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Optimism and Compliance: An Examination of Disempowering Processes Within Online Patient
Communities

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Abstract

Patients diagnosed with long-term conditions (LTCs) are now being asked of medical practitioners to take an active role in their own health care as “expert patients.” This trend has accelerated the increase in people with LTCs who are using the internet for both information and social support. A valuable resource to these patients, and of interest to researchers, is a new type of online space: online patient communities (OPCs) created for patients suffering from specific illnesses. In order to better understand potential disempowering processes within OLPs, I follow the research and examine the illness narratives, focusing on their various external influences and the work they do within these communities. Among the findings discussed, are group norms of optimism and compliance within certain communities.

Optimism and Compliance: An Examination of Disempowering Processes Within Online Patient Communities

“Telling one’s own story is good, but it is never inherently good, and the story is never entirely one’s own” (Frank, 2009, p. 196).

Toward a more comprehensive view of medical information

Patients diagnosed with illness or facing surgery are provided with various information and patient education materials (PEMs) through clinics, hospitals, and other medical facilities, including online information provided by medical groups and organizations. In addition, patients also seek information about their health from nonprofessional sources. According to a Pew Research study, between 2012 and 2013, 55% of Americans searched the web for information about a specific disease or medical issue and 43% looked for information on a certain medical procedure or treatment (Fox & Duggan, 2013). In addition, 86% of internet users living with a disability or chronic illness have searched online for medical information (Fox, 2007). These results align with findings that an estimated one-half of adults in the United States suffer from at least one chronic illness (Ward, Schiller, & Goodman, 2014). With the use of the internet to access health information by people who suffer from chronic and long-term conditions growing, this trend represents a new form of patient empowerment, where patients “control the content and flow of the information available to them” (Brady, Segar, & Sanders, 2017, p. 1088).

Although much research has been devoted to eHealth and online patient communities in the field of technical communication, an overwhelming majority of this research has held the traditional concerns of the field (Koeber & Still, 2008) and examined such elements as credibility markers (Freeman & Spyridakis, 2004; Thon & Jucks, 2017), information quality

(Zhang, Sun, & Xie, 2015), and layout and design (Lazard & Mackert, 2015; Willerton, 2008; Renguette, 2016). Scholars within the field of technical communication have advocated for more research investigating the production and use of technical documents and communication outside traditional organizational boundaries, to explore the impact of technology on and within larger society and people's everyday lives (Bellwoar, 2012). This broader approach aims to better align the medical humanities with the rhetoric of health and medicine (RHM), while being more inclusive of the patient perspective (Edwell, Singer, & Jack, 2018; Hannah & Arduser, 2018; Meloncon & Frost, 2015; Segal, 2005, 2009; Walkup & Cannon, 2018). As Judy Segal suggests, "Researchers on writing and medicine have a role to play in making commentary on Internet health more complex, more realistic, more rounded, and more useful" (2009, p. 353).

Medical advice rarely accounts for the unseen contingencies of everyday life for those living with serious illness. Engler et al. (2016) took note of a critical information gap that exists for patients: Instructions on how to live psychologically, socially and culturally with chronic illness. As stated by the researchers, "Websites on cancer often focus on biomedical information and lack information on the wider experiences and social effects of diagnosis, treatment and living with cancer, aspects that some cancer patients and their family members alike wish for more information about" (pp. 1325-1326). Critiquing the traditional biomedical approach to health information, Polls (2014) points out that for people living with serious illness, "distinctions between medical and other matters are ultimately irrelevant," as "medical practice is always a daily life practice" (p. 84). Thus, in order to better understand patient information needs and experiences with illness and treatment, researchers must step out of the sanitized lab and into the messy, digitalized world of the flat-nailed, featherless biped.

Empowered patients and online patient communities

Although there have been anxieties regarding lay persons accessing of health information (Lerner, 2018; Scott, 2016; Segal 2008, 2009), one thing is clear – patients will undoubtedly continue online health information seeking practices. This is especially true for those diagnosed with chronic and long-term conditions (LTCs), who are now being asked of medical practitioners to take an active role in their own health care as “expert patients.” This trend has accelerated the increase in people with LTCs who are using the internet for both information and social support (Allen, Vassilev, Kennedy, & Rogers, 2016; Brady, Segar, & Sanders, 2017). One valuable resource for these patients, and of interest to researchers, is a new type of online space: communities created for patients suffering from specific illnesses.

Online patient communities (OPCs) have been shown to have numerous benefits for members, including sharing technical and factual information (Albright et al., 2016; Allen et al., 2016; Coulson, Buchanan, & Aubeeluck, 2007; Uden-Kraan et al., 2008), discussing everyday topics related to illness (Albright et al., 2016; Coulson, et al., 2007; Kazmer et al., 2013; Uden-Kraan et al., 2008), and providing and receiving emotional support (Albright et al. 2016; Allen et al., 2016; Coulson et al., 2007; Uden-Kraan et al., 2008). Furthermore, these communities have demonstrated the ability to help create well-informed, empowered patients (Brady et al., 2017; Kazmer et al., 2013; Uden-Kraan et al., 2008). OPCs have also been shown to have a positive impact on the patient-physician relationship, increasing both trust and satisfaction with care, and making them a valuable asset to medical providers (Audrian-Pontevia, & Menvielle, 2018). Furthermore, Information exchanged within online communities is also easier for patients to comprehend because it is both tailored to personal needs and “formulated in their ‘own language’” (Uden-Kraan et al., 2008, p. 408).

Researchers have also shown that patient knowledge can contribute to medical science for conditions where the cause and treatment are largely unknown, as in the case of amyotrophic lateral sclerosis (ALS). Kazmer et al. (2013) showed how patients with ALS formed and distributed knowledge about living with this little-researched disease, arguing that these expert patients could contribute valuable information to the medical community. Polls (2014) also pushed the boundaries of medical evidence by asking how patient knowledge, techniques developed by patients to live with their illness on a daily basis, could be turned into science and made accessible alongside official medical and technical information.

The combined research pointing to patient empowerment through online communities and forums is impressive, yet the definition of empowerment has been taken for granted. Empowerment has traditionally been contrasted with compliance, where the patient passively accepts care and treatments from the medical practitioner without any autonomy. As Wentzer and Byghold (2013) explain, patients are empowered when they “are in possession of the knowledge, skills, and self-awareness necessary to identify and attain their own goals” (p. e387). Existing research tends to measure empowerment in relation to the patient-physician relationship and acquiring knowledge to make informed decisions regarding which medical treatments or technologies to choose from. In contrast, the few studies viewing empowerment as a means for exploring alternatives to the medical script or organizing community for social action have illustrated some disempowering effects on patients.

Researchers must fully consider that what is under analysis is not a stationary text, but a living, growing, and reacting social community with its own culture that naturally forms values, norms, and is provisionally shaped by the society in which the contributors live. Rodriguez

(2013) has argued that the narrative discourses within these online spaces are what creates the communities themselves:

For much of our history narratives were shared face to face and formed the foundation of communities based on physical place; but the possibilities for communication enabled and mediated by technology allow for communities that are unbound by geography and are more solidly based around collective interests. (p. 1225)

In addition to providing the foundation for online patient communities, personal accounts of illness, or illness narratives, are necessary as a means to make sense of the illness experience to others and, most importantly, to one's self. In order to better understand potential disempowering processes that take place in online patient communities, I follow the research and examine the illness narratives, focusing on their various external influences and the work they do within these communities.

Social isolation and stigmatization of the ill

Participation in supportive social encounters is important for a patient's overall wellbeing and quality of life but may be critical for individuals suffering from chronic diseases (Coulson et al., 2007; Kazmer et al., 2013). Many of these patients find that living with chronic illness has resulted in the loss of previously held social contacts, requiring them to create new social ties to avoid isolation. In addition, when someone is diagnosed with a serious illness, they must adjust to financial losses as they gradually lose the ability to work, which is compounded by medical costs (Bury, 1988). Depression often ensues. A study that assessed suicide deaths between 2000 and 2013 found that people with chronic illness were at an increased risk of suicide (Ahmedani et al., 2017). The study also revealed that 62% of suicides were committed by people who had been diagnosed with at least one major physical health condition within the previous year.

Furthermore, more than 38% of those who died by suicide had more than one physical health condition compared to 16% of the control group, after adjusting the results for substance use and mental health disorders. These findings are the first of their kind and highlight the need to both better understand and improve efforts to help ill people cope with their diagnosis through social support with other patients.

Social isolation may occur for several reasons, including loss of mobility, driving restrictions, fatigue, and side effects from treatments. In addition, many serious illnesses carry social stigmas, such as HIV/AIDS, diabetes, and lung cancer, which are often seen as being caused by one's own poor choices. Markle, Attell, and Treiber (2015), for example, found that stigmatizing experiences encountered by patients frequently lead to social isolation, even social rejection. Assessing the online blogs of authors struggling with multiple chronic illness during mid-life, the researchers found both stigma and social rejection to be common themes. One author, embarrassed by his appearance, regarded his isolation as "voluntary house arrest," while another expressed her emotional pain at losing the friends, even family, she once had: "Those who used to be our friends and even family stop calling. Not even returning our calls... It is not like we have some contagious disease that passes through the phone!" (Markle et al, 2015, p. 1276). These bloggers were able to find a supportive community online where they could not at home and used that space to share personal stories of their illness experiences with others.

The significance of the illness narrative

The term "illness narrative" is attributed to psychiatrist and social anthropologist Arthur Kleinman, who has devoted much of his work to investigating the cultural framing of symptoms and diseases. Illness narratives are the stories ill people tell and retell, a process that frames both one's understanding of what is happening to them and future possibilities. Stories make us

human. “To be human is not simply to live a life, but to reflect on that life by telling it in multiple ways to multiple audiences, throughout the course of our lives” (Frank, 2009, p. 188). We tell stories to understand ourselves, the world around us, and our place within it. Through stories we develop our identities as we grow, reflecting on the stories we once told ourselves, and frame possible futures. Wentzer and Byghold (2013) explain that, in philosophy and communication theory, narratives are “cultural compasses that navigate individual behavior and compose social order,” functioning as “vehicles for power, tradition, and liberation” (p. e389).

When someone is diagnosed with a serious illness, they experience a “biographical disruption” to their life narrative, where they are jolted from the identity they once had and are left grappling for a story in its place (Bury, 1982). Björkman et al. explain, “becoming ill calls for new narratives of who a person is when former roles, identities, and activities are no longer available” (2016, p. 2968). Further, “without these narrative acts, the patient cannot himself or herself grasp what the events of illness mean” (Charon, 2006, p. 66). The stories we tell are shaped by the communities in which we tell them and are derived from the many stories circulating both inside these communities and extending out into wider culture. These stories, or narrative resources (Frank, 1995), are the tools that allow individuals to explore new identities and make sense of their lives.

Although researchers have demonstrated how the exchange of personal experiential knowledge within these online communities helps create expert patients (Markle et al, 2015; Engler et al., 2016), the sharing of stories also provides the social support and narrative resources needed for identity exploration. For example, Albright et al. (2016) found that pulmonary fibrosis (PF) patients shared stories with one another while reciprocating social and emotional support. A common trend through OPC research is patients intentionally seeking out others who

are not only experiencing the same illness but also who are similar demographically (e.g. Engler et al., 2016; Fergie et al., 2016). By hearing the stories of similar others, patients are provided with additional narrative resources for their own identity building.

Culture, meta-narratives and stereotypes

The illness experience, however personal, is constrained not only by powerful institutions but also cultural understandings of symptoms and illness categories, which differ among societies. In addition, symptoms and diseases “hold special significance not just in the society as a whole but also in the distinctive life worlds shaped by class, ethnicity, age, and gender” (Kleinman, 1988, p. 24). Socially constructed and culturally mediated, some narratives maintain power over others, particularly those circulating wildly. Long-term exposure to these narratives renders them virtually undetectable as they become taken-for-granted truth (McKenzie & Lefrance, 2017, p. 191). These dominant narratives have been referred to as master narratives, or meta-narratives, and they often espouse stereotypical ways of understanding health, illness, interventions, and the capabilities of modern medicine. Because the narratives within OPCs themselves create the community, trends in communication can be analyzed to reveal the influence of cultural meta-narratives on the meta-narratives of the online communities themselves.

Zhang and Ding (2014) performed a comparative rhetorical analysis of online narratives in patient forums for HIV/AIDS for the U.S. and China. The authors looked at how the posts rhetorically constructed the meaning of HIV/AIDS in each culture, revealing how traditions of reasoning and sociocultural beliefs shape how the illness is interpreted and responded to. The Chinese participants saw the illness as destiny, stemming from moral defect, whereas the American participants framed the illness as an individual matter, avoiding discussion of the

larger social and political actors. These findings illustrate the extent of the impact dominant cultural narratives have on the meaning individuals ascribe to certain illnesses, even limiting imagined possibilities, such as social activism in the case of the American narrative. It is important to note that each individual community, including OPCs, also preserves their own meta-narrative, which is influenced by and borrows from the plots of meta-narratives circulating within that particular culture, in that particular society, at that particular point in time.

Considering the impact of cultural meta-narratives on OPCs, it's important to take into account how our culture views illness.

Illness is threatening and unnerving to both the sick and the well in a society disillusioned with ideal health. Mortality has been safely shuffled away for the star of the show: medical technology which will restore health and cure all ails. The ill are both a testament to the inevitable and a frightening contradiction to the superiority of medical science. Frank (2009) explains identifying with another through their personal story: "What might go badly for the character is a stand-in for what might go badly for the listener" (p. 188). Markle et al. found that blog authors felt they needed to talk about their experiences and feelings, but friends and family turned them away. Described by one author, "I struggle NOT to discuss my health outside my support groups and doctors... because people don't WANT to hear it. They get queasy and feel strange. I watch their faces cringe up..." (p. 1267). Peters-Golden (1982) conducted a study in which the views of cancer patients were compared to those of people who were not ill. The study revealed that 61% of healthy individuals reported avoiding people who had cancer because the interaction caused them to feel more personally vulnerable to illness and death (Trusson & Pilnick, 2017). Not only do most people not want to hear it because it makes them uncomfortable, they also defensively resist it, often attempting to imagine it away.

Arthur Frank (1995) shares a story of a boy, who, upon hearing the first-person account of a holocaust survivor, details how he, in the same situation, would have devised and successfully carried out an escape. Along the same lines, he also tells of his experience speaking with a young man about his own ordeal with cancer. The young man explains to Frank that he does not need to worry about getting cancer because he has taken the necessary steps, through diet and fitness, to prevent any type of disease. Kathryn Conway (2013) also provides two examples to this effect. A woman by the name of Christina Middlebrook tells her mother over the phone that she is disturbed to come to know that her cancer treatment only results in effective remission in one-quarter of cases. Her mother's response: "My mother tells me that I am not thinking right... She tells me that I should focus on the percentage of patients who make it three years" (p. 22). Journalist Marjorie Williams, suffering from terminal liver cancer, writes: "Someone tried to cheer me up by reciting the happy tale of a sister-in-law's cousin who had liver cancer but now he's eighty and he hasn't been troubled by it in forty years... I wanted to scream, DON'T YOU KNOW HOW SICK I AM?" (p. 22).

Meta-narratives are often supported by and stem from medical institutions, reflecting a biomedical rhetoric that can assign stereotypical labels to persons with certain disabilities or illnesses. One example is the meta-narrative on genetic risk, which applies to genetic testing of individuals at-risk of hereditary disease who are considering having children. Leontini (2010) explains, "these scripts show that the increased options by biotechnology come with the collateral pressure on parents to consider any number of sophisticated techniques, however ethically controversial or physically and emotionally invasive, to ensure that future progeny will not be predisposed to hereditary disease" (p. 10). Huntington's disease (HD), which is a neurodegenerative disease that causes disability, near-complete incapacitation, and death within

15-20 years from its sudden onset in mid-life, is a hereditary condition for which there is no prevention or cure. Persons who test positive for HD can either adopt, forego having children, or choose the technological route, which involves choosing “healthy” fetuses that test negative for the disease early on during the pregnancy. Testing positive for HD can also affect opportunities for home loans and life insurance, as well as cause problems in close relationships and result in irreversible knowledge. Leontini observed that the participants in her study, despite some feeling torn between their options, reflected this meta-narrative in their personal accounts, which limited them in imagining alternatives to the courses biomedicine had presented them with.

Another example is that of awareness – the call for women to be proactive in preventing breast cancer by eating healthy, living right, and performing self-exams and having regular mammograms. The call is familiar, and may appear to be sound advice, but all these “preventative” measures have little or no impact on susceptibility to the disease or chance of survival. In fact, frequent mammograms have no significant effect on breast cancer mortality (Harding et al., 2015). Pitts (2004) found repeated calls from women on their blogs to other women to prevent their own deaths. For instance, one blogger cautions, “Breast cancer kills the unaware, the innocent, the untested.” Reflecting the ideal health script, these meta-narratives place both responsibility for improved outcome and blame on the ill patient.

Narratives of restitution and triumph

Heavily influenced by the ideal health meta-narrative and institutional medicine, restitution narratives look toward regaining a former state of health through self-discipline, a positive attitude, and advanced technologies and medical interventions. Arthur Frank (1995) explains that the restitution narrative’s plot is one of: “Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again” (p. 77). The restitution narrative involves talk of

treatments, possible outcomes, praising competent physicians, following doctor's orders, and always looks to a future without illness. Because every story is written with an audience in mind, stories tend to be fashioned in a manner that is non-threatening, contradicting the nature of illness itself. Author Frank (2009) explains that, "being ill requires learning to figure out, as quickly as possible, what someone else's preferred narrative of that illness is, and then fitting yourself into that narrative, if you wish to gain their help or maybe avoid their hindrance" (p. 189). But, for those who are ill, these stories are "at best a silly romance and at worst a cruel denial of their situation" (Conway, 2013, p. 22).

In a nearly identical vein, Kathlyn Conway has proposed what she calls the "triumph narrative" (2013), in which "a person battles a disease, overcomes numerous obstacles, and, in the end, returns to a life having learned some important lessons" (p. 22). The term "triumph" is a logical fit to the battle metaphors that have invaded the way we discuss cancer. Terms such as "beat," "conquer," and "win the battle" have become so pervasive in our talk about cancer that they have become overlooked, natural – we forget they are metaphors (Segal, 2009). The military metaphors of illness were first publicly criticized by Susan Sontag (1978) in *Illness as Metaphor*. Sontag argued that metaphors not only placed the blame on patients who could not overcome their illness but also called on a positive attitude to fight disease. As Cobb and Starr (2012) state, "metaphors obscure the pain and the complications of the disease and its treatments in an attempt to deny the body's limits" (p. 98). The battle metaphor is present in most accounts of cancer, where narrators may identify themselves as "survivor" protagonists, most notably in breast cancer narratives.

Steinberg (2015) describes the breast cancer patient as being "caught between clinical imperative and cultural fantasy." It appears that the idea of the empowered woman and the

demands of ideal health have coalesced, in what Cobb and Starr (2012) call our “post-feminist makeover culture,” to create the breast cancer “survivor,” a woman who says things like “breast cancer is the best thing that ever happened to me” (Segal, 2008). These expectations of what illness should be for a woman constrain what is considered permissible and limit what can be honestly said about the experience. In a study that asked women who had completed treatment for breast cancer what they thought of the label survivor, Kaiser (2008) found that many of the participants either modified the meaning of the term or rejected it altogether. Kaiser notes, of those who embraced the term, that the biographical disruption of illness and the search for a new identity could be a reason many women are drawn to the breast cancer culture and the survivor identity. And the stories constructed by new members of this culture will draw on those triumph stories the group presents them with.

Counter-narratives

In its [standard breast cancer story] insistence on the necessity of a positive attitude (“when you stay positive, you stay powerful”), it’s also coercive. If, as a person with cancer, you violate the code of optimism, or if cancer somehow failed to improve you, you’d better be quiet . . . So I thought I’d speak up. (Segal, 2012, p. 311)

When dominant narratives circulate and become part of cultural discourse, they require counter-discourse (Segal, 2008). Arthur Frank (2009), borrowing from feminist theory, talks of narrative acts of reclaiming one’s lived experience from the dominant narratives that have told the patient’s story for them, often powerful institutions and systems. McKenzie and LaFrance (2017) explain that counter-narratives are a way for people to “talk back” to master narratives that tell injurious stories of their experiences and their lives. Meta-narratives are both powerful and loud: they are an amassment of all the voices telling and speaking in support of these

singular versions of experience. Although counter narratives can take place on either an individual or collective level, gaining sufficient volume in wider society requires a significant amount of community support and a number of harmonic voices. Thus, resisting voices are seldom heard. But when those voices are given a platform, they almost always cause a disruption.

First published in 1980, Audre Lorde's autobiographical account *The Cancer Journals* criticized the medical practice for sexist treatment of female patients and called for patient advocacy. Thirty years later, and much attributed to the influence of the Susan Komen Foundation and the subsequent storm of advertising, breast cancer had developed its own unique culture, what Barbara Ehrenreich has referred to as a cult. In "Welcome to Cancerland" (2001), which appeared in *Harper* magazine, Ehrenreich shares her own experience while critiquing what has been called the "Pink Ribbon" culture of breast cancer. In "Welcome to Cancerland," Ehrenreich also shares her experience on the Komen.org message board, where she posted her own "heartfelt complaints about debilitating treatments, recalcitrant insurance companies, environmental carcinogens, and... 'sappy pink ribbons.'" The responses to her post on the forum made it clear her attitude was not welcome and the article itself was met with letters from angry readers (Segal, 2009). Although group norms can repress counter narratives, the opposite may also be true.

Turner (2013) investigated the community blog for women who have undergone hysterectomy and oophorectomy (surgical removal of the ovaries), the Hysterectomy Educational Resources and Support (HERS) Foundation. The group is viewed as having an anti-hysterectomy stance, which has had a stigmatizing effect on their messages and has largely discredited the impressive amount of open survey data the group has collected since 1991, long

before the medical community began to research the effects of the procedure. Turner explains: “The data, all based on voluntary reporting and with no sampling, are far more extensive in terms of listing outcomes than any other research” (p. 166). A counter narrative to the medical meta-narrative of improved vitality and sexuality after surgical removal of the sex organs, the HERS women deconstruct the claims of experts as well as those of women who share restitution stories following the procedure. Findings from long-term research on the procedure has only been released in recent years. Comparing the survey data to the new research findings, Turner concludes that the data submitted by women to HERS were consistent with the research. Despite the new research findings, HERS remains discredited and even despised by the medical community (Turner, 2013).

Optimism and compliance

Although there is little written on the subject, the narratives within the online communities shared themes of reinforcing compliance and optimism as group norms. Despite efforts by the medical community in recent years to move away from the compliance model and toward patient empowerment, it appears that much work still needs to be done. It appears that OPCs may very well be acting as an extension of clinical practice, mirroring the real-world environment where medical encounters take place. It appears people are limited in imagining anything outside the narrative resources they already have, and most of those resources come directly from institutional medicine and the pharmaceutical industry.

Wentzer and Byghold (2013) analyzed two online communities, one for women who had experienced repeated miscarriages and another for COPD patients, deriving plot-structures from meta-narratives they created from the chains of discussions. In both cases, the narratives revealed that the patients supported and encouraged one another to follow the prescribed medical

treatments, reinforcing the patient compliance model. In neither case did the patients collectively question their rights, issues of compliance, or the prescribed treatments. When individuals did bring up these types of questions, they were silenced by the other participants not responding to these posts. Sandaunet (2008) observed a similar forum control in an online support group for women diagnosed with breast cancer, where participants felt afraid to complain or act in a way that made them stand out from the group. Messages that indicated a depressed mood or helplessness were not responded to and ignored by the group. As one participant explains, “if you try to mention that you are struggling mentally, you do not get any response...in a way you feel they say that ‘Ok. . .but we do not want this’” (p. 138). In addition, within these online spaces optimism can take on a more extreme form.

Wentzer and Byghold (2013) found that, in the case of the women battling infertility, a narrative that appears to worship Medicine is revealed. The authors note that while the language the women use is fused with biomedical terminology, there is also a “biblical tone of sisterhood where the child is the salvation and the doctor is the Savior,” and “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” (e392). This sort of ideology takes compliance to an extreme and resembles Ehnrich’s description of “breast cancer survivors” forming a religion around the technology that helped cure their disease. In a similar vein, Arduser (2011) describes the online community for patients in her study as “a diabetic’s confessional booth,” the stories unfolding in the posts evidencing a dominant influence from the patient compliance model. Although behavior that deviates from prescribed treatments is confessed, it is confessed and in a tone that conveys morality. It is said that there are no atheists in foxholes, and illness is no doubt

a spiritual experience for many. But there are no too few reasons why Medicine should not be seen in such a light.

Additional narrative resources

Although counter narratives do indeed cause a disruption, on their own this disruption does not often last long or make much progress. I do not believe the battle is futile, but perhaps there is also another way. One in which technical communicators, health professionals, and possibly patient communities could all be involved. This resistance would strike these harmful meta-narratives where they are weakest, dismantling them from their foundation. By turning resistance narratives into narrative resources, showing the ill that there are other ways to express, or even live, their experiences, and making present factors such as public policy and environmental carcinogens, meta-narratives will be deprived of their own strength. Two recent studies, both published in *Technical Communication Quarterly*, hold promise for such efforts.

To teach patients with diabetes rhetorical skills, Edwell, Singer, and Jack (2018) conducted an eight-week writing course, "Writing Diabetes." Patients were instructed to write several genres, including letters, poems, case reports, and first-hand narratives, which allowed them to both feel empowered in writing their own story and to share their knowledge with other patients. The authors recommend similar future studies as one way to foster collaboration between the medical sciences and humanities. In the same issue, Walkup and Cannon (2018) introduced information sources on alternative addiction models to a drug and alcohol treatment facility for the residents to access. These models are alternatives to the Cognitive-Behavioral Therapy (CBT) model that is exclusively taught to patients in nearly all addiction centers. The CBT model is an older model which holds the addict as solely responsible for their problem and does not recognize the multiple factors that contribute to addiction, including societal factors and

poor mental health care. By providing residents with access to sources explaining alternatives to the CBT model, patients were able to improve their own health literacy and gain a more accurate understanding of the nature of their own addiction. In essence, by simply placing these resources within the center's library, they became not only narratives of resistance to the CBT model but also narrative resources for the patients.

Conclusion

On a quantitative level, there is a significant amount of research showing the empowering qualities of online patient communities, yet qualitatively this empowerment has only been assessed in terms of the patient-physician relationship and sharing knowledge with others. In contrast, the few studies viewing empowerment as a means for exploring alternatives to the medical script or organizing community for social action have illustrated some disempowering effects on patients. Although these patient communities have proven to be a valuable asset to the medical community and benefit the patient-physician relationship, these results reveal a stronger relationship between the two. It appears that some of these communities may be functioning as extensions of medical clinics and institutions, and possibly, strangely, attributing a spiritual dimension to medical science itself.

The stories we make for ourselves and our communities are comprised of bits and pieces of plots from the many stories available at one time within a particular culture. It only makes sense that these patient communities would borrow from the many narratives available from various medical and clinical settings. And, perhaps, it is natural to view potentially life-saving technology in a religious light, especially considering the moral overtones of health and of illness. Unfortunately, some patients pay great costs to abide by certain treatments and do not consider any alternatives. Others may blame themselves for their disease or a poor outlook,

without considering the environmental and occupational causes of their suffering. Yet some my tirelessly strive for prolonged life through various regimes that have no proven efficacy to provide the benefits of longevity. On a collaborative level, additional narrative resources are necessary in order to enlighten the narrative imagination, bring about new understandings and possibilities, and motivate for change in wider society.

On individual terms, Judy Segal offers some compelling advice:

Maybe we would be better off, sometimes, if we did not rush to the most available genre or, then, the most available story – if we stayed quiet a while, reflected, read, listened, and composed ourselves more carefully. Maybe the trick is to consider exactly what we want to say and what would be the best way to say it. (2008, p. 18)

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