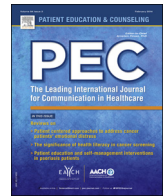




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Changing hospitals, choosing chemotherapy and deciding you've made the right choice: Understanding the role of online support groups in different health decision-making activities

Elizabeth Sillence*, Lauren Bussey

Department of Psychology, Northumbria University, Newcastle upon Tyne, United Kingdom

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ABSTRACT

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.

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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

* Corresponding author at: Psychology and Communication Technology Laboratory, Department of Psychology, Faculty of Health and Life Sciences, Northumberland Building, Northumbria University, Newcastle upon Tyne NE1 8ST, United Kingdom.

E-mail address: elizabeth.sillence@northumbria.ac.uk (E. Sillence).

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

Table 1
Participant characteristics for each health issue.

Health issue	Description/comments	Total number of participants N = 18
Cancer <ul style="list-style-type: none"> • Life threatening • Treatment decisions 	Bowel cancer (3) Lymphoma (1)	4 male (Participants: 1,2,3,5)
Sleep problems <ul style="list-style-type: none"> • 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 <ul style="list-style-type: none"> • Stage of life • Decisions around screening, termination and testing 	Issues with screening, pregnancy complications or infertility	3 female (Participants: 4, 10,12)
Hip replacement <ul style="list-style-type: none"> • 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 <ul style="list-style-type: none"> • Lifestyle vs medical intervention • Diagnosis decisions 	One participant had IBD and the remaining three had coeliac disease	4 female (Participants: 6,16,17,18)

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