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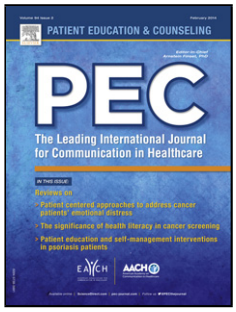

Title: Changing hospitals, choosing chemotherapy and deciding you've made the right choice: Understanding the role of online support groups in different health decision-making activities

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TITLE: Changing hospitals, choosing chemotherapy and deciding you've made the right choice: Understanding the role of online support groups in different health decision-making activities

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Highlights

1. OSGs prompt decision making and allow people to evaluate and confirm decisions.
2. Experience narratives valued by people contemplating health service use change
3. Interactivity of OSGs is a key factor in usefulness as decision resource
4. OSGs support a wider range of health decision-making than simply treatment choices

Objective: To investigate the ways in which people use online support groups (OSGs) in relation to their health decision-making and to identify the key features of the resource that support those activities.

Method: Eighteen participants who used OSGs for a range of health conditions participated in qualitative study in which they were interviewed about their experiences of using OSGs in relation to decision-making. Exploration of their experiences was supported by discussion of illustrative quotes.

Results: Across the health conditions OSGs supported two main decision-making activities: (i) prompting decision making and (ii) evaluating and confirming decisions already made. Depending on the activity, participants valued information about the process, the experience and the outcome of patient narratives. The importance of forum interactivity was highlighted in relation to advice-seeking and the selection of relevant personal experiences.

Conclusion: People use OSGs in different ways to support their health related decision-making valuing the different content types of the narratives and the interactivity provided by the resource.

Practice implications: Engaging with OSGs helps people in a number of different ways in relation to decision-making. However, it only forms one part of people's decision-making strategies and appropriate resources should be signposted where possible.

Keywords: Online support groups; Decision-making; Patient narratives; Trust; Experiential information

1.Introduction

Understanding how people engage with resources to support their health-related decision-making has become increasingly important as patients are encouraged to be more responsible for their own care and treatment [1]. Online personal stories or narratives of health and wellbeing are quickly becoming a 'go to' resource for people affording users with opportunities to find information and share experiential and anecdotal knowledge [2]. The ease with which people engage with such accounts over and above statistical based information [3] suggests they are potentially powerful in relation to decision-making [4]. In experimental settings, however, the effect of crafted narratives on decision-making has been mixed [5], with some researchers suggesting that only narratives that convey the *outcome* of health decisions, as opposed to those that convey information about the *experience* of the treatment or the *process* of decision-making, impact upon or bias treatment choices [6]. Although there are a small number of studies examining the effect of online curated personal experiences on decision-making in more naturalistic settings [7,8] there are as yet very few studies focusing on the role of interactive online support groups in this context.

Online support groups (OSGs) represent one of the most widespread interactive Internet resources. In the health domain, OSGs foster information exchange through personal experience and offer social and emotional support [9,10]. In terms of decision-making OSGs are useful places to report on decisions and decision-making processes [11,12] although there is very little research asking participants directly about OSG influence on health-related decision-making. Whilst we know that simply reading others experiences is useful, the wide-ranging nature of interactive online personal experiences available on OSGs and the relational issues that exist around advice exchange [13,14] mean that the ways in which OSGs relate to decision-making are complex and varied and will depend not least on the type of decision being made. Drawing on a series of in-depth interviews, we ask what is the role of OSGs in health-related decision-making? We examine a range of different health conditions in order to understand what type of decision-making activities [15] are best supported by OSGs and identify the features of OSGs that underpin that support.

2. Method

2.1 Participants and recruitment

Following ethical approval from (Blind for review) and moderator consent, participants were recruited via online support groups. 18 people (males =7) aged 27-66 (mean = 49.33 years) took part in the study. 17 participants lived in the UK and one in the USA. The participants had experience of five focal health issues (see Table 1 for details). **These issues represent a range of chronic, acute and stage of life health conditions and were considered likely to cover a breadth of decision types from treatment and procedural decisions, through service provision, lifestyle and screening issues. Focusing on multiple conditions allows a more comprehensive overview of the role of OSGs in decision-making.**

Semi-structured interviews asked participants to describe the health condition that had prompted them to use OSGs, detail their use of OSGs, their motivations for seeking information and advice and then to focus specifically on OSGs in relation to decision-making. Here, participants were asked to reflect on the ways their engagement impacted on any form of health-related decision-making. The majority of interviews took place via telephone (n=3 via email, n=1 face-to-face). All interviews were audio recorded and transcribed verbatim. To maintain anonymity names were changed and any identifying information removed.

2.2 Analysis

We began by drawing up all the reported decisions made under each health topic. Deductive thematic analysis [16] was used to analyse the data in relation to different activities involved in health decision-making [15]. For each activity, we discussed and agreed upon the different components of the activity as evidenced in the data paying particular attention to the importance of the interactive nature of the OSG and finally we sought to detail the ways in which different narrative types related to the activity itself.

3. Findings

Participants recognised the importance of OSGs in their health decision-making but also stressed that it usually formed just one part of their overall strategy. Discussions with friends, family and healthcare professionals (HCPs), as well as more general web-based information, were also important. In relation to decision-making, participants had sought information and advice from other OSG users for a number of different reasons. For some, they needed to be in contact with people with first-hand experience of the issue, either at a practical or emotional level. For others, they had been referred to a forum by their HCP in the first instance. In describing the ways in which they used OSGs in relation to decision-making we noted underlying support for two key activities: prompting decision-making and evaluating and living with decisions made. These two activities are described in sections 3.1 and 3.2 and draw on comments made by participants about the types of narratives that underpinned the activities and their engagement with the interactive nature of OSGs.

3.1 Prompting decision-making

Participants described the ways in which OSGs had prompted their decision-making. Some people had actively visited the OSGs in order to seek assistance with a decision they faced whilst others came across potential options regarding their situation whilst using the OSG for support or general information. Thus OSGs prompted decision-making in three different ways: Firstly, as a stimulus for decision-making through exposure to new ideas and suggestions. Secondly, as an interactive medium for questioning the experience of similar individuals, people were able to make choices they were previously aware of but had been unable to decide upon or enact because they lacked relevant information. Finally, the OSGs provided places for discussing decision-

making processes that enabled participants to reflect on their own motivations and priorities.

Offering new possibilities and options

Involvement in OSGs meant that participants had access to new treatment options, products and services they had not previously considered. Participants discussed the suggestions they had received from forum members regarding for example, homemade systems for preventing sleep apnoea whilst others, focussed on treatment decision-making, described the way other members detailed new treatment options, advised seeking second opinions or suggested looking further afield for treatment. As one participant states this was something they would never have considered if it was not for the OSG.

> After that horrible experience with this doctor I said do you know what I'm going to take the advice of [people on the website] … they say travel to find the best surgeon possible for the surgery …and as soon as I'd made that decision in my mind to travel it was like a huge weight was lifted off me because my reluctance to proceed with the surgery was because I wasn't able to find a good surgeon locally and I didn't want to travel and as soon as I'd decided to travel which was one of the main pieces of advice given on this website then I never had a doubt after that (p9, hip)

Although there were exceptions, for example, one participant recalled being directed to call immediately for an ambulance by a fellow OSG member, advice around decision-making was usually exchanged in a more indirect manner, often through the discussion of personal experiences. These personal narratives often detailed why the poster had made the decision, their experience of the treatment, product or service itself and information about the outcome. Of course not all ideas and experiences were seen as equally useful or applicable and people managed these sometimes quite different suggestions and options by reflecting on the extent to which the personal experience resonated with their own circumstances, experiences, demographics or priorities.

> Well I think that comes down to your own personal …what resonates with you what feels right for you as to whether you take something like that on board (P13, sleep)

> I suppose one is looking for somebody of the same sort of …. if we are talking about sport for example then somebody at the same sort of level of activity. ….I would never sort of blindly followed advice that I had got off the forum especially if It didn't feel like the thing… if it felt totally different from what I would have done for myself I wouldn't have taken that advice I don't think. He would have had to sound pretty reasonable to me before I would do it. (P7, hip)

Providing practical, lived experience of considered options

Some participants were already considering certain options in relation to their decision-making but were yet to select them either because they lacked information about the option

itself or were faced with ongoing uncertainty about whether or not the option was feasible or even desirable. Members of the OSGs provided descriptions of the choices they had made so that participants could reflect upon these considered options with increased understanding and knowledge. By interacting with members and asking them questions about their experiences participants were able to get a real sense of what making these decisions would entail whether this meant moving to a different hospital or centre or undergoing invasive tests or procedures as explained below:

> I initially went to (Hospital name) I could see that perhaps umm the care I received (there) was lacking and it wasn't really for me but I was able to go onto the forum and find that oh (Centre name) is the best place for you. So I was able to ask questions well can you do that? Can you just change you know? There was a lot of knowledge on there people have been through a lot of experiences so I was able to move to (centre name) cos I was armed with all that knowledge and the care was a lot better and was a lot better suited for me (P13, sleep)

> There were another couple of ladies who were going through IVF having problems and …. if it hadn't been, I think talking to them gave me lots of information about what was involved and tests and it actually prompted me to go and look on the Internet and find a clinic where I could go and have the test done and I actually did ….but I think if it hadn't have been for that I perhaps wouldn't have done it I wouldn't have had that information or I would have had to look a lot harder for it (P10, pregnancy)

Finding out how to do things, and what certain treatments and procedures involved provided an important vicarious experience for participants. It allowed them to feel empowered and more confident about making their decisions. Another way in which OSGs influenced considered options was with regards to treatment options and diagnosis. People wanted to know about the 'real life' positives and negatives associated with any treatment decision and engaging with members through OSGs could lead to people changing their minds about options they had previously considered.

> I always use others experiences to help make my decision about future medical procedures and treatments because they allow me to see what the real life positive and negatives are as well as the pure science or medical information available. I would probably have had a major medical surgery if I hadn't read online forums which showed me how the procedure has many disadvantages (P17, Digestive)

Another participant described how she turned to an OSG to help diagnose her condition after remaining unconvinced by the medical diagnosis she had been given. Although she had previously considered a diagnosis of Irritable Bowel Syndrome (IBS) it was only when she identified a poster on the OSG whose symptoms were a perfect match for her own that she made the decision to contact her GP again.

Discussing decision-making as a way of reflecting on priorities

A number of participants valued OSGs as providing a safe place for 'discussion' about their decision-making. In this way they found the forums a useful place to rehearse their arguments or talk about the difficulties they faced in relation to decision-making with people in similar situations. OSGs offered an opportunity for people to discuss their current state of deliberation free from the pressures of family and friends as highlighted in this example about treatment decision-making below:

> I had to make quite a tough decision about chemotherapy … so what I did was I went online and I said I am in crisis today exclamation mark I've got four different versions of a treatment plan and I don't know which one to follow …. My (family member) says this, my oncologist says this, my surgeon says this and this is what I think and I don't know where I am and people were then writing back and going "well if it was me I would choose this one because I've got three kids and I would want to live as long as possible but you've said that you're not bothered about that so I can see why it's difficult for you then somebody else would write and say what's the point in actually having the expertise at your fingertips in terms of your oncologist if you're not going to follow his advice …. you go through all of that and in the end somebody will end it off by saying I am as confused as you are but in the end I hope you make the right choice for you right (P1, cancer)

Here the participant was able to listen to the factors other people thought were important in making the decision but was reassured by the recognition that the choice was ultimately his alone to make. Members of the OSG acted as a sounding board to the participants' thinking and offered gentle prompts and reminders as to priorities and responsibilities. Ongoing discussion with forum members about decision-making allowed people to reflect on where they were and where they wanted to be.

> One of the ways it's helped me with my decision-making well …. I wanted to hear from people who had survived the cancer so to speak but were left like me permanently disabled. Chatting to these people really helped and I had discussions with one of the moderators about developing another topic 'moving on.' Talking to people in that group has helped me realise and accept that I am not going to get better in terms of the issues I have now and that acceptance has helped us to move on. (P3, cancer) 77

3.2 Evaluating and confirming decisions already made

Our participants also described the ways in which OSGs were useful in evaluating and confirming decisions that had effectively already been made. Once again the interactive nature of the forums was important here as it allowed people to ask questions, explain their reasoning for choosing certain options and to seek reassurance from those who had or were still facing similar decisions.

The lived experience of those who have made similar decisions

Many people wanted to hear from others who had lived experience of making the same or similar decisions. Participants wanted to know about their decision-making processes, how they had made the decision and to some extent hear about the actual experiences of choosing a particular treatment or having a certain test. People also wanted to know something about

the actual outcomes associated with making, in particular, difficult decisions. They contrasted the ability to ask someone 'who really knew' about the outcome of their decision with well-intentioned friends and family simply 'reassuring them' that it would be ok.

> I think I'd made my decision but I kind of wanted …. people in my life were telling me that of course I'd made the right decision and the health professionals were telling me that that was the only decision really and I just kinda wanted other people who had been in that situation to say'yeh I've been through all of that and that that's exactly what I felt as well its completely normal and (P14, pregnancy)

> I felt reassured (by the replies) cos i thought if there's other people that have done it and nothing actually happened to them then i assume I am making the right choice … definitely yeh it played a big part *(in the decision*) cos it made you worry less cos you think the doctors telling you that it could be very very risky but then this person's telling you that they came out fine the other side and it made me more comfortable in my decision(P4, pregnancy)

Throughout the interviews it was apparent that despite the wide range of people and experiences available via OSGs participants were still very mindful of the importance of finding similar people with whom to interact and exchange information and advice. This was clearly the case for people seeking reassurance that they had made the 'right' decision', for example, participant 14 describing that she was *"only wanting to hear from others that have made that decision"*.

Participants also described the ways in which they had sought reassurance from OSG members with respect to decisions made for them by their HCPs. As the quote below illustrates, participants in this situation were not looking to change their decision and were happy with the decisions made on their behalf but found it reassuring to hear about other's experiences of the treatment in question.

> The decisions that were made in the course of my treatment …..they were presented as recommendations and it was still up to me to agree and affirm consent as it were so I was really using it much more as a means of helping me to understand the recommendations and therefore enabling me to sign my consent as it were so it was really trying to understand why are the medical professionals the specialists advising to do this (P5, cancer)

4. Discussion and Conclusion

4.1 Discussion

This study has shown how OSGs play an important role in two key decision-making activities. The groups prompt decision-making through the suggestion of new ideas and options, the provision of vicarious learning experiences and the opportunity to reflect on and discuss-decision making processes. Secondly, they facilitate the evaluation of decision-making through interactive contact with people who have faced and made similar decisions. That personal experiences play a role in decision-making activities resonates with earlier

work by Entwistle et al [8] who found that curated personal experiences were seen as being potentially useful in supporting different decision-making activities. This current study, however, extends this work by identifying the main features of OSGs that support these decision-making activities.

So firstly, we identify the importance of different narrative types as way of providing people with information in relation to decision-making. Personal experiences may contain information about the process by which a decision was reached, information about the experience of following through on a decision and information pertaining to the decision outcome [6]. In this study people sought and valued different types of narrative content in their decision-making, for example, experience narratives were most often described in relation to options that participants were already considering. For those that had already made their decisions outcome narratives in addition to experience narratives were seen as important. Whilst for those people discussing their decision-making ideas process narratives i.e. understanding how others had made decisions or would make decisions were valued.

These findings extend our understanding of the relationship between different narrative types and subsequent behaviour and affect into a naturalistic setting. We know in experimental settings using hypothetical treatment options, exposure to different narrative types affects participants' behaviour in certain ways with process narratives leading to further information search behaviour and experience narratives improving evaluations of the decision-making process [17]. In our current study we see that outcomes as well as experience narratives increase participants' sense of reassurance with decisions already made. We also note that experience narratives in particular provided people with sufficient practical information to encourage changes health service use [18,19].

Secondly, we identified the importance of the interactive nature of OSGs. **Participants were able to seek and select relevant personal experiences from the forums and as active users were also able to interact with members, ask questions and seek clarification, in fact only one participant reported being a full time 'lurker'.** Forum responses were valuable in relation to all aspects of decision-making, allowing people to further assess the extent to which the source and content of the message resonated with their own outlook, experience and position. The interactive nature of the OSGs allowed participants to screen the kinds of information and experiences they were interested in and this meant a more targeted and specific use of the resources in relation to decision-making. Although we have noted this pattern of engagement across a broad range of personal experience resources [20], in terms of decision making in particular being able to assess the 'fit' in relation to the poster's experience is key. An interactive environment allows people to select and respond to trustworthy and emotionally engaging accounts of experiences that convey personally relevant information. In combination with the range and diversity of experiences represented OSGs offer a vast resource for people in terms of decision-making. As new members join, the increasing wealth of experiences within the group makes it likely that someone somewhere will be able to offer and discuss a resonating experience in relation to any decision point however important, seemingly inconsequential or specific. This suggests that OSGs can impact upon a potentially much broader range of decisions than curated material alone.

Finally, the findings allow us to say something about the kinds of decision-making strategies that OSGs support. The ways in which information exchange occurs on OSG offers people something different to rational information provided by HCPs or irrational strategies used by people in dealing with risk and uncertain situations. 'In-between' strategies [21] based on trust and emotion resonate with the information and advice exchanged within OSGs and that feeds into decision-making. **OSGs formed one element of decision-making and the integration of information and advice from friends, family and for the most part HCPs was also apparent. This suggests a dual role for OSGs in firstly supporting the 'informed choice' model of decision-making in relatively straightforward, less clinical contexts, but secondly encouraging patients to reflect further on their 'preferences' and thus contributing to improved dialogue within a broader conception of shared decision-making [22].**

In terms of limitations, the self-selecting sample in this study reported an overwhelmingly positive role for OSGs in decision-making and it may be that those with more negative experiences did not want to engage with this research. The study also contained predominantly active OSG users and lurkers may have a different experience in relation to decision-making. Finally, it is important to understand how HCPs respond to information derived from OSGs and the practical implications of that in relation to shared decision-making.

4.2 Conclusion

We have highlighted the role that OSGs play in decision-making of various kinds from treatment options and testing to health service use, products and services. We have noted that people engaged in different decision-making activities value different types of narrative content in terms of the messages they read and interact with online and that the interactivity of OSGs is a key constituent of its ability to support decision-making activities. OSGs are not used in isolation but as part of a set of strategies involved in managing the uncertainty and risk associated with decision making. Understanding more about this integrated strategy is a key area for future research.

4.3 Practice implications

Healthcare providers should be aware of the different decision-making activities that OSGs can support and recognise that for some people involvement in OSGs can help them to feel more comfortable with the decisions that have reached in conjunction with their medical team. Engaging with OSGs does not necessarily alter decisions but can raise new ideas possibilities that patients may wish to discuss with HCPs and signposting people to appropriate forums can be a useful way for people to discuss their options and their current decision-making thinking in a safe environment.

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Table 1: Participant characteristics for each health issue

Health issue	**Description/comments**	**Total number of participants N=18**
Cancer • **Life threatening** • **Treatment decisions**	Bowel cancer (3) Lymphoma (1)	4 male (Participants: 1,2,3,5)
Sleep problems • **Chronic, but with acute periods** • **Lifestyle vs intervention** • **Service provision**	Three participants had sleep apnoea and one participant had a child with sleep apnoea	3 female, 1 male (Participants: 11,13,14,15)
Pregnancy and infertility • **Stage of life** • **Decisions around screening, termination and testing**	Issues with screening, pregnancy complications or infertility	3 female (Participants: 4, 10,12)
Hip replacement • **Non-life threatening** • **Service provision** • **One off treatment decision**	Had all undergone hip resurfacing	2 male, 1 female (Participants:7,8,9)
Digestive health conditions • **Lifestyle vs medical intervention** • **Diagnosis decisions**	One participant had IBD and the remaining three had coeliac disease	4 female (Participants: 6,16,17,18)