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Narratives of empowerment and compliance

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

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ARTICLE INFO

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, 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.

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

the online participation results in an actual change of the clinically significant illness factors of the individual participants [12,15], nor as to whether the possible collective dynamics and effects of participating in online support groups carry any influence.

In our study of the communication in two online patient support groups, we aim at opening up these issues of collective dynamics and critical potentials. By applying literary theory, we seek to explain social action in online communities, and to develop a framework of deep semantic analysis of identity formation and meaning production in the two cases. The overall questions that we seek to answer by our analysis are if health communication in online support groups is a means to individual empowerment and further, a medium for collective empowerment as well? And in case collective empowerment is facilitated (mobilized), does this make a stance for a critique of the compliance tradition, and for action against the hegemony of medicine?

2. Theoretical background

Medical humanities is an interdisciplinary endeavour that draws on humanistic disciplines of literature, arts, anthropology, ethics and philosophy in pursuit of medical education goals, among others to strengthen the understanding of human subjectivity in illness [16:3,17,18]. Within the humanities, there is a long tradition of understanding humans as intentional beings whose knowledge of the world always bears a first person perspective, i.e. an irreducible subjectivity that can only be made an object of scientific study as 'text' [19]. Experiences of human existence are typically expressed in written texts such as the bible, literary art works, and journals, or more generally in any production by human hand and spirit, from paintings to architecture, and even software design [20]. All 'texts' have the communicative purpose of expressing some sort of meaning. In late, post-modernity, the focus has shiftet from the objectivity of textual product itself, to the reader's recepetion of the text, i.e. to the meaning making process in itself. The text and the reader co-configure each others meaning and identity. Explanation and understanding are themselves the results of interpretative processes, i.e. of hermeneutics [21].

2.1. The textual paradigm

Within the paradigm of the text, Ricoeur sums up four principles of communication and social research: the first principle is "the fixation of action: meaningful action is an object for science only under the condition of objectification, which is equivalent to the fixation of a discourse by writing" [19:203]. The principle points to the necessity of textualization in order to fix the ever-changeable state and flux of socially interwoven action into an object of analysis. This principle is easily followed in online patient support groups as the users carry out the fixation themselves through their writings.

The second principle addresses the problem of the part–whole relationship, also known as 'the hermeneutical circle', i.e. the meaning of an act, an utterance, a sentence, or an online post is to be understood in relation to its other parts, i.e.

the other acts, sentences, posts and patterns of relationships and interaction that make up the whole of the text [19:211]. Understanding online-patient communication (and explaining its social actions and meaning) is therefore not reducible to a few posts or even to a long string of posts between several users, but to the whole production of the community. The coherence between the posts makes up the totality of the text that determines its meaning. An objection would be that online communication does not share the characteristics of a demarcated text, but rather, it is borderless, due to its on-going, cumulative production of content and new user profiles. It is true that information technology enables an on-going communication that in many ways reassembles the elusiveness of the spoken word. At the same time, though, it possesses the characteristics of the written word and the textual world; it leaves traces, small signs that are easily summed up in online activities as number of users and postings.

'The whole of the text' and the demarcation criteria in dynamic online environments encompasses a given number of posts produced in a specific period of time, similar to how the print year and place of a book guarantee its reference. The third principle asserts the autonomy of the text [19:206], which means that the meaning of the text does not reside in the intention of the author(s), in our case the empirical patient-user(s), but in the textual structure of the text it-self: 'the world of the text' and its rhetoric for addressing the reader.

> Therefore, what we want to understand is not something hidden behind the text, but something disclosed in front of it. What has to be understood is not the initial situation of discourse, but what points to a possible world. Understanding has less than ever to do with the author and his situation. It wants to grasp the proposed worlds opened up by the references of the text. To understand a text is to follow its movements from sense to reference, from what it says to what it talks about. In this process, the mediating role played by structural analysis constitutes both the justification of the objective approach and the rectification of the subjective approach [19:218].

Structural analysis can guide the interpretational process as it explains the deep semantics of the text's linguistic layers, as well as makes the researcher's perspective/analysis/interpretation open for inspection.

The fourth principle is 'The universal range of its addressees', which explains that the meaning of the text depends on being read in order to be actualized, and that the scope of its meaning is potentially unfathomable. Different readers, at different times, might disclose different meanings. As researchers, we seek to assume the role of the ideal reader [22], who, with an unbiased mind, reads and reflects on the entire content, the whole of the text, its coherence, contractions and meaning. In 'Time and Narrative', Ricoeur elaborates on the rhetoric of the text and the aesthetics of the reader: the interpretational process is guided by three cognitive steps in reading [23:168ff]: firstly the expectation you have as a reader (and researcher): you expect the text has something to say! Secondly, the questions you pose back at the text when your expectations are not immediately rewarded. The second reading, searching for coherence between the parts of the text, is a tacit, reflective process of questions and answers back and

forth between the understanding of the reader and the world of the text. It can go on for a length of time, depending on the engagement of the reader and accessibility of the text. Finally, the interpretation is at its end when the reader frames the question where the text as a whole is the answer. The third reading is therefore also a critical reading, as the reader might discover that the meaning conveyed was more or less informative to her own world of action. The following paragraph elaborates on the above principles of text interpretation, and makes the 'three readings' explicit as analytic perspectives on communication in online patient support groups.

2.2. Methods

The first principle of fixation of action is easily accomplished in online communication, as social interactions are fully mediated by digital signs. For the analysis of on-going online communication, the second principle of the part–whole-totality of the text means that the demarcation criteria of the text must be defined by the analyst, in this case the researcher. We have defined our textual object of study as the total sum of posts that were published on the public website www.sundhed.dk from the launch of the site to 6 months later in the case of 'Recurrent Miscarriages' and 18 months later for 'Talk on COPD'. In that historical period, the site concerning recurrent miscarriages had 232 patient users, the COPD site 398 patient users, with 631 posts (January to August 2008) and 3670 posts (January to August 2009) [24], respectively. Because the sites are 'living texts', many users have joined the sites since then, and many new posts have been published. Subsequently, we have cross-read the sites, in order to 'spot-check' and validate whether the interpretations that we are going to present in the following were still valid: this is very much so. The identities of the communities are still the same, in spite of the new users and postings, and of the fact that the COPD-site has moved to be hosted by the COPD patient association.

As regards online analysis, the third principle of the autonomy of the text means that the validity of the interpretation cannot be reduced or falsified by interviewing the empirical patient authors: text productions have their own lives, and exist independently – on the internet – of the lives of their authors. The validity of the following analysis therefore resides on the one hand on the solidity of the textual material – which in principle is public for any reader to access and control. On the other hand, given the relativism of the fourth principle, 'the universal range of its addressees', the justification of the research analysis is strengthened by making research questions and theoretical assumptions explicit. The reliability of this analysis is therefore grounded in the theoretical framework that has guided our reading, and the transparency of our interpretational process.

2.2.1. The process of interpretation

Our first reading was guided by the following research questions: What are the main subjects of their communication? In what rhetorical style are the messages written? How do they present themselves? How do they relate to each other and to the surrounding world in their writings?

The results of our first reading pointed to different kinds of group identityformations on the two sites. Whereas the
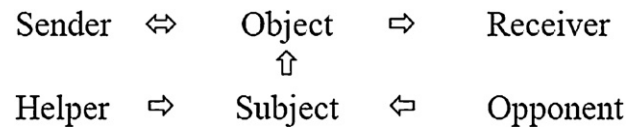

Fig. 1 – The Actant model.

patient users on Recurrent Miscarriages constructed shared opinions and identities by exchanging stories about the lack of understanding they experience from the surrounding world, families, employees and friends, the COPD-community had on open, inclusive tone towards co-citizens in the style that they might not be COPD-patients, yet. Our second reading identified the literary style of the narrative as a dominant form of communication. Identity was presented or construed on an individual and on a collective basis through modes of story-telling.

2.2.1.1. Narrative analysis. Narrative analysis is central in literary theory. Greimas' Actant model offers a deep semantic scheme for analyzing the narrative [21,25,26]: what conflicts, desires and relations generate the subject's action, and eventually foster the story being told. The model expresses the project of the protagonist, 'the object' that 'the subject' strives for, for instance the princess and half the kingdom. The conflict axis points to the hindrances and solutions which the subject experiences on his or her way to arriving at the goal, whereas the communicational axe demonstrates the power relations and dependencies between the sender, the King who gives the princess, and the receiver (Fig. 1).

In philosophy and communication theory, narratives are considered a universal cultural mode of expressing and construing identity, whether that be in daily life, in therapy, or as a social group: narratives organize spatial events into temporal orders for people to relate to and understand; stories shape and configure people's minds about themselves and others, their pasts and futures. They are, in other words, cultural compasses that navigate individual behaviour and compose social order. As such, they are also vehicles of power; tradition and liberation. These social, collective powers of the narrative are also termed meta-narrative, and defined in the words of Hurvitz et al. [16:13]:

> One characteristic of meta-narratives is that, unlike particular individual stories being recounted, they are not immediately apparent to the listener or reader. Indeed, the meta-narrative embraces (and assumes) a particular worldview and ideology, which teller and listener take for granted. The first task of those who seek to challenge a particular meta-narrative is to deconstruct it and lay bare the various assumptions and the communicative and literary devices used to penetrate them.

We find that the narratives in online support groups are both a new historical archive and a cultural source for information on patients' own accounts of illnesses and illness stories, as well as a new vehicle for construing patient identities, especially related to those diagnoses which are either rare or of stigmatizing consequences to the patient. It is therefore of special interest whether the online support forum is a

'momentum' of joining forces to overcome the isolation and/or stigmatizing effect of the diagnosis at a collective, empowering level.

Our second reading therefore concentrates on the narratives on the two sites, how they unfold and which actantial characteristics, conflicts and norms of desires are dominant. Mapping these stories, their themes, lengths and numbers of participant writers naturally leads to reflections on coherence: are there shared conflicts and desires? How do the stories relate to each other on each site: What kind of meta-narrative is evolving in their online culture? And do the meta-stories of the two sites respectively differentiate from one another?

Our third reading presents the synthesis of the patient narratives, as two meta-narratives: the meta-narratives point to explanations of why the patient users participate in the online communication, and understandings of the kind of identity and sociality they develop by the online interaction.

The research questions: whether the identity formations in online communication support groups are sources of individual as well as collective empowerment and/or compliance – can now be answered by comparing the plot of our second reading: the 'individual stories' with the plot of the meta-narrative of the site.

3. Analysis of the online patient support groups

On the public platform, www.sundhed.dk, users can follow the communication on six patient networks. User rights with regard to writing contributions are restricted to patients in treatment, relatives and clinical staff. The vast majority of the communication is between patients. The forum 'Recurrent Miscarriages' is about women who have pregnancy problems. The 232 patient users are all in treatment in a special fertility unit at a university hospital – by a chief physician referred to as OBC. OBC is concurrently testing his research hypothesis that the recurrent miscarriages are caused by the immune system fighting pregnancy hormones. The 398 patient users in 'Talks on COPD' suffer from decreased lung function diagnosed as 'chronic obstructive pulmonary decease', or in Danish lay-term 'smoker-lungs', as about 85% of the injuries are related to smoking. Regional health care authorities and the Danish Lung Association are behind this site.

3.1. Analysis of text production in 'Recurrent Miscarriages'

The tone of writing is very personal. Little time is spent on reading, before you understand that these strings of mails to headlines such as 'Pregnancy', 'Thoughts and feelings', 'Medical treatment', and others are very personal, and full of grief, pain and longings: grief over the many lost foetuses; hopes and comfort that next time they might eventually succeed. Most of the correspondence takes the shape of stories: individual stories that sum up personal experiences with recurrent miscarriages, i.e. stories co-authored by many users that evolve over fairly long, real-life timespans that are interrelated: thematically, in the morals and plots of their stories. At one point, the narrative mode of storytelling points to a dialogical style

of posing questions and answers. But it is not the logic of two users but between many: an expansion of the dialogical style to reading and writing processes of multiple users; a multi-logical form of narrating – with similarities in how they respond to each other: what questions to ask and what morals to tell about their shared object of motherhood.

3.1.1. Patient narratives in the recurrent miscarriages forum

Often, the patients' stories take their points of departure in a question, such as the story of 'Pernille1975'. In the heading she asks: 'How many have experienced that HCG didn't rise as it was supposed to?' (HCG is the abbreviation of a blood sample that specifies pregnancy hormones in the blood). A string of replies develops with several episodes evolving around first a pregnancy test showing two lines, which indicate pregnancy, then to some blood samples examined for antibodies and the scanning of the foetus with the observation of heart beat. Four weeks and 25 posts later, the story culminates at a second scanning where there is no sign of heart activity. Finally, the story ends with the other patient users offering their condolences, showing their sympathy and encouraging Pernille1975 not to give up hope.

In order to balance the despair of the many tragic outcomes, several users call for stories with happy endings, and another user witnesses the meaningfulness of their endeavours by sharing her experience of participating in her sister's childbirth:

> Just want to share this merry event with you guys. I have just come home from the labour ward, after helping my sister and brother-in-law with delivery. It was just such a big and inexpressible experience that I find difficult to describe...[...]. my sister was so tough, she did it all splendidly. It all ended well..[...].. I wish that this dream will come true for all. Anitten, 07.07.08.

Her story has a mythical character that conveys some core characteristics of the support group as a sisterhood. A sisterhood of women who share a common faith and hope of a child and in which membership can only be achieved by persons with first-hand experiences of miscarriages. Only the story of 'Anne-Mette' deviates. In her contribution: 'I have made a decision', she gives up her patient identity and by that her membership of the community. Anne-Mette's argument is that the project of motherhood has too many personal costs in relation to her general health, to the risk of a premature baby, and to the importance of other expectations of life, such as travelling: "After this decision, my body feels much better. I don't have "contractions" any longer, and I don't feel as tired. In a way, my life has been on stand-by since we decided to become pregnant".

Except from a very emotional and compassionate tone, they talk about their bodies with a vocabulary that is closer to that of clinical professionals than that of laypersons. They develop a shared, specialized language to talk about their illness. Parallel to this scientific language is a religious tone of voice, where beliefs and hopes of a child have a resemblance to prayer and Christian salvation. This is expressed in its most extreme form in the signatures of the users, accompanying all their mails, e.g.: "Pernille, We have been trying for nearly 6

years; please let our dream come true". "FinallyMum, after 7 years with countless fertility treatments, 6 miscarriages from week 5 to 11, a premature birth in week 21. Treated by OBC". "Noemca, Mother of 3, two on this earth, and one in heaven", and others. In these signatures, the users are not presenting their conventional academic or professional merits, but life events that have an existential impact on who they are as persons, and what their lives are about. But they are also presenting facts that are not normally part of public discourse. Without the online community, these women are often isolated and their sufferings are subject to taboo.

The patient users complain in a tone of irony and sarcastic humour about the lack of other people's support of their life-projects. Their relations and colleagues, mothers-in-law, and friends and families with children are clearly stigmatized by their recurrent miscarriages. But it also becomes clear that the many emotional, physical and relational costs of participating in numerous fertility treatments, of the recurrent miscarriages, and of the 'burials' of the dead foetuses are not directly discussed among the users. Indirectly, it becomes evident that the pregnancy project comes at a high price that involves ethical dilemmas; the breaking off of marriages/partnerships and of social isolation resulting from the surrounding people's lack of understanding and support of the partly self-inflicted costs.

3.2.   Analysis of text production in 'Talks about COPD'

COPD stands for Chronic Obstructive Pulmonary Disease, and it is a lung disease that affects many people. In more than 85% of the cases, the cause is smoking, which has resulted in a destruction of lung tissue, and most patients are aged between 50 and 60 years when the diagnosis is made. The COPD diagnosis is divided into mild, moderate, severe, and very severe COPD, depending on how much lung function remains (as measured by FEV1, i.e. the amount of air the patient can exhale in one second). There is much difference in how sick the people involved in communication on the forum 'Talk about COPD' are, and they are using the FEV1 value and age to identify these differences.

3.2.1.   Patient narratives on COPD
Recurring themes in "Talk about COPD" is exercise and smoking, and the communication thus reflects precisely the primary advice from the established system to the chronic COPD patients: smoking cessation and rehabilitation courses. The patient narrative on smoking cessation is 106 posts long, written by 16 users, including participants who are relatives of the patients. The tone of communication is positive and constructive, and covers a wide range of issues from practical information through the exchange of experiences and advice to more abstract and philosophical reflections about what it means to live with a COPD diagnosis. People communicate about e.g. electric bicycles for exercise, retirement- and disability pensions, flexible jobs, and dialogues about these topics often link to information pages along with own experiences with the issue in question. A post entitled "Electric bicycle", for instance, requests information and experience with this device, and results in series of responses of different types. One reply is a suggestion to search the site ("Talk about COPD") for information on electric bicycles (a topic which has been

discussed several times). A second patient user asks about age and FEV1 in order to better respond, other users explain their experiences with the use of electric bicycles, and which model is best, and others again illuminate the possibilities of subsidy for electric bicycles. Thus a differentiated knowledge on devices for exercise related to the COPD condition is illuminated.

An example of postings that reflect the situation of living with a COPD diagnosis is entitled: "My head has not understood that my body is sick". The author (BS) writes that he keeps thinking that he can do the things that he used to do before he fell ill: "We all know how it is. We will just do an ordinary thing like emptying the dishwasher, and it is already done in our heads, but we have not even started and already lost our breath". Many agree, saying it is the "horrible truth" and thus reflect on how difficult it is to completely accept a COPD diagnosis. Here, accepting is tantamount to understanding that you cannot do anymore what you could before. Another example shows a contrast between a personal experience and external expertise. The dialogue starts by a user recommending to others to attend rehabilitation courses. "Toria" responds by telling how hard she thought it was to participate in such a course and that she does not dare to join again as she felt she got worse. In response to this, other users write that she has to pull herself together and get out of bed and do something. "Toria" chooses to listen to the "expertise", represented to her by the other users, and not to 'listen' to her own feelings and experience of getting worse when attending rehabilitation classes.

3.3.   Meta-analysis of patient narratives in online communities

The patient narratives presented in the above analysis are exemplary of the user-generated content of the two online patient communities. They point to some collective characteristics of the users' interaction, such as developing shared, inter-subjective interpretations of coping with either recurrent miscarriages or COPD. Creating these stories, which often stretch over fairly long, real-life timespans, e.g. four weeks in "How many have experienced that HCG didn't rise as it was supposed to?', and with multiple readers and writers involved in telling and shaping the narrative, e.g. the 106 posts on 'Smoking cessation' by 16 different patient users. So, these co-authored stories do not only arise from first-person experiences of the disease in question, but are rhetorically the result of the first-person plural: 'we'. The stories told on life with miscarriages or with COPD are therefore the products of social action. Applying Greimas' Actant model on their joint text production makes a deep-semantic analysis possible in order to reveal the deeper motives and purposes, 'the desired object' that initiates the groups' communication and use: 'the subject's project'.

3.3.1.   The collective patient identity on 'Recurrent Miscarriages'
Interpreting the multi-logical narratives on recurrent miscarriages through the Actant model gives the following plot-structure of the users' communication (Fig. 2).
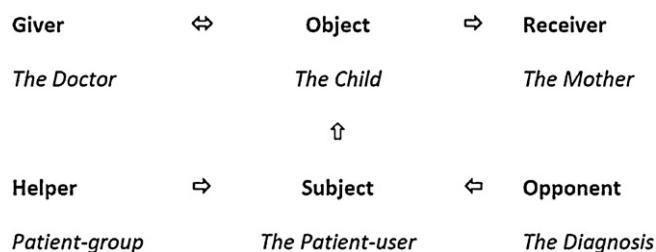
Giver	⟺	Object	⟹	Receiver
The Doctor		The Child		The Mother

⇧

Helper	⟹	Subject	⟸	Opponent
Patient-group		The Patient-user		The Diagnosis

Fig. 2 – Meta-narrative on the online community of Recurrent Miscarriage [22–24].

Giver	⟺	Object	⟹	Receiver
Treatment		Prolonging life		The COPD-member
Self-responsibility				Motivation

⇧

Helper	⟺	Subject	⟸	Opponent
Confessions		Patient-users		Decreased lung function
Support, scorn				Death, lifestyle, smoke

Fig. 3 – Meta-narrative on the patient network 'talk about COPD'.

The plot-structure refers to a collective 'myth' that is being created and reproduced in the patients' communication on 'Recurrent miscarriages'. In sum: a meta-narrative is created by the patient users and contains their shared history and hope for the future. They are all protagonists, the subjects of the story who desire and strive for motherhood, but suffer from recurrent miscarriages, but also related problems of broken partnerships, chromosome errors, infertility, prevent the bearing of a child. The doctor can give her the child (make her body carry through a pregnancy) if she follows his advice; the treatments (insemination, hormones, cerklage and haemoglobin treatments, surveillance, scans) and the patient community can help her by expressing belief (reading, posting, encouraging) in her project.

The observant reader will notice that the arrow between the Giver and the Object points in both directions: the Doctor's interest in the patients' goal is related to 'OBC's research hypothesis. He needs patients to participate in his research programme in order to prove his research hypothesis: that the recurrent miscarriage is caused by the (defect) immune system.

On the one hand, the rhetoric of their communication adopts the clinical, biomedical language on how they talk about their bodies and share information. On the other hand, there is a biblical tone of sisterhood where the child is the salvation and the doctor the Saviour. Myths of rational progress through Medical Science, and eternal life and love through the birth of the child, the Messiah, are synthesized in their communication. This meta-synthesis of otherwise dichotomous positions into a shared interpretation of the meaning of recurrent miscarriages is collectively created and repeatedly reproduced by the form of 'multi-logical narratives'. By 'multi-logical narratives' we wish to label how the 'dialogue' of an 'I' and a 'You' of users reading and responding to each other becomes a collective 'We', i.e. the first person plural users who reflect an 'Us': a shared identity.

3.3.2. The identity of the patient community of 'Talk about COPD'

A shared story that configures all the patient users' communication and narratives is about creating motivation: to believe in treatment recommendations, i.e. changes in habits and lifestyle. Even though the changes are hard, involve (self-)disappointments and a reward where you can only hope to postpone death and not cure the disease, it is comforting that you are not alone, i.e. the 'we', the shared identity and fate created and expressed by the patient users bring consolation.
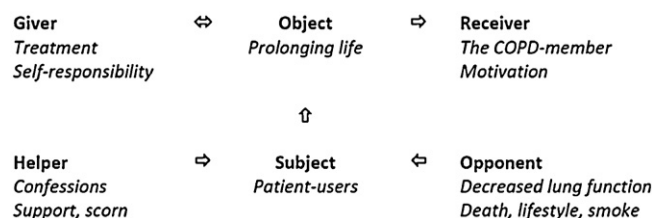
The meta-narrative of 'Talk on COPD' can be expressed by the following actantial-model (Fig. 3).

The joint project for users in "talk about COPD" is the desire to maintain motivation, and the belief that smoking cessation and exercise can actually prolong life for them. In a cheerful and ironic tone, they repeat again and again to each other: you must keep faith in medical recommendations. Notwithstanding that the situation is experienced as a great loss, e.g. to stop smoking, the message is that you must take responsibility for yourself and take up the fight against yourself and the deadly diagnosis. The message is that you can fight (if not defeat) the disease. Help is smoking cessation, exercise, and the consistent support of other users. Users of "talk about COPD" thus help each other to maintain the motivation to comply with the advice and guidelines issued by health authorities for treatment of COPD patients.

4. Discussion and conclusion

The initial research question asked was whether online communities are a means for patient empowerment as a platform for information, critic and community building. This empowerment could both be understood from an individual perspective and from a collective perspective, addressing issues of compliance and the hegemonies of doctors.

4.1. Empowerment by social media

The empirical studies revealed the benefits of patient support groups as activities of expressing personal health experiences and developing a shared identity as a member of a group with common interests and hopes. In this sense, online patient groups are a means to empower patients in regard to giving them the possibility of managing their illness from collaboration with co-patients and through the guidance of professional health care information. The collaboration consists in information sharing and rituals of confirming each other's endeavours to follow health instructions. The main effect of the online groups' communication therefore points to the compliance tradition of health care services. The communication is about adhering to the recommended treatment, eventually becoming a 'good patient' who, in the two cases, is either rewarded by bearing a child or by prolonging life, even though the quality of their 'normal lives' has changed substantially. The patient users of 'Recurrent Miscarriages' pay a high price, physically and socially, of inactivity and isolation by persistently pursuing a child. Due to the fact that the social

life, habits and identity as a smoker are to be replaced by diets and exercise, the COPD patients have to find other qualities of life. But these individual costs of complying with treatment recommendations are not collectively unfolded or discussed. Therefore, critiques of health care services and of the inherent understanding of a good life in the prescribed treatments are simply not part of their communication. The core goal of their communication seems to be the construction of a shared understanding of how to behave with the diagnosis as a more or less univocal project.

4.2. Configuration of online group identity by multi-logical narratives

Elements of empowerment are unfolded by the media as the patients are given a 'voice' to share experiences and knowledge. Through multi-logical narratives, they create a 'we', a collective identity with a shared history and hopes for the future. Belonging to a group with shared interests and mutual support for realizing one's goals can be understood as a sign of empowerment. At the same time, however, the group dynamics leave little room or attention for reflections on questions that are not easily answered within their dominant plot and metanarrative. Questions such as: What happens to the unborn foetuses? Or: At what expense do treatments and changes in life style come to one's other relations, socially and in relation to one's own body, sexuality, work and free time? These questions rarely pop up, and when they do, they are not responded to, which points to limitations in the empowering potential of the online groups.

Compliance can therefore be said to be reinforced. The purpose of their communication is to motivate each other to comply with treatment, not to change their rights and possibilities as a patient group.

4.3. Meta-narratives of compliance in online patient support groups

The patient users share the same goals and understandings on how to arrive at the desired goal of their project: the life of a child or the postponement of death. Participating in the communication motivates the patient user to stick to the project. Collectively, an ideal patient behaviour is configured in the sense that the patient users empower each other to comply with the treatment. This might also be the blind side of the assemblage, as alternative views on how to live and continue living with the chronic diagnosis of recurrent miscarriages or COPD are excluded. The multi-logical narratives create a shared community identity and a rhetorical style of participation. At the same time, these stories, or collective myths of meaning creation, leave out alternative beginnings and endings. This conclusion reflects back on the expectation of the online community as a collaborative medium, which seems to have an amazingly quantitative potential of including many utterances, but in terms of quality, it leaves little room for diversity regarding body perceptions and expectancies towards life beginnings and endings. Therefore, in these cases, the reformative potential of the online community seems to be conservative as regards alternative understandings of health.

Summary points

- Social technology has empowerment potential.
- Demonstrate difference in individual empowerment and collective empowerment.
- Social technology can contribute to treatments in patient communities.
- The methodology of the study adds qualitative and textual analysis to the quantitative research on communication with IT.
- Develops a new concept of 'multi-logical narrative' to explain how shared meaning and knowledge is created collaborative in online communities.
- Argue how an 'ideal patient' is configured in online patient communities.

These insights give reason to reconsider whether the collective dimensions of empowerment are compatible with the patient role. The early speculations on the potentially empowering effects of online support groups [10] draw on analogies to online support groups for e.g. AIDS patients, but also mention that the AIDS patients were networked politically by the gay rights movement before they were caught up in a network of contagion. This might point to a substantial difference, concerning potential empowering effects, between people networking as citizens and people networking as patients. However, this question remains open for further research.

Authors' contribution

Helle Wentzer is main author. Ann Bygholm secondary author.

Conflict of interest

There are no conflicts of interest.

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