



# Narratives of empowerment and compliance: Studies of communication in online patient support groups

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## ABSTRACT

**Purpose:** New technologies enable new forms of patient participation in health care. The article discusses whether communication in online patient support groups is a source of individual as well as collective empowerment or to be understood within the tradition of compliance. The discussion is based on a qualitative analysis of patient communication in two online groups on the Danish portal [sundhed.dk](http://sundhed.dk), one for lung patients and one for women with fertility problems.

**Methods:** The object of study is the total sum of postings during a specific period of time – a total of 4301 posts are included. The textmaterial was analyzed according to the textual paradigm of Paul Ricoeur, and the three steps of critical interpretation. Thus, the analysis moves from describing communicative characteristics of the site to a thorough semantic analysis of its narrative structure of construing meaning, interaction and collective identity, and finally as a source of collective action.

**Results:** The meta-narratives of the two groups confirm online patient support groups for individual empowerment, for collective group identity, but not for collective empowerment. The collective identities of patienthood on the two sites are created by the users (patients) through specific styles of communication and interaction, referred to as ‘multi-logical narratives’.

**Conclusion:** In spite of the potential of online communities of opening up health care to the critical voice of the public, the analysis points to a synthesis of the otherwise opposite positions of empowerment and compliance in patient care. On a collective level, the site is empowering the individual users to comply with ‘doctor’s recommendations’ as a group.

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## 1. Introduction

The role of the patient in treatment has traditionally been discussed in a dichotomous way as a question of either compliance or patient empowerment [1]. Patient compliance has to do with adhering to the recommendations of the medical

authorities, whereas patient empowerment has to do with the patients’ rights as individual citizens to pursue his or her conceptions of life and quality of health. Compliance is the extent to which a person’s behaviour (in terms of taking medication, following diets, or executing lifestyle changes) coincides with health advice [2]. The term was coined in the 1970s and, since then, the role of self-care has been much discussed. Lutfey

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and Wishner [3] argue that “compliance” indicates patients obeying physicians, and that the actual word implies an understanding of the problem as a behavioural characteristic of the individual patient. Instead the term “adherence” is proposed, which includes not only behavioural attitudes but also the patient’s social and economic situation. Others [4] argue that both “compliance” and “adherence” imply treatment problems as the consequences of the patients’ behaviour and claims that appropriate care requires fundamentally different sets of roles for health care professionals and patients – roles that imply a truly collaborative approach where patients and health care professionals relate as equals rather than the hierarchical approach underlying compliance and adherence. In a truly collaborative approach, the patient is responsible for managing the illness, and the role of healthcare professionals is to provide expertise and help patients acquire knowledge necessary to make informed decisions. These efforts to equalize patients and health care professionals have also been referred to as patient empowerment [1,5]. Empowerment is the discovery and development of one’s inherent capacity to be responsible for one’s own life. Patients are thus empowered when they are in possession of the knowledge, skills, and self-awareness necessary to identify and attain their own goals. Use of the concept of empowerment within the field of healthcare includes the understanding of empowerment as either a process or an outcome, and a distinction between empowerment understood at the individual or at the collective level [6,7]. Empowerment finds some of its theoretical underpinning in the work of Paulo Freire [8,9] and, according to him, empowerment implies more than just an individual perspective and should be seen as a social action that involves group efforts to identify their problems, to critically assess the social and historical roots of problems, and to develop strategies to overcome obstacles in achieving their goals. Thus, one fundamental feature of this conception of empowerment is to make use of individual knowledge and competence to collectively initiate change.

Online patient support groups began to emerge in the 1990s, and much has been expected from their potentially empowering effect. One of the early studies [10] looking into the content of online support groups for patient diagnosed with ALS (amyotrophic lateral sclerosis), points to the organizing potential of computer networking and suggests that online support groups might represent the beginning of a new kind of empowerment of patients, a possibility to query the traditional paradigm of bio-medicine. In other words, both the individual and the collective level of patient empowerment are at stake here.

Most studies of online support groups, however, focus on the individual level. Uden-Kraan et al. [6] investigate to what extent patients feel empowered by their participation in online support groups through a questionnaire to 528 people active in online groups for patients with breast cancer, fibromyalgia, or arthritis in the Netherlands. In the questionnaire, the items determining empowerment at the process level were ‘exchanging information’, ‘encountering emotional support’, ‘finding recognition’, ‘helping others’ and ‘sharing experiences’, and, at the outcome level, they were ‘being better informed’, ‘feeling more confident in the relationship with their physician’, ‘improved acceptance of the illness’,

‘feeling more confident about the treatment’, ‘increased optimism and control over the future’, ‘enhanced self-esteem’ and ‘enhanced social well-being’ [6:62]. These items were elicited from a qualitative study by the same authors interviewing 32 patients participating in the aforementioned online support groups [11]. The result of the questionnaire study shows that the most frequent processes in these online support groups were ‘exchanging information’ and ‘finding recognition’ and, on the outcome level, they were ‘being better informed’ and ‘enhanced social well-being’. Despite the fact that the most important items had to do with information exchange, the authors stress that online support groups should not solely be seen as sources of information, as the information exchange in these groups adds personal information to factual knowledge. The overall conclusion from these studies is that participation in online support groups can make a valuable contribution to the empowerment of patients. A study conducted by Bartlett and Coulson [12], involving 246 participants across 33 online support groups, supports this conclusion.

Another study [13], including both quantitative and qualitative elements, focusing on the communication in a weight loss community, shows similar results. The analysis of the qualitative part, based on a grounded theory approach, produced themes of social support, and the major themes were ‘information’, ‘encouragement and motivation’ and ‘shared experiences’, which are closely related to process results gained by Uden-Kraan et al. [6,11]. The analysis of the communication in the weight loss community also points out, without further elaboration, that advice and encouragement from other participants empowered participants to perform behaviour that led directly to weight loss [13:11] and not just to cope with being overweight. In line with these studies are also the results from a quantitative meta-analysis of research on online support groups conducted by Rains and Young [14], in which two hypotheses were tested. The first hypothesis suggests that participants in online support groups experience more social support, become less depressed, gain more quality of life, and undergo changes in self-efficacy. The second hypothesis concerns the structural characteristics of the online forum and relates to the size of the group, the technical mode(s) of synchronous and/or asynchronous communication, the frequency of contact with the group, and how the duration of the intervention is expected to affect the health benefits. So, it is suggested that patients will experience a more positive outcome in the groups that have more members, synchronous and asynchronous channels available, greater frequency and contact among members, as well as a longer duration. From the meta-analysis of data samples from 28 studies with 4081 participants with 12 different health conditions, the first hypothesis was confirmed – the patients experienced more social support, became less depressed, gained more quality of life, and did undergo changes in self-efficacy. The second hypothesis on specific structural characteristics was not confirmed.

There seems to be confirmation of the fact that participation in online support groups actually does lead to patient empowerment in the sense of improving the general well-being of the participants through providing an experience of being informed, motivated and in better control of their condition. There is, however, no significant indication as to whether

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