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“You will burn and you will burn out; you will be healed and come back again.”

Fyodor Mikhailovich Dostoyevsky, *The Brothers Karamazov*

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1. Introduction

My second semester in Science and Society Studies (STS) marked some kind of illumination or revelation to me, owing to the fact that I discovered that the Internet could be used as a medium for conducting research. Being only used to the more traditional forms of research, I was somewhat puzzled, but more amazed because I found this fact fascinating and was convinced that I would do something similar for my thesis. My research project actually grew from an interest and curiosity in methodology, and was later on supported by another aspect of the Internet I find very intriguing- online grieving. Probably like any other Internet user, I would come across manifestations of grief and mourning online, mostly in social networking sites, and ask myself the question of what it was that made people want to express these emotions on the Internet. Was it because the lack of face-to-face interaction was comforting? Did the “offline world” not offer enough in terms of letting feelings out and getting something satisfactory out of this process? What was it about the Internet that made people who chose to reflect personal feelings and experiences on it do so?

Since this aspect on its own was not enough to make my research interests fit into the broader framework of STS, I started looking for additional conceptualizations that could help me position it within the field. Looking through the specific medium that would eventually become my research site, I realized that the issue of knowledge exchange and (re)production was also quite relevant, and started to think of my research interest in terms of how knowledge is circulated and created, and how these processes are shaped and influenced by the particular medium that is the Internet. At this stage, what is termed “e-scaped medicine” (Nettleton 2004), the fact that medical information previously not available to non-experts is now widely online and is being circulated outside the medical domain, helped me merge the handling of knowledge with a particular approach focusing on its specific characteristics.

What I have in hand, then, is an intermingling of several notions: the Internet as the arena of knowledge sharing and production, the Internet as the tool and medium of research, and online grieving. The first aspect corresponds to the broader discussions of the utility and efficacy of the Internet in the dissemination of scientific knowledge, and beyond that to the discussions about the Internet as a separate entity on its own. There is much discussion about the content and quality of the Internet as a tool for sharing knowledge, and also about the content and quality of the information produced within. Moreover, these discussions tie nicely with the expert – non-expert discourse that suggests that the boundaries between the two groups are no longer as clear as they once were, and that people are no longer docile recipients of information that is being offered to them. This means that they not only approach the information they have been offered with skepticism and try to make it fit into a

schema shaped by their own expectations, accumulations and so, but they also engage in activities that might be termed as patient activism. Reading some of the skeptical and angry forum posts made me wonder if this group of people could be preparing the grounds for a new kind of health activism, one that has to do with raising awareness about the use of psychiatric drugs.

At this point, debates on lay experience and how (or if) it is mobilized comes together with the aspect of pharmaceuticalization, which defines the “process by which social, behavioral or bodily conditions are treated or deemed to be in need of treatment, with medical drugs by doctors or patients (Abraham 2009: 100). This notion is of course closely related to the notion of medicalization, and is considered to be its direct outcome by some scholars. The importance of pharmaceuticalization for my research is that it may lead to a certain kind of patient activism, one termed “injury-oriented adversity” by Davis and Abraham (2011: 610) which is initiated by people who believe that they or their loved ones have been negatively effected by medication.

These main foci of interest led me to attempt to formulate a research project that would both try to answer these questions and do so by using virtual research methods that I really wanted to try and experience myself and also contribute to the discussions of medical information being exchanged and produced online. The research asks the main following questions:

What do online forums; especially support groups mean to their members in terms of what it has to offer that an offline setting does not or cannot? Put more openly, what is it about these spaces that people want to go on them to live the “survivor experience” and to grieve and to bereave? Furthermore, what can these spaces tell us about the interactions between experts and non-experts, and under this light what are the specific ways in which expert knowledge and scientific information is circulated and evaluated, and what kind of framings emerge from these processes?

I try to answer these questions by conducting a case study on a suicide survivors’ forum- a forum where people who have lost a loved one to suicide come together, the Alliance of Hope. Founded in 2008 as a charitable non-profit, the Alliance of Hope Forum is part of a broader website devoted to suicide bereavement and has around 6,500 international members. The main reason why I wanted to conduct the case study specifically on this forum is that it is one of the most active ones among its counterparts, is quite large in content compared to other forums dealing with the same issue and, of course, is an English-speaking forum which is favorable for my research project.

In an attempt to answer the questions stated above through a case study, in the merged chapters of state of the art and theoretical framing, I first try to lay out the most popular and current debates on my research arena and also elaborate on the connecting elements and work towards positioning my research interest and research questions within the wider scope of STS debates. Next comes the methodology section where I elaborate on the approaches I will adopt when answering my research questions. This chapter also includes a part for ethical considerations. I then move on to elaborate on the findings and analyses of my empirical work, offer a conclusion and end with my references.

2. State of the Art/Theoretical Framework

To position my research project within the broader framework of Science and Technology Studies (STS), I mainly focus on two specific notions: science-public relations and cyberspace. Both are extremely broad terms that may be studied from various perspectives, therefore what I hope to achieve in this chapter is to give an overview of the debates surrounding these notions and to point out how they specifically relate to my own research.

2.1. Science-Public Relations

2.1.1. An Overview

The relations between the domains that have come to be dubbed as “science” and the “public” is a largely explored field in STS, and it seems to be the consensus that these relations are transforming, though scholars may differ on the nature and extent of this transformation.

One of the earliest works related to the issue is by Callon (1999) who points out to the mistrust between science and the public and mentions an “age of suspicion” (1999: 82) when the taken-for-granted authority of science is being questioned, and lay persons are becoming more and more involved in debates related to issues of science and technology. Callon urges that the implications of this new era be taken into consideration and studied carefully. He argues that the public can no longer be kept outside the domain of science, and that the several different ways in which these two realms engage have to be analyzed. He thus proposes three different models to explore this, the first of them being the “public education model” in which science is granted absolute authority- what Gieryn calls an “epistemic seal of approval” (1999:1). This first model in which science is completely universal and objective can be argued to be the equivalent of what Steven Shapin (1990) calls the canonical account of the relations between science and the public. This account mainly tells of the boundary work maintained by scientists, the results of which helped scientists emerge as those

possessing “cultural competence” (Shapin 1990: 993), making them the one true bearer of knowledge. This process has resulted in the creation of a “gulf” between the science and the public, the latter becoming more and more isolated from scientific practice. Bensaude-Vincent (2001) also draws attention to how this certain gulf (or gap) was created and maintained by scientists to ensure their privileged status as experts. As the public increasingly started to be perceived as a threat to scientific activity and “legitimate knowledge”, the “public education model” Callon (1999) speaks of emerged as the dominant mode of interaction between science and the public. Interaction, however, might not exactly be the right word to choose because the public had one simple role: to receive the information they had been given. Since they were conceived of ignorant masses in need of the “enlightenment of science”, the public became passive recipients of information they were offered. As Callon (1999) has argued, any skepticism or mistrust from the public side would be seen as a direct result of their incompetence or ignorance, therefore resulting in an intensification of education initiatives to save them from falling prey to the superstitions and false beliefs lying in wait for them. This also corresponds to what Irwin and Michael (2003) call the “deficit model” which operates with questionnaire surveys and measures scientific literacy with a set of survey questions and assumes that “science has a set of universal or absolute procedural values, against which these subjects are measured” (2003: 24).

Scholars have challenged this approach in several ways, mostly on the basis that it is too simplistic an understanding of the public, and completely fails to take into account the specific ways in which they understand and assess scientific knowledge and expertise. Shapin (1990), for instance, has argued that this approach is laden with presuppositions about who is a scientist and who is a layperson, and claimed that the public education model or the canonical account neglects how the categories of science and the public themselves are constructed and maintained; in his well-known work on Cumbrian sheep farmers Wynne (1992) has shown how failing to take lay experience and expertise into consideration was a big mistake on the part of the scientists and has demonstrated how lay people are too complex in terms of “social relationships, networks and identities” (1992: 282). What Callon (1999) calls the “public debate model”, then, can be perceived as a challenge to the approach that conceives of the public as passive recipients of information. Callon argues that while the “universal value” (1999: 85) of science is a persistent persuasion in this model, there is more room for more complex relations between science and the public. Certain deficiencies and drawbacks science might have are recognized, and any cases of mistrust are not interpreted in terms of ignorance or incompetence, but are explained through the fact that what science produces in the laboratory might not always fit with the “outside world”. Non-experts are given a voice and are no longer seen as masses in need of education and the boundary work

maintained by experts is recognized, thus it becomes clear that the authority of science is not a given, but it is produced and maintained by public debates; it is a negotiated phenomenon (Gieryn 1999).

The traditional boundaries between science and the public have started to blur, and this means that science can no longer distance itself from the public, it can no longer claim sole authority over it. Callon suggests that what comes next is a “co-production of knowledge” in which there is an “equal footing” (1999: 93) and within which the non-expert public actively participate in the production of scientific knowledge. The collective of lay people and experts produce knowledge, disseminate it, and also engage in processes of identity (re)creation. Perhaps this approach is too optimistic for the entirety of science-public relations, but it does point out to the fact that science has had to make certain efforts to engage with the public and adopting strategies of science communication.

Bensaude-Vincent especially refers to the 1980s as a period of time when the status of science as the sole authority started being shaken by public reaction. This questioning of expertise led to increasing mistrust and installed the belief that commercial interests and the will to make more profit is what drives scientific activity (Bensaude-Vincent 2014: 108). This contributed to the demolition of the conceptualization of the public as passive recipients of information and innovation and made it visible that “common people” can also become legitimate analyzers and creators of knowledge and that they are not just docile recipients of whatever has been offered to them (ibid: 108). This new situation further increased the blurring of the boundaries between science and the public, between who is considered an expert and who an outsider to the scientific community and thus scientific knowledge; the traditional dichotomy that added to the understanding of a “gap” could no longer hold, not only did the monopoly of scientists over truth as the sole experts started to diminish, but their integrity within themselves as an entire community also started being questioned. This fragmented view of the scientific community did not help maintain the divide between scientists and the public, because the scientists were no longer perceived as a “separate world”, incomprehensible and out of reach (ibid: 110).

2.1.2. Lay knowledge and lay expertise

This point corresponds to the fact that lay knowledge and lay expertise had to be taken more seriously in shaping and analyzing science-public relations, and several scholars have attempted to conceptualize this new set of relations. The “ethnographic turn”, as proposed by Irwin and Michael (2003) takes lay epistemology into consideration as well as the locality of knowledge and allows exploring the complex and multidimensional relations of the public to

science and understanding science. It enables a more profound grasp on the dynamics between the two domains. Brian Wynne's work certainly stands out in the lay epistemology and lay reflexivity framework; he demonstrates that the ways in which the public experience and evaluate scientific knowledge is never a solely intellectual process, but one that involves a complex set of notions such as social relationships and networks, interactions and interests and identities that are constantly made and remade (Wynne 1992). A very important facet of lay reflexivity is the fact that when people are lending support and faith to certain scientific practices and dismissing others, they make informed judgments about "trustworthiness, credibility, usefulness, power, etc." (Irwin & Michael 2003: 28). Therefore, they are no longer docile recipients of information that is being offered to them to "educate" them for their ignorance or illiteracy, but are active individuals that not only have their unique ways of knowing, but also an influence on the operation of science itself, especially when it comes to major scientific institutions that are more or less dependent on private funds.

The circulation, handling and (re)production of scientific knowledge on The Alliance of Hope Forum constitutes the core of my research. In order to relate it to the continuum of science-public relations, I now introduce the terms lay knowledge and lay expertise. The term "lay knowledge" has come to embody the "judgments about expert claims that non-expert citizens can make based on their everyday experiences of living in a particular society" (Evans & Plows 2007: 831). These experiences encapsulate beliefs, imaginations and/or perceptions about the organizations involved and how they operate. To give the concept more structure, it is possible to think of the term "lay expertise", as defined by Collins and Evans, referring to people "whose expertise has not been recognized by certification" (Collins & Evans 2002: 238). The authors use the term "experience-based expertise" to coin this kind of expertise which is not necessarily accompanied with degrees or certificates, in a world where the boundaries between expertise and non-expertise; and who is an expert and who is not is not so easy to distinguish anymore. This framework does not restrict expertise to scientists and allows asking questions about the different kinds of knowledge that are being produced by different groups, how the process works and what outcomes they might have (Evans & Plows 2007).

2.2. Cyberspace

The Internet is one of the most important arenas in which lay knowledge and lay expertise may emerge and proliferate. Before moving on to debates on the specific qualities of such knowledge production, I refer to the term "cyberspace" to encapsulate some of the thoughts

and discussions on the Internet as an entity on its own and as a medium where non-expert expertise is demonstrated.

Michael Benedikt defines cyberspace as “a globally networked, computer-sustained, computer-accessed, and computer-generated, multidimensional, artificial, or ‘virtual’ reality” (Benedikt 1991: 122). He considers cyberspace to have its own geography, physics and nature, in which also the influences of what he calls the “human law” come into play; it is an arena where different kinds of associations between humans can be realized. Even though some authors seem to be in doubt about the reality or the authenticity of the relationships formed on cyberspace, they seem to be in agreement on some of its features, such as its potential effects on the future. David Thomas sketches out cyberspace as “a powerful, collective, mnemonic technology that promises to have an important, if not revolutionary, impact on the future” (Thomas 1991: 31). Michael Heim, even though convinced that “what technology gives with one hand, it often takes away with the other” (Heim 1993:74) in the sense that while benefitting from the opportunities of creating and/or joining our communities of choice thanks to the advantages offered by cyberspace, we start living in communities that are more “fragile, airy and ephemeral” (Heim 1993: 74) - also states that cyberspace is a “metaphysical laboratory, a tool for examining our very sense of reality” (Heim 1993: 59). Sherry Turkle also elaborates on cyberspace, saying we are learning to live in virtual worlds, which the term “cyberspace” stands for her, and even though the term originated from science fiction, it has now become part of our everyday lives (Turkle 1995: 9). Turkle also points out to the opportunity of building new kinds of communities on cyberspace and argues that “the virtual” and “the real” should not be studied separately, nor should they be positioned against each other. They both have their things to offer, and there is no reason why one should be favored while the other is being completely dismissed.

When studying cyberspace, one thing that becomes prominent is the perceptions and visions related to it. In the book *The Internet Imaginaire*, Patrice Flichy (2007) elaborates on the imaginations of cyberspace and states that the “Internet imaginaire” is a notion related to the visions and perceptions of and expectations about the Internet technology in Western societies. Characterized by its collectivity, this notion is more than thoughts and understandings and is a totality of utopias and ideologies as well as expectations related to new technologies. Related to the notion of this particular imaginaire, in her book *Alone Together*, Turkle points out to the role acquired by technology as the “architect of our lives” and deems it “seductive” when there is an intersection between the offerings of technology and our needs as human beings (Turkle 2011: 1). Throughout the book, Turkle seems to adopt a rather hesitant approach towards the authenticity of what she calls our “culture of

simulation”, because she argues that what is at the basis of authenticity is empathy, one’s ability to put oneself in the shoes of others and as such relate to their feelings and experiences. Turkle places this ability to emphasize opposite “a clever collection of ‘as if’ performances”, which, according to her, are what the new technology has to offer. According to Turkle, we expect this empathy from robots that are computers and online life in general. It is at this point that Turkle’s reluctance of online relations becomes clear once more; she simply states that such relations run the risk of being reduced to mere connections that become redefined as intimacy (ibid 2011: 16). This is an interesting point to consider for this research in particular, not because it aims to focus on the feelings of intimacy and perceptions of closeness the online environment creates for those partaking in it, but because it falls in line with the overall argument over the authenticity, the realness, the validity of online relations. It seems that according to Turkle, the answer is clear. A kind of “connectivity” established online brings along its “discontents” since many crucial elements remain missing. As previously mentioned, Turkle especially stresses the ability to empathize and argues that when a robot is taken as a companion, alteration is nonexistent; therefore empathy becomes impossible. It might be a good idea to pause for a moment and evaluate Turkle’s suggestions from the perspective of the Alliance of Hope Forum. The first thing to be questioned is whether or not what is taken as a companion and interacted with can be reduced down to a “robot”. It is highly likely that the people on the forum do not consider their collocutors to be “just” robots, and feel a certain understanding and support resulting from this. This is frequently expressed in the messages posted on the forum.

2.2.1. Virtual Reality

The term “virtual reality” is highly associated with the notion of cyberspace. In *The Internet Imaginaire*, Flichy (2007) quotes Negroponte who says, “Basically, virtual reality makes the artificial as realistic as the real” (133). Truly, what constitutes the character of debates around virtual reality is an interaction and the interconnection between the artificial, real and realistic. According to Flichy, what virtual reality achieves is the simulation of the real through a copy of it, which Flichy deems an illusion. An arena in which the multiplicity of imaginaires is particularly interesting, according to Flichy, is virtual reality. Flichy states that there is a consensus on the idea that virtuality is opposed to reality, but argues that the discussions on the remaining points are diverse (2007: 129). Flichy elaborates on the different meanings attributed to the word “virtual”: it has been defined “either as a tool for knowledge, action and creation, or as a means for withdrawing into oneself and escaping into an imaginary world, or last, as a means of communication” (2007: 129). In the case of the

Alliance of Hope Forum, it appears that it is an arena in which these meanings of the virtual exist combined.

Flichy also points out that studies in this domain were mainly focused on “human-machine interfaces” and not necessarily on the interaction facet (2007: 134) and states that the interaction between the virtual and the real take through not only through man-machine dialogue, but also through communication between individuals and thus takes this communication as a new opportunity for the establishment of further virtual reality (2007: 140). Zizi Papacharissi (2002) recognizes the potential of the Internet as an arena where people can invent new forms of expressing themselves and initiate citizen activism and argues that cyberspace is both a public and private space. She says this is so because it is an arena that appeals to people who want to reinvent both their public and private lives. Papacharissi suggests that entering into cyberspace means to “transcend physical space and bodily boundaries” and that this directly influences how one behaves and what kind of attitudes they adopt when going online, which, according to Papacharissi is different from when we are “offline”.

2.2.2. Virtual Communities

The term “virtual community” is a highly used one when looking at computer-mediated communication and its components; therefore it is useful to start with this term when trying to conceptualize and understand the forum that is the subject of my research. Virtual community is a term that brings utopian and dystopian visions together, just like the aforementioned virtual reality. Shawn P. Wilbur (2002) suggests the term be taken up with caution and in a critical manner. He very nicely demonstrates that the term virtual community shows our presumptions about what makes up the term- “an unmodified, ‘real’ community and primarily computer technology” (Wilbur 2002: 45). Kevin Robins argues that the terms virtual reality and cyberspace are imagined in terms of an opposition to the “real world” (Robins 1995:86). “Virtual communities” is part of this imaginaire and embodies a vision of the coming together of people from all over the world while they mostly (but not necessarily) remain fixed at their localities. Within this imaginaire, virtual communities are presented as groups in which “intellectually and emotionally rich” conversations are developed, “a social link is recreated” (Flichy 2007: 90). Flichy argues that the production and spread of this particular imaginaire resulted in an “aura” and diffused on gigantic scale.

A crucial part of the debates of cyberspace is related to the nature of the relations established within them- whether or not they can be considered as part of reality or if they should merely be considered as virtual. Scholars seem to hold different positions on the issue; some in favor

of considering virtual realities and its communities as part of reality itself and not as a separate entity (Kellogg et al. 1991), some criticizing it for its lack of human encounter and face-to-face communication; therefore failing to provide loyalty and obligation, as well as a permanent and solid sense of belonging (Heim 1993). Indeed, the negative and/or dubious characteristics attributed to virtual communities of cyberspace seem to be centered on the idea of human interaction- interaction that takes place in the physical presence of humans. For instance, Michael Heim argues that the absence of “the direct experience of the human face” leads to a “shrinking in ethical awareness and rudeness enters” (Heim 1993: 78). However, one cannot help but ask why some scholars seem to be so convinced that physical co-presence is so central to conceiving and maintaining “real” interaction that might hold true meanings for its participants.

One also frequently comes across discussions over the authenticity and “realness”, or the durability over the relations formed over the Internet. Whether or not these relations can truly be deemed “genuine”, whether or not the collectives formed on this arena really conform to the notion of “community” has been widely debated and it seems a consensus has not been reached yet. Critics who doubt the “meaningfulness” or “completeness” of “online life” have based their arguments on the lack of face-to-face contact and thus social cues. They have furthermore argued that engaging within the virtual reality can make one lose their sense of “the real world”, resulting in a loss of contact with “real life”. Wellman and Gulia (1999) touch upon the concerns surrounding communities formed on the Internet and state that such concerns were also present before the advent of the Internet. They argue that the debates stemming from these concerns resulted in sociologists realizing that communities do not necessarily have to be composed of people living together, constantly sharing the same physical space, but that they can also exist in forms of social networks and be based on this premise. However, while acknowledging the community building potential of the Internet, the authors are reluctant to take for granted some of the qualities that have frequently been associated with virtual communities such as the absolute provision of social support and information, and a sense of belonging (1999:2). They do, however, acknowledge the Internet as a “separate reality”, one of the many ways in which people can interact and form communities (1999: 3).

Maria Bakardjieva is another scholar who writes on the issue and conceptualizes the interactions of virtual communities as “immobile socialization” (2003: 292), that is, the socialization of private experiences through the invention and utilization of new forms of expression and narration online. Bakardjieva is among the scholars who challenge the idea that virtual communities do not correspond to the “offline” notion of community, mainly because, she argues, there is no such definition that a consensus has been reached upon. A

very interesting claim Bakardjieva makes is related to the origins of the term “virtual community”: She asserts that the word community was carefully chosen by the first group of people to engage in online interactions such as engineers and research to convey a sense of “significance and nobility” to their activities. She further goes on to argue that a discussion of the “real” versus the “virtual” community is futile because “real” communities are themselves “virtual” since they are “mediated and imagined”; thus there is no reason to suppose one is superior over the other. While strongly opposing a competition between “real” and “virtual” communities and recognizing the latter as a legitimate entity on its own, Bakardjieva does not resonate the much expressed and celebrated “empowering” feature of the Internet and virtual communities because she also warns that different people bring different variables into the practices of the Internet, and one cannot simply assume that the experience will be empowering for each and every individual. Bakardjieva (2003) includes virtual communities within the broader concept of what she calls “virtual togetherness” in which the “reality” or the “genuineness” of the realm and the relations formed within are not questioned, but the fact that users “produce something of value to others- content, space, relationships and/or culture” is stressed, and taken as the basis of describing virtual communities (2003: 294). What is important in “virtual togetherness” is that the boundaries between public and private are blurred; these are no longer sharp distinctions.

In their 2004 article, Blanchard and Markus elaborate on their conceptualization of a sense of community created and sustained in virtual communities. They point out, in a similar vein with Li and Lee (2013) to the activity of giving and receiving of information, help and emotional and technical support which, they argue, does not always exist in communities in the more traditional sense (2004: 66). They identify feelings of membership, feelings of influence, integration and fulfillment of needs, and a shared emotional connection as important bases for the establishment of a sense of community (2004: 67). Feelings of membership refer to concepts such as “community boundaries, perceptions of emotional safety, members’ sense of belonging to, and identification with the group, personal investment of time into group, and a common symbol system” whereas feelings of influence point out to “feelings of having influence on, and being influenced by, the community” (2004: 67). The other two criteria are related to how much personal needs related to the motivation of going on an online community are met and satisfied within the group, how much feelings of mutual support are present and to the “spirit”, the perception of being a community (2004: 67). Blanchard and Lee find it appropriate to assess virtual communities with the same criteria, but also argue that a feeling of belonging and attachment is not to be found always in all *virtual social groupings*, but when they are present, the grouping becomes a *virtual community*. Accompanying this phenomena are processes such as the mutual exchange of

support, the development and maintaining of norms and boundaries, social control, etc. (2004: 69). The important point in the formulation of the authors is that they make a fair distinction between the two different states of being present in an online collectivity: they use the words grouping and community to make a distinction. They also question whether the feelings or the process comes first, and propose that it is the process that is the precedent. Members in a virtual grouping begin to adopt community-like behaviors and when these are continued enough for the sense of virtual community to sustain itself, the situation is resumed (2004: 69). However, this does not mean that this phenomenon will last no matter what, if the community-like behaviors such as the exchange of support and information are given up, then the sense of virtual community will cease to exist.

According to Denzin (1999) online relations depend on sincerity in order to work, even if it is just in appearance and not really present. Thus, “online sympathy contributions” are not meant to form long-term relations, or even completely solid ones, but are sufficient to exist on a level that will sustain the presence of the online group. Apart from contributing to the existence of the group, another task is to establish a framework and arena in which it is possible to converse about and deal with troubling feelings and/or situations (159). The emotional charge of these interactions is compelling and motivating for the readers to engage in conversation because of their moving character.

It is important to acknowledge that distinctions such as real, virtual, online, offline and even the term community itself should be taken up with caution instead of being taken for granted. Even though the term virtual has come to embody “what appears to be (but is not) real, authentic and proper” (Wilbur 2002: 47), it is important to be aware that making such major and unquestioned differences between different realms might not always be the best thing to do. As Benedict Anderson very nicely points out, if we continue to assess and evaluate online life with our conceptions, understandings and experiences of offline life, our analyses will end up constrained (Anderson 1983). What is more, we also need to keep in mind that the distinctions between what is “real” and what is “virtual” are now so much more difficult to make, since what is formed on the Internet is not so easy to distinguish from what is pursued outside this domain (Fernback 2007). It seems wise, then, to take cyberspace as an entity on its own- without any connotations of its relation to or comparison with the offline world, and treat it as a realm where liaisons that are worth investigating are taking place. This way, we can focus on the dynamics of the online world and its motivations and characteristics instead of asking whether it is real or not, and can reflect on questions that can help understand this arena better. In an attempt to achieve this, for my research, I take up the very basic definition of the term virtual community as suggested by Wilbur: “the experience of sharing with unseen others a space of communication” (Wilbur 2002: 50).

Looking at the meanings traditionally associated to the Internet and online spaces can help understand why this distinction may seem so sharp at first. Shani Orgad (2006) has pointed out that the Internet has been often perceived as the manifestation of globalization, especially with reference to its capacity to transcend national and cultural boundaries. It has also been suggested that it renders space and time irrelevant (Orgad 2006: 878). However, as Orgad also shows, and as has been stressed by numerous studies, this is not always the case, and online spaces do not always necessarily rule out the characteristics associated with offline spaces. The relations and differences between online and offline contexts are far more complex, and social and cultural borders do not necessarily disappear nor are they easily transcended on online contexts (Orgad 2006:878). It is important to be aware of this and take it as a starting point so that the cultural dimension is not ignored or taken for granted when looking at user motivations and practices. The various elements of this dimension such as expectations, values, experiences, norms and preferences influence and shape the form of interactions on these online spaces which are extremely crucial to consider when aiming to get a better understanding of the specific dynamics that are being looked at. To achieve this, Orgad calls for “reflexivity to the cultural dimension of computer- mediated communication”. I believe this will be a very important basis, since it will help me refrain from making overly simplistic or generalizing assumptions. In her book *Alone Together*, Turkle also explicitly touches on the subject of online confessions. Since a significant number of posts on the forum can be evaluated under this heading, it is important to review Turkle’s reflections at this point. She mentions that this activity is deemed “therapeutic”, stemming from the belief that it helps get things “out” and makes bad feelings “less toxic” (231). Turkle finds that what lies at the heart of such suppositions is the possibility of dealing with negative situations and/or feelings without direct human contact. Turkle once again expresses her doubt of the effectiveness of online interaction, and claims that what really is happening is not a “real” conversation and that the “sharing” of feelings is nothing more than venting (231) and thus the motivation behind going online, according to Turkle, is not to really solve things and change them for the better, but simply to feel better (233). Furthermore, Orgad also argues that “the survivor culture” or the belief in “talking about it makes things better” is a particularly Northern American trait. She argues that “the belief in the power of talking (online) as an essential part of the cure”, “the view of the fighter who sticks around” is closely related to a particular North American culture and belief system (Orgad 2006: 891). This suggestion will also be part of my framework since I am looking at a US-based forum.

2.3. E-health

The Internet and its implications for public access to knowledge previously deemed inaccessible has been heralded for its equalizing and democratizing potential. This medium has often been associated with patient empowerment and deemed a pluralistic and democratic domain (Roberts 1999; Gibson 1991; Sharf 1997; Hardey 1999; Hardey 2001). These authors claim that the Internet basically alters the power relations between doctor and patient by making it possible for patients to access medical information and thus helps increase their feelings of control and awareness; the Internet helps them make more informed decisions regarding their health and thus they are no longer passive recipients of what doctors say to them or prescribe them. What this sense of empowerment stems from is the fact that the hierarchical relations between doctors and patients- or experts and non-experts- are disrupted. What is at hand now is informed, aware and educated patients who challenge traditional medical relations, patients who can dramatically alter established doctor-patient dynamics and negatively influence the expert status of health professionals. Not all researchers, however, are willing to accept this thesis and argue that while it is certain that expert knowledge is more and more available on the Internet to non-experts, it is too bold a claim to suggest that this availability will lead to dramatic changes in doctor-patient relations and decision-making processes. Alex Broom (2005), for instance, states that the empowering potential of the Internet is not a concrete and monolithic one; it has no clear boundaries or definitions and is a unique process for each individual. Therefore while it can have substantial positive outcomes for the individual patient, as a whole its potential for dramatic transformation is not something to be taken for granted. What is more, this process is not solely determined by the “empowerment” of the patient but also heavily relies upon how medical professionals are willing to take it up and deal with its implications. Henwood et al. also adopt a skeptical approach and warn against a technological deterministic treatment of the Internet (2003). The authors grant the Internet its potential to help patients make more informed decisions about their health and to better assess the risk associated with the treatment they have been advised by their doctors but also urge this implication be taken up with caution so as not to suppose results that may actually not be there. Oudshoorn and Somers (2007) make a similar warning and suggest that the democratizing approach so frequently associated with the Internet is not an “inherent capacity” (2007: 669) of this technology but is something that needs effort and shaping. Moreover, the authors argue that the Internet can even act as a tool that adds to the existing differences and boundaries between patient and doctor; after all to assume the eradication of the frontiers between the two domains would be to completely ignore debates on the “digital divide”.

For the purpose of my own research, I believe it is best to stay out of debates over the quality of health information (re)produced online and its potentials in the long run, on discussions whether evidence-based patient choice is a solid outcome of acquiring health information online and whether this really will reverse the “information asymmetry” (Eysenbach&Diepgen 2001), leave them as open questions, but take one thing for certain: That medical knowledge has “e-scaped” (Nettleton 2004) the medical domain. The body itself as well as the information related to it, argues Nettleton, is no longer constrained within the boundaries of the medical realm that is at the helm of health professionals, but has “e-scaped” into the world outside that specific domain and is being viewed, experienced, discussed and examined by non-experts. Medical knowledge and health information are no longer things that are produced and disseminated within the medical domain but are to be found on the Internet; they are now communicated within broader fields of society (669-673). At this point, Nettleton refers to the 2002 book by Scott Lash, *Critique of Information*, and makes a distinction between knowledge and information. She argues that what is prevalent in the media, including the Internet, is more information than knowledge. Scott identifies the dominant and distinguishing qualities of information as being suitable for flow, being disembedded; it is spatially and temporally compressed (Lash 2002:2). Nettleton and Burrows (2003) argue that e-scaped medicine will no longer force non-experts to rely on expert opinion; that they will be able to acquire medical information themselves and the degree of trust between doctor and patient will be altered. The fact that medical knowledge “has been dislodged from its ‘traditional institutional base’” (Nettleton&Burrows 2003:180) is a postulate that fits with the framework of my research interests. This approach, instead of forecasting substantial changes in the patient-doctor relations and the status of the health professional, focuses on the availability of medical information to patients, recognizes their online activity and observes a transformation in their statuses from being passive recipients to active consumers and producers of information.

The notion of “e-health” is particularly relevant to and important for my research, because it can be acknowledged as the precursor to the exchange and (re)production of knowledge on the Alliance of Hope Forum, and the debates surrounding it will help to situate my research interest to the domain and also guide my analyses.

2.4. Biosociality and Patient Activism

Before going on to elaborate on patient activism, it is first necessary to speak about the term “biosociality”. Coined by Paul Rabinow (1996), biosociality is also worth mentioning and integrating into my own work. This term has often been referred to by scholars looking at patient organizations, and points out to a new kind of social interaction of knowing about a

disease, experiencing it and acting upon it. It helps to understand how developments and advancements in biology shape the knowledge that is produced, both by experts and by laypersons. Departing from the notion of biosociality helps to further situate my research interest within the domain of STS even though the group I am looking at does not necessarily fall under the term of patient organizations or patient groups. Considering the forum I will be looking at in particular has a separate area where books and articles are reviewed, it is beneficial to consider this notion to get a better understanding of the knowledge assessment types and processes. Madeleine Akrich (2010) has argued that electronic forms of communication, such as discussion lists and forums are good places to observe the creation of knowledge, and its articulation with professional knowledge. The specificities of this certain medium make it interesting when looking at how lay knowledge and lay expertise are created on them, and this will be one of the main aspects I am willing to investigate during the course of my research.

When elaborating on biosociality, Beth Greenhough writes that this phenomenon is closely tied to the fact that our “corporeal substance” is constantly being defined and examined for a variety of medical purposes, which puts us in a situation where we think about ourselves, our bodies and our health in terms of biomedical terms (2011: 153). She argues that detailed analyses of these processes through which knowledge is created and consumed within these domains will help us understand better why and how the power and authority of biomedicine and pharmaceutical industries are being questioned (2011: 154). Greenhough asserts that this constant biomedicalization results in the formation of “biomedical communities”, which can be interpreted within the framework of biosociality. What these groups do, then, is to get involved in collective action in order to achieve “sophisticated understanding” of the scientific and medical questions surrounding their specific area of interest and/or concern, and to have a better grasp on the available treatments, alternatives, and all sorts of information related to the issue. There are two crucial points in this campaigning/activism Greenhough talks about: The fact that they are very much focused on “ending stigmatization” and the fact that digital technologies are essential in their formation of new and alternative kinds of social networks and in the enhancement of these networks (2011: 158). Both these points correspond to the Alliance of Hope Forum, where people interact about the issue of suicide, which can be argued to carry a certain social stigma and where people form and engage in an alternative kind of social network in which they also exchange information on medical and scientific debates on the use of medication and its relation to suicide. Most importantly, they do so on the Internet.

Patient groups have has previously been defined and studied by several STS scholars and Steven Epstein’s take on the term fits best with my research interest and conceptualization

efforts. When looking at the term patient groups, he states, “these groups are not always organized by patients per se, but may be brought together by parents, relatives, partners, activists, advocates speaking on behalf of broader constituencies whose interest transcends any specific disease” (Epstein 2008: 504). He expresses the need to look at the processes of representation of these groups, rather than “quibbling over who qualifies as a patient”, he suggests that we embrace “elastic classifications and ask what we can learn from the juxtaposition of examples” (Epstein 2008: 504). Because he does not define the term strictly, and leaves plenty of room for alternative groups to be included, I found Epstein’s approach quite enabling to look at my research interest and to position it within broader frameworks. I am convinced that considering my research question within the scope of patient organizations will be enriching and will help to consider the medical debates going on within my research area as well. Some of these debates are centered on rejecting professional help and the delegitimization concerns of health professionals. This framework can also help to situate the lack of trust in physicians resonated in online spaces for suicide survivors, a theme that has been mentioned in previous studies. Strong opposition to medication and the need to take action are themes that are easy to come across on suicide survivor forums, and working within the frameworks of biosociality and patient groups/organization can help answer the question of whether or not a new genre of patient activism is emerging on these online spaces.

2.5. Online Grieving

Another phenomenon that is directly related to my research interests is what has come to be termed as online grieving. Before moving on to elaborate on online grieving, it might be a good idea to give brief accounts of what is meant by grieving and bereavement. In my own research, I use the word grief related to the word mourning, and take up Therese A. Rando’s definition, which defines mourning as “the overall process through which an individual comes to acknowledge and accommodate the loss” and it is acute grief reactions that are demonstrated by the individual during this period that demonstrate how that loss is perceived and dealt with. These reactions can take psychological, behavioral, social and physical forms (Rando 1993). A strongly related term to mourning and grief is bereavement, which is a process that is initiated by the loss of someone close and entails the “restructuring of social engagement, with both the living and the dead” (Walter et al. 2012: 3). It is a process that involves a kind of re-adaptation and can be argued to be a more social than an individual one, when compared to expressing grief. Current psychological approaches agree that there is no ideal or uniform way of grieving or an ideal duration of it and that the objective of these processes is for the bereaved to “incorporate the reality of the death into their relationship with, and understanding of, the deceased” (Rando 1993).

In a nutshell, the term online grieving defines modern practices of experiencing death and its aftermath, facilitated by what the new media has to offer which dates back to the 2000s and refers to the increased interactivity and the ability of non-expert users to upload and modify media with ease (Walter et al. 2012). However, the facilitating character of Web 2.0 is not enough to explain why people choose to experience and manifest grief online while dealing with the loss of a loved one. There have been several explanations to the question of why and how the culture in which people grieve is evolving (Chapple & Ziebland 2011). For instance, Sanderson and Cheong (2010) look into the relationships between social media and grieving and suggest that social media is facilitating and reformulating traditional grieving practices because it offers the bereaved what they tend to seek after having lost a loved one: 24-hour availability of help, anonymity and privacy while discussing these matters and avoidance of confrontation while seeking help. These perceived advantages have been repeated by users in a number of studies. Another explanation that has been put forward in efforts of explaining online grieving stems from the activity of information seeking. Ruthven states “many of the ways we cope are information-based” (Ruthven 2012: 121) and argues that dealing with death involves a number of practical questions, as well as more personal question that can help deal with the event. He looks at how an information need is being dealt with, and says:

“Understanding how we resolve information needs, and the methods by which we choose how to resolve these needs can tell us much about the information needs themselves but also how people make decisions about what information channels are appropriate and useful”
(Ruthven 2012: 120)

As the use of the Internet becomes more and more widespread, it is not surprising that people refer to it for gathering different kinds of information and it can even be argued that the Internet is replacing some of the more traditional sources of information (Walter et al. 2012). Besides answering practical questions, such as ones related to the funeral ceremony or juridical issues, the Internet can also be useful when the bereaved may want to seek information that can help them through difficult times. Several studies show that users of such online groups have expressed an interest in finding and communicating with people with similar experiences who might have a better understanding of what the individual is going through and may possess knowledge originating from experience that can be more of use to the person seeking help and information online. Considering the nature of the loss in my own research, it might be considered that being online and interacting with people with similar experiences is something that is valued more highly, because suicide in general is perceived to be something that is not very easy to talk about, which brings me to the next set of explanations that have been offered for understanding the phenomenon of online grieving.

Carroll and Landry (2010) argue that the phenomenon of online grieving is something that originates from the society's openness to and interest in death and bereavement, and also speaks back to the degrees of openness. This relates to what some authors had to say about the place of death and dying in modernity, namely a sequestration that secludes them within certain spaces such as hospitals and cemeteries so that they are not visible and present at all times in the flow of daily life, therefore not disrupting it (Giddens 1991; Mellor and Shilling 1993 in Walter et al. 2012). Another aspect of keeping issues related to death at a distance is the implications this has for the bereaved. In most modern societies, at least in the Western context, the bereaved are expected to continue their everyday activities soon after the death of a loved one, but are also expected to keep their grief to themselves (Walter et al. 2012) This holds especially true for suicide, which can be argued that makes the situation even more difficult for the ones dealing with it, stemming from the social stigma or the burden it brings. This introduces the argument that the Internet offers an alternative and facilitating space for marginalized or problematic kinds of grief to be expressed and experienced, and fits into the broader narrative of the Internet being considered as a free space for everyone. However, such assertions should be approached with caution since they are used very loosely, and tend to ignore the intricacies certain online spaces operate with. For instance, in my own research, The Alliance of Hope Forum has several rules the members are expected to conform to, and a certain "netiquette" that is expected of them. Even though there are still some gray areas and points open to discussion, we can still conclude that the Internet is changing the way in which people experience death and the ways in which they grieve by offering users new sets of tools of and strategies for coping. It is interesting to reflect on what is it in our societies that causes this change and what this change can cause in our societies in return.

3. Materials and Methods

3.1. The Alliance of Hope Forum

After having visited several suicide survivor forums for some time, the one I have chosen for my case study is "The Alliance of Hope Forum" (<http://forum.forsuicidesurvivors.com>) because it is one of the most active forums of its kind, is free of charge and quite large in content. The forum belongs to the website "Alliance of Hope for Suicide Survivors" (<http://www.allianceofhope.org>) which uses the following definition:

"The Alliance of Hope for Suicide Survivors provides healing support for people who have lost loved ones to suicide. It was founded in 2008 by Ronnie Walker, a licensed clinical mental health counselor who lost her stepson to suicide in 1995."

Our services help people survive the lonely and tumultuous aftermath of loss and eventually go beyond just surviving, to again lead meaningful and productive lives.

It is our aim to ensure that no survivor goes without the support they need. Since our founding, we have helped thousands of survivors from many cultures and faith traditions all over the world.”

Apart from the forum, the website has several other sections; such as a blog, an online store on suicide bereavement related books, a memorial section where people can post messages about the ones they have lost with the option of including a picture, video or song. There is a 250-word limit for the messages, and they have to be approved by the founder and CEO herself before getting published. It is also possible to “locate a name” by searching the memorial database which is ordered alphabetically. The website also has a Pay Pal donation link, but donation is not mandatory for participation. It also has a page on Facebook with 7200 “likes” as of October 2014, and it is possible to read daily posts from members and page administrators.

The forum, which will be my main research site, presents itself as such:

“Our community forum hosts thousands of members from around the world and more than 30,000 posts describing the survivor experience. It is carefully tended by a mental health counselor and trained team of veteran-survivor moderators. Many members tell us it is their ‘lifeline’.”

It is quite striking that the presentation is quite similar to those included in Shani Orgad’s study of breast cancer online spaces, with an emphasis on globalism and reaching out to people around the world. (Orgad 2002). It is a good reason to keep the “reflexivity” principle she suggests in mind when looking at depth into the forum. The forum has also been named “One of the Top 50 Web Forums for Counseling, Advice and Support”¹. Apart from that, it has been recommended by international organizations such as the American Association of Suicidology, American Foundation of Suicide Prevention, Canadian Mental Health

¹ The forum was put in this list by the website www.mastersincounseling.org, a website that is “an informational tool for students who may want to enroll in an online degree program to obtain a Master of Counseling degree”.

Association, Survivors of Bereavement by Suicide (SOBS) and many others. In 2011, it was rated a Top Health Nonprofit by GreatNonprofits².

The forum is comprised of five main sections: the welcoming section, the introduction section, a more detailed community connections section and a section for donations and feedback. Each section has several sub-sections, the introduction one being the largest. There are a vast variety of topics that are being discussed on the forum, and this makes it absolutely necessary to narrow down where one is looking at. For example, there are different topics for different types of loss (sibling, parent, spouse, friend, etc.) as well as different topics for what is possibly experienced after losing someone to suicide (addictions, guilt, blame and forgiveness, medications, relief, etc.).

In order to understand the nature of the circulation and the production of knowledge on the forum, I attempt to first browse through and collect messages via virtual ethnography, and then to categorize them under several headings by referring to the phenomenon of “frames and packages”. This framing approach also helps me determine what conclusions could be drawn from the forum in terms of “lay” and “expert” relations, the perception of the survivor experience and the question of the particular “activism” or “biosociality” to be seen or not on the forum.

3.2. Virtual Ethnography

The particular location and characteristics of my research object inevitably lead me towards taking up virtual ethnography as the initial method to be employed. As defined by Christine Hine, virtual ethnography “transfers the ethnographic tradition of the researcher as an embodied research instrument to the social spaces of the Internet” (Hine 2008: 257). This means that the objectives of the more traditional forms of ethnography, such as documenting the richness of social interactions and investigating their meanings and functions, are pursued on online spaces. It can be beneficial to introduce Anne Beaulieu’s “co- presence” concept here for it can help understand how online ethnographies are constituted. Beaulieu talks about the notion of co-presence instead of co-location; which, in a nutshell, is about focusing on presence and constructing the field instead of physically sharing a space with the subjects of investigation. It relocates the importance of space, therefore making room for the inquiry of alternative places of knowledge production. By adopting this approach which is about the researcher constituting his/her field by “achieving interaction” and maintaining a “shared

² GreatNonprofits (www.greatnonprofits.org) is a website that presents itself as “the leading developer of tools that allow people to find, review, and share information about great -- and perhaps not yet great -- nonprofits.”

meaning” (Beaulieu 2010: 457), one can get away from the imperative of physically occupying the same space with who/what is being observed and “being in the field” can come to nestle different sets of activities that can help understand a variety of sites. It is through the innovative writings of scholars such as Anne Beaulieu and Christine Hine that this form of inquiry gains legitimacy, and finds ground to grow on and improve from. Co-presence certainly has its advantages and disadvantages, but this is the case with any other method and co-presence should not be discredited for that. Beaulieu’s conceptualization of co-presence goes hand in hand with Hine’s (2000) conceptualization of the Internet as a “placeless place”, which is a strategy for conceptualizing the Internet as a space to be examined.

One of the main components of virtual ethnography is “lurking” which can be considered to be an “unobtrusive method” in which things can be observed undisturbed in their natural state (Hine 2008). However, lurking- a passive form of participant observation- cannot qualify as virtual ethnography by itself, since it lacks engagement and does not allow the researcher to develop a detailed and more profound understanding of what is being investigated (Beaulieu 2010). It is, nevertheless, a very important tool for the researcher and can make up a very efficient starting point. Most importantly, it allows developing what Hine (2008) calls “cultural familiarization” with the online space that is being looked at. Personally, lurking has constructed a big part of my empirical work, and even though it certainly is not enough to draw any sound analyses from, it is quite helpful in getting a better idea of the community of interest, and the patterns that are unique to it. If supplemented with active participation, lurking can provide a deeper understanding of the relations being studied. However, active participation and the forms it can and will take can also be problematic. At a very basic level, this means that the ethnographer has to come forward as a researcher and his/her presence must be accepted by the potential informants (Hine 2008). This requires serious consideration and delicate work from the researcher.

Apart from the ethical concerns on the part of the researcher, concerns over data to be collected in virtual ethnographies have also been raised. Even though it may appear that the virtual ethnographer has easy access to “what is already out there”, the process is not as simple as that, and involves a number different questions in relation to what Beaulieu and Estalella call “understanding the particular mediation involved” (2001). The issues arise out of the fact that the communication is computer-mediated, which has strong implications for the overall research. Some of these concerns include questions over the authenticity of data- whether enough trust can be placed in what people say online and whether their accounts can be taken as a basis to draw conclusions from (Hine 2008). Hine responds to these concerns by arguing that the question of authenticity is not unique to virtual ethnographies; and ethnography-whether online or offline- always runs the risk of deceit, but this risk goes

alongside a variety of occasions to build and strengthen trust. Once again, the ball is on the court of the researcher. To maintain trust, virtual ethnographers have employed a set of different strategies; such as keeping blogs related to their work and regularly updating them, taking chances of meeting some participants offline and so on.

3.2.1. Ethical Considerations

Internet ethics constitute a major part of my methodology and deserve attention as a crucial topic to be considered when conducting research online. It can be argued that the online medium is gaining increasing scholarly attention and is now considered to be a “legitimate research tool for gathering data about how people operate in the social world” (Bowker & Tuffin 2004: 229). The “legitimization” and acceptance of online research has also made its components subject to cogitation and criticism. While online methods have been attributed a number of logistical and practical benefits such as the possibility of reaching a wide range and big number of people and the ease with which the textual conversation to be analyzed can be saved and retrieved (Pfeil & Zaphiris 2009), there are also some serious challenges to take into consideration. This chapter deals with one of the most prominent of those challenges, namely the issue of ethics.

The specific medium that is the Internet opens up new sets of challenges for the ethnographer when dealing with research ethics. The more traditional and conventional ethical guidelines do not always manage to keep up with the questions raised by this new medium. As Frankel and Siang put it:

“The ability of both researchers and their subjects to assume anonymous or pseudonymous identities online, the complexity of obtaining informed consent, the often exaggerated expectations, if not the illusion, of privacy in cyberspace, and the blurred distinction between public and private domains fuel questions about the interpretation and applicability of current policies governing the conduct of social and behavioral research involving human subjects.” (1999: 1-2)

One of the most special features of computer-mediated communication is that it is mainly text-based; therefore text is often the only available data for the researcher to unobtrusively study the community of interest. Fernback (1999) considers this type of data that is most of the time already in accessible format to be ideal for being studied by interpretative methods. The content and style of the texts to be found in an online community is key for understanding the nature and operation of that community and can lead to valuable findings (Pfeil & Zaphiris 2009: 6). While this is an advantage for my research project in the sense that it relies on the analysis of “naturalistic” data that is already “out there”, it can also be

problematic because the lack of further cues, especially social ones, can lead to misinterpretations and what is more, and what this chapter actually deals with, a number of ethical questions come into play due to the ambiguous nature of this particular medium.

Another point that may complicate things in the case of research on online support communities, which my own research falls under the category of, is the sensitive and fragile nature of these communities, which urges the researcher to act with increased care (Pfeil & Zaphiris 2009). This might seem in contradiction with what Herring (1996a) claims: if the research is more focused on the structure and composition of the messages rather than personal details of the people who have composed them, ethical issues are less compelling on the researcher. While my method is indeed concerned with the structure and composition of the texts, it is not completely exclusive of personal details or information that might be considered sensitive. Therefore, it becomes crucial to construct a case-specific ethical guideline since there are no monolithic or set-in-stone guidelines that correspond to the various and rich nature of online research and that could apply to all sorts of it (Pfeil&Zaphiris 2009).

It can be argued that the origin of the ethical issues concerning online research mainly stem from the fact that the Internet is extremely difficult to conceptualize as a private or public space. This has a direct influence on decisions made about obtaining informed consent- the blurred distinctions between these two arenas hinder online research from having an absolute set of rules concerning ethics. Since informed consent is not required for research that gathers its data from spaces considered to be public even if the data is private, it becomes central to the research to make a decision about the nature of the field to be studied. However, the public-private dichotomy does not function in the online world as it does in the offline world, and it is much more difficult to determine whether a space is public or private. To illustrate the ambiguous character of this medium and to highlight the difficulty of applying terms we are familiar with from the “offline world”, Waskul and Douglas (1996) have called it “publicly private” and “privately public”.

To estimate the perceived level of privacy of an online community, Eysenbach and Till propose three measures:

1. In online communities that require registration or subscription in order to become a member and gain access, members are more likely to perceive the community as a private one.
2. The number of real or assumed users is a factor when determining how public or private a domain is: the greater number of users, the smaller the perception of privacy.

3. The unique features of an online community specify how private it is perceived to be. These features are its “norms and codes, target audience, and aim” (2001: 1104).

When I first started browsing the forum on which I am conducting my research, I admittedly did not have many clues about the ethical challenges that would reveal themselves. My main activity on the forum was to “lurk” and try to get a better understanding of the environment and the qualities that relate to my research interests. At that time, I had saved some posts thinking I could use them in the later phases of my project. The forum is a public one, I have access to all the messages without having to register or fulfill any other condition, and so I could not see why it would be problematic for me to use those messages in my research. However, I started to become aware of some issues that were rather concealed to me when I immersed deeper into literature on Internet ethics. I have to admit that I was- to put it bluntly- completely panicked to see how strict some researchers were towards the idea of conceptualizing online communities as public spaces. This meant that my research project could be at risk because of the possibility of rejection; especially considering the sensitive nature of the forum I am investigating. However, as I continued reading I felt more at ease and noticed that it is indeed possible to work my way around conventional guidelines. Conceptualizing the forum as a public space eliminates the need for obtaining informed consent, and one of the topics on the forum has helped me a great deal in reaching this particular decision. In a thread titled “This is a public forum”, the site administrator writes:

“FOOTPRINTS: When we post on a public forum, we leave "footprints" for anyone in the world to see. Anything we post might be identifiable by others if we include a recognizable avatar, user name, other names, dates, links or even a vivid description of events. For some this is not an issue, but for those who wish to remain anonymous it can lead to unwanted attention or even exposure to possible confrontation.

USERNAME: We urge members to choose a username that is not their real name. If you post your real name, the name of the deceased or any other names, dates, cities, etc, your post can be recognized by others. Our forum is set to prevent search engine spiders from crawling through in an Internet Search, but nothing is ever ‘absolute.’ We also encourage members to carefully consider using recognizable photos in avatars.”

The quoted passages make it clear that the “publicness” of the forum is obvious to its administrators, and users are being informed on the issue. Therefore I find it appropriate to use content from the forum on the condition that certain information such as the names of individuals and the names of medications are concealed.

3.3. Packages and Frames

Having conceptualized The Alliance of Hope Forum as a public space, I started collecting messages that could possibly answer my research questions. As Hine (2008) argues that virtual ethnography is quite suitable for the use of interpretative methods for understanding message content, I found that the notion of packages and frames are helpful in examining the perceptions and conceptualizations to be found on the forum.

In their 1989 article, Gamson and Modigliani introduce the concepts of “packages” and “frames “ to illustrate how a policy issue gains cultural meaning and attributes. The term “package” refers to the totality of the elements that surround a socio-political issue. The components of these packages can be distinguished as a number of interpretative and sense-making tools, such as “metaphors, catchphrases, visual images, moral appeals, and other symbolic devices” (Gamson & Modigliani 1989: 2). These alternative packages make up the different kinds of discourse over an issue and are constantly made and remade, and renewed if necessary, depending on updates and new events. Various packages compete on the interpretation of an issue, with the aim of making its own interpretation as the most prominent among others.

These sense-making and interpretation processes operate on both cultural and individual levels. What is inside a “package” that fights over interpretative dominance on an issue is composed of sociocultural elements, but individual artifacts also play an important role in shaping a package. This level is a more cognitive and emotional one, in which individuals bring their own “life histories, social interactions, and psychological predispositions” to the process of meaning constructions (Gamson & Modigliani 1989:2). The issue then is approached with a baggage of experience-driven understandings and expectations. To get a better understanding of what a package is, and how it operates, we can take a look at its internal structure. At the core of a package is a “central organizing idea” (Gamson & Modigliani 1989: 3) or a “frame” that the package is built upon, conceptualizing the phenomenon at hand.

Frames do not simply refer to pro or con attitudes towards phenomena or a policy measure, neither are they very definitive and clear-cut in terms of a policy position. They embody more diverse attitudes than those of pro or con, and are more ambivalent than that in nature (Gamson & Modigliani 1989: 4). Packages are not stable in time because frames change and evolve. They have to incorporate recent events and new personal experiences within their storylines, or scenarios they operate with.

Nisbet and Scheufele (2009) further define frames by referring to them as “interpretative storylines” that help lay out what is at stake and why the issue is of importance. A framing-centered research makes it possible to investigate how various actors shape science and/or technology-related debates, how the media plays part in this process and how public perceptions, understandings and levels and modes of participation differ (Nisbet & Scheufele 2009: 1770). Hellsten and Nerlich refer to framing as “the use of metaphors as common points of reference that establish relationships between the sciences, the mass media and their publics (2008: 93). These authors stress the role of discourse metaphors in the construction of narrative frames and spell them out as facilitators in understanding new issues and complex processes. They do so by referring to shared values and experiences and by the use of dramatic and evocative language and image at time (2008: 95).

As already mentioned, these frames help to characterize a discourse, which is inevitably a “value-added process” (Gamson & Modigliani 1989: 5). This is something that not only determines how a package is composed, but also determines if/how it succeeds. The authors lay out three different determinants at this point:

1. Cultural resonances: Resonances are the earliest stages in the value adding process. This refers to the concepts and symbols that are used in constructing and describing a position. These tools differ in terms of their potential and efficiency; not all symbols make the same kind of resonances. The ideas expressed in some cases and the languages used are more relatable and more relevant for the larger public; they make their ideas appear more “natural and familiar” (Gamson & Modigliani 1989: 5). Nisbet and Scheufele argue that “applicability” to a pre-existing value structure or thought scheme is key in the success of a frame; a successful framing is one that links two things together in a such a way that the appearance of the exposure of one directly reminds the publics of the other, they go hand in hand (2009). Resonances also facilitate the happenings at the next stage, which refers to the work of sponsors, by directing the attention and effort of sponsors towards a certain direction.
2. Sponsor activities: These activities are not activities of mere support and/or lending advice, but refer to a more organized and complex set of strategies employed by sponsors of packages that work to promote a collective agenda rather than a personal one. The “agents” achieve this through the materials provided through the resources of an agency, that is ready and easy to use and to distribute.
3. Media practices: The ways through which different kinds of media are employed and used and which norms and practices are adopted at these stages are critical to the value adding process. (Gamson & Modigliani 1989: 5-7). Nisbet and Scheufele argue that media frames alone rarely, if ever, determine public opinion on their own. They suggest that media frames

and practices might and do help shape ideas and positions, but these are not born out of mere media influences, but are the outcomes of a merge between the already existing accounts of personal experience and social interaction and an evaluation of media practices (2009:1770). The media success of a certain package is rarely the result of media practices alone, but is often a complex outcome of a series of factors, including strong resonance with popular culture, compatibility with social patterns and media routines and/or heavy and influential sponsoring (Nisbet & Scheufele 2009: 1770).

This last point brings us to two different issues to be taken into consideration when analyzing an “issue culture”. We have seen that individual cognitive processes play an important role in how discourses are shaped. This should bring to mind the arguments of “lay wisdom” or “lay knowledge” alongside “lay epistemologies” because these intellectual activities are the results of a new kind of interaction between science and the public, which ties the issue to the science communication aspect and also ties nicely with the question of pharmaceuticalization and bioactivism. Framing is an indispensable part of science communication; therefore urge us to take a closer look at what it is at the basis of science communication, science-public relations.

Since the impact of the media constitute an important part of how frames and packages are produced, I believe this approach is useful when looking at content produced on the Internet. By helping understand how science-public relations are acted out on the specific forum, and how perceptions of professionals, medication use, pharmaceuticalization and so on, frames can demonstrate how these issues are perceived and shaped on The Alliance of Hope Forum, and help consider which possible conclusions might be drawn from the analyses of these particular framings.

4. Analysis

The following analysis has been derived from several different sections of the forum. I have tried to pick topics with the most responses for analysis, as well as topics that could be argued to have a more questioning and/or blaming nature. The reason why I went for topics with more responses is that I believe they give the opportunity to observe more diverse opinions and are more “likely to address more contentious issues” (Sobkowicz & Sobkowicz 2012: 454). I also chose to collect my data from topics with most responses simply because I would have more diverse material to look at. I did not alter the posts quoted in the following parts except for concealing names of persons and/or medications, and any grammatical mistake or typographical error remains unchanged in its original state. For purposes of readability, user names are underlined.

I collect the most prominent themes of my analysis under a certain heading that sums up how the issue is being framed and then go on to explain the perceptions, thoughts and beliefs that make up the frame. In the following subchapters I first attempt to conceptualize and describe the forum from the viewpoint of its users and try to demonstrate the meanings attached to this particular place. In the two following subchapters I contrast the different opinions on the use of medication and health professionals by providing the motivations and reasons stated for these attitudes. These two subchapters help understand that the forum is in fact a much more complex space where there is no unity of opinions and attitudes, and they also help to reflect on the broader issues of how people deal with scientific/expert knowledge and when and how they deem this knowledge to be credible and trustworthy. The two subchapters also demonstrate the crucial importance of personal experience in the formation of opinions and attitudes on matters concerning experts. The next subchapter aims to add to what the previous subchapters have to offer in terms of providing an insight into how people draw boundaries and make certain distinctions and thus (re)create themselves as groups belonging to certain categories and excluded of others. This part hopes to contribute to the understanding of how individuals interact with science as an institution and doctors as a group of professionals. Finally, the last subchapter describes the micro-activism to be found on the forum, and offers two types of this call for action: one related to the individual and the other having to do with society at large. While the former is about learning and knowing for one's self, the latter can be interpreted as being about utilizing the information and knowledge acquired during this process to "save people's lives".

4.1. The forum as users see it: "A safe place"

Online mourning constitutes a major part of my research interests and it ties with the issue of virtual communities and the debates over the qualities they possess or lack. One of my research questions was asking what it was about these forums that made people want to go on them to express their grief and to mourn, to experience the aftermath of suicide.

Vanderwerker and Prigerson (2004) have put new media forward as "protective technologies" that help people through the aftermath of suicide; Carroll and Landry (2010) have stated that the rituals of mourning have changed due to what the Internet has to offer; Chapple and Ziebland (2011) have argued that the Internet is transforming the ways in which people experience bereavement by suicide. These studies and many others have offered explanations as to why this was the case, why the people they conducted their studies on chose to go online to express and experience grief, and found similar results. In a nutshell, the forum is conceptualized as *a safe place* that offers privacy, anonymity, 24/7 availability; a place where people who have had the same experience offer each other understanding and support as well as advice; and a place where one does not have to worry about being judged.

I collect this part of my data from a thread titled “*What is it about this site...?*” started by Ronnie Walker who is a moderator on the forum as well as the actual name behind the entire website. In this thread, Ronnie Walker talks about the private messages she regularly gets about how the forum has helped the person sending the message and directly asks people what is it about the website that makes them want to go on it to help cope with their situation. She asks why the forum has helped so many people and states that she would like to know the answers so she can utilize them when she is seeking grants and funding for the website. An interesting part of Ronnie Walker’s post is where she talks about discussing the subject with her husband: “*Last night, my husband and I were talking about the forum and what really happens here.* As a process engineer who helps companies measure and improve performance, he of course was quite analytical *and said* ‘Because it exposes people to so much information and wisdom from people who have been there before, it provides a map and accelerates the rate at which people can come to grips with what has happened.’” Her husband’s answer and interpretation is nothing shocking, but the way in which Ronnie Walker presents it is quite interesting, stressing that he is a process engineer and thus was quite analytical. This, however, is not the main focus of the analysis. The answers to Ronnie Walker’s post first characterize the forum in a few similar ways. lakerat and pamL call it a “*lifeline*”, Takecare4 and Silver Rain say it is like “*a family*”, hazel thinks she has found a “*kinship*” on the forum and thinks it is “*the best therapy she could possibly have*”, Sandy.W, bigdaddy192 and MissingHim see the forum as a “*community*”, Tootsiepop writes that it is what “*helps her stay alive*”, LoneLobo deems it “*Godsend*”. The characteristics of virtual relationships have been and will certainly continue to be debatable, as well as the question of whether their health-promoting effects can be on the same level as those of “real relationships” (Burrows et al. 2000). However, it becomes clear that at least for some of its members the authenticity and utility of the forum is certain.

This is what Ryan’smum has to say about the forum:

“A = Available Allies who understand, respond and care

L = Loyal and compassionate people who listen.

L = (A) Lifeline, keeping us afloat when we feel like sinking

I = Intelligent and clever administrators who help us through this grief.

A = Amazing threads and responses

N = Never-ending 24/7 support

C = Considerate and caring responses

E = Energetic and experienced administrators who keep this site alive.

O = Open and responsive administrators

F = Friendly and fortuitous

H = Helpful advice and information provided

O = Over and above any other support I have experienced

P = Promise of hope and on-going support given.

E = Entertaining and enterprising offering worldwide support.”

This post is important, because it is like a sort of summary of the thoughts and feelings expressed by members about why they choose to go on the forum and go through the aftermath of losing a loved one to suicide.

The reasons given by the members about why they continue to go on the forum can be grouped under a few main headings. Many of the members express their gratitude for being understood, and express how much it means to be with people who “get it”. lakerat, for instance writes, *“Each day I would read and find inspiration in someone’s post or a similar feeling I was having was being shared by someone else here [...] I have found my peace and happiness now and I owe it all to every single person on this forum.”*. hazel adds, *“I listen and share with people that truly ‘get it’”*. Sandy.W puts it as such: *“Coming to this forum, I found others who had been walking this path for so much longer than I.”* while Celosia says it is *“helpful to get advice from people who have been there themselves, as they actually get it...”*. JayWOB also expresses how the advice he has gotten from the forum was *“so on-point on several occasions”*. AlexisME says the forum is the only place where they feel understood. Some members express being understood in relation to professionals. Takecare4, for instance, writes that they *“don’t want to speak with a counselor just yet”* and hazel says, *“Most of us are not trained professionals, but you can’t beat experience and sadly, all of us in this club are sharing the same experience of losing someone to suicide.”* While in Takecare4’s post it does not become quite clear why they do not want to see a counselor, hazel puts it very openly: The fact that they are lacking the experience shared by everyone on the Alliance of Hope Forum. This is a nice demonstration of how experience is being favored over expertise in this member’s understanding. karin writes that grief counseling *“left her angry”* whereas on the forum she had some of her *“painful questions answered”*. OksZh also mentions feelings of anger: *“I tried seeing a therapist after my mom committed suicide but he*

only made me angry. He never felt the pain so I felt like he didn't understand and was just sitting and nodding." Another reasoning related to health professionals is from DecemberMoon, who writes *"I didnt have the money to seek professional help from a counselor"*. These contrast these negative experiences (or lack thereof) with what they have found on the forum. They are being understood, and they do not doubt it because they know that the people they are interacting with have gone through the same things whereas a doctor or a counselor might not necessarily share the experience. So it becomes clear that this shared experience renders the community of high value to its members, feeding them with a feeling of not being alone as expressed several times. For ecamp51 this feeling is accompanied by the sense of "being normal": *"Before I came to this site I was begining to question my own mental health. Maybe I was abnormal. Through this site I learned what I was going through was perfectly normal. Just to know what you are feeling is normal and other people are going through the same thing is very, very helpful."* If this member went to seek professional help, perhaps he/she would be diagnosed and feel "abnormal" but being on the forum with people who have the same experience helps him/her feel "normal". BSWs.t. writes: *"No one could understand what I have experienced and continue to go through on this journey...this site has helped me to recognize that I am not alone. It has made me FEEL less alone, so many wonderful people who have the same struggle, and have come to bring each other strength, support, and hope."* While Marie 2 Michael writes, *"Here our pain and struggles are shared by all."*, reee says *"Trying to manage the grief, sadness, questions, inevitable guilt has become more tolerable because I am not alone, and I do believe there is strength in numbers."* It becomes clear, then, that people value shared experience highly and thus feel understood, which can be argued to help foster their sense of a community. As MissingHim puts it: *"We have all become 'Real' through our love and pain."*

Studies on online support groups have stressed the perceived advantages of these arenas, such as privacy, anonymity, 24/7 availability, and so on. These are also expressed on the Alliance of Hope Forum, altogether making it a "safe place" among its members. bmbmom, for instance, writes: *"There is no place I can go that allows me to discuss this most painful part of my life in anonymity. This privacy is very important to me. I don't have it anywhere else. [...] This forum is freedom."* Stressing the perceived constant availability of the forum is hazel: *"I feel I have access to 'counselling' 24/7 here."* and Leigh: *"This website is like a best friend who is available 24/7."* It is of course interesting that hazel should use the word counseling in apostrophes, which can be interpreted as an indication that she is aware that what is happening on the forum is no professional work, but still she feels that she has access to what it has to offer whenever she needs it. As for bmbmom, the anonymity and the privacy

she feels the forum provides her with is a very important point, so much so that she calls it “freedom”.

Of all the responses in the thread started by Ronnie Walker, the stress on the forum being a judgment-free environment is perhaps the most prevalent. pamL states: *“This has given me an avenue to vent, to talk about the horrible emotions, and the feelings that swirl around and around....and all this with no judgement, no telling me to get over it, no telling me that I am doing this wrong.”*, KMorgan writes *“I feel like I can honestly express myself here without judgement, worry, or having to give explanation of why I feel the way I do.”* and DecemberMoon says: *“This is the one place I and many others can come to where no one passes judgement on one another.”* For soultender, the forum is *“...where we can come shed our tears and not be judged or told we need to ‘move on’. This is the lifeline that society and our families withdrew from us because they were too uncomfortable to deal with us. Here we receive the soothing balm of empathy in a world turned upside down.”* This account is in line with that of Marie 2 Michael who talks about the stigma of suicide as something they do *“not have to worry about”* on the forum. It is safe to say, then, that the people who have posted the following comments and those who have posted similar things feel a pressure to “move on” and continue with their lives- something they feel they do not have to deal with when they are on the forum. This is in line with the claim put forward by Carroll and Landry (2010) who argue that the contemporary American society discourages long periods of mourning and urges people to get back with their lives as early on as possible. The forum, then, can be perceived as a space where grief can be extended, a place where it can be expressed and experienced by its members for as long as they like. AlexisME writes, *“Suicide is a topic that no one wants to talk about in the real world” because “suicide is not a worthy way for someone to leave this earth (in the eyes of the media/public). It is nice to finally have a place where this topic can be discussed openly, loved ones can be remembered, and people can begin/continue their healing process.”* to which Silver Rain adds: *“The suffering and rejection and stigma by society is not felt on this site. Everyone is bonded by what they have been through on here and you only feel compassion and love.”* These two posts demonstrate how members feel about society’s view of suicide and those who have committed suicide. These opinions are contrasted to what they find on the forum.

Perhaps related to these points, people have also expressed that the experience of being on the forum is “empowering”, as for instance Bea’s older sister put it. Celosia also talks about being *“stronger together”* whereas karin says that she feels *“more in control and therefore more comfortable”*. Erik’sMom summarizes the role the Internet plays in this: *“In talking with some of my new, and much needed friends on this site, it occurred to me, what did folks do back in the ‘old days’? The days before internet, social media, etc.? How did folks relieve*

their pain, lessen their pain, share their pain, let it all out?” This quote puts forward the perceived importance of the Internet in dealing with the aftermath of suicide, and shows how crucial it is deemed to be. Finngarian says the forum experience is *“like journaling, but with feedback”*- another statement that helps us understand why the forum is preferred. It helps people get emotional feedback from others that have had the same experience as they did, therefore creating a sense of community or family, and thus providing a “safe place” to mourn.

4.2. The anti-medication formulation: “Medicine as murderer”

The posts that express an anti-medication attitude, or at least skepticism towards the use of medication most of the time tell stories experienced by a family member or a friend, and recount how this led to changes for the worst, and finally to suicide. We see that in the narratives related to medication use, different actors such as doctors and pharmaceutical companies also come into play, showing that perceptions of the motivations, interests, competencies and capabilities of these domains are crucial in the formation of opinions (Brown&Calnan 2012) alongside personal experience or the experience of a loved one. The formulation of medicine as murderer is used by a few different members who think that medication use plays the central part in the suicide of their loved ones. The expression itself not only refers to medication as the culprit, but it in fact embodies a range of different attitudes that can be grouped as:

-
- a. A skepticism/distrust towards the pharmaceutical industry
 - b. An anti-medication attitude
 - c. A skepticism/distrust towards health professionals

Quite often, these different attitudes are intertwined and are very hard to separate from one another, but they all stem from the belief that medication use and the mistreatment and/or neglect of health professionals is what ultimately caused the suicide of a loved one. At this point, negative thoughts and feelings do not only center on the medication but are present in a way that distributes the blame between these three different elements. The following subchapters prove that medication is never solely a material, health-related object but embodies a much more complex set of meanings and attributes. As Cohen and colleagues put it:

“Because they are swallowed or injected inside physical bodies, it is initially difficult to consider how the effects of drugs resonate beyond an individual consumer’s body or being, to

shape social relations in families, groups, communities and larger societies- and in turn be shaped by these social relations.” (2001: 449)

The subchapters aim to capture this multifaceted relationship. Firstly, the medication because it is what is thought to be made the person commit suicide, then the doctors because they are the ones that prescribed those drugs in a rather inattentive manner and finally the pharmaceutical companies because their priority is to promote the medication and to make more profit. I now move on to elaborate on each of these attitudes.

4.2.1. Pharmaceuticalization

The basis of the negative attitude towards pharmaceutical companies seems to be the argument that the pharmaceutical industry is profit-based and is not considerate enough of the wellbeing of their customers. Within this framing, criticism focuses on the pharmaceutical industry for being “profit driven”. This is very much in line with what has been come to be termed pharmaceuticalization, which signifies a process “by which social, behavioral or bodily conditions are treated or deemed to be in need of treatment with medical drugs by doctors or patients” (Abraham 2009: 100). This notion can be thought of as accompanied by medicalization, and has even been argued to foster this very process because of the major role pharmaceutical companies have come to play within it. While the “biomedicalism thesis” regards pharmaceuticalization as an inevitable and even necessary outcome of the progress in medical science as well as the growing needs of more and more people to be diagnosed and treated, there is also strong opposition to this process on the grounds that the pharmaceutical industry is profit-driven, and that the benefits of the medications they sell are often exaggerated or simply wrongly stated (Davis&Abraham 2011). Davis and Abraham (2011) identify two different kinds of consumerism in Western societies that have emerged with the process of pharmaceuticalization: injury-oriented adversity and access-oriented collaboration. While the former is established and maintained by persons who believe they themselves have, or a loved one has been negatively affected by certain medications, the latter does not embody a negative attitude towards pharmaceuticalization and is not opposed to it. The traces of “injury-oriented adversity” Abraham speaks of can be observed on the Alliance of Hope Forum, but whether or not it is in the extent to cause a “de-pharmaceuticalization” through active and effective campaigning remains an open question.

One example of the adversity towards pharmaceutical companies is from a thread from May 2013, where Joni, member and moderator, makes a post about the NIMH³ rejecting the

³ National Institute of Mental Health (NIMH) is an American governmental research organization specializing in research on mental health.

upcoming version of DSM⁴, which is considered to be the “Bible” of psychiatric diagnosis. In her post, she quotes posts the link to an article on the Scientific American blog and ends with “*I’m not gonna say a word*”, indicating that the message to be received from the article seems quite obvious to her. The blog Joni links to is that of the American popular science magazine Scientific American, and is written by a self-proclaimed science writer who talks about how NIMH who has stated that it will “re-orient its research away from DSM” categories and interprets this as a sign that DSM is not to be relied upon completely and concludes that psychiatry is “in a crisis” and that “the science of mental illness is still appallingly primitive”. Her concluding remarks “*I’m not gonna say a word*” suggests that she is in full agreement with what the author on the Scientific American blog has posted.

The first reply to Joni’s post comes from Ronnie Walker, who states that the expansion of diagnostic distinctions cause concern because of the many pharmaceutical industry-related people being involved in the process: “*There have been substantial concerns around the New Diagnostic and Statistical Manual (DSM5) because it is so greatly expanded in diagnostic distinctions ... and because so many individuals who worked on it had direct connections to the pharmaceutical industry. [...] Many feel that the pharmaceutical industry has had a large influence in expanding diagnoses that lead to the prescription of drugs as treatment for those same issues.*”

Even though Ronnie Walker refers to these concerns in a generalized language and not necessarily as those of her own, it is an important indicator of why the pharmaceutical companies are not trusted among some of the members. She brings the issue of pharmaceutical companies into topic, even though the original post does not exclusively refer to them. This could mean to suggest that she considers the DSM to be something pharmaceutical companies benefit from. She argues that the fact that they are highly involved in the update process of something that more or less defines what a mental disorder is in the US makes some members question whether it is merely profit that is being considered. Overall, it is a statement that lacks any personal comments but channels its arguments from the viewpoint of “others”. This could be due to the specific status of Ronnie Walker on the forum as a moderator.

After several posts, Ronnie Walker writes again, this time in a different manner. She comes up with a new version of Shakespeare’s “To be, or not to be”:

⁴ Diagnostic and Statistic Manual of Mental Disorders (DSM) is being published by the American Psychiatric Association and it is the main tool for the classification of mental disorders. Widely referred to by health professionals and pharmaceutical companies, the first DSM was released in 1952, and the latest in 2013.

*“To be, or not to be, that is the question:
 Whether 'tis nobler in the mind to suffer
 The slings and arrows of misdiagnoses
 Or take arms against psychiatric experts
 With conflicts of interest.
 To die, to sleep
 Without Ambien – Is it possible?
 To sleep and end
 One’s heart-ache, with serotonin-reuptake inhibitors
 like Paxil or Zoloft - to end one’s grief, (which is now called Depression)
 Devoutly to be wished. To fall asleep
 And dream of loved ones. To sleep, perchance to Dream; Aye, there's the rub”*

One interesting thing in Ronnie Walker’s post is that she refers to “*psychiatric experts with conflicts of interest*” which makes one think about the opposition to the physician-industry collaboration which is by certain groups perceived as a moral danger because they argue that in such a collaboration patients’ needs are neglected over the profit the pharmaceutical industries and doctors would make (Wadmann 2014). This, alongside the line “*to end one’s grief (which is now called Depression)*” is an interesting and humorous projection of the skepticism and distrust on Ronnie Walker’s side. She gets several positive responses to her post, indicating that it was “*epic*”, “*pretty darned impressive*” and an off-topic chat starts until Sandy W., one of the moderators intervenes and mentions getting “*off-track*”. It is quite interesting that a moderator intervenes at this point and makes a warning about an ongoing discussion on the grounds that it is “*off-topic*”. Sandy W.’s post is a reminder for the rest of the members that a specific subject is to be discussed on that particular thread, indicating that there are certain regulations after all that forum users are expected to accord with. Since this is not necessarily related to what this subtopic mainly deals with, more reflections on the matter are to be found in the concluding chapter of the thesis.

After Sandy W.’s warning, to get things “*back on track*”, federico sanchez writes: “*Phew! And I thought I would need to read the entire DSM-V to see if anything new is really out there. Thank-you NIMH! Glad to hear I am not missing much.*

Sadly the DSM-V—I hear—adds many more labels for mental disorders, many that are probably just normal reactions to certain events.”

The post starts with a “*Phew!*” imitating a sigh of relief and continues with sarcastic comments. Besides indicating mistrust in the DSM by saying that not having to read the new one is “*not much missing much*”, it also adds to the idea that these manuals are prepared with

the intention of extending diagnoses and bringing more profit. The member states that it is “*sad*” that “*just normal reactions to certain events*” get medicalized and classified as mental disorders. Here the process of grieving and bereavement is normalized, conceptualized as “*just normal reactions*” observed after a traumatic event, and thus the entire experience is formulated as something that does not require medical intervention in the form of medication use, which makes certain activities of pharmaceutical industries emerge as actions not born of necessity but rather pursuing further financial profit.

A similar profit-centered argument is expressed by Joni in the same thread with the statement “*Anything natural that threatens profits is swept under the rug.*” and “*Scientists learned early on not to rock the boat with any real cures that would slow the flow of money into big pharma’s coffers.*” and by DieselFreak as well: “*it is very unfortunate that our pharmaceutical industry is driven by profit, rather than to genuinely help those who need it.*” This sentence not only deems pharmaceutical companies as profit-driven, but also seems to place some kind of responsibility on them in terms of helping those in need, which, these companies, according to this particular member, do not seem to be doing. Joni’s statements not only claim that the pharmaceutical industry and scientists work together in making sure profit is continued and increased, but also refers to natural alternatives as “*real cures*”, which indicates her doubt about medication as well. To continue the examples of people referring to the pharmaceutical companies as profit-based entities, glbivdaus writes: “*The greedy pharmaceutical companies killed him (referring to her husband) and really me too!*” which is a very definitive statement about the member’s perspective on the pharmaceutical industry.

These fragments are nice demonstrations of the injury-oriented adversity Davis and Abraham (2011) speak of and of the skeptical and untrusting attitude that accompanies it. The fact that more and more mental disorders are being defined and classified- thus medicalized- is tied to the phenomenon of pharmaceuticalization. The opinions expressed present the pharmaceutical industry as in sole pursue of financial profit, especially in cases where no medical intervention is perceived to be required. Since the members I have quoted are doubtful about the medicalization itself in the first place, the medications developed and offered alongside are doubted, as well as the doctors who prescribe them.

4.2.2. Anti-medication attitude

One of the earliest threads on the Alliance of Hope Forum from May 2008 asks the members if they have “taken anti-depressant, anti-anxiety, or sleep medications to help through the aftermath of suicide”. Of the 141 that have voted in the poll, 88 (62%) chose “Yes... and it has helped me”; 20 (14%) chose “Yes... and it did not help”; 22 (16%) chose “No, I never took anything” and 11 (8%) chose “I took herbs, homeopathic, or other natural remedies and

they helped”. The constraints and limitations of the possible answers the members had to choose from is of course debatable, for instance the last option only foresees a positive effect of “herbs, homeopathic, or natural remedies” and completely leaves out the possibility of them not working. But the interesting point here is that even though the use of medication seems to be quite prevalent among forum members, there is also an attitude of distrust and rejection towards psychiatric medication. Members who oppose the use of psychiatric medication seem to ground their opinions on two main points: the side effects of these drugs and the difficulties experienced during the process of getting off of them.

For instance, in a thread where a member is asking others their opinions on using psychiatric medication, glbivdaus writes: “[...] *I NEVER wanted him to take these meds that all had suicidal side effects. The first time he continually used them, he shot himself.*”

The problem with the medication is expressed here, presenting them as “*all having suicidal side effects*” and the member makes a direct link between her husband regularly taking psychiatric medication and committing suicide. Her opposition of the medication is expressed in capitals- “*NEVER*”, so the attitude is underlined and the mode of suicide is expressed right after the mention of regular medication use. It is put bluntly, perhaps to strengthen the desired effect. glbivdaus draws on a personal experience and goes on to generalize it to the entirety of psychiatric medications.

In a different thread, the same member writes: “*I will again like to say that the drugs killed my husband. All three had suicidal side effects. This is the first time in over 20 years that he had stayed on them. Obviously it was not a good choice. Always before we worked our way through his episodes and he did not continue his meds. His psychiatrist called me back with him and said if he would stay on them the episodes would not continue. By trying to prevent them, mostly because he did not want me to have to get through the bad times, he was killed by them. I will ALWAYS believe this....I had seen it too many years. Drugs did not help him, love, patience, healthy living is what helped him. I would really like to scream and curse the doctors and pharmaceutical companies. I really feel a lot of anger about this sometimes.*”

glbivdaus once again expresses her conviction that the drugs “killed” her husband. She differentiates between the time when her husband did not take medication regularly and after he started doing so, and she puts her husband’s psychiatrist forward as the one who convinced them that the “episodes” would not come back if the medications are taken regularly. While drugs are seen as practically the murderers of her husband, love, patience and healthy living are conceptualized as things that actually did help him- there is a clear distinction between medication and these other three.

To this post by [glbivdaus](#), [Joni](#) is the only member to reply, and hers is the last message on the thread. It goes: *“It is being proven that antidepressants work no better than a placebo. Our minds are capable of miracles. If we believe we’ll get better, we will. The premise these drugs work on is a theory - it has never been and can’t be proved that they work. Many call it junk science. To give them to children is just plain wrong.”*

[Joni](#)’s reasoning here is put in very simple words: If someone believes they will get better, they will. She argues that the placebo effect of antidepressants are “being proven” but does not necessarily quote any sources or studies, and tosses the entire mental health profession by referring to people calling it “junk science”. It is interesting that “junk science” is the choice of wording here; it is used to express the perceived delegitimacy of science- so while there is mistrust and skepticism, it seems to be not directed at science as a whole but only to parts of it which [Joni](#) deems to be “junk”. Another interesting point is that she never refers to herself specifically in this case, she does not say, *“I call it junk science”* but refers to a more general language from others’ point of view. This is reminiscent of [Sandy W.](#)’s post quoted above where she talks about pharmaceutical companies. Like [Joni](#), she expressed a skeptical and negative opinion but the subject of her statement is never herself. An important thing to note is that both [Sandy W.](#) and [Joni](#) are forum moderators.

To get back to the issue of anti-medication attitude, another example of the concern over the side effects of medication is found in a post by [Finnigarian](#) who writes: *“[...] I could go on for ages on not just what the drugs used to treat these problems do to developing brains in children, but what they also seem to do to mature adult brains. Don’t get me started on psychiatric drugs. I could go on and on for years.”*

The expression *“I could go on for years”* suggests that there is a lot to say about the side effects of psychiatric medication on both children and adults. [Finnigarian](#) introduces children to her argument and makes a comparison between them using psychiatric medication and adults doing so.

[kaitymai](#) is another member who makes a direct link between the use of psychiatric drugs and suicide: *“My son’s suicide was a direct result of the side effect of the antidepressant he’d been on for 2 months. I won’t go into the details here but he was prescribed antidepressants for anxiety and in two months went from being a happy young man to a dark, depressed, suicidal one....the change apparently was so quick.”*

For this member, it is very clear that the anti-depressants are what caused her son to commit suicide. She describes the changes she witnessed in him in dramatic expressions. Although she states that her son had been on antidepressants for 2 months, she then goes on to say that

he also was a “happy young man” and was transformed into a “dark, depressed, suicidal one” after taking medication regularly. It can be argued that there is some sort of inconsistency in her statement, because her son’s pre-medication state is explained merely through anxiety, and a pre-medication depression is completely ruled out.

Joni writes: *“I can’t tell you how many times I’ve read here that loved ones have killed themselves after starting, changing, or quitting these drugs. The premise they go on has never been and can’t be proven.”* She challenges the notion of psychiatric medication on a very basic level and makes an interesting point: *“Something to think about – mass shootings were unheard of prior to 1989, the year Prozac and then other SSRI’s came out.”* Even though she does not directly suggest a connection between the two, she presents her expression as *“something to think about”*, implying that psychiatric medication might have to do with the emergence of mass shootings. In a different thread, Joni also argues *“latest studies have also shown that antidepressants are no more effective than a placebo, meaning it is the power of your mind that makes you feel better.”*

It seems clear that the posts on the forum are a credible and trustworthy source for Joni, and they have strengthened her opinion on the negative effects of medication. She mentions the posts she has read on the forum, which can be taken as an indication that Joni identifies herself with the members of the forum and the opinions expressed by them, bringing to mind the well-known debates on the authenticity of virtual communities and the relations to be developed on them. While Joni is making her claims on the non-effectiveness of antidepressants, she refers to “latest studies”, once again not exactly indicating which ones, but we somehow get the idea that she is talking about scientific efforts, and it is interesting once again that science is being challenged by science; one facet of it is being rejected with another.

Another message mentioning the side effects of medication is by a different member.

Finnigarian’s post combines the two main concerns expressed on the forum over psychiatric drugs: *“[...] I have a lot of concerns about those types of medications. I think they can be helpful for some people in some situations... but people don’t understand that there are risks as well. They can also be very hard to stop once you start taking them, when people wean off them even very slowly the side effects of that can be pretty miserable. It’s all a question if the risks outweigh the benefits or not...”*

According to this member, the final decision on using drugs or not is something that needs to be reached after an evaluation of risks and benefits. She does not dismiss the usefulness of them in some cases, but also asserts that they have serious side effects and a difficult quitting phase that should be carefully considered before taking them. In a different thread she writes:

“Make sure you know how hard it is to get off them too once you start taking them.”

Finngarian’s post demonstrates that people make an assessment of risks and benefits before making the decision to get on board with a certain technology/innovation or not.

What all of these posts, and the ones to follow have in common is that they are examples of anecdotal evidence. Moore and Stilgoe (2009) argue that the analysis of anecdotal evidence is composed of many different elements such as efforts undertaken when doing boundary work, and the formation and utilization of lay knowledge and lay expertise. The boundary work aspect of the issue will be discussed later, but at this stage it is important to express that anecdotal evidence is a completely individual and experience-driven notion; it is a “local and embodied knowledge” that is often accompanied with a “context of expert ignorance” (Moore&Stilgoe 2009: 656). Whether or not we can truly talk about an ignorance of experts is debatable, since we see that members often refer to science as an institution in general and choose to make their arguments against science with the help of science. Still, the notion of anecdotal evidence is important to bring up in the sense that it can come to embody the entirety of lay experiences and claims, and also help voice their concerns and doubts. It is useful to consider the quotations from the members within this framework because it is highly related to how their knowledge claims are made, and also has a lot to do with the way relations between “lay” and “expert” groups are perceived and constructed.

4.2.3. Negativity towards doctors

Among the discussions related to medication use, one of the themes that attract attention is the negative feelings towards health professionals, especially doctors. These arguments seem to center around the belief that doctors do not care for their patients but simply try to make more profit, or that they do not understand what the patient is suffering from because they have not experienced something similar.

The first example is from a post by DieselFreak on a thread where a new member is asking the others their opinions on the use of medication: *“[...]My twin brother was given a cocktail of [X], [Y], [Z] and something for his blood to keep the lithium from poisoning him. he was only 13!!!! I think sometimes doctors abuse there power, or just don’t care enough about there patients.”*

This member tells a personal story and mentions the pills his/her brother was given, drawing attention to the fact that at the time he was “*only 13!!!!*”, using several exclamation marks to express the perceived gravity of the situation. The last sentence suggests two things about doctors resulting from the conviction that it was wrong of them to prescribe the drugs they did to a 13 year-old: either that they abuse their power, which is also interesting in the sense that

it agrees to a difference in power between doctor and patient; or that the doctors do not care enough about their patients- both negative statements. The sole member to react to the post is Joni, who writes: *“13!?! All those meds? And they haven't even been studied in children!!! Allopathic (modern) medicine is drug-based and these drugs are synthetic - completely foreign to the human body.”* Joni underlines that the medications have not been “studied” in children, once again suggesting that a complete dismissal of the institution of science and medical profession is not the case, and that the mistrust is partial.

In one of her posts in yet another thread about medication use, Joni says: *“Doctors simply aren't trained to look for the underlying causes of mental illness. There is always a physiological reason our brains go awry – hypoglycemia, allergies or sensitivities to man-made chemicals, nutritional imbalance or depletion, excess histamine, heavy metal poisoning to name a few. Doctors don't look at you as holistically as they should. JD Rockefeller almost single-handedly changed the course of medicine with his Flexnor report from one of homeopathic to petroleum-based medicine, yet wouldn't let anyone touch him but a homeopath.”*

The first sentence condemns doctors- though not on an individual but more on an institutional level- of not conducting a thorough assessment of their patients simply because they are not “trained to” investigate further into the causes of a disorder, but rather work to make the symptoms go away. This statement traces the problematic aspect to the education and training the doctors receive and to the way they practice medicine. Joni then goes on to list a number of reasons why the brain might have “gone awry”, which, according to her, does not always suggest a mental disorder and a need for an intervention through psychiatric medication. To strengthen her position on the use of medication, she gives the example of JD Rockefeller.

In a reply to this post by Joni, Finngarian writes: *“[...] I have a friend whose doctor refused to answer that question regarding a medication that wouldn't have helped her anyway because she wasn't diagnosed properly. HE REFUSED TO ANSWER HER. It was an SSRI that a friend of mine spent a year trying to stop. It was horrible.”*

Here, Finngarian tells the story of a friend who had a negative experience with her doctor regarding a question she posed to him. According to Finngarian, the main problem was that his/her friend was not “properly diagnosed” to begin with, and was given a medication that would not have been use to her anyway. With capitals, he/she stresses the fact that the doctor refused to answer her, perhaps indicating how difficult it is to believe that this happened or drawing particular attention to the fact that it could happen.

In a different post later on the thread, Finngarian writes: *“Why is the answer always more more more? They don’t realize they stop working and then you’re stuck in withdrawal or ever increasing symptoms!”*

This statement makes it apparent that Finngarian thinks that the doctors do not have understanding for what their patients experience when they try to make things better by prescribing them more medication, which, according to Finngarian seems to only make things worse. According to Joni, this could be owing to the fact that *“some doctors get bonuses when they write so many scrips for meds”*. Here, there is a certain blame directed towards doctors about writing more prescriptions for the sole sake of getting extra bonuses from pharmaceutical companies.

In a different thread, Joni writes: *“Most doctors only know what the sales reps tell them, then pass them out like candy. These drugs make changes in your brain! They are not studied long term! Most of the studies out there are funded by big pharma!”*

It’s only a theory that chemical changes cause depression. There are no tests that can prove it. If it is chemical changes, there is a physiological reason why they’ve gone awry in the first place! Doctors need to start taking the time to find out the whys instead of writing more scrips. They need to do some homework. We’re talkin’ life and death here. “

The most prominent theme in this post is the call to responsibility directed at the doctors. Also, Joni mentions the lack of studies investigating the long-term effects of these drugs and also the lack of evidence to prove that depression is caused by chemical changes in the brain. Joni first argues that the doctors are not completely knowledgeable about the drugs they prescribe, but instead rely on the accounts of sales representatives of major pharmaceutical companies and thus prescribe medication without trying to find out more about the medication first- without *“doing their homework”*. This imperative then is explained as being a matter of life and death- a formulation that helps the gravity of the situation come across.

4.3. Appraisal of medication: “Functioning”

So far, we have seen quotations from members who express negative opinions on the pharmaceutical industry, health professionals and the use of medication. However, this is only one dimension of the views expressed on the forum and is certainly not generalizable to it as a whole. There are many members on the forum who express a gratitude for medication in general. This does not resonate as much for doctors or pharmaceutical companies; therefore it is not as intertwined and difficult to distinguish from one another as is the case with negative opinions, but the members who express positive views of medication do not seem to hold

negative views of the pharmaceutical industry or health professionals either. The main reason why people seem to appreciate medication seems to be the ability it gives to continue with one's daily activities, something members refer to as "functioning".

An interesting thing to be noted for the posts featured in this subchapter is the fact that they all tell personal stories, of things experienced firsthand. Each anecdote is related to something personally experienced and acknowledged by the poster and in that sense differs from the posts that express negative views on the use of medication, which recount not only personal stories but also stories of experiences by family and/or friends.

One example of medication helping people get back on track with their daily lives can be found in a post by lakerat who puts it as such: *"[...] As for the [X], I absolutely love it. I have energy and a smile on my face. Going to work is not as stressful and yesterday I joined a fitness gym with my teenage daughter and enjoyed every minute of it. I am now convinced I need to stay on the [X] and can really see a BIG difference in my mood swings and attitude. I am also a lot more prepared to help with my sister and niece and don't feel like I am going to fall apart at any second. :D"*

Like some other members, lakerat attributes having energy and being able to smile to a medication, which she *"absolutely"* loves. She finds daily obligations such as going to work and optional activities such as exercising not as difficult which has persuaded her that she needs to continue taking the medication. Apart from the ease the medication provides to execute activities; lakerat also mentions a more inner process- a *"BIG"* difference in her mood swings and attitude. She then goes on to express that she feels more ready to help family members and ends by saying that she does not feel like she is "going to fall apart any second", adding a smiley at the end of the sentence which is interesting, because it could suggest that she now considers the feeling of *"falling apart at any second"* as a comical past experience that she has left behind thanks to the medication.

Another example can be found in a post by Hestia: *"[...] It's too soon to say for sure how it's working yet. I don't feel a whole lot better, but I did notice I'm able to concentrate a little more. I was able to read a book and follow some shows on television, and I've even been writing a little this evening. Those are all good signs."*

This is another demonstration of psychiatric medication helping people "get back on track" by allowing them to continue mundane everyday activities we often take for granted, such as reading a book and watching television. Although Hestia does not want to jump to conclusions about the medication because it is "too soon", she does notice certain significant

changes and talks about them as “good signs”- motivations for staying on that particular medication.

A post by bmbmom is as follows: *“[...] I know one can become dependant on it. I probably am. I don’t worry about it too much. I never take more even though it’s prescribed for over twice as much. It has allowed me to think when I couldn’t shut my mind up(round and round with thoughts, images, smells, sights). It has kept my emotions in check when I felt like I was coming out of my skin. It has helped me sleep when sleep wouldn’t come.”*

It becomes clear that for bmbmom, the benefits of medication outweigh the risk of becoming dependent on it, a subject she “does not worry about too much”. She explains this by her habit of not taking the medication in doses more than she has been prescribed and then goes on to list the benefits she acquires from the medication, such as being able to think- at this point referring to her mind as something that can be shut down or turned on. With the help of the medication, she has managed to keep certain stimulants under control and kept them from interfering with her personal life as much as they used to. She also mentions being able to control her feelings better and expresses a gratitude for being able to fall asleep after a lack thereof.

Sleep deprivation seems to be something most members are glad to leave behind. For instance, neverthesame writes: *“[...] I was prescribed [X] to help me sleep and it has been very helpful for me. I am on a low dose and only take it at bedtime. I don’t think I would have been able to function without the med allowing me to get rest. I know it is a personal choice whether or not to use medications to combat the anxiety and sleeplessness, but if anyone has any questions, feel free to ask.”*

Like in the previous examples, this member also writes about the help he/she has received from the medication to keep functioning and for being able to sleep. He/she feels the need to stress that they are on a low dose that is only taken at bedtime- therefore perhaps emphasizing that the medication is only being taken to help with sleep deprivation and puts the importance of being able to sleep as something that has allowed her to function. He/she is also willing to answer any questions other members might have regarding medication use and feels the need to stress that she is aware that the attitude on medication use is a personal decision.

paulie1963 writes similar: *“[...] I was unable to function all I did was work which consisted of staring at a computer screen all day to sleeping. At times I was actually experiencing physical symptoms strange things and panic. I decided to see a psychiatrist and I have been on a combination of two anti-depressants and they have saved me. Am I still crushed absolutely, however, I can at least eat, sleep and attend to a activity.”*

paulie1963 also uses the word “functioning” to describe what he/she was not able to do and to attribute the change the medication has brought along. He/she writes about not being able to do anything besides looking at a computer screen and sleeping, and also mentions some other troubles he/she has experienced. We then find out that after seeing a psychiatrist and being prescribed medication, he/she feels “saved”. This does not mean that the member has gone through the process of grieving completely, he/she still is “crushed”, but they are at least able to execute daily activities thanks to the medication.

Ronnie Walker echoes the sentiments: “[...] as a grief counselor, specializing in working with survivors of suicide, I have found that many people find antidepressants to be a life-saver, allowing them to function in day to day life, where they were not able to function at all. I have seen no evidence in literature or with my own clients, that taking antidepressants interferes with how someone grieves or makes grief last longer. There is no research in this area. It’s my personal belief (based only on my observations of clients) that for many people, antidepressants buffer the pain a bit. The pain does not go away. Grief is still processed ... healing continues and many people who could not function at all, are able to get back on their feet to work and take care of families.”

In this post, Ronnie Walker, who in a different post refers to SSRI antidepressants as what helped her “*through the darkest days*”, inserts her professional stance and her experience with clients, as well as her knowledge of the “*literature*” as tools to support her point of view and challenges the idea that anti-depressants mask or prolong grief. She also uses the word “functioning” to illustrate the utility of medication and states that they have been deemed “lifesavers” by people experiencing the aftermath of the suicide of a loved one. Here, Ronnie Walker puts an emphasis on being able to work and to support and take care of one’s family as the benefit anti-depressants bring by “*buffering*” the pain.

The will and the need to keep functioning can also be observed in a post by a different member, Vicki, who writes: “*I have been taking an anti-depressant, an anti-anxiety and sleeping pills. I don’t think I could have made it through the last 12 weeks without them. I try to use the anti-anxiety and sleeping pills only when I need to but if the anti-depressant isn’t taken as directed it won’t work. I see or speak to my MD at least once a week and also see a therapist specializing in counseling for suicide survivors once a week. This has been the most horrific experience of my life and I need to do everything I can to function as best I can for my surviving daughter.*”

The importance of the need to continue “functioning” and the significance of the help obtained through medication during this phase becomes apparent in this post as well when she writes that she “*could not have made it through*” if it was not for the medication. Vicki feels

the need to assert that she does not want to rely heavily on medication by pointing out that she tries not to take the anti-anxiety and sleeping medications when she does not feel in need, and by stating that she needs to use the anti-depressants as prescribed because otherwise they will not work. She also writes about the help she is receiving from professionals, summarizing all of her efforts at the end as things she needs to do to continue functioning during the “*most horrific experience*” of her life.

A similar post is by psyquestor: *“I’ve been taking [X] for about a week and I noticed a difference within three days. I smiled and laughed for the first time in forever. I had more energy and was able to cope. I didn’t have as many ‘flashbacks.’”*

This member also mentions a number of differences he/she attributes to the use of medication, such as being able to smile and having more energy, as well as being able to deal with thoughts and feelings and experiencing fewer flashbacks.

In a post by ryanshope, it once again becomes clear why medication is appreciated: *“[...] i had tried several – but they made me feel worse. then I came across a dr. – not by choice – but because of anxiety attacks – and he managed to get the component i needed in the right dosages. now i always sleep and feel better. without them i don’t sleep and i get very aggressive with people. i guess the anger starts coming out and then the crying.....i believe i have always been depressed it just didn’t really show up until after [X]’s death then it just took hold and wouldn’t let go. don’t think i would be here now if it wasn’t for the meds. sleep deprivation can do crazy things to the mind.”*

This member first mentions her negative experience with medication and then says that her encounter with another doctor was not necessarily intentional or planned, but rather was an inevitable result of an anxiety attack. What this doctor did was to achieve success in terms of dosages- something that helps with ryanshope’s sleeping and eating patterns. She states that she experiences lack of sleep and aggressiveness when she does not take the medication and then provides an interesting insight: he/she argues that they have always had a tendency for depression but this did not emerge until the suicide of a loved one. Her statement about *“not being here now if it wasn’t for the meds”* makes it quite clear what sort of lifesaving effect the medication has had on him/her.

At times, members make posts contrasting between the state of taking medication and not doing so to illustrate their point of view on the benefits of medication use. One example is from a post by psyquestor: *“By mistake I missed my medication last week on Thursday and again on Saturday, due to having so much to do that day. Well, if I had any doubts that it was helping, they are all gone now. Yesterday I had a very bad day, spent the entire morning and*

afternoon in tears. I got nothing accomplished and took a nap (which I never do). I had no physical or mental energy to get through my day. I'll have to be more vigilant in taking my meds."

psyquestor states that after missing their medication for some days, they no longer have any doubts about their utility because they have seen what it is like to be without them. Because he/she missed the medication, they have spent a very bad day in tears, did not manage to get anything done and did something out of the ordinary for him/her- taking a nap, and were deprived of energy. The member then adds by a sentence that demonstrates her determination about being more careful when taking the pills.

The negative consequences of being off of medication also becomes clear in this post by ryanshope: *"i too have actually gotten of them thinking i felt o.k. it didn't take long after the meds were out of my system that i started falling back into the depression mood and the crying and a bit of anger. went back to the dr. and she asked me why i got off of them, when i told that i thought i was doing fine then took a nose dive she said not to ever get off of them again. not without her help anyway. needless to say i stay on them and i can keep my moods and emotional well being on an even keel."*

This member first writes about his/her process of quitting the medication as a decision she has made on her own, and then makes a direct link between the medication being "out of their system" and "taking a nose dive" with the depression coming back, accompanied by crying and anger. ryanshope presents this experience as a lesson learned and expresses that they now stay on the medication and do not try to quit them without consulting a doctor first. The state of being on them now is expressed together with "needless to say", showing that it is an easy and obvious decision, followed directly by an example of the benefit of the medication- a more stable emotional state.

Related to the appraisal of medication, an appreciation for pharmaceutical companies can be observed in a post by Sandy W. who writes: *"[...] Personally, I am deeply grateful for the pharmaceutical companies. I realize the pour billions into research that often fails and loses money, however when they find a successful drug they often reap enormous financial benefit. Again, that's the job of business."*

It's a real Catch-22. Drugs, well intended often bring about horrible results. However, these drugs often save lives. I need to remind myself how valuable the drugs that are developed are to most people. When my son Mike was 15, he was diagnosed with Addison's disease. It cost less than \$20. a month to purchase the drugs that he needed to take twice a day to stay alive. That's right, without these drugs he would have died. [...] President Kennedy had the same

disease, at the time there was no cost effective way to manufacture the drugs needed, it cost him well over a thousand dollars a month just to remain alive. That cost would have bankrupted us and we would soon have run out of funds, Mike would have died very young.”

The post starts with the word “personally”, stressing that it is a personal opinion being expressed, perhaps to keep any critical comments at bay from people opposed to medication. The reasoning of this appreciation is provided through an experience with her son who needed to take a certain medication to “stay alive”. The “life saving” quality of drugs is mentioned in this sentence, and then stressed once again in the next: “That’s right, without these drugs he would have died.” Sandy W. also gives the example of a public figure to strengthen her argument.

4.4. Making distinctions that matter: “Sad, not depressed”

This phrase is directly taken from a post by one of the members who write about refusing to be on medication, telling her doctor that she is “*sad, not depressed*”. This is a very interesting distinction because it is also a good demonstration of how members differentiate between situations that call for medical intervention and ones that do not. The member here draws a boundary, therefore determining what comes inside and what stays out. She uses these boundaries to demonstrate “internal differentiations” (Gieryn 1999: 10). Boundary work, as put forward by Gieryn, is often associated with demarcating what is science and what is not, and the role of lay people is quite significant in the process. Boundaries can be conceptualized as tools for the categorization of “objects, people, practices, and even time and space” (Lamont&Molnar 2002: 168) and also as tools of challenging scientific claims. As expressed here, being depressed is rejected, and it is being replaced with being sad, the two things positioned as opposite to each other.

As part of the boundary work maintained between the two different states of “being sad” and “being depressed”, the aftermath of the suicide of a loved one and what comes along with it is formulated as something that is “*perfectly, painfully normal*”, therefore normalizing the grieving process and differentiating it from the state of being depressed in which case using medication would be apprehensible. For some members, this refusal of the state of depression and the use of medication is accompanied by an advocacy for what they call “natural remedies” or “natural alternatives”. The phase a suicide survivor goes through is put forward as “*just normal reactions*” and this line of thought is also against the over-classification of certain situations as mental disorders.

This refusal to be classified as depressed people with a mental disorder also results in some of the members adopting alternative remedies to help deal with the aftermath of losing a loved one to suicide.

For instance, in a reply to a topic titled *“Not a medication, but an alternate to psychotherapy”*, which asks other members whether they have any experience with “somatic experiencing”, Joni writes: *“[...] EFT⁵ has helped me many times, especially for public speaking, an abscessed tooth, and going to the dentist (which I’m terrified of!). It has also helped the pain of a kidney stone a few weeks ago. I use it whenever I’m nervous about anything. If it works because we think it will work, that’s fine with me. I know our minds have incredible power that we haven’t even begun to tap yet: Anyway, nothing works for everyone, I guess.”*

Here, Joni talks about EFT as an alternative to psychiatric medication and gives examples of several instances when this has worked for her. She then expresses that she is rather indifferent to the opinions that suggest it might be working because of a placebo effect, because she believes in the power of the mind that is yet to be explored further. Since for Joni the situation is not something that requires medical intervention, she sees no need to take medication and consorts to alternative remedies. “Being sad” and not “being depressed” is offered as the reason for not using medication- there simply is no need for it.

In a different thread kaitymai says: *“[...] So after his suicide I went to the doctor and he prescribed sleeping pills and [X]... which I took periodically for 6 weeks. After the six weeks when I went back to see him he tried to put me on [Y]. I refused them, telling him I was SAD not depressed. I did use alcohol for a time before bed to deaden the pain and help me sleep but no longer need that either. It’s been 14 months now and I see a naturopath. She has me on various vitamins and I feel physically better than I’ve felt in a long time. The sadness is still there but not as excruciating as it used to be. It is interesting to read how different people cope, everyone using methods that they feel comfortable with to help them get through.”*

Here, the distinction is taken on a different level: While she seems to have no trouble with taking sleeping pills, she adopts a different attitude towards antidepressants. So it is not completely clear where the boundaries related to medication are being drawn. An antidepressant is rejected because kaitymai does not consider herself to be depressed, but she does take sleeping pills. The sadness, positioned against the condition of being depressed appears as something that is trying to be worked out by something different than psychiatric

⁵ Emotional Freedom Techniques (EFT) works to release “blocked energy” from certain acupunctural points on the body.

medication. Alcohol is a past remedy attempt, now replaced by regular visits to a neuropath and vitamins.

One of the members who is a strong advocate of natural remedies is Joni, who in one of her posts writes: *“Humans have been grieving for thousands of years and survived... you will, too. Antidepressants will prolong grief. It doesn’t go away. There are many natural alternatives to drugs that are perfectly safe.”*

In this excerpt, Joni first presents the grieving process as something that is completely normal and has been going for a very long period of time. She says that it is a process people have managed to survive through, and resorting to antidepressants during this period will only prolong and extend the process and be of no use. According to Joni, the bereavement process is one that needs to be experienced and trying to suppress it with medication is futile when there are *“many natural alternatives that are perfectly safe”*. This statement indicates that Joni not only considers medication to be useless but also dangerous, conceptualizing alternative remedies as *“perfectly safe”* things as opposed to drugs.

In a different thread, Joni echoes the same sentiments: *“In my opinion, medication would be my last option. What you’re feeling is what we feel when we are grieving. It’s perfectly, painfully normal.”*

Here too, Joni stresses the normalcy of the feelings one experiences in the aftermath of the suicide of a loved one and indicates that medication would be her last option, dismissing it to a certain degree, but not fully rejecting it as a possibility. Like the previous members, because Joni does not agree with being conceptualized or diagnosed as a depressed individual, the use of psychiatric medication is seen as something that is unrequired and unnecessary. No help can be expected of it, because it is not the remedy in the first place.

4.5. Responsibility

4.5.1. A Call for Action: Saving Lives

I chose the phrase “saving lives” to express the moral obligation that is sometimes voiced in some of the posts related to a negative experience with a certain medication or health professional in which people are encouraged to “spread the word” about a negative experience they have had with a doctor or a certain medication. It can be seen from certain messages that some members call others to take action and not keep silent about what they know or what they have experienced. It is possible to come across such expressions in threads where members talk about the negative side effects of medication, sometimes even blaming them as the culprit of the suicide of their loved ones. These instances are at times followed by

calls to action, often in forms of writing about it on the Internet or reporting it to the FDA⁶. The responsibility is almost always replaced on fellow members alone. What is expected of them is not to remain silent but to talk about the experience, to undertake some kind of micro activism which is perhaps not as big scale nor organized in the conventional sense of activism or patient movements, but still carries with it certain moral codes and related expectations.

For instance, a post by needhealing says: *“I can’t speak for everyone, but I started taking anti-depressant-depressants after my brother died. Not only did I lose 10 years of my life to these devil drugs, and tried to commit suicide myself while on them, I feel they robbed me of my soul! I stopped taking them 4 years ago and I feel I am still not the same, better, but not the same. I lost all creativity and was a walking zombie! Please, I beg everyone who has had a similar experience with these drugs to get the word out!! Tell everyone you know! You just might save a life!!”*

This member holds what he/she calls the “devil drugs” responsible of a suicide attempt and a number of other things, which he/she refers to as a “robbing of the soul”. He/she attributes the loss of creativity experienced to the use of medication and says that even though he/she is off of them for four years now, they do not feel quite the same as before. Finally, and perhaps more importantly, she urges people with similar experience to “get the word out” - perhaps calling for some kind of activism, even though she does not really make suggestions or recommendations about how one should do so. The importance this member attributes to not keeping silent about the side effects of medication and making sure that related experiences are heard becomes quite apparent when he/she writes “You just might save a life!!”, indicating that taking action to prevent others from going through similar experiences can save their lives.

To this post the first reply comes from Ronnie Walker, who writes: *“As the mental health clinician for this forum, I want to weight in on some of what is being said in this thread. Years ago, when I led traditional in-person support groups, we would always read a statement at the beginning of each group ... reminding people that everyone grieves differently ... and that there is no one right way to grieve and no one right route to healing. We also encouraged people to share their own experiences ... but refrain from telling others what to do. It is important to remember that now. I appreciate the opinions and experiences shared above and urge that they be considered. However, as a grief counselor, specializing in working with survivors of suicide, I have found that many people find antidepressants to be a*

⁶ The US Food and Drug Administration (FDA) is a drug regulatory agency, claimed by some to be the most sourceful and effective one, so much so that similar agencies in other countries pay extreme attention to its decisions (Davis&Abraham 2011).

life-saver, allowing them to function in day to day life, where they were not able to function at all. I have seen no evidence in literature or with my own clients, that taking antidepressants interferes with how someone grieves or makes grief last longer. There is no research in this area. It's my personal belief (based only on my observations of clients) that for many people, antidepressants buffer the pain a bit. The pain does not go away. Grief is still processed ... healing continues and many people who could not function at all, are able to get back on their feet to work and take care of families. ”

The expression at the very beginning of the post, “*as the health clinician for this forum*” is very interesting, because it seems to have the function of verifying Ronnie Walker’s authority and could be argued to be yet another demonstration of the boundary work going on. Ronnie distinguishes herself from the rest of the members and introduces her position as what the rest of her post and her arguments are grounded on. In a way she advocates for antidepressants, giving examples from her own professional experience of how they have helped people “get back on their feet” and then finally asserts her own personal experience on the subject.

Joni, however, seems displeased with Ronnie Walker’s post as she immediately answers: “*Ronnie, you know I have nothing but the utmost respect for you. I'm not an expert, but have read hundreds, if not thousands of hours worth of information on antidepressants. All I'm really trying to say is this: Please do your homework on anything a doctor prescribes you.*”

While stressing that she is no expert- so in a way, participating in the boundary work initiated by Ronnie Walker, Joni points out that she still has the right to speak about antidepressants because she has spent a lot of time reading on them and she believes that she has the necessary knowledge to form an opinion and to urge others to “do their homework” about the medication they have been prescribed.

As a different example, when talking about writing about negative experiences online, Joni says: “[...] *You can save others with this, I'm sure.*” referring once again to the possibility of “saving lives”, therefore representing the need to take action as a kind of moral obligation that could prevent others from experiencing the same things, thus saving their lives. The responsibility of saving lives is distributed among the members of the forum, just like in the previous example of researching a drug. This activity is conceptualized as doing one’s “homework”, so it is a kind of obligation which, when fulfilled, could save lives. It is attributed utmost importance.

4.5.2. A Call for Knowledge

Like the previous statement, this expression is also a call for taking action but is different in the sense that it refers more to an intellectual process that would pave the way for what one can do to “save a life”. The activity envisaged here is an intellectual one, one of learning about medication and their possible side effects and the difficulties one might experience when getting off of them. This is often voiced as a need to first question the situation and then to get informed about them by doing research and reading about topics that could be of interest.

In one of her posts, Finngarian writes: “[...] *Question everything, go get on a computer that has internet access and start asking around. Your doctor or nurse or their drug books won’t always give you the correct information.*

And I’m a nurse. I did not know these things until I found people who had troubles with them. They do not teach us this stuff. ☹”

Here, Finngarian is referring to the side effects of medication and in what might be called a minor activism, she urges people to do research and to get informed about the medications they or someone they know has been given. She refers to the Internet as the arena to get informed and to get the “*correct information*” one might not always receive from health professionals or their resources. Also, as an “insider” she states that she was not aware of these issues until she met people with personal experiences and then goes on to say that they are not being taught about these things, indicating that it is up to individuals to do research and learn further. We see that as a nurse, she considers herself to be inside a certain circle but also reflects that not all that needs to be known is apparent within this circle, and suggests that it is up to the individual to discover more information that they have been offered.

Another thing that can be observed within this frame is the epistemological authority possessed by some members that shows how they refer to the knowledge they have acquired. Something that becomes clear through the analysis of some of the messages on the forum is that members, mostly ones that have had negative experiences with doctors and/or medication- either personally or through a loved one- are actively doing research and putting effort into staying informed and knowledgeable about the topics that are of interest to them. This is perceived as a sort of responsibility, and has a moral resonance to it. It also shows that these members are not passive recipients of the information they already have or are being offered and work to create a knowledge system of their own through their own resources they deem trustworthy.

On the forum, an active and inquiring epistemological standpoint is at times accompanied by a call for activism, even if on a minor scale. People who have had negative experiences with doctors and/or medication are first encouraged to read about the relevant issues and then to “spread the word”- most of the time referring to writing about these experiences online. It can be argued that this suggests that the members perceive the online medium as a tool for reaching out to others and also for making a difference.

In her study on breast cancer patients using the internet, Victoria Pitts has found that there is an “equalizing effect” to gaining medical information and becoming more knowledgeable in such areas for a patient that “evens out” the hierarchies of knowledgeability and power between patients and doctors, as well as patients and the pharmaceutical industries (2004: 43). This could be one of the reasons why the members feel the need to do research on medications they or their loved ones have been prescribed and also urge others to do the same. Certainly, this is a process that requires intellectual work and is more than a mere act of reading; it is a complex process that combines different choices made and different strategies employed. It seems to be the case that this attitude sometimes leads to a call for taking action, perhaps not on a major scale, but still significant.

In the following section, I try to give examples of the epistemological authority some members seem to have and the calls for action that at times accompany this phenomenon.

A thread from February 2012 “*Before you take any medications...*” and is started by KaycieGene, who writes: “*My mother struggled with many different issues after my father’s death 17 years ago. Three weeks ago, the medications the doctors had shoved down her throat to ‘fix it’ killed her. She was 44 years old. Don’t let this happen to you. Question what they’re giving you, and ask for alternatives. Pills cant and wont fix everything.*”

This member first acknowledges her mother having dealt with a number of issues after the passing away of her father, and then makes some very negative statements about the way these issues were handled by doctors. She writes that the doctors “*shoved down*” the medication, indicating that her mother was in a rather passive position. One important point in this post is that it shares something in common with most of the messages that express negative feelings towards health professionals: it refers to them as “*they*”. KaycieGene urges others to be more investigative about what “*they*” have “*given*” them; both of the words putting the patient in a passive and recipient position while situating doctors as a separate entity. This member urges others to look for alternatives to medicine and to be aware of the limitations of medication. The task of questioning the medication they have been prescribed is attributed to the members on the forum, since, apparently, doctors do not seem to take on the task.

To this thread, Joni replies and says: *“People don’t realize how potent these medications are and latest studies indicate they only work in about a third of the people taking them. I’ve also read that those with mild depression shouldn’t take them, but can be effective in some with moderate to severe illness. People need to research any drug - especially those that work on your brain! Be responsible for your health.”*

This could be given as another example of anti-medication attitude, epistemic authorship and a call for action going hand in hand. When making her argument about medication being potentially very harmful and people not knowing about this, Joni refers to *“latest studies”*, showing that she has been doing research and reading on the subject. However, she does not specify from where she is getting the information. Joni is calling people to be *“responsible for their health”*, especially when taking a medication that effects the brain and uses the word *“need”* when talking about doing research on prescribed drugs, showing how important it is for her to make sure that the medication is inquired and not taken without questioning.

In a different thread, glbivdaus writes that her husband was prescribed antibiotics for a lung disease and was at the same bipolar. After his passing away, the member *“began searching his meds and was shocked to find that the antibiotics had all these side effects”* and discovered that *“they are a last resort antibiotic and should never be given to a person with psychiatric problems”* and adds that *“the information is vast on this subject”*. The member here states that she has done research on her husband’s medication and learned some things she was unaware of beforehand. This is due to the research she has conducted on the subject, so it becomes apparent that she perceived it to be her own responsibility.

In a reply to this topic, Joni asks glbivdaus whether she has reported this to the FDA or not, and says that *“they need to know all adverse drug reactions”*. She also writes: *“The FDA itself has said that maybe 1% of adverse reactions are reported. That needs to change.”* This post can perhaps be interpreted as an example of the minor activism that is going on on the forum. Even though Joni is not sure *“whether or not they’re ever going to do anything about them”*, she still thinks that the FDA should be informed about the adverse drug reaction the original poster writes about. She quotes the FDA saying that only a very small fragment of adverse reactions are being reported and argues that this is something that needs to change, urging glbivdaus to not keep silent about it, even though the medication in question is not a psychiatric medication but an antibiotic.

Another member to reply to this topic is karin, who writes: *“[...] Your husband’s story, your story is something that needs to be heard. It is important, I think it is important to you and it is important to many here on this forum, it is important to me.”* This member also echoes the need for glbivdaus to not keep silent about her husband’s story, stressing its importance

several times by saying that it is important to glbivdaus, to the other members of the forum and to karin herself.

Afterwards glbivdaus replies and says *“Thank you and you can be assured that it will be heard. So many people don’t know about these dangerous drugs. You can find out about it in numerous articles, youtube, everywhere.”* glbivdaus then posts links to a website dedicated to spreading the word about this certain antibiotic and to a Forbes article on the same topic. This demonstration of epistemic authority is then accompanied by an excerpt which gives us a better idea of the member’s understanding of taking action: *“Yes, I did report it to the FDA. Most all side effects are not reported as they should be. In the article in Forbes it was stated that one third of all patients taking flouroquinolones had psychiatric side effects.. This drug is a last resort antibiotic. I tell everyone I see about it. I put some of the websites in my thank you notes sent out and in the one I had put in the local paper.”*

This fragment is particularly significant, because it provides further insight into how one achieves activism within their personal contexts and practices. What she is doing is exactly “spreading the word”- telling people she knows about the side effects she is aware of, sending out thank you notes with links to websites that are the sources of her information and doing the same for the notification she has put in the local newspaper. This is an interesting excerpt because we see that this member relies on both traditional and new media to help her do what she is planning, and thus it can be argued that this attitude somehow challenges the established conceptions about new media in terms of its capacity to reach a greater number of people since the member still feels the need to make her point on a local newspaper as well.

Joni then goes on to tell glbivdaus: *“[...] Keep telling people about this. It will help you. There are all kinds of sites where you can write articles. You educated me about it.”*, and is encouraging her to talk about what she knows and gives her a tips about where she might do so. By suggesting writing about it online, Joni believes that glbivdaus will not only be able to help herself, but others as well by “educating” them.

The post by member fiercelove under a different thread is a good example of how knowledgeable the members can be as lay persons: *“[...] I can tell you lithium is one of the only known and time tested anti suicide drugs. Actually it is a naturally occurring mineral salt that comes in different forms, lithium carbonate for example. Research has shown that in communities where there is naturally occurring lithium in the water supply, the suicide rates are significantly lower than for other populations. My psychiatrist said there is no substantial difference between the lithium that is prescribed and the ones you can buy over the counter as a nutritional supplement, except the prescribed doses are much stronger. More is not always better. I wonder if you could talk to your doc about an even lower dose? Over the counter*

lithium is much cheaper also. The amounts found in the drinking water I spoke of? Trace amounts. Often people who have emotional or mental health difficulties are extremely sensitive to drugs, among other things. I am not a doctor, but what if all you need are a few micrograms, as opposed to milligrams?"

From this post, it becomes apparent that this particular member is putting time and effort into staying informed. She talks in detail about lithium and it becomes clear that he/she conducts research on the topic and also speaks to his/her psychiatrist about the issues that are of interest to her. Through this transmission of information, she makes a suggestion to the original poster who had questions about the lithium she was prescribed and proposes that she should talk to her doctor and perhaps ask for a lower dose.

A different fragment that demonstrates the knowledgeability of members as laypersons is to be found in a post by federico sanchez: *"Interestingly, responses to antidepressants in major depression can be predicted by temperament traits to a substantial degree (and not by the number, type, severity, or course of depressive symptoms). Patients who are dysphoric and are highly sensitive to social approval (i.e., high Harm Avoidance personality trait (low threshold for fear) and high Reward Dependence trait) are most likely to improve on serotonin uptake inhibitors (SSRIs). In contrast, those who have a high fear threshold but are not socially dependent are most likely to improve on noradrenergic inhibitors. This comes from studies of Personality Disorder patients who have been administered antidepressants.*

Increased glutamatergic action in the raphe nuclei increases serotonergic activity. When this happens, the nucleus accumbens, through its serotonergic afferents, will respond automatically by lowering the threshold for impulsivity/aggressivity, making it more likely that these kinds of behaviors will be enacted. Impulsivity or aggressivity (as we will see shortly) can facilitate suicidal behavior. If to this we add a low 5-HT serotonergic activity related to low harm avoidance, then this neatly explains the well-known facts that improvements in depressive symptoms corresponding to rising levels of serotonergic activity can increase suicidal behavior, especially among young people. Under certain conditions, this would also explain the increased risk of suicide with use of SSRI's, especially in the beginning of treatment of depression of people under eighteen years of age.

Among older people, even though the absolute risk is low, SSRI antidepressants were associated with nearly a five-fold risk for suicide for people over 66 during the first months of treatment, even after adjusting for depression and psychiatric care, and were often more violent in nature."

This post almost sounds like it has been taken from a medical journal. federico sanchez uses a number of medical terms, provides cause and effect arguments and explanations, and talks in figures. It is almost crafted to guarantee that not many members who read it will understand it, at least after reading the post only once. The post makes it apparent that this member is quite knowledgeable about the topics that are of interest to him. It is clear that he has conducted research on these different subjects and has created a knowledge system of his own which he is happy to share with others. However, like in most of the previous examples the source of the knowledge acquired remains unclear, and thus we cannot get a fuller grasp of the details of the process.

I have tried to demonstrate in these two subchapters that responsibility is attributed to the members of the forum; they are urged to do research, read and learn so that they can get familiar with expert knowledge itself and also be able to challenge it. This is tied not only to personal benefit but also to the possibility of “saving lives” at which point a moral obligation emerges.

5. Conclusion and Discussion

The first question this research project aims to answer is related to the issue of the forum as a space- how to conceptualize and define it, and which characteristics it holds related to the general discussions on the characteristics of online (support) groups. It also seeks to explain how the forum is defined and conceptualized by members themselves at which point the “survivor experience” comes in and the traces of the bereavement process is to be found. Another main investigation point is related to the handling and assessment of expert knowledge and what analyses related to this point can contribute to the broader discussions on “lay” and “expert” relations. To answer the research questions I have looked into a number of posts from the forum and tried to demonstrate how they could propose answers to the questions posed. To complete the analysis, I sum up what has been described in the empirical part and draw several conclusions.

5.1. The Forum as a space: Opportunities and restrictions

The Alliance of Hope Forum seems to be yet another verification of the claim that the Internet is being more and more used as a space for expression and exchange. It is a setting where very personal experiences are recounted in a highly emotional manner and thoughts and opinions on matters related to science and medicine are being shared. We have seen that these personal experiences related to the suicide of a loved one are being told in a quite emotional manner, often including specific details and we have also seen that the highly emotional aspect of these narratives is also to be found on the other sections of the forum, especially in

topics where people discuss a set of issues such as medication use, opinions on and feelings about health professionals and views on the pharmaceutical industry. This helps conceptualize the forum as a place where “people are given a space to articulate their experiences, perceptions and understandings” (Hardey 2002: 31). Within this space, the individual user gets to (re)write his/her own biography, and to construct a narrative of his/her own that helps deal with the aftermath of the trauma of losing a loved one to suicide. This finds its expression in one of the posts by a member who says the forum is like “a journal, but with feedback” - indicating that it is a place where what would normally go into a private journal can be written down on the forum and additionally these writings get feedback in the form of comments.

The offering of advice, support and understanding on the forum as well as the articulation of knowledge is considered to be something which adds to the “empowerment” aspect so often associated with online support groups, especially health-related ones. This empowerment, however, as Armstrong and colleagues have also pointed out (2011) rather has its limits. The authors call this an “empowerment within limits” and suggest that while all the aforementioned points can contribute to the well-being of the user and can help provide a certain feeling of being in control, it is not without restrictions. Feelings of autonomy and solidarity offered by online support groups are, at the end of the day, not unconditional. The very first topic to appear on the forum is about the “rules and regulations” one has to follow on the forum, indicating that there is a certain code of conduct that is expected of its users, certain community norms one has to conform with in order to participate in the first place. So while online support groups have been attributed a number of advantages such as perceived anonymity, 24/7 availability, being judgment-free and so on (Coulson et al. 2007) - points which certainly are affirmed by the users on the Alliance of Hope Forum - one also needs to be aware of the certain regulations and restrictions on the forum. One very obvious example is when moderators interfere in discussions they consider to be “off-topic” and warn members to “get back on track”. This is quite interesting in the sense that it makes one think that the forum is not necessarily an absolutely free space, but is rather a place where certain things are expected of people. In that sense, the virtual community that is the forum does not seem so different from “real life communities”. Burrows and colleagues refer to what online support groups have to offer as an “elective affinity between technological, social and cultural imperatives [...] a complex amalgam of the anonymous, the public, the supportive and the individualized” (2000: 103). The authors formulate these spaces as places where not only the personal but also the social act together - a locality where the “real” and the “virtual” are not separable but are blended together. Since people are expected to conform to certain standards and follow specific rules on forums, just like they do in “real life”, it is interesting to reflect

on why they choose the latter to express their feelings, articulate their experiences and exchange ideas and information. It seems that the perceived anonymity, constant availability and trust is the key factor in making this particular decision. Members have also often underlined the forum as being a judgment-free environment where they do not have to deal with the stigma of suicide they deem to be present in offline contexts, and have stressed the importance of being surrounded by people who have had the same experience and share the same feelings. This shared experience is what seems to be the glue that holds the pieces together. It is something they cannot necessarily find in the outside world, especially among health professionals they might turn to for getting help and support. It is also important to note that a lot of members talk about “holding it together” around family and friends and see the forum as a place where they can freely “let it all out” and “be themselves”.

Since a substantial part of the debates on virtual communities center around their authenticity and longevity, there are certain points to be made on the subject. It seems that all the qualities attributed to online forums, especially online support groups are echoed by the members on the Alliance of Hope Forum. The perceived advantages of 24/7 availability, privacy, anonymity and the feeling of being in a judgment-free environment have been stressed by all members as well as feelings of companionship originating from the sharing of a common experience. In this sense, the authenticity of the forum, or how “real” it is does not seem quite debatable for its users. How long this interaction and its perceived benefits would last is a question that cannot be answered here and now, but it is worthy to note that there are members on the forum that have been active users throughout years. The forum is conceived of as a space for free expression where one also finds understanding and comfort, but there are also instances in which an authority figure (i.e. a moderator) comes into play and intervenes and in this way shapes the course of conversation. “Off-topic” discussions are not welcome. Members are urged to be mindful of each other’s experiences and there is a certain language and decency expected of them. In this sense, the online setting is not that different from the offline one. One consideration of this is related to the meanings attributed to online support groups as spaces where people can “be themselves” and express themselves “freely”. The freedom offered on the forum is not a total one.

5.2. Forum members: Community or not?

After attempting to illustrate the forum as a space with various characteristics, I now move on to elaborate on the specific kind of community formation (or lack thereof) on the forum. Instead of pondering on the more conventional and recent debates on virtual communities, I take a different approach and conceptualize the forum as a thought collective (*Denkkollektiv*). Borrowing this notion from Ludwik Fleck’s fundamental work *Genesis and Development of a*

Scientific Fact (1935), I prefer it over various other definitions, mainly because it stresses the intellectual exchange of ideas and also points to a certain viewpoint which makes particular perceptions and ways of thinking possible while excluding others. Using Fleck's concepts help visualize the forum and its users, especially on matters related to science and medicine. It aids us in understanding why people take certain sides and express certain opinions, and gives us the possibility of taking a closer look into their cognitive processes. As Fleck puts it:

"The statement that 'someone recognizes something' demands some supplement as 'on the basis of a certain fund of knowledge', or, better 'as a member of a certain cultural environment', and best, 'in a particular thought style, in a particular thought collective.'"
(Fleck 1935/1979: 39)

The important point about this quote is that it points out to the complex process of cognition by first stressing that there is at all times a certain amount of knowledge and information available to an individual as a part of society- the "existing stock of knowledge" (ibid: 38) and then underlines that this repertoire of knowledge is influenced by the specific environment and cultural milieu of the individual. Cognition, then, ceases to be an isolated activity but is conceptualized as something that is influenced by what is already known and recognized, it gives meaning to new information through these influences, and thus is never solely an intellectual process but a highly social one at the end of which knowledge (*Gebilde*) is created and given meaning to. The next part of the passage quoted above introduces the notions of thought style and thought collective. I have already mentioned that the Alliance of Hope Forum can be conceived of as a thought collective. A thought collective, argues Fleck, can emerge out of the interaction between two people in which they exchange thoughts and ideas. This, like for any other forum on the Internet, is the basis of the Alliance of Hope Forum. People express and exchange ideas. Fleck also argues that this particular interaction creates a certain "mood" in which people express thoughts they otherwise would not or could not have expressed- a mood that makes specific ways of communication and expression possible. This point ties nicely with the Alliance of Hope Forum being an online support group and what the members have stated about the forum immediately come to mind- a place where they can talk freely and express themselves without fear of being judged or misunderstood.

I have already tried to demonstrate that there is no single attitude adopted on the Alliance of Hope Forum and that opinions vary and differ. This means that there are several thought collectives within the forum that exist simultaneously, there are more than one viewpoints that are difficult to change or even to contradict. We have seen how people that are against the use of medication make their arguments and stick to them, we have read how people

express their gratitude for pills and say they will continue using them regularly. This is because they belong in different thought collectives and possess different thought styles (*Denkstil*), which almost conditions their ways of thinking and formulating. The aforementioned mood, which arises in a thought collective, is what puts a thought style into action, it points at the readiness to accept or reject something, in this particular case a scientific claim or medical knowledge. This readiness, or lack thereof, hinders certain things obvious while making certain others invisible: “[...] it is the entirety of intellectual preparedness or readiness for one particular way of seeing and acting and no other” (Fleck 1935/1979: 64). The fact that experiences and emotions play an important role in this process is another point that corresponds well to the Alliance of Hope Forum. Personal experiences with highly emotional resonances do not only shape thought styles but also strengthen them, making them even more rigid and solid. A forum member who believes that medication “killed” their husband and another who thinks her son “would have died” without them have one thing in mutual: Within their own thought styles, and with the help of these thought styles they give meaning to experiences and knowledge, create solid thought structures (*Denkgebilde*) that are difficult to challenge and to change (ibid: 44). Fleck also stresses that within these thought styles, a characteristic way of expression is also to be found. This can be observed in the posts quoted in the empirical chapter of this thesis where people talk about drugs *killing* one of their loved ones, the pharmaceutical companies are defined repeatedly as *greedy* and *profit-driven* and doctors are almost always referred to as “they”. It can also be observed in the posts by people who appraise medication on the grounds that it helps them *function* and say that they *made it through* the aftermath of the trauma with the help of medication.

Back to the original question: How to conceptualize an online forum? Can we truly call it a community, which would then mean that we attribute our conventional understandings of the term to this space on the Internet? By introducing the Alliance of Hope Forum as comprising of several thought collectives, I have already answered this question since the original definition by Fleck himself includes the word community. I would now like to take a further step and say that the accumulation of these several thought collectives make up the thought collective (*Denkgemeinschaft*) that is the entirety of the Alliance of Hope Forum. A thought community, as defined by Fleck, is “stable or comparatively stable” (Fleck 1935/1979: 103), which I believe is the point where it differs from a *collective*. It embodies a “comradeship of mood” (ibid: 106) in which people are bound together with mutual points- in the case of the Alliance of Hope Forum, the experience of losing a loved one to suicide- and have their own regulations, customs and terminology. The Alliance of Hope Forum then is a thought community in which various thought collectives coexist, and within these thought collectives

several thought styles are utilized that shape understandings and perceptions of the experience of losing a loved one to suicide, the process of bereavement, and expert knowledge.

5.3. Experiential knowledge over expert knowledge

A very important feature of the Alliance of Hope Forum is that anecdotal evidence constitutes the basis of sharing and exchange. In literature, anecdotal evidence is at times positioned against scientific knowledge, and is presented as something that carries hostility towards experts. I would argue that this assumption is not necessarily true for the Alliance of Hope Forum since we have seen that people who appraise medication utilize anecdotal evidence as well. The using of anecdotal evidence means that the members recount their own personal stories and not only attribute central importance to it, but they also position it against expert knowledge. This privileging of personal knowledge over expert knowledge (Burrows et al. 2000: 116) stems from the conviction that doctors and pharmaceutical companies (almost always presented as a whole, single entity) have not been through the same experience or a similar one, so they do not understand the complex set of feelings that the users on the forum might feel. While the doctors are blamed for not trying harder to empathize and simply prescribing medication, the pharmaceutical industry is accused of thinking solely of making profit. The “human element” is considered to be missing in both institutions, so when the knowledge they have to offer is scrutinized and their claims and advice are rejected, it is on the grounds that they do not understand because they “have not been there”. Boundaries are drawn based on the experience of (or lack thereof) losing a loved one to suicide, and thus the “boundary work” put forward by Gieryn (1983) is carried into a different level, this time “laypeople” being active agents of it. The members on the forum who express negative opinions on health professionals and the pharmaceutical industry challenge the authority and legitimacy of these institutions based on expertise originating from personal experience. They recount anecdotes and thus offer highly personal anecdotal evidence such as being treated a certain way by a doctor or seeing changes for the worse in a spouse after regular medication use. The evidence offered by these members is inseparable from their own selves, it is extremely subjective because it stems from a personal experience and is recounted by the very person who experienced it. It is perhaps for this reason that anecdotal evidence has been positioned straight up against expert knowledge and has been labeled “nonscientific” (Burrows et al. 2000). Although anecdotal evidence has at times been utilized to sharpen the distinction between the boundaries of “lay” and “expert”, and has been presumed to be accompanied with hostility towards knowledge produced and information offered by the latter group, it is possible to say that this cannot be held true for the Alliance of Hope Forum as a whole. The analysis part has already shown that the number of people who express positive

opinions towards doctors and medication is quite high, which shows us that science and medicine are not completely rejected on the forum.

Under this light, the forum emerges as a space where people can discuss matters related to science and medicine, a space where various opinions on the matter can coexist. It is an arena where people get the opportunity to think and talk about such matters, an opportunity to express opinions and through this process (re)narrate experiences and identities (McEwen&Scheaffer 2013). We have seen that during this process, members' personal experiences such as those of their own or those of their loved ones are prioritized, they are preferred over what experts know. However, this is not to suggest that this prioritization at all times equals to hostility towards experts and to the rejection of scientific knowledge for we have also seen instances where people use them to tell personal stories and then express appreciation for the two mentioned entities. This presentation of anecdotal evidence and its dominance, then, should not be taken as something that sharpens distinctions between "laypeople" and "experts" but rather assessed as a tool for understanding how and when boundaries are drawn between the two. As Moore and Stilgoe (2009) have shown by referring to the mobile phone controversy in the UK, the conceptualization of "anecdotal evidence as nonscience" polarizes and even radicalizes differentiations and distinctions and brings with it certain assumptions. An anti-science attitude is one of those assumptions, and the following subchapter attempts at proving that this indeed is not the case.

5.4. Attacking science with science

Health-centered support groups on the Internet are often conceptualized as places where people can challenge the authority and credibility of science, and thus feel more knowledgeable about their condition and get empowered. This is also true for the Alliance of Hope Forum, but is only one facet of it. It would not be quite right to claim that this is the general attitude of the users on the forum since we have seen that there are a certain number of people who hold quite positive views of health professionals and medicine and talk about the benefits of using medication and getting professional help - again in the form of personal experience and anecdotal evidence. This shows us, then, that science and medicine still are credible and trustworthy institutions, maintaining their special and distinctive positions (Evans 2005). In his 2002 article titled "How Lay are Lay Beliefs?", Ian Shaw talks about the adoption of expert explanations and advice during the quest for meaning and/or remedy by those suffering from a certain condition. He states that the "acceptance of this rationality" becomes "common sense" (2002: 292) and that the practice of consulting a professional, thus recognizing their authority, still persists. Referring to science and scientific studies is a theme to be found not only among people who find them to be beneficial and necessary, but also

among people who attempt to challenge them, who raise a voice against them. Shaw nicely explains this case of “attacking science with science”:

“There is no one in western society who is unaware of professional explanations and orientates their perceptions of life (to varying degrees) around such rationalities. Common-sense understandings are imbued with professional rationalizations, and even resistance to medical treatments are oriented around medical rationality” (2002: 293).

However, this is not to suggest that those in favor of science and medicine make “rational” decisions while those opposing them are not. The point trying to be made is that e-health does not necessary equal to “anti-medicine” or “non-science”, but it simply means that people on these fora have their own specific ways of handling scientific information and evaluating it, which, most of the time, involves science itself. Wynne calls this “relationality” and considers it to be the “ontological ground for being and knowing” (2008: 22) - a process that involves social, cultural and hermeneutical features (Engdahl&Lidskog 2014: 707) in which people craft their own personal ways of thinking about and living with science, and the recognition of science as a credible and potent entity is an important part of this work. What this shows us, then, is that the positioning of experiential knowledge against science and offering it as something to be studied in sharp contrast to medical knowledge is to articulate and strengthen an assumption that does not always prove right (Pols 2013) for we have seen that when medication is being challenged, it is not only based on personal experience but also on the grounds that “studies show” that they only display placebo effects, or are harmful in the long run, and so on. When doctors are criticized, it is directed towards a specific individual and not the profession as a whole, and certain things are expected of them such as learning more about the medications they prescribe, so what they do is not being discarded completely but is requested to be supplemented. When people are being urged to read and learn about the medications they use, they are being referred to scientific studies and articles. There certainly are members that completely reject the institution of medicine and have an absolutely negative opinion concerning them, but this attitude seems not generalizable.

The forum is a blend of the appraisal and acceptance of different forms of authority: both that of science and of self (Hine 2012). The authority of science is mobilized to explain the choice of using medication in relation to the benefits it brings such as being able to move on with one’s life and dealing with sleep deprivation and it is also used as a tool to question certain parts and/or products of science that are deemed untrustworthy and are approached with skepticism. Experience-based authority stems from the practice of recounting one’s story, creating personal narratives and being the author of one’s own suffering and is employed in the shape of offering support, understanding and advice.

5.5. Back to Mertonian norms?

Robert K. Merton is one of the most influential figures in the social studies of science and is mostly known for the ethos he has laid down for scientists- qualities he suggests scientists should possess. As early as 1942 Merton wrote that “science is not immune from attack, restraint, and repression” (267) and that “a tower of ivory becomes untenable when its walls are under prolonged assault” (268) and as a remedy, offered a set of values and norms to be adopted by scientists. Abbreviated at times as “CUDOS”, these norms are communism, universalism, disinterestedness and organized skepticism. While communism is positioned right against secrecy and property rights, it points to the open and transparent practice of science and the sharing of its results. Science is something that is of the public; it is not above it nor separable from it, therefore constant and diligent communication is expected of it. Universalism points to the impartiality and objectivity of science and states that its claims are not to be assessed in relation or according to the personal and/or social attributes of the individual. Disinterestedness is about the pure passion for and interest in scientific quest; it denotes the concern for the benefit of humanity and rejects a wish for fame and fortune. Finally, organized skepticism defines a mindset that is at all times ready to doubt and to question, and not take for granted (Merton 1942; Krishna 2013). Certainly, these Mertonian norms have been criticized for painting a too idealistic picture of the scientist, and for being almost utopic. But the important point in them is that practicing science is not separable from being a member of a certain society, it is not distinguishable from being affected by certain cultural imprints and affecting cultural and societal structures in return. The authority and prestige of science does not originate from its superiority, from it being above the public, but from the fact that it is a respectable and trustworthy practice that is working for the benefit of society.

The practitioner of science as envisioned by Merton seems to be exactly what the members of the Alliance of Hope Forum expect. They criticize doctors for being too involved with pharmaceutical companies, and envision a direct link between the prescription of medication and making profit. Scientists and healthcare professionals are considered to be insensitive towards individuals, and a more humane approach is expected of them. The same groups and institutions are approached with skepticism because they are believed to conceal the actual results of studies that might not fit with the agendas they are believed to have. This also means that the *universal* character of science is doubted, because the personal motivations and pursuing of scientists/doctors are believed to be above what is envisaged by the norm of universalism. Individual cases do not matter, results are distributed and prescriptions are written for a general case which helps keep things stable, anything that might challenge this establishment is ignored or dismissed as nonscientific. This conviction then eludes the

possibility of doubt and skepticism as the basis of scientific endeavor. Because scientists are believed to be in close contact with pharmaceutical companies and because health professionals are viewed under the same light, it is believed that profit is the main motivation instead of the well being of individual patient.

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Appendix

Appendix I. Questions in the Association of Internet Researchers (AoIR) Working Committee recommendations on Internet research ethics paper (2002) answered in relation to the Alliance of Hope Forum

Where does the inter/action, communication, etc. under study take place?

The forum of interest is The Alliance of Hope Forum, a forum that is accessible to any Internet user. It does not require a paid or free membership to gain access to the discussion board.

What ethical expectations are established by the venue?

Even though it is not entirely possible to state the exact ethical expectations of the community since it can vary from member to member, one can still get an idea of the principles the forum is operating upon. They define themselves as “a community of hope, dignity and respect, comprised of people from diverse cultures and faith traditions” that is made up of people “who provide compassionate support, information and wisdom born of their own experience”. They also consider themselves to be “linked by an invisible bond” and state that they are “respectful of each other and joined in their commitment to live meaningful lives”.

Who are the subjects/posters/authors/creators of the material and/or inter/actions under study?

The subjects under study are the content posted by forum members. The focus is on the content of their messages and not their personal lives or details of those lives.

What can be said about the timing, medium and addresses of informed consent and how the material gathered is to be used?

My argument is that informed consent in this case is not required because it is repeated several times on the forum that it is a “public” one and members are cautioned against this fact. The following is a screen capture of a forum post that is suggested to be read before participating on the forum, and is posted by the founder/moderator.

The fact that the forum defines itself as a public one is somewhat comforting because much of the discussion around Internet ethics stems from the question of whether online communities are public or private spaces. The Alliance of Hope forum clearly defines itself as a public one and also appears to acknowledge some of the issues that could rise. It is clear that the moderators have warned the members about disclosing names, pictures and sensitive information and it can be suggested that this level of awareness eliminates the need for obtaining informed consent for analyzing posts from this forum when also considering the fact that my main focus of interest is not personal details, but the content of discussion and the lines of framing.

Appendix II. Screenshots from the Alliance of Hope



Alliance of Hope

for suicide survivors

A healing place for those grieving loss after suicide

WelcomeBlogBookstoreCommunity ForumCounselingMemorialsMilitarySurvivor ExperienceAbout

Welcome

Sometimes in life, events occur that fracture the very foundation on which we stand. Our life, as we have known it, is forever changed and we find ourselves in an unexpected struggle, first just to survive and then to move forward.

The Alliance of Hope for Suicide Survivors provides healing support for people coping with the shock, excruciating grief and complex emotions that accompany the loss of a loved one to suicide. We hope that you will find resources here to help you deal with, and eventually heal from, what may well be the worst pain you will ever feel.



It is important to know that people can and do survive loss by suicide. They are forever altered and may never stop missing their loved ones, but they do survive and go on to lead meaningful and contributory lives.

This site was designed by survivors for survivors. The culture here as well as on [our forum](#) is one that recognizes and respects the courage and resilience of suicide survivors at all stages of their personal journeys.

We invite you to [join our supportive community of survivors from across the world](#). You will find many friends here.

Ronnie Walker, MS, LCPC

Community Forum

We have been named "One of the Top 50 Web Forums for Counseling, Advice and Support"

Review This Charity on GreatNonprofits

322 reviews.
Average rating: ★★★★★

Read reviews about ALLIANCE OF HOPE FOR SUICIDE SURVIVORS

Volunteer. Donate. Review.

"I'll cry with you," she whispered "until we run out of tears. Even if it's forever. We'll do it together."

There it was . . . a simple promise of connection.

The loving alliance of grief and hope that blesses both our breaking apart and our coming together again.

Molly Fumia, Safe Passage

Lend a Hand - The Idea is Simple But Powerful



Are you a survivor of suicide loss who has gone beyond just surviving? We invite you to reach out to someone newer in grief.

Our services are made available by your donations.

Donate Now


Secure donations through Network for Good

Our founder, Ronnie Walker, describes challenges of those left behind.

After suicide, survivors ne



Figure I: The Alliance of Hope website



The Alliance of Hope Forum: a healing place for those grieving loss to suicide

Search...
Advanced search

[Web Site](#) | [Blog](#) | [Book Store](#) | [Donate](#)

[Board index](#)

[FAQ](#) [Register](#) [Login](#)

It is currently Sun Oct 26, 2014 12:52 am

View unanswered posts • View active topics

WELCOME TO THE ALLIANCE OF HOPE COMMUNITY FORUM		TOPICS	POSTS	LAST POST
	About the Alliance of Hope Community Forum How to register -- Guidelines for using a public forum -- Uploading photos -- Meet the moderators -- Reviews & awards	6	17	by Steve S.  Sat Mar 29, 2014 8:24 pm
	This is a Public Forum This forum can be an excellent source of information and healing support for survivors, but should be used sensibly. We encourage users to post in a manner that maintains anonymity. That will allow you to connect with others, receive support and more fully express yourself. CLICK ON THIS FORUM TO READ ADDITIONAL GUIDELINES.	1	1	by forum  Fri Nov 02, 2012 10:14 am
	Alliance of Hope Links Moderator: Moderators Team Subforums: D Website , D Blog , D Bookstore , D Facebook , D Feeling Suicidal? -- Crisis Intervention, D Suggestions for New Survivors	0	0	No posts
	Join Us on Facebook We can be found under: "Alliance of Hope for Suicide Survivors."			
	Feeling Suicidal?			
NEW TO THE COMMUNITY? PLEASE INTRODUCE YOURSELF HERE		TOPICS	POSTS	LAST POST
	Introduce Yourself Just joined? Make your introductory post here and subsequent posts on other topics, in the most appropriate forums below. Moderator: Moderators Team	3723	42071	by Annabelle  Sun Oct 26, 2014 12:22 am
	Share About Your Loved One Our loved ones brought much into this world. This is a place to share about who they were: their talents and passions, their hopes and dreams, their challenges, accomplishments and contributions. Moderator: Moderators Team	555	3888	by sharry  Mon Oct 20, 2014 11:10 am
	We Remember Them: Birthdays & Yearly Anniversaries If the person you remember was born or died during the present month, we invite you to honor them. What gifts and blessings did they bring into this world? Moderator: Moderators Team	13	609	by gaywidower  Fri Oct 17, 2014 4:02 pm
AFTER INTRODUCING YOURSELF, PLEASE USE THE FORUMS BELOW FOR OTHER DISCUSSIONS		TOPICS	POSTS	LAST POST
	The Survivor Experience Those who have lost loved ones to suicide know that there no experience quite like it. This is a place to share any aspect of your experience with others who	3698	33216	by mountain  Sat Oct 25, 2014 10:08 pm

Figure II: The Alliance of Hope Forum main page









	Signs, Serendipity, Life after Life Many people have a sense that their loved one is not "gone" but has "crossed over" to some other dimension. Have you had experiences in which you have felt the presence of your loved one? Moderator: Moderators Team	659	6237	by gloria heller  Sat Oct 25, 2014 9:46 pm
	Secondary Wounds Sometimes, survivors experience additional pain when others do not understand, let them down, or blame them. These additional "wounds" are very painful because they are already raw with grief. Has this happened to you? Would you like to share about it? Moderator: Moderators Team	775	7853	by kclark  Wed Oct 22, 2014 6:11 pm
	Guilt, Blame and Forgiveness Guilt and Blame are quick to surface in the swirl of emotions following a suicide. As healing takes place, many survivors find that Forgiveness does not change the past, but it changes some of the pain of the past and unlocks a door to the future. What have you noticed about guilt, blame or forgiveness? Moderator: Moderators Team	389	3796	by gabbyfr  Sat Oct 25, 2014 11:06 am
	Accomplishments Healing after suicide requires courage as well as hard work. We take ground inch by inch. This is a place to acknowledge accomplishments and achievements (large and small). Did you take a shower? Leave the house? Organize, complete or communicate something? What has been happening? Moderator: Moderators Team	551	3881	by melimc  Mon Oct 20, 2014 7:17 pm
	What Helps? It's as simple as that! What helps you get through the day, the night, find your way in the world? Moderator: Moderators Team	92	589	by Finnigarian  Mon Oct 20, 2014 10:01 pm
	Turning Back Into Life At some point on the path of grief, almost imperceptibly, our challenges and accomplishments shift. If you are at the point where you are beginning to "turn back into life," what are you noticing? How is this shift showing up for you? Moderator: Moderators Team	92	1049	by Bellefield  Sat Oct 25, 2014 3:14 pm
	Sleep & Dreams Survivors often report difficulty falling or staying asleep. Many also experience dreams about the deceased. Some dreams feel comforting -- some are troubling. What has been happening for you? Moderator: Moderators Team	354	1822	by SandyW  Sat Oct 11, 2014 8:18 pm
	Pets Have you been comforted by pets ... or felt that they shared your grief? Post about that here. Moderator: Moderators Team	182	1006	by Jackson  Tue Oct 21, 2014 12:32 pm
	Medications This is a place to discuss / debate the benefits, side-effects, recent news ... anything having to do with medications. DISCLAIMER: The opinions in this section are personal and may not be right for you. Consult your own physician for all medical decisions. Moderator: Moderators Team	88	685	by SadGeorgia  Tue Oct 14, 2014 3:25 pm
	Addictions A place to discuss addictions and self-destructive behavior suffered by those who have died, as well as those who grieve their loss. Moderator: Moderators Team	74	705	by abcrilley  Thu Oct 23, 2014 2:12 pm
	Holidays, Anniversaries & Special Occasions A place to share thoughts, feelings, concerns, accomplishments, and tips for getting through those special days. Moderator: Moderators Team	435	2595	by AndrewsDad  Sat Oct 18, 2014 7:57 pm
	Relief from Grief Moderator: Moderators Team Subforums: D Inspiration , D Music , D Happy Times: Past and Present , D Kindness from Others , D Kindness to Others , D On the Lighter Side	707	4422	by marcher  Thu Oct 23, 2014 2:00 pm

Figure III: The Alliance of Hope Forum main page- continued

MILITARY, POLICE & FIREFIGHTER SUICIDE		TOPICS	POSTS	LAST POST
	Military Suicide Moderators: Moderators Team	35	120	by Finngarian  Mon Oct 13, 2014 11:04 am
	Police Suicide Moderators: Moderators Team	1	7	by Morgan89  Thu Nov 14, 2013 6:00 pm
	Firefighter Suicide Moderators: Moderators Team	4	31	by Finngarian  Thu Sep 25, 2014 9:13 pm

COMMUNITY CONNECTIONS		TOPICS	POSTS	LAST POST
	A special place for those who experienced suicide after an argument, separation, or divorce Moderators: Moderators Team	26	176	by Whoami  Sat Oct 25, 2014 7:58 pm
	A special place for those who have lost spouses, partners or fiances Moderators: Moderators Team	630	5705	by gabbyfr  Sat Oct 25, 2014 3:15 pm
	A special place for parents who have lost children Moderators: Joanne, Cyndi S., Moderators Team	419	4636	by echo  Thu Oct 24, 2014 10:01 am
	A special place for children who have lost parents Moderators: Moderators Team	98	674	by Lizzy  Fri Oct 24, 2014 10:57 pm
	A special place for those who have lost siblings Moderators: Moderators Team	173	1214	by Lucaloe  Thu Oct 23, 2014 5:05 pm
	A special place for those who have lost friends Moderators: Moderators Team	0	0	No posts
	A special place for those comforting children after a suicide Moderators: Shelby, hazel, Moderators Team	68	506	by Takecare4  Sat Oct 04, 2014 11:55 am
	A special place for those with losses related to ... Moderators: Moderators Team Subforums: D The Gay Community , D Multiple Losses , D Murder/Suicide , D Twins	71	472	by Deekal01  Mon Sep 29, 2014 11:08 am
	In the News & Book Reviews Moderators: Moderators Team Subforums: D In the News , D Book Reviews	154	594	by JansMom  Sat Oct 11, 2014 5:04 pm
	Notes from Survivors Moderators: Moderators Team Subforums: D ... to the Newly Bereaved , D ... to those Struggling with Suicidal Family Members or Friends	68	552	by Trace  Fri Sep 26, 2014 12:14 am

Figure IV: The Alliance of Hope Forum main page- continued

WE VALUE YOUR PARTNERSHIP		TOPICS	POSTS	LAST POST
	Donate Now Our work is funded solely through the generosity of members and friends of the forum. Click here to make a tax-deductible donation.			
	Donate Your Birthday It's easy to create a "birthday wish" and ask facebook friends to contribute to our cause.			
	Other Ways to Help	2	12	by Sandy.W  Wed Aug 13, 2014 8:06 am
	Alliance of Hope Fundraisers Fundraisers sustain our work. Click here to find our more.	2	6	by Bellefield  Mon Nov 18, 2013 4:52 am
	Forum Feedback: What People Say Members, please share about your experience here. Has it made a difference? How?	16	69	by Sandy.W  Mon Jul 21, 2014 6:15 pm

MODERATORS		TOPICS	POSTS	LAST POST

STEWARDS		TOPICS	POSTS	LAST POST

LOGIN • REGISTER

Username: Password: I Log me on automatically each visit ☐ [Login](#)

WHO IS ONLINE

In total there are **15** users online :: 1 registered, 0 hidden and 14 guests (based on users active over the past 5 minutes)
Most users ever online was **475** on Mon May 06, 2013 3:57 pm

Registered users: sharry
Legend: Administrators, Global moderators, Moderators Team, Sustaining Members

BIRTHDAYS

Congratulations to: **chatterboxshelly (46)**, **dads B (36)**

STATISTICS

Total posts **132571** • Total topics **14558** • Total members **6729** • Our newest member **Derekbb**

[Board index](#)

The team • Delete all board cookies • All times are UTC - 6 hours

Powered by phpBB © 2000, 2002, 2005, 2007 phpBB Group

Figure V: The Alliance of Hope Forum main page- continued

[Board index](#)
[Welcome to the Alliance of Hope Community Forum](#)
[This is a Public Forum](#)

[FAQ](#)
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How to Participate in a Public Forum

LOCKED

Search this topic...

Search

1 post • Page 1 of 1

How to Participate in a Public Forum

[Day forum](#)
• Fri Nov 02, 2012 10:14 am

We are a community of hope, dignity and respect, comprised of people from diverse cultures and faith traditions. Linked by an invisible bond, we are respectful of each other and joined in our commitment to live meaningful lives.

Privacy on the forum

FOOTPRINTS: When we post on a public forum, we leave "footprints" for anyone in the world to see. Anything we post might be identifiable by others if we include a recognizable avatar, user name, other names, dates, links or even a vivid description of events. For some this is not an issue, but for those who wish to remain anonymous it can lead to unwanted attention or even exposure to possible confrontation.

USERNAME: We urge members to choose a username that is not their real name. If you post your real name, the name of the deceased or any other names, dates, cities, etc, your post can be recognized by others. Our forum is set to prevent search engine spiders from crawling through in an Internet Search, but nothing is ever "absolute." We also encourage members to carefully consider using recognizable photos in avatars.

USE DISCRETION: There are times that we ask posters to edit their writings because of the possible ramifications of identifiable details. Those posting such details may have come to terms with them, but the possibility always remains that someone else involved with the loss may still be struggling. Reading the details may cause them additional pain. -- We are also vigilant about what we call "toxic" posts. Many times readers get drawn into a "right/wrong" situation, blaming or taking sides. We are all on the same side on this journey - to survive and heal.

INTERPERSONAL ISSUES: It is common for interpersonal issues to arise following loss to suicide. It is common to feel angry towards those who may have mistreated our loved ones or who don't understand our grief. Dealing with these issues is a very important part of the survivor journey, but the specific and recognizable details of these issues are best addressed in a private setting. Venting and blaming in a public forum, at the expense of another is more hurtful than healing - for all concerned.

This forum is not designed to provide personal medical or mental health advice.

THE ADVICE, OPINIONS AND RECOMMENDATIONS YOU READ ON THIS FORUM ARE NOT INTENDED TO REPLACE COMPETENT MEDICAL HELP.

This forum is not monitored 24 hours a day, 7 days a week.

WE CANNOT PROVIDE CRISIS SUPPORT THROUGH THIS FORUM. IF YOU ARE FEELING SUICIDAL, CLICK HERE FOR LIFELINE PHONE NUMBERS:
<http://www.allianceofhope.org/alliance-of-hope-for-suic/feeling-suicidal.html>

Questions? Contact Me
 Ronnie Walker 📧
 Executive Director
 Alliance of Hope for Suicide Survivors
 847 868 3313
Ronnie-Walker@allianceofhope.org



forum

Site Admin

Posts: 84

Joined: Thu Jan 17, 2008 10:26 pm

Figure VI: A thread on the Alliance of Hope Forum

Appendix III: Abstracts

English Abstract

“Like a journal, but with feedback”: This is how an online support group is defined by one of its members. It is interesting to look at online support groups, because first they tackle the questions related to the issues of community. Can we really call these phenomena communities? What makes them a community and what disqualifies them as such? Furthermore, the question of virtual support comes into play. The act of seeking comfort and solidarity in an online setting, among people previously unknown raises questions about the motives behind this particular choice. What does that tell us about the perceived qualities and advantages of online spaces? Reflecting on these questions is important, because they directly correspond to debates surrounding one of the most defining- if not *the* most defining- technology of our time, the Internet.

Not only does the Internet offer new possibilities in terms of community formation and maintenance, it also paves the way for new paths in the expert-layperson interactions. As the boundaries between the two domains become more and more blurred, the Internet emerges as the key actor in this transformation. Information previously available only to certain groups becomes more accessible, non-experts find the opportunity to (re)craft their own knowledge systems and patterns of perception through this newly introduced access and find themselves in a position to challenge some of the traditional conventions of power relations.

This case study, conducted on a suicide survivors’ forum, aims to bring the aforementioned points together and merge them in order to answer some of the popular questions persistent in the field of Science and Technology Studies (STS). By analyzing content from the forum, it attempts to demonstrate how beliefs, thoughts, perceptions and cognitions related to the matters of online support, expert-layperson interaction and expert knowledge are shaped.

German abstract

Zusammenfassung

„Wie ein Tagebuch, aber mit Feedback“: So wurde eine Online-Selbsthilfegruppe von einem ihrer Mitglieder definiert. Es ist interessant, sich Online-Selbsthilfegruppen näher zu betrachten, denn sie beschäftigen sich zunächst einmal mit den Problemen einer Gemeinschaft. Können wir dieses Phänomen der Online-Selbsthilfegruppen wirklich Gemeinschaften nennen? Was macht sie zu einer Gemeinschaft? Was spricht dagegen? Darüberhinaus kommt die Frage nach „virtueller Unterstützung“ mit ins Spiel. Die Suche nach Trost und Mitgefühl unter Leuten, die sich vorher nicht kannten, in einer Online-Umgebung lässt unmittelbar die Frage nach den Motiven dahinter aufkommen. Welche Schlussfolgerungen können daraus über wahrgenommene Qualität und Vorteile einer Online-Umgebung gezogen werden? Das Nachdenken über diese Fragen ist wichtig, denn sie stehen im unmittelbaren Zusammenhang mit einer der bedeutendsten Technologien – wenn nicht sogar *der* bedeutendsten Technologie – unserer Zeit, dem Internet.

Das Internet bietet nicht nur neue Möglichkeiten für den Aufbau und Erhalt von Gruppen, sondern es bahnt auch neue Wege für den Dialog zwischen Experten und Laien. Während die Grenzen zwischen diesen zwei Domänen mehr und mehr verschwimmen, entwickelt sich das Internet als Schlüsselfigur dieses Wandels. Informationen, die zuvor nur bestimmten Gruppen vorbehalten waren, werden einfacher zugänglich. Nicht-Experten finden über diesen neuen Zugang die Möglichkeit, ihre eigene Wissensbasis und eigenen Wahrnehmungsmuster (wieder) aufzubauen und sind so in der Position, die Konventionen traditioneller Machtverhältnisse herauszufordern.

Diese Fallstudie, durchgeführt an einem Forum für Suizid-Hinterbliebene, soll die zuvor genannten Punkte zusammenbringen und durch deren gemeinsame Betrachtung Antworten auf die aktuellen Fragen im Feld der Science and Technology Studies (STS) liefern. Durch Analyse des Foreninhalts soll demonstriert werden, wie Glaube, Gedanken, Wahrnehmung und Erkenntnis mit Online-Unterstützung, der Beziehung zwischen Experten und Laien, sowie der Ausbildung von Expertenwissen im Zusammenhang stehen.

Appendix IV. Curriculum Vitae

Cagla Taskin

Personal Information

Date of Birth: December 7, 1988

Place of Birth: Ankara, Turkey

Contact information: +905333714764 / cagla.taskin@gmail.com

Education

2010 - Present: University of Vienna, Institute for the Social Studies of Science and Technology: Master's Studies in Science, Technology and Society (STS)

2005 – 2009: Hacettepe University in Ankara, Turkey
Department of Sociology

1994 – 2005: TED Ankara Koleji
Primary Education and High School

Work Experience

January 2014 – Present: Büyükharf Publishing

Translator, copywriter and editor