting decision making data from men newly diagnosed with PCa. The fact that men are reporting on the thinking behind their decisions to peers rather than a researcher within an anonymous online environment may also affect the types of decision making processes that people feel comfortable offering. Based on the Heuristic Systematic Model (HSM) [15] it is hypothesized that people who actively use the Internet for health-related purposes might be more motivated to engage in more systematic decision making processes and communicate these online compared to previous studies on treatment decision making using face-to-face interviews [8]. We also expected more systematic decision making processes would be reported in online forums compared to blogs, as posters to the online forums might be aware that their choice of treatment would be queried and discussed by other members.

2. Methods

An Internet search identified online forums/websites which allow individuals with PCa to post their treatment decision making experiences through an online interface. To ensure that messages selected were public in nature which required no inform consent from the members, only forums in which messages were publicly posted and no membership or passwords were needed to access the messages were identified. Also, to ensure a sizeable sample would be obtained and the groups selected were active, only forums containing at least 100 members with at least 50 messages posted to the group within the past 30 days were selected.

All together, four websites met the criteria and were selected. All four websites contained an online forum which allowed members to post a message about their disease management experiences. As the total number of messages posted to the forums was large, only messages posted to the forum between July 2008 to April 2009 were retrieved. Purposive sampling was conducted in which messages threads were browsed by subject title, and those that appeared to address the topic of treatment decision making were opened and viewed. Messages that included a treatment decision and an explanation of how that decision was reached were selected for data analysis. In addition, one of the websites contained a blog which detailed some members' stories of how they coped with PCa. Stories posted to the blog at the same period were viewed and those included treatment decision making process were selected. In all, a total of 137 messages were selected. 41 (31.3%) messages were from the blogs and 90 (68.2%) messages were from the online forums.

First, messages were coded as to whether they captured systematic information processing or non-systematic processing. Specifically, messages were categorised into one of the three codes: 1. Systematic information processing; 2. Non-systematic processing; or 3. A mixture of systematic and non-systematic processing. After the initial coding, messages were further coded into a subcategory of the decision making process. In the present study, a

hybrid approach, which incorporated both the data-driven inductive and the theory-driven deductive approach of data analysis, was adopted to explore the subcategories of treatment decision making processes. Messages were first analysed deductively based on the framework of decision making processes developed by Steginga et al. [8] based on interviews with patients with PCa. Within the framework, subcategories of "expert opinion heuristic", "availability heuristic", and "lay beliefs about cancer treatments and cancer causes" were developed under the category of non-systematic process and the subcategory of "treatment side effects and clinical aspects of prostate cancer" were developed under the category of systematic information process. However, as this framework has not been applied to the analysis of messages posted to online messages, an inductive approach was also adopted to analyse messages that do not fit into the themes of the coding framework. Constant comparative methodology was used and formative subcategories were generated in relation to the research question and then were revised through subsequent reviews of the messages. The subcategories were recreated, combined, and modified until the subcategories captured best the treatment decision making processes of members. Messages were coded by the two authors independently and any disagreements were resolved after discussion.

3. Results

Results showed that just under half of the messages (49.6%) reported non-systematic decision making processing. One third (36.5%) of messages reported systematic information processing in treatment decision making and a small proportion (13.9%) of messages reported a mixture of systematic and non-systematic information processing. The inter-rater reliability of the coding of decision making processes was satisfactory (Kappa = .86). A Pearson Chi-square analysis was conducted to examine whether messages posted to forums differed from those posted on the blogs in terms of decision making processes. Results showed an insignificant difference between groups, χ^2 (2) =.40, n,s,, suggesting that the

decision making processes presented in forums did not differ from those posted to the blogs. Details of the decision making process observed in messages are presented in Table 1.

< Table 1 appears here >

Over the course of re-evaluating the coding frames, it was found that the pre-existing subcategory “lay beliefs about cancer treatment and cancer causes” from Steginga et al. [8] was similar to a newly created subcategory “misbelief about treatment”. These two subcategories were therefore collapsed into one named “misbelief about treatment”. In addition, it was noted that treatment side effects and clinical aspects of PCa were two distinctive themes. Also, many members appeared to consider their own health condition with regards to the clinical aspects of the cancer when making the treatment decision. Therefore, the subcategory “treatment side effect and clinical aspects of PCa” were divided into two subcategories named “treatment side effect” and “self health condition”. 11 new subcategories were also created for the present study, resulting in a total of 17 subcategories (see Table 2 for an overview).

< Table 2 appears here >

Non-systematic processing was identified when the judgement involved the use of previously held knowledge structures in the form of simple decision rules or heuristics. In the present study, nine subcategories were formed under this category and they were described as below:

Expert opinion heuristic [16] messages were defined as those indicating a deferral of decision-making responsibility to health care professionals mainly due to their expertise in the subject area. An example included: “My urologist who specializes in ED and does not play an active role in prostate cancer treatments, sat my wife and I down when he gave us the news and basically said "If you were 65 or 70 I would talk with you about lots of

options. However, at 55 you only have one option and that is surgery..." (M90). Expert opinion heuristic was the most prevalent type of decision making process (16.3%) observed in the present study.

Availability heuristic messages were defined as decisions which were made based on previous experiences and memories, or other people's experiences. An example included: "I did not want surgery....my brother did and the outcome was not good....all of the cells were not removed and he died some time later in diapers and castrated." (S8). Availability heuristic accounted for 6.3% of the messages.

Other people's opinion heuristic messages were defined as those indicating a deferral of decision-making responsibility to people other than medical experts. An example included: "...after thoroughly discussing removal of the prostate with my spouse she was more for it than I. So I decided to have it removed." (S40). Other people's opinion heuristic was observed in only a small portion of messages in the present study (1.8%).

Misbelief in treatment messages were defined as decisions which were made based on knowledge or belief about the treatment which was largely incorrect. An example included: "The best way to get it out for a hoped-for total cure is laparoscopic-robotic surgery and it's the best method for nerve sparing." (M79). Misbelief in treatment was observed in only a small portion of messages in the present study (3.2%)

Gut feeling messages were defined as decisions which were made based on a strong belief about something which cannot completely be explained by reason. An example included: "I feel like I'm definitely going to go the LR surgery route." (S18). Gut feeling was observed in only a small portion of messages in the present study (3.6%).

Faith in staff messages were defined as those showing a trust or confidence in medical professionals regardless of their level of experience or expertise in the subject area. An example included: “I did like him (the surgeon) and the hospital and decided that I would go that route.” (S7). Faith in staff was observed in only a small portion of messages in the present study (3.2%)

Fear of the alternative treatment messages were defined as decisions which were made based on the desire to avoid the alternative option due to irrational fear. An example included: “I don't want radiation, which scares me more than the knife.” (M53). Fear of the alternative treatment was observed in only a small portion of messages in the present study (1.4%)

Proof of cancer removal messages were defined as decisions which were made based on the need of evidence that the cancerous cells were taken out of the body. Surgery is the most commonly chosen option for members showing this decision making process. An example included: “...i did not even like the idea of ‘dead’ cancer remaining in my body. This is a mental thing.” (M5). Proof of cancer removal accounted for 10% of the messages in the present study.

Need for instant action messages were defined as decisions which were made due to the need to take action promptly, regardless of the fact that treatment might not be necessary accordingly to the member’s current stage. An example included: “I am an action person and cannot sit around just hoping and waiting.” (S13). Need for instant action was observed in 4.1% of messages in the present study

Systematic information processing is present when a more thoughtful judgement is made based on gathering and analysing relevant facts and information. Eight subcategories

characterising the different aspects taken by members into consideration were formed under this category and they were described as below:

Treatment side effects: Treatment side effects were one of the common concerns of members when making treatment decision. The most common side effects reported by members were impotence, incontinence, and loss of sex drive. An example included: “I didn't fancy the side effects of hormone treatment, primarily the loss of sex drive, as my wife and I still enjoy a very active sex life.” (S34). Treatment side effects made up 7.7% of the messages in the present study.

Treatment outcome: Treatment outcome, specifically the effectiveness of a given treatment, seemed to be the most important concern of members when making treatment decision and they accounted for 16.3% of the messages. An example included: “According to their database, being under ***, with a Gleason of *** and a PSA under ***, I had a 97% cure rate and a 94% chance of having no long term quality of life issues. *** defined "cure" as a PSA that drops below .02 and stays there for 10 years.” (S3)

Staff experience level, which refers to the experience of the staff in performing a particular treatment, accounted for 4.5% of the messages. An example included: “Eventually decided on Brachy because the surgeon has been doing the procedure for 8 years with the same team, regularly goes on refresher courses, and does 8-10 procedures once a month. I did ask him if he was any good, said he'd done over 700 procedures without any complaints. Good enough for me.” (M80)

Self health condition, which is defined as making the decision based on the patient’s health condition was also commonly observed (14%) in the messages. This included clinical aspects of the cancer as well age and other physical and mental health issues. This category did not include reference to the effectiveness of any treatment outcome but rather attempted to draw a line of best fit between aspects of the patient’s health and the treatment. An

example included: “From what I have learned from the Net, this would appear to be the best option, as I fit the parameters necessary for this option: Gleason around ***, fit, ***-so life expectancy of 10 yrs or more, and a PSA of less than 20 (***)...” (M31)

Time availability was evident in only a small portion of messages (2.3%). An example included: “I chose LRP as it would have the least time constraints on me and my family.” (S39)

Location of the treatment was evident in only a small portion of messages (1.4%). An example included: “I decided that, most things being equal regarding various centers and doctors around the country, that being close to the center, home and family would be the best alternative, both for pre-op and post-op issues.” (M66)

Cost of the treatment was evident in only a small portion of messages (1.8%). An example included: “I was debating on going to *** to a surgeon that had done over 2000 surgeries but the difference in costs, $20,000 in *** vs $50,000 in *** helped in my decision since my insurance was only covering 80%.” (M60)

Knowledge of the extent of disease, which refers to the desire to know more about the degree of aggressiveness of the disease, was observed in only a small proportion of messages (2.3%). An example included: “One significant benefit to having surgery vs. brachytherapy or external radiation is that with the surgery, you'll know for sure the extent of your disease with a biopsy of the prostate, lymph nodes, and seminal vesicles.” (M55)

4. Discussion and Conclusion

Discussion

This study of decision making processes adds to our relatively scant knowledge of the online 'landscape' in terms of PCa and patients' discourse about experience with disease. The findings of this study map out the online domain, they paint a picture of patients communicating their health decisions to peers and reporting on their decision making processes. Men accessing online PCa forums are thus exposed to both systematic and non-systematic decision making about treatment options. Despite some concerns over the quality of the information exchanged in PCa support groups [9] it appears that online at least the PEx landscape is varied with both a strong deferral to the doctor alongside detailed consideration of the patients own health.

Whilst almost half of the messages analysed contained non-systematic decision processes this figure is still way below the 91% reported by Steginga et al [8] in which they asked men to say aloud their thoughts related to their decision making about PCa treatment (although it should be noted that at the time of their study only half the men had made a treatment decision). Differences between the environments and the audiences involved i.e. justifying decisions to a researcher face-to-face, or offering explanations to peers online may go some way to explaining the findings. Given the careful approach taken to these messages forums and blogs by members in terms of proving credibility and expertise [17] it may be that online posters are motivated to collect and analyse information in a more systematic way and that the medium allows them to present their thoughts in a considered and deliberate manner. This is perhaps contrary to many perceptions of the Internet as an anonymous and thus carefree environment for communication [18]. However, non-systematic processes did prevail and in common with the Steginga et al [8] study, deferral to the doctor - the expert opinion heuristic, was the most frequently coded type of non-systematic decision making process. Whilst this was usually reported in terms of a straight forward recommendation by the

clinician (asked for or otherwise) it was occasionally presented as the outcome of a more complex dialogue with the doctor. It could be reasonably assumed the members who shared their treatment decision making processes in the forums are active Internet users and might have used the Internet to aid their treatment decision making. Whilst there has been concern that the rise in the use of Internet for health information might present a challenge to medical expertise [19] our findings concur with others [20] suggesting that despite the proliferation of the use of Internet, doctors' views and professionalism are still highly valued by patients with PCa.

In addition to deferral to the doctor men also made use of the availability heuristic, citing both positive and negative recollections of treatment options and their outcomes. Unlike previous studies there was far more discussion of needing to 'simply get rid of the cancer' and to 'get it out'. The idea of needing instant proof of cancer removal was recognised by many as being somewhat irrational. Although it was on occasion presented as the only thinking behind the decision (for surgery) it was often combined with more systematic processes. This finding is in keeping with the HSM and demonstrates the way in which systematic and non-systematic processing can co-occur within PCa treatment decision making. These mixed messages, for example, included careful consideration of treatment side effects and outcomes alongside expressions of the need for instant action. In the online domain at least men appear to be using more systematic processing than in earlier studies of treatment decision making in PCa. Messages indicated that men were considering treatment outcomes and side effects as well as practical issues of cost and time availability. They were also thinking about how different treatments sat in terms of their own specific health conditions. This included the detailed clinical aspects of their cancer as well as other physical and mental health issues. Messages of this kind reflect the fact that making important

decisions takes place over time. Whilst the verbal protocols used in other studies perhaps provide a snapshot of the decision making process immediately following diagnosis [21], it may be that online messages reflect the culmination of the (sometimes lengthy) decision making process that PCa patients engage in.

There is little control over the accuracy of information and feedback provided on the web and as such there have been concerns that health information exchanged online might be incomplete or inaccurate. Research in this area has found instances of inaccurate or 'non-evidence-based' information from online support groups [22, 23]. An analysis of messages from an epilepsy forum, for example, found that 6% of postings were objectively inaccurate [24]. However, only a very small amount of messages observed in the present study reflected a lay belief or misbelief in PCa treatment. Findings suggest that online forums can be a venue where men with PCa can communicate useful information and exchange personal experiences of disease management.

There was no difference between the blogs and the online forums in terms of the types of decision making processes reported. We might have expected a difference given that posters to the online forums, unlike those to the blogs, are aware that their decisions and decision making can and probably will be queried. Perhaps writing the more personal, diary-like blogs serves a beneficial function for the writer [25] and only incidentally provides a resource, albeit, a non interactive one, for other patients.

Previous studies have indicated that the Internet can empower cancer patients to make treatment decisions [26, 27]. Searching health websites can unearth new information to take forward to meetings with the clinicians [28] and PCa message boards explicitly encourage people to take an active, thorough approach to their investigations [17]. This certainly seems to be 'good advice' but what about exposure to treatment decision making online? What are the

implications for people accessing such messages? This study shows that men reading these message boards are exposed to positive examples of patients having made their decisions after careful consideration of the relevant information. To this extent posting personal experiences of decision making online could be argued to be a form of positive public involvement in health care. The patients have found out about the specific clinical aspects of the cancer, the different treatment procedures and outcomes and taken in account factors such as their age and life priorities. Readers can also see however that the majority of men have based their decisions on rules of thumb such as 'the doctor knows best' or on their gut feeling for 'needing proof' that the cancer has been removed. In the worst case scenario they are exposed to decisions which are actually based on some erroneous beliefs about the cancer or its treatment. We know that people often have strong initial preferences and expectations for the sorts of information they are seeking (e.g. Renner [29]) so despite exposure to a variety of processes and decisions it could still be that people seeking advice about treatment decisions will seek out like minded others to provide support for their pre-existing views [17].

Conclusions and implications

A third of the decision making processes communicated between online peers in this study were based on careful consideration of treatment outcomes and specific health factors. These results present a far more mixed picture than previous studies in which the vast majority of men (over 90%) with PCa employed non-systematic processes. Men looking online for information about treatment options for PCa are exposed to a range of decision making processes, some systematic and some non-systematic both within message forums and blogs. How they choose to use the information they read is a different matter and whilst we know people are not neutral processors of such information, it is useful to know that the

landscape of experiential narratives on offer as an information resource is more varied then would be surmised from previous studies of PCa decision making.

Despite the call for cancer patients to be involved in choices about their treatment [30] it is interesting to note that this study reinforces the influential role of the clinician in patient decision making. It is worth noting that given the relatively small numbers of older adults online (Fox, 2011) the group of PCa patients represented in this study may not be typical of all PCa patients. However there is some evidence to suggest that growing numbers of PCa patients consult the Internet for information and advice about the disease (Paulter et al, 2001; Steginga et al, 2002 Clinicians, when discussing treatment options with PCa patients, should be aware of the varied decision making processes reported within online forums and blogs. Patients accessing these resources are likely to raise questions based on the information they have read online and clinicians need to communicate clearly about how this information relates to the patient's specific circumstances. Lay beliefs and misconceptions about PCa and its treatment are not widespread on PCa message boards. As such clinicians should strive to deal with these on a case by case basis rather than viewing the resource as a whole in a sceptical or overly negative manner. Within the choice agenda patients should still feel able to seek out and act upon the clinician's recommendation.

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Table 1. Decision making processes observed in messages

Decision making processes	Forum (N=96)	Blog (N=41)	Total (N=137)
Non-systematic processing	47.9%	53.7%	49.6%
Systematic information processing	37.5%	34.1%	36.5%
Mixed	14.6%	12.2%	13.9%
Total	100%	100%	100%

Table 2. Subcategories of systematic and non-systematic decision making processes observed in messages

Subcategories of decision making processes	Forum (N=157)	Blog (N=64)	Total (N=221)[a]
Non-systematic processing			
Expert opinion heuristic	14.6%	20.3%	16.3%
Availability heuristic	6.4%	6.3%	6.3%
Other people's opinion heuristic	1.9%	1.6%	1.8%
Misbelief in Treatment	3.8%	1.6%	3.2%
Gut feeling	3.8%	3.1%	3.6%
Faith in staff	1.9%	6.3%	3.2%
Fear of the alternative treatment	1.3%	1.6%	1.4%
Proof of cancer removal	11.5%	6.3%	10.0%
Need for instant action	3.2%	6.3%	4.1%
Systematic information processing			
Treatment side effects	7.6%	7.8%	7.7%
Treatment outcomes	17.8%	12.5%	16.3%
Staff experience level	4.5%	4.7%	4.5%
Self health condition	15.3%	10.9%	14.0%
Time availability	1.3%	4.7%	2.3%
Location of the treatment	.6%	3.1%	1.4%
Cost of the treatment	1.9%	1.6%	1.8%
Knowledge of the extent of disease	2.5%	1.6%	2.3%
Total	100%	100%	100%

[a] The total number of subcategories is larger than the total number of messages as some messages displayed more than one subcategory of decision making processes.

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