



Exploring the benefits and challenges of health professionals' participation in online health communities: Emergence of (dis)empowerment processes and outcomes



Sara Atanasova^{a,*}, Tanja Kamin^b, Gregor Petrič^a

^a University of Ljubljana, Faculty of Social Sciences, Centre for Methodology and Informatics, Kardeljeva pl. 5, 1000 Ljubljana, Slovenia

^b University of Ljubljana, Faculty of Social Sciences, Centre for Social Psychology, Kardeljeva pl. 5, 1000 Ljubljana, Slovenia

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ABSTRACT

Background: Various online applications and service has led to the development of online health communities (OHCs), which in addition to the peer-to-peer communication offer patients and other users also interaction with health professionals. While the benefits and challenges of patients and other users' participation in OHCs have been extensively studied, a thorough examination of how health professionals as moderators (i.e., those who provide clinical expertise to patients and other users in OHCs) experience participation in OHCs is lacking.

Objective: The aim of this study is to explore the main benefits and challenges of health professional moderators' participation in the OHCs.

Methods: The study undertakes an exploratory qualitative study, with in-depth semi-structured interviews with health professional moderators ($n = 7$) participating in the largest OHC in Slovenia, *Med.Over.Net*. The data was analysed using inductive thematic analysis approach and principles of grounded theory.

Results: Four themes of health professional moderators' experiences were identified: (a) benefits of addressing OHC users' health-related needs, (b) challenges of addressing OHC users' health-related needs, (c) health professional moderators' benefits, and (d) health professional moderators' challenges.

Conclusions: This small study demonstrates that health professional participating in OHCs as moderators perceive themselves as facilitators of patients and other OHC's users empowering processes and outcomes, in which OHC's users improve their health literacy, develop skills, expand their social support, and gain other important resources necessary when dealing with health-related issues. Health professional moderator's role, however, also involves several duties, responsibilities and limitations that are often experienced as difficulties in providing patients and other users with adequate counselling and online medical service. OHCs also represent an important terrain for personal and professional empowerment of health professional moderators, although the presence of disempowering processes also needs to be noted.

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1. Introduction

The widespread use of online health communities (OHCs) plays an important role in the transformation of the experiences of health care and chronic condition management among Internet users, patients, caregivers, health professionals, and policy makers alike [14,16]. OHCs, such as PatientsLikeMe, WebMD, and Med-Help present an Internet-based platforms that not only encompass participation from (potential) patients and/or caregivers, but they

also include health professional moderators [11,16,27,43], and as such differ from online health support groups, that typically include patients only. Health professional moderators that participate in OHCs are usually health professionals (health care providers or doctors) who deliver health consultations and moderate health-related discussion and thus provide patients and other OHCs' users with reliable health-related information and clinical expertise.

Various studies have demonstrated that participation in OHCs provides patients and other users with several positive psychological benefits, like higher self-esteem, self-efficacy, and control related to managing their own health issues or health issues of the ones they care for, enhanced satisfaction from helping others, improved confidence in the relationship with doctors in formal

* Corresponding author.

E-mail address: sara.atanasova@fdv.uni-lj.si (S. Atanasova).

(‘offline’) medical encounters, more competent use of health services, and even improved social well-being and quality of life [24,27,37].

Ordinary users’ experiences, benefits, and challenges associated with participation in OHCs have received a lot of research attention (e.g., [23,36,40]), but almost no research is focused on question of what are the experiences of health professional moderators in OHCs. Health professional moderators in OHCs provide counselling, clarifications, explanations, as well as possible solutions, resources, and opinions about medical issues, remedies, and therapies for patients and other users [12]. As such, they can substantially reduce the potentially problematic effects of OHC for users [10,13]. For example, health professional moderators can help users to distinguish between valuable and misleading medical information, provide them with clinical expertise, facilitate group interactions, help to integrate new or less involved members, and encourage users who only read messages (i.e. lurkers) to start actively participating in the OHC [12,13]. In addition, they might contribute to the success and sustainability of OHCs [41].

Despite the acknowledgement that health professional moderators can improve the quality of OHCs, only a limited number of studies have been concerned with their role in OHCs (e.g. [10,12,11,13,17]), but none of these empirically investigated health professional moderators’ actual experiences of participation in OHCs. There have been a few studies that focused on moderators’ perspectives (e.g., [7,16,38]), but the investigated moderators in these studies were former patients, patients living with chronic illnesses, and/or the initiators of OHCs rather than health professionals. Nevertheless, these studies do present relevant findings. They demonstrated that moderators may provide a unique insight into the OHC phenomenon, as they can offer medically related advice, and prevent health risks among patients [38]. They also reveal that, users, who take on a moderation role in OHCs experience a positive impact on their personal and health-related life areas: improved illness management, better relationships with their doctors, and a higher level of confidence in accessing health services [7].

Our research focuses only on moderators in OHCs that are health professionals and studies how they perceive and experience their participation in OHC. We designed a small qualitative study to explore the participation of health professional moderators in *Med.Over.Net*, the largest OHC in Slovenia, in order to identify the main benefits and challenges of the engagement of health professionals as moderators in the OHC. With semi-structured interviews conducted with health professional moderators ($n = 7$) of *Med.Over.Net* community and data analysed using inductive thematic analysis approach and principles of grounded theory we sought answers to the following questions: What benefits and/or challenges do health professionals experience when participating as moderators in the OHC? What benefits and/or challenges do they see for themselves, OHC users and for the OHC as a whole?

2. Materials and methods

2.1. Recruitment process and sampling

Health professional moderators were recruited from *Med.Over.Net*, the largest OHC in Slovenia,¹ which was established in 2000 with focus on health, medicine, social work, and education related

¹ Slovenia is a European Union country with approximately 2 million inhabitants and at least 1.1 million weekly Internet users in the 16–74 cohort. In fact, Slovenia is one of the most typical EU countries with respect to usage of information-communication technologies. According to many of Eurostat information society indicators, it takes close to the median position among all EU countries [32].

topics. This particular OHC was selected as it is one of the most visited online communities in Slovenia. It has more than 400,000 monthly visits and on average more than 70,000 monthly users, and it has already been the subject of studies on OHCs [27,28]. *Med.Over.Net* is an open access stand-alone online community that offers a variety of online discussion forums, i.e. online support group forums and online counselling forums. The counselling forums, which are the focus of this study, cover topics ranging from acute or chronic health conditions to medical specialties handling particular diseases and medical states (e.g., dermatology, gynecology, oncology, psychiatry, preventive medicine etc.). In counselling forums health professional moderators represent the primary source of clinical expertise and support for patients and other users. *Med.Over.Net*’s counselling forums are moderated by 150 health professional moderators and are structured in a question and answer (Q&A) format, where questions are posted by patients and other users and then answered by health professional moderators. The health professional moderators are health care experts (medical doctors and specialists), psychotherapists, psychologists, and medical staff, employed in public and private health institutions in Slovenia and independently from this participate as volunteers in the studied OHC.

Health professional moderators in the study were recruited with the help of an online expression of interest form. Recruitment of participants was conducted with the support of *Med.Over.Net* community managers. In the online form, we explained the purpose of the study and their rights as participants, as well as asking for their contact information. The choice of interviewees was limited to health professional moderators from the field of health care or medicine. The study undertook a mixed purposeful sampling approach composed of both convenience and snowball sampling, resulting in recruitment of seven health professional moderators who participated in the studied OHC and who were willing to participate in the interviews. We obtained informed consent from all participants.

The sample size is in line with Braun and Clarke’s [5] guidelines for thematic analysis, which categorize suggestions by the type of data collection and the size of the project. As this was a small scale project, we followed the guideline of including 6–10 participants in the interviews. Data saturation was indicated by the overall thematic data replications.

2.2. Data collection

The data were collected through in-depth, semi-structured, face-to-face interviews conducted with health professional moderators from *Med.Over.Net*. In the interviews, the participants were asked to share their views and experiences concerning the following topics: reasons for voluntary participation in the OHC, start of their involvement as health professional moderators, opinions and views about the *Med.Over.Net* OHC in particular, benefits and challenges of participation in the OHC, the role of health professional moderators, relationships and interactions with users of the OHC, and the role of the OHC in the overall health care system.

Participants were offered an incentive in the form of a gift card in the amount of 20€ before participation in the interviews. All except one of the interviews were conducted one-on-one in person in a quiet and secure room at the authors’ office, participants’ workplaces, or their homes. One of the participants was hearing-impaired and as an interpreter was not available for the interview, we conducted the interview via email. All of the interviews, except for the one conducted by email, were audio recorded and transcribed verbatim. The interviews, each lasting on average 1 h and 8 min (except for the one conducted via email), were conducted in January and February 2015. The personal characteristics of the participants were anonymized to guarantee confidentiality and

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