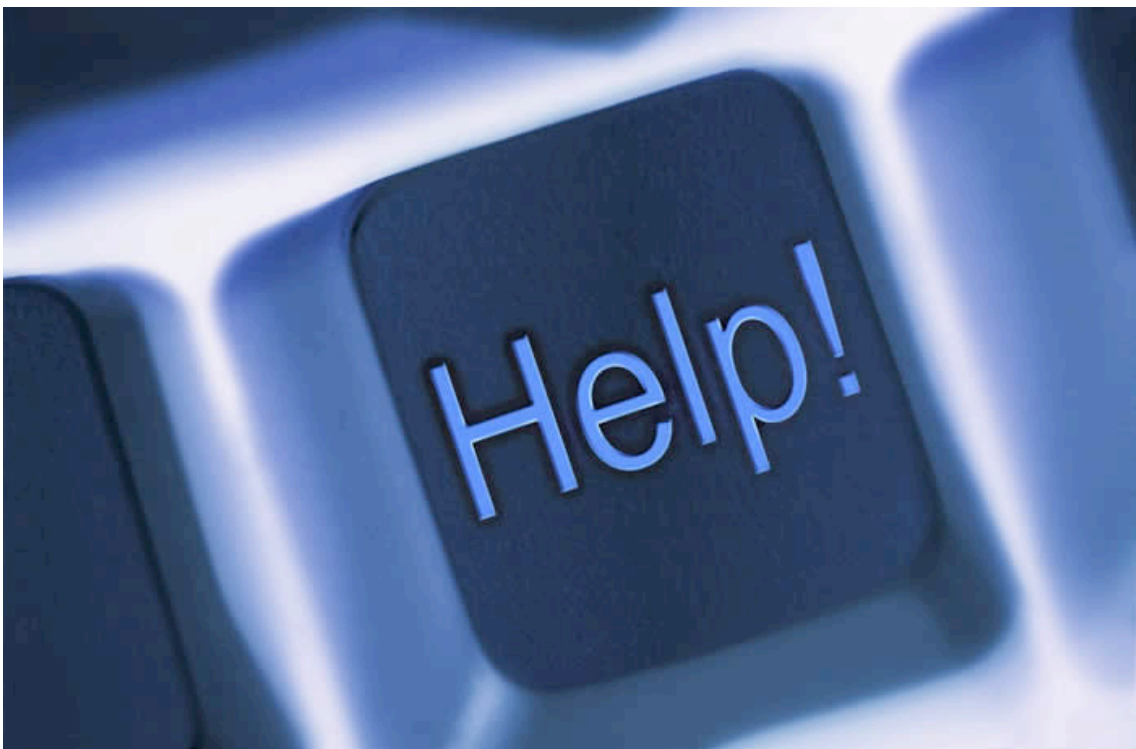


# **“A Sisterhood of Sorts”**

*Empathy in virtual health communities*



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## **Abstract**

This study shows how a group of women with infertility issues find friendship, emotional support, and information using the anonymous environment of one virtual community. Through interviews with 11 women and an analysis of online journals and forum postings, the case study looks at how women use the anonymous and non-temporal nature of the Internet to be empathetic and supportive, and further explores how that empathy helps women feel less isolated and ostracized. Online support groups fill a void that traditional face-to-face interaction and doctor-patient relationships can not fulfill by providing women emotional and social support from their peers. This support is strengthened by the ability for women to choose how much or how little they disclose about themselves, thus giving a feeling of anonymity. Using Lievrouw's Social Shaping of Technology theory as a framework, it was found that women are shaping the technology they use to discuss infertility by creating text-friendly language and online methods of showing support. In shaping this technology to fit their needs, women adapt the "strong-tie" social networking behavior usually reserved for family and friends to better understand strangers online. Disadvantages to the technology are its ever-changing makeup of users and the difficulty in finding the veracity of medical advice. Results from this study show healthcare providers that social media is a valuable tool in understanding the psychological effects of fertility treatments, with further research made into how users deal with the changing population of users and how this technology is used after a person is able to become pregnant.

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## **Introduction**

In looking at fertility treatments, mainstream media often focus on the dramatic success stories of women getting pregnant, like California's "Octomom" delivering eight babies after in vitro fertilization and a mother in Pennsylvania delivering twins then sextuplets after being told she would have difficulty conceiving. Newspapers, magazines, and television say little about those who struggle for years to have a child with no success or those who can't afford in vitro fertilization. Since biblical times, women have been struggling with fertility and suffering in silence at the inability to have a child. Modern women now have careers and purposes beyond that of bearing children, but the core desire to have one and the lengths to which people will go to conceive a child still exist. While these are people who make up the vast majority of the millions of American women with fertility issues, they are the ones who are talked about the least.

Now, couples are choosing costly and emotional procedures to help them get pregnant. They use surrogates to carry their children, use donor eggs, become artificially inseminated and have in vitro fertilization. Beyond the actual procedures is the psychological process that goes with trying to conceive a child. Historically, the emotions involved with infertility have been kept private, with women not even expressing them to their family and friends. But with the onset of the Internet, women have been given a medium to discuss their feelings anonymously, openly and honestly from the privacy of their living room through virtual support groups. These groups fill a void that the traditional doctor-patient relationship cannot fill by offering 24-hour peer support.

This study shows how a group of women with infertility issues find friendship, emotional support, and information using the anonymous environment of one virtual community. It shows what mainstream media often do not: the years between when a woman realizes she has difficulties bearing children and the time when she becomes pregnant or, in many cases, stops trying. Through interviews with 11 women and analysis of online journals and forum postings, this case study looks at how women use

the anonymous and non-temporal nature of the Internet to be empathetic and supportive, and looks at how that empathy helps women feel less isolated and ostracized.

The hypothesis is that women with fertility issues use virtual communities as a way to talk about a stigmatic condition which they can not talk about with close family and friends. Furthermore, women communicate empathy by forming friendships with others with similar fertility issues and are able to more freely talk about the deeply private issues involved with infertility (i.e. menstrual cycles, sexual activity, and medical treatments) when they are with people who are not in their offline network.

Therefore, the research questions are:

- How do women with infertility issues experience empathy on-line?
- How does anonymity contribute to the ability to express empathy and emotion in the context of an online health community?

Using Caplan and Turner's (1998) theory of comforting communication along with theories of virtual identities, social support, and computer-mediated communication, this study looks at how the Internet fills a void that traditional face-to-face interaction and doctor-patient relationships cannot fill by providing women emotional and social support from their peers.

## **Theoretical Framework**

Research into empathy and anonymity in online health communities involves three fields: Social Networking, New Media, and Virtual Identities. The purpose of this literature review is both to present these fields as the distinct and separate research areas which they are and to show that they have common threads which connect them all. In showing how these fields are connected, this theoretical framework will provide a depth of background information useful for the overall analysis of the theme of empathy in on-line communities.

A lot of research exists about *how* and *why* people communicate on-line as well as how people understand each other offline. There is less literature about how people show that they comprehend and understand others' feelings, or how they show empathy, online. Caplan and Turner (2007) state that there is little research about empathy in

online support literature and an overall lack of theories about online emotional support despite a large amount of literature on communities and computer-supported social interaction. This report therefore can both draw from the literature that already exists on online health communities and social support and add to the research field in discussing empathy more specifically.

This review begins by discussing Lievrouw's Social Shaping of Technology theory, which states that technology not only shapes society, but is also shaped by the society which uses it. It then explores the society which uses the Internet by discussing the basic elements of a social network, most specifically those found in Granovetter's "Strength of Weak Ties" theory. Since this theory was developed in 1973, it makes no reference to the Internet, and therefore goes on to discuss more contemporary articles which apply Granovetter's views to new media. While Granovetter's theory shows how networks form, Albert Bandura's Social Cognitive theory shows how information travels through these networks.

What follows is a discussion of how on-line social networks are used in communication. Walther and Boyd's research into Computer-mediated communication and social support, which references Granovetter's Strength of Weak Ties and applies it to on-line social support, is particularly useful in describing the social relationships examined for this report. This is followed by a history of computer-mediated communication (CMC) and a discussion of research into its benefits and drawbacks, and a presentation of Caplan and Turner's candidate theory of Comforting Communication. The framework concludes with Camerini et al.'s definitions and descriptions of virtual health communities, which offers a natural transition to the methodology section of this report.

### **Social Shaping of Technology**

On-line social media and networking has become a modern social phenomenon which has been shaped by both the users of the Internet and the developers of the sites which they visit. Virtual Health Communities encompass both the offline emotions, relationships, and drama found in traditional communities and

the ability to transcend time and space which can only be found on the Internet. This relationship between society and technology is described in the Social Shaping of Technology theory, a theory which places emphasis on the importance of human choice and action in technological change, rather than seeing technology as something that is politically and ethically neutral (Lievrouw, 2006).

The theory is a critique of technological determinism, which states that knowledge and the products from it are social phenomena (Lievrouw, 2006) and that while technology shapes society, society does not in turn shape technology (Mackay and Gillespie, 1992). Social Shaping of Technology, however, shows that the effects are reciprocal. “Whilst not denying that technologies have social effects, the focus, rather, is on the social forces which give rise to particular technologies. Sociologists of technology, it is argued, need not restrict themselves to the effects of technologies (Mackay and Gillespie, 1992: 686).”

Social Shaping of Technology focuses on “the social processes of the conception, invention, design and development (Mackay and Gillespie 1992: 687)” of technology. Lievrouw (2006) describes several “moments” of technology development: origin, actors, dynamics, choice, formal properties, distributive mechanisms, and consequences. Together, these moments move development in one direction or another and thus “shape” technology.

The *origin* of a situation is a creative moment which describes the first movement and trial in the development process (Lievrouw, 2006). This process can be active or spontaneous and set out by teams or an individual. In many virtual communities, the origin is when a person has an idea to start a Web site. DailyStrength, the Web site used for this case study, had its origin in the late 1990s when three social media experts saw the need for a social networking site about health. The three left their jobs at other Web sites to start DailyStrength<sup>1</sup>.

Individual users can be described as *actors* who shaped the technology of DailyStrength. Lievrouw describes *Actors* as anyone who makes choices which affect new media development. Users can shape the development of new media by deciding

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<sup>1</sup> <http://static.dailystrength.org/promo/backgrounder.pdf>



which aspects of a Web site are important (and thus generate the most traffic) and how these aspects are used.

As actors interact and technology evolves, *dynamics* are formed. Dynamics involve the movement and momentum of an idea, expression, and its adoption. DailyStrength's development from an idea of three technology experts to that of a large social networking site involved several dynamics including new ownership, changes in site usage, press coverage, and word-of-mouth popularity. As on-line communication with friends and family in the form of email became mainstream, people became more comfortable communicating online. Those with stigmatic health conditions like infertility realized that the Internet was an appropriate place for venting repressed emotions that couldn't be expressed to family and friends in a confidential setting. Thus, communities like DailyStrength grew in popularity and on-line forums began to replace or fill a void that traditional offline support groups couldn't fill.

*Choice* is characterized by contingency and determination in both the direction and design of technology. Social dynamics lead to a wide variety of choice, and contingency to these dynamics allows for more choice while determination with a fixed plan limits choice. This happens continuously throughout the development process as users of communities are given more choice in how they use their technology.

*Formal Properties* make an innovation observable by potential adapters. Properties can be influenced by ergonomic or aesthetic considerations. This, when used in the context of virtual health communities, involves Web site design, advertising, and site usability. Site traffic statistics for DailyStrength show that most people find the site by conducting a Google search. As formal properties like Web site design and Search Engine Optimization terms are strengthened, sites are able to gain popularity and become more of a social phenomenon.

*Distributive Mechanisms* describe how ideas, things, or practices spread. Granovetter's Strength of Weak Ties theory, which is described later in this chapter, shows how social networking through weak connections allows the spread of ideas and information. As with formal properties, site usage of virtual health communities have

the distributive mechanisms of word of mouth and popularity, which allow them to be found easily through Internet search engines.

*Consequences* are the effects, impacts, and other outcomes of technology. The expression of empathy in virtual health communities is one consequence of technology. This subject will be expanded further in later in this report. The hypothesis of this study, however, is that the consequence of creating an anonymous online environment of people with similar health conditions is that it fosters greater expressions of emotion and empathy.

Combined, these “moments” show how technology is shaped by human interaction, creativity, and innovation. The development of online health communities involves a mixture of all of these “moments” in order to further create a social phenomenon. This development process, and further social shaping of technology, is an ongoing process as an online community changes to fit users’ needs.

## **Social Networking**

Evidence of technology’s shaping of society, and society’s shaping of technology, is evident with the rise of online social networking, as people have turned what was once an offline network of coworkers, classmates, friends and family into an online network via Facebook and MySpace. This new online element of traditional social networking can also involve the addition of networks formed with online friends who have never met in person, like those friendships formed in virtual health communities. These networks can exist completely separate from one’s traditional offline social network and provide valuable social support.

Social Networking, however, is not a new term. Networks have always existed in offline form via communities, tribes, families and other naturally-formed groups. While the invention of Web sites like Twitter, Facebook, and MySpace brought the term “social networking” to the mainstream, research into social network theory dates much further back. One of the earliest references to social networking came in the early 1900s, when Georg Simmel presented a concept of the intersection of social circles. He

stated that social structure originates from many links to primary and secondary groups (Diani, 2000).

Network theory blossomed in the 1970s with theories from Ron Breiger, Ronald Burt, Mark Granovetter, David Knoke, Peter Marsden, Barry Wellman, and Harrison White (Emirbayer and Goodwin, 1994). A theory which has often been cited as relevant to current on-line social networking is Mark Granovetter's (1973) "The Strength of Weak Ties." The theory discusses how one's strong ties of close friends and family are not necessarily the most important in learning new information or building a personal network. Instead, Granovetter emphasizes the importance of weak ties, or casual friends and acquaintances, in building bridges to other social groups and thus allowing information to flow more quickly. Granovetter notes that "emphasis on weak ties lends itself to a discussion of relations between groups and to the analysis of segments of social structure not easily defined in terms of primary groups." (Granovetter, 1973)

Before Granovetter's work, sociological theory focused on small group interaction, the importance of friends and family in building communities, political structure, and social mobility. (Granovetter, 1973). Granovetter's work offers a look at the "bridge" between micro and macro-level interactions and how small-scale interaction turns into larger-scale patterns, which then returns to affect small groups.

Granovetter said that we are connected through "ties," all of which are characterized and measured by "a combination of the amount of time, the emotional intensity, the intimacy (mutual confiding), and the reciprocal services (Granovetter 1973)." Relationships can range from a very strong tie, like a husband or wife, to a very weak tie, like a fellow parent at a child's school. Granovetter also introduces the concept of a "bridge," which is a line in a network which provides the only path between two points, and is thus an integral part in connecting networks. Bridges serve a local purpose and are used in smaller networks, where there are less people to provide ties to other networks.

As with bridges in a highway system, a local bridge in a social network will be more significant as a connection between two sectors to the extent that it is the only alternative for many people - that is, as its degree increases. (Granovetter 1973)

A strong tie can not be a bridge, because strong ties have the same friends and social circles and therefore both people will be able to connect to other networks. While strong ties serve a purpose of intimacy, trust, and social support, Granovetter argues that it is the weak ties, the coworkers, casual acquaintances, and friends of friends, who build and link networks. Weak ties and local bridges serve to create additional, shorter paths between networks, thus facilitating the spread of information to more people and across a greater distance.

Granovetter argues that those with many weak ties serve to provide people with knowledge beyond that of their own friendship circles. In virtual health communities like the one studied in this report, these weak ties are especially important in spreading information about new treatment, coping strategies, and current research. They also strengthen the likelihood of being able to find anonymous social support, in that people are connected over further geographical regions and fields of interest, and thus probably do not have the same offline relations. Thus, Granovetter argues that the “personal experience” of the individual is greatly affected by the larger social structure around him.

Granovetter’s work was published in 1973, long before the mainstream spread of the Internet. Still, his ideas on networks, connections, and interaction can be applied to new media. In 2002, Caroline Haythornwaite applied Granovetter’s theory to new media and found that new media has a positive effect on weak ties and weak-tie networks by providing opportunities for these ties to strengthen and develop.

Haythornwaite (2002) argues that the use and impact of media are dependent on the type of tie connecting individual communicators. On-line organizations, like virtual health communities, serve to provide an organized opportunity to send and receive messages and to further strengthen ties and connect those who weren’t previously connected. Different kinds of ties, such as work, friendship, and kinship, serve separate purposes, but Haythornwaite notes that “all look for more opportunities as their ties strengthen, and as their need or desire to communicate increases (Haythornwaite, 2002:387).” Because of this, strong and weak ties have a “dual usefulness,” both of which can benefit from new media use. Still, the researcher notes that to see how strong

or weak a tie is, it is important to look at both the on-line and offline use of the relationship. It is the tie that drives the exchange of information, not the medium in which the information is spread.

Haythornwaite also argues that new media are responsible for the very existence of many ties. Therefore, networks formed online can be fragile.

It is not the characteristics of the medium that matter (such as asynchronicity or synchronicity, text or video), but the way the introduction of the medium creates a social network of ties, how its presence sustains a network, and how its removal disrupts such a network (Haythornwaite, 386).

This is especially problematic with health communities. Once a user is cured of their illness, dies, or solves their emotional problem, they may not frequent an online support group any more, thus changing the dynamics and network structure of a given community. Unlike in face-to-face relationships, where people can be tracked down by a telephone call or a knock on the door, online relations can simply “log off” and disappear with little or no explanation. For these and other reasons, early studies of computer-mediated communication (CMC) used theories of social presence (Short et al., 1976) and media richness (Daft and Lengel, 1986) to show that CMC wasn't as appropriate as face-to-face communication for emotional conversations or delivery of complex information, which is often found in strong-tie communication. Benefits to CMC focus more on the beginning stages of developing networks and relationships. Research shows that CMC provides access to more connections who people are weakly or latently tied to. Communication is extended in time and space and provides access to more participants. The “reduced cues” which Daft and Lengel state are missed in on-line interaction instead serve to help weakly-tied persons by reducing the risks associated with contacting strangers. CMC is thus seen as an ideal medium for contacting someone a person doesn't know, thus broadening one's knowledge-base and exposing him to new ideas and approaches.

Haris Memic applied Granovetter's Strength of Weak Ties theory to new media by doing a case study of four social networking Web sites. Memic verified that friendship relation in social networking websites is similarly structured to that of face-to-face social networks. All four networks of the web sites he studied were in

complete synchrony with Granovetter's original theory. He also confirmed that bridges in educational social networking websites are disproportionately likely to be weak ties. This study, however, offers a "snapshot" of a social networking site, and does not account for how weak ties are added and subtracted over time. Not much of the current research shows how these relationships are sustained over time, what happens when users leave, and how the structure of these ties changes as a result of this.

Haythornwaite notes that those using on-line media to form weak ties are forced to use "strong tie behavior" to make initial contact by offering frequent communication, self-disclosure, and negotiation of communication norms. This requires effort usually reserved for strong kinship and social relationships, which must be extended to strong ties online. Internet users make on-line media interaction more closely match the conversations found in the real world, says Haythornwaite. Emoticons and acronyms provide code for personal exchanges, and norms and standards are reinforced by continued use. Members in on-line groups are constantly reconstructing relationships and social ties. Ties are reinforced or lost altogether as exchanges are reciprocated, which leads to the additions and deletions of online relationships.

Albert Bandura, in his Social Cognitive Theory of Mass Communication, stated that new media is also shaping communication by offering a rapid and far-reaching transformation of new ideas over time. Diffusion of Innovation, which is a part of his theory, describes how information transfers from person-to-person.

Bandura (2001) states that media influences can spark dialogue, leading viewers to discuss and negotiate what's important in their lives. This leads to a sharing of knowledge that further leads to change. With the internet, communication can be personally tailored to factors that interest individual users. Interactive technology can also create individualization of the level of guidance needed to make changes. This technology also enables, motivates and guides people to effect personal and social changes. In implementing a "social-linking function," like that seen in on-line social media, communication media "can connect people to

interactive online self-management programs that provide intensive individualized guidance in their homes when they want it (Bandura 286).” Much of the learning is also created through other users. “The media teach, but other adopters provide the incentive motivation to perform what has been learned observationally (Bandura 286).”

Bandura states that social structures include networks of people, each with their own ties, and the people who provide connections to other clusters through a liaison role. People vary in their position and status within social networks, which affects the impact on what spreads through a network. Brief contacts with several acquaintances will result in more new ideas and practices than deep and prolonged contact with a circle of close friends - the larger the network the greater the spread and volume of knowledge. Adoption rates are also greater if the network has a particular interest than from a general communication network. Bandura states that “the evolving information technologies will increasingly serve as a vehicle for building social networks (292).”

This causes a constant restructure of technology. As the Internet continues to redefine itself, so do the communicators who use it, and ideas about how such interaction takes place are constantly changing. “In this social construction of media use, i.e. its definition and redefinition according to use, patterns of exchange and media use are constantly emerging (Haythornwaite 389).”

### **Social Support with Weak-Tie Connections On-line**

Social support, traditionally defined as the exchange of verbal and nonverbal messages of emotion, information, or referral (Walther and Boyd 2002), is designed to reduce stress and show that a person is cared for and about. Traditionally, this is done with strong-tie connections, but increasingly social support has found a place online through computer-mediated communication (CMC) with weak ties. Virtual health communities allow users from opposite sides of the world to support each other when they are going through complex health procedures like chemotherapy, infertility treatments, and gastric bypasses. In some cases, the communicators are close friends communicating by email, but in increasingly more cases patients have formed

friendships through online support groups designed for people with similar conditions to theirs.

Walther and Boyd (2002) conducted an empirical study of Usenet participants which showed that social distance, anonymity, interaction management, and access made the Internet an attractive place to communicate. They describe five types of social support found online:

- *Informational Support* is given in the form of advice, information, and feedback of a practical nature
- *Emotional Support* is given with expressions of caring, concern, empathy, and sympathy
- *Esteem Support* involves expressions of admiration and understanding of one's worth
- *Tangible Aid* is actual physical assistance.<sup>2</sup>
- *Social Network Support* involves referring someone to another person or group which shares common experiences and interests.

Group support is another element of social support found online (Walther and Boyd, 2002). Online self-help groups are similar to those found offline. All members of the group often experience the same problem and are looking to provide and receive help, and there is an emphasis on a healthy self-concept as members draw validation from one another (Walther and Boyd, 2002). For example, in an on-line support group for alcoholics, users offer online prayers for each other, congratulate each other on sobriety anniversaries, and offer to be "sponsors" to others trying to get sober, similar to those found in offline Alcoholics Anonymous programs. Online support groups can offer all of the types of support Walther and Boyd (2002) describe.

Walther and Boyd argue several disadvantages of Face to Face (FtF) communication in terms of providing and receiving social support. Close ties are likely to offer unqualified acceptance of a friend or family member with a problem and can be less forthcoming and have less knowledge of the actual problem, given that they do not have personal experience of it. Receiving social support from a close relation also carries the disadvantage of a reciprocation obligation. "The potential reciprocity debt,

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<sup>2</sup> This aid is the least commonly seen with CMC, given the lack of physical proximity among users.



like the obligation to provide support in close relationships mentioned above, may be an unattractive aspect of FtF support exchange in close personal relationships. (Walther and Boyd, 2002)” In CMC, however, these disadvantages are ameliorated. In online forums it is expected that a person is seeking support and “relational dependency and obligation” to reciprocate support isn’t as much of a factor.

### **Computer Mediated Communication**

The human interaction, creativity, and innovation found online happens mostly in the form of Computer Mediated Communication (CMC), a general term to describe communication facilitated by a computer (i.e. email, chats, forums, etc.). The earliest CMC, in the 1970s, was a dial-in bulletin board system used mostly by experts in computer engineering and has since expanded as a communication tool for most people in the developing world. Given this change in nature of both the content and audience of the Internet, research surrounding CMC has also required constant revision. For example in 1984, Naomi Baron reported that CMC is “ill-suited for social uses of language,” but 14 years later she updated her research to state that “email is in many respects an ideal tool for maintaining social relationships.”

Baym states that there are four media qualities with the greatest interpersonal implications:

- *Spatiotemporal* - With the internet, location and time are no longer an issue. Asynchronous communication allows persons to reply on their own time, which helps to expand user engagement and deepen communication. Users are also able to communicate with a wider variety of people in other states and countries and communicate with people with similar issues or interests who live far away.
- *Participants* - A lack of physical appearance cues means more anonymity, a higher degree of privacy, the option to create multiple identities, and less social risk.
- *Electronic nature of the medium*- Electronically, it is impossible to judge the size and nature of an audience after publishing something publicly online, and users lose control over who sees their public content.
- *Written nature of the medium*- Messages can be stored, replicated, and edited before being sent out, therefore leading to better thought-out statements than those made in face-to-face interactions.

Much along the same line as Baym's media qualities is Walther's Hyperpersonal model, in which he states that mediated interaction online is usually personal and also has the potential to become "hyperpersonal," or more personal than face-to-face contact. The Hyperpersonal Model of Computer-Mediated Communication, developed by Walther in 1996, suggests that interpersonal communication becomes "hyperpersonal" on-line because it gives users several advantages in communication that are not available in Face-to-Face (FtF) communication. Walther suggests that on-line users are able to enhance the messages they construct with self-editing, censorship, and selective disclosure. This allows users to further manage the impression others have of them and aids to development of desired relationships.

Previous research has shown that CMC-based relationships cover a wide range of intimacy, but regardless of how close a relationship becomes, certain processes take place at first meeting. At first meeting on-line, physical features like voice and appearance aren't present. While some have argued that the lack of nonverbal cues hurts CMC's ability to form impressions (Kiesler et al. 1986), Walther (1992) argued that impressions will instead develop with a reliance on language and content cues. The Hyperpersonal Model argues that "as receivers, CMC users idealize partners based on the circumstances or message elements that suggest minimal similarity or desirability (Walther 1996:2539)." As senders, CMC users are selective in how they present themselves by revealing attitudes and other aspects of themselves in a controlled and socially attractive way. The "editing, discretion, and convenience" (Walther 2006) of CMC allows users to remove environmental distractions and focus on message composition. In virtual health communities, users can choose whether or not to post pictures of themselves and choose which image represents them when they post on an online forum. Some do not use a picture, others have symbols like a peace sign or a butterfly, and others display pictures of their pets. This, like Walther argues, allows users to determine what first impression users get of them, instead of the first impression being their physical appearance. This serves to heighten the feeling of anonymity which can allow users to feel more comfortable discussing private health issues online.

With these implications, forming online identities becomes very important. While most academic and popular attention has been put on that of fantasy, multiplicity, and disembodied experiences online through role-play sites, studies have shown that the vast majority of online interaction is authentic and real. This is especially true in online health communities, where users are talking about real health conditions they have as well as their personal feelings about how those conditions affect them. The relationships they form with others in similar situations are authentic as they discuss personal problems in an online context.

CMC allows researchers to rethink communication theories, and also offers new opportunities for people to form relationships. A study by Kraut et al. (2000) stated that the internet's primary use is interpersonal communication, with online discussion groups as the main way people form relationships online. The researchers added that the internet can "facilitate the formation of new relationships, social identity, and commitment among otherwise isolated individuals." These isolated individuals include those with stigmatizing conditions like infertility. CMC helps them feel less alone.

### **Virtual Identities**

Identities formed on virtual communities often differ from those formed offline. As noted before, computer-mediated communication allows people to shape how others view them, with a weaker and sometimes non-existent reliance on physical cues. The amount of anonymity is controlled by the user, who negotiates how much and which parts of their identity is disclosed.

Identity, in its most broad sense, can be defined as the dichotomy of the individual and the social (Resnyansky, 2010). One's personal identity can be defined by a number of factors including age, sex, name, hobbies, and place of birth. But while these attributes can be used to *identify* a person, they do not serve to cover the complexity of the phenomenon of identity, which involves social dimensions.

Social identity is about sharing a group's norms and values, collective memories, grievances and projects. Social identities are not inherited, they are socially

constructed, contextually specific and dynamic. . . The social aspect of identity plays an important role in the processes of human interaction<sup>3</sup>. (Resnyansky, 2010:254)

Resnyansky (2010) argues that on-line identities should not be considered a simple extension of offline identities, and should instead be treated as “a specific kind of identity with independent and ever-increasing importance.” Still, she argues that creation of online “selves,” which differ from those offline, is a dated concept. The majority of internet users are instead interested in creating representations of their “real” selves for professional and personal interactions (Resnyansky, 2010: 254).

The combination of personal and social identities is critical when building an identity within an online community, as computer-mediated communication involves both defining oneself and defining how oneself fits into the community as a whole. Much like Resnyansky, Kennedy argues that a shift needs to be made from discussing how anonymity online leads to forming multiple anonymous identities to a discussion of “how online identities are continuous to offline selves (Kennedy, 2006: 859),” and argues that it is necessary to look at offline selves in order to fully understand online selves.

Kennedy states that much early research into online identity focused on how online identities often involve multiple personalities and anonymity. Turkle (1996) provided much of the early work about online identities with her studies of multi-user domains (MUDs), or online role-playing games, but more recent work has instead focused on stable and unified cyber-identities. Turkle’s more recent work in particular focuses on how computers have become “multifarious extensions of our multifarious selves. (Wright, 2007: 544),” and discusses how relationships with computers have been “humanized” to make us think differently about our cognition, decision-making process, and what it means to be “real”.

With the areas available for CMC becoming more diverse, Kennedy also argues that it is important to differentiate between identities presented in separate online environments. For example, identities presented in Second Life, a virtual world which allows users to communicate using avatars, would be different from identities presented

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<sup>3</sup> ICTs, or Information and Communication Technologies, describe all technologies for communicating with computers. This is similar to the term, Computer Mediated Communication.

on DailyStrength, a virtual community focusing on individuals with specific health conditions. Second Life fosters the anonymous and multiple identities that Turkle discusses, while DailyStrength requires identities which more closely match their offline counterparts. There, users' identities are often shaped around the health condition that they are discussing. Profiles for women with infertility issues focus on their efforts to conceive, their relationships with their spouse, and their desires to be a mother. Other elements of identity, like location, interests, and career, take less precedence.

Kennedy's empirical study of an online community showed that there was also a difference between *being* and *feeling* anonymous (Kennedy, 2006). On the one hand, people can feel anonymous by not needing to display their name/age/gender, etc. but don't have to truly be anonymous in what they actually post about themselves. In Kennedy's study, a group of women with low-education and low-income backgrounds in the United Kingdom took a course in web design and were then asked to make personal web sites. Despite the fact that the pages were "anonymous" in the fact that they didn't use the students' names or pictures, Kennedy found that aspects of their offline identities were still prevalent through, for example, the link one provided to an African entertainment Web site and the picture of the flag of Trinidad on another's site. These aspects told about participant's race and cultural identities.

Anonymous users in virtual health communities also prove not to be completely "anonymous." One user in the DailyStrength infertility forum spoke about a \$14,400 check she wrote for her recent IVF<sup>4</sup> treatment, thus giving away clues about her economic identity. Religious identity is also expressed. "I realized that by adopting a newborn God would be giving the next best thing to having my own biological child," wrote one user who had recently found out she was unable to get pregnant.

### **Critics of Computer Mediated Communication**

While the internet has long been touted as a place for persons to have access to information that is not available to them otherwise, critics note that access is not

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<sup>4</sup> IVF, standing for in vitro fertilization, is a process used by couples with infertility issues which allows an egg to be fertilized in a laboratory and then placed in the womb.

available for everyone. The “digital divide” (Rice and Hawthornhwaite, 2006) describes access to and use of the internet according to boundaries of gender, income race and location. Those without access are thus further excluded from the human and social capital that it is possible to gain from using the Internet. Studies show that minorities are less likely to have computers and Howard et. al (in Rice and Haythornwaite, 2006) showed that of those who have access, more men, whites, higher income, and higher educated individuals are likely to be online. In a 1999 UCLA study (in Rice and Hawthornhwaite, 2006) respondents cited lack of an available computer, knowledge about how to use it, and expense as barriers to using the internet. A similar audience is used in this study as well, as all respondents had university degrees. It was thus difficult to see whether or not those with lower education used the site and how that communication differed.

Van Dijk, with findings similar to the UCLA study, identified four obstacles affecting Internet and other new media use: intimidation by new technology or a bad first experience, lack of access to computers, reduced user-friendliness, and lack of usage opportunities. Shapiro also cited a “disintermediation,” or “circumventing of the middlemen” (Shapiro, 1999:55), which takes the power away from editors, journalists, and doctors and puts it in individuals’ hands. Medical information is mixed with emotional language and personal experience in online support groups, and with greater anonymity it is harder to know what evidence there is behind a person’s statement.

Early studies also cited the Internet as a place for superfluous and artificial relationships and communities. Schement (in Rice and Haythornwaite, 2006), said that international communities involve “secondary relationships” in which people know each other in only one dimension. Stoll (in Rice and Haythornwaite, 2006) said that CMC is too limited for meaningful relationships to form and is not a good source for meaningful friendships. Thus, a “pseudo-community” is developed. Beniger, in 1988 (pre-internet) research, described pseudo-communities as the blurring between interpersonal and mass communications, creating an impersonal or contrived social environment. But Cerulo (1997), rejected this idea saying that the term “community” should be re-conceptualized with new media in mind. With the development of the

internet, “community,” should not be a term which assumes that new media are cursory or impersonal, she notes. New media are instead changing human social interaction and changing how social bonds are conceived. Along the same line, Wellman (2001) also states that while network ties form in cyberspace, they represent places where people unite with common needs or interests and “relations in cyberspace are joined with relations on the ground.”

Turkle (1996) disputes that the Internet only creates what Schement describes as “secondary relationships,” and instead claims that Main Street, the local cafe or bar, and other physical “community” places can similarly be found on-line, thus transcending virtual-physical space. The Internet is a place for interaction where people substitute missing visual cues with text cues and language they have created and causes otherwise quiet people to participate (Van Dijk, 1999).

### **Social Support and Comforting Communication Online**

Much along the same line as Computer Mediated Social Support, Scott Caplan and Jacob Turner (2007) outlined a theory of online comforting communication stemming from Burleson and Goldsmith’s 1998 theory of comforting communication in which the researchers define (offline) comforting communication as a sub-category of “supportive communicative behaviors” (as described in Caplan and Turner, 2007). While social support involves a wide range of support from relationships, comforting focuses on alleviating emotional distress. Burleson and Goldsmith contend that emotions come from cognitive reassessments of upsetting experiences, which later help improve emotional distress. Appraisal theorists say that in order to change a negative or upsetting emotion, there must be a “reappraisal process (Caplan and Turner).” Reappraisals involve a new interpretation of an unchanged situation or a change in a situation. Burleson and Goldsmith state that comforting communication, both online and offline, involves a comforter helping another work through his emotions, therefore helping the reappraisal process. These adaptive reappraisals are most likely to result from conversations which focus on expression of thoughts and feelings from a distressing experience (Caplan and Turner). According to the appraisal theory of

comforting communication, these conversations must occur in a way where both participants feel secure and comfortable with discussing distressing feelings and events. In order to successfully do this, a non-threatening environment is required, and Caplan and Turner propose that a computer-mediated environment may be “easier and more effective” (Caplan and Turner, 2007:988) .

The researchers state that the internet provides a safe and secure place for participants to discuss personal and upsetting experiences. CMC requires less personal and social risk than FtF conversations, leading Caplan (2003) to argue that lonely and socially anxious people may be especially fit to use online social interaction because “they feel safer, more efficacious, more confident, and more comfortable with online interpersonal interactions and relationships than with traditional FtF social activities (Caplan and Turner, 2007: 989).” Online social interaction allows users to be anonymous, and is thus more attractive to people who are otherwise reluctant to seek FtF support. One group that may particularly benefit from CMC support is those who suffer from stigmatized conditions like AIDS, cancer, eating disorders, and physical disabilities (Caplan and Turner, 2007). As with the participants outlined in this study, who are dealing with the stigma of being infertile, people with stigmatized conditions are often reluctant to reveal their condition to others and therefore have anxiety with FtF interaction. Caplan and Turner argue that Computer-mediated social support interactions can be especially helpful in creating a conversational context that is less “socially risky” than FtF communication. Online in an anonymous environment, stigmatized individuals can discuss personal and sensitive topics without having to worry about revealing embarrassing information about themselves. Compared to FtF interaction, online comforting provides weaker social ties, greater control over self-presentation and a less anxiety-provoking environment (Caplan and Turner, 2007).

### **Emotions and Empathy**

John Canfield argues that emotions do not exist without being attached to someone, and in order to understand feelings like fear, anger, and happiness it is important to look at both the emotion itself and the person experiencing it (Canfield,



2009). “In addition it seems plausible that light cast on either of the two - self or emotion - will provide a better understanding of the other (Canfield, 2009:102).” Canfield argues that clarity and understanding of emotions leads to a better grasp of the self, rather than the opposite. In Canfield’s view, it is therefore impossible to conceptualize individual emotions, as there are infinite definitions of individual feelings, with the emotion felt subjectively by the individual. Canfield says that researchers must examine interrelations of self and emotion based on “assumed interpretation” of each. With emotions, one can not generalize. One woman’s expression of being “afraid” of not being able to get pregnant can be stronger or weaker than another’s. Being “afraid” for one can mean being so fearful of not becoming a mother that they can’t eat or sleep properly, while “afraid” for another can mean she merely thinks about her fear a few times a month. It is thus important for the researcher to define her own interpretation of each emotion and to discuss what the subject’s interpretation of the same emotion is.

It is therefore important to understand *how*, *why*, and *to what degree* women with infertility issues are expressing their feelings online and how these emotions are communicated to others. One of the greatest ways these emotions are communicated is through empathy, one of the key elements of comforting communication cited by Caplan and Turner (2007). Empathy allows the person giving support to understand and legitimize a distressed person’s feelings. In 1759, Adam Smith coined the term “sympathy” to describe “the shared feeling that results when we observe other people in emotional states, the compassion we feel for their sorrow, the resentment when they are slighted, the joy when they triumph (Davis 1996:2).” Smith described the feeling of sympathy as a “fellow-feeling,” from observing others in an intense emotional state. The term empathy, stemming from sympathy, was not constructed until the early 1900s by Titchener as a translation of the German term, *Einfuhlung*, invented by Lipps in 1903 (Davis 1996). Lipps argued that witnessing another’s emotions makes a person imitate another’s emotional cues. The sharing of emotions from person-to-person is said to create better understanding of each other (Davis 1996).

In a clarification of the conceptualizations of empathy in nursing literature, Kunyk and Olsen (2000) state that despite a large body of literature on empathy, its definition remains unclear. The researchers use concept analysis to create five conceptualizations of empathy: as a human trait, a professional state, a communication process, caring, and a special relationship.

As a professional state, empathy is defined as a communication which must be learned, giving professional caregivers the ability to choose the appropriate response for patients. This allows the professional to stay objective.

In on-line interactions there is no caregiver-patient interaction, but instead communities of patients interacting with each other. Conceptualizing empathy as a human trait and a caring mechanism is therefore more appropriate when looking at online communities. As a human trait, empathy is described as a natural ability to feel and understand others. Aesthetics, experience, maturity, awareness, and creativity are seen as ways to express this understanding (Kunyk and Olsen, 2000:321). As caring, empathy is described as a compulsion to act when understanding a client. Stages involved in caring include becoming engrossed in the experiences of others, and experiencing another person's feelings. Empathy can also develop as a "special relationship," where both parties reciprocate emotions and support and form a friendship or common bond.

There is also a physiological component to empathy. Psychologist Ezra Scotland found that subjects who imagined how a specific person felt when experiencing a painful medical procedure reported stronger feelings of empathy than those who were instructed to simply watch the procedure take place, and author J.D. Trout stated that "when a person suffering is similar to us, empathy really ramps up (Trout, 2009:22)." Virtual Health communities, designed for groups of people with like-illnesses and conditions, would therefore naturally foster feelings of empathy.

Caplan and Turner state that there is little research about empathy in online support literature and an overall lack of theories about online emotional support despite a large amount of literature on communities and computer-supported social interaction.

Preece (1999) researched the balance of empathy and factual information in on-line interpersonal communication. She found that empathy is especially found in online social support groups, where people discuss their concerns with others who may have been in similar situations. In her study of messages found in on-line support groups, Preece found that empathy was “an essential ingredient in participants’ discussions. (Preece, 1999)” Preece cited a need for people to have communication with people other than their doctor for medical support.

The communication was about much more than just exchanging factual information. It was about identifying and communicating with others experiencing similar problems. These people could identify strongly with the fear, the pain, the inconvenience, the frustrations, and the delights expressed by others who were recovering from an accident, surgery or illness. . . Empathy was the compelling ingredient in many of these conversations. (Preece, 1999)

Comforting communication is, at its roots, about the expression of empathy. Burlison and Goldsmith (1998, cited by Caplan and Turner) speculate that successful comforting communication helps individuals work through their thoughts and feelings about upsetting events. Online support provides a safe situation and a supportive audience for this kind of communication, and the audience is more likely to be empathetic and encouraging toward letting an individual talk about his condition. “As a result, online communication provides us with an incomparable opportunity to gain emotional support where otherwise we might not be willing or able to do so (Caplan and Turner, 2006).”

### **Media Health and Virtual Communities**

Traditionally, the goal of health education has been to encourage individual behavior that will result in good health (Seale, 2002). This form of education has led to media campaigns and messages promote health behavior by giving information and motivation to reach health goals. The traditional health education model has also been associated with critiques of moral and political agendas (i.e. environmental, feminist, and social projects), which lead to an awareness of the limitations of classic health campaigns geared only toward individuals.

“The overriding perspective of health educators has often been that a health-promoting media ought to deliver accurate, objective information about health risks and healthy behavior, free from any distortions of ideology, pressure from commercial interests, or obligation to entertain. (Seale, 2002:3).” Michele Kilgore (cited by Seale) analyzed news reporting of female reproductive system cancers in 1996 and found that much of the stories used language which caused excitement about higher success rates, with terms like “dawn of a new era” and “breakthrough,” thus leading women to have unrealistic expectations. Stories found that these cancers were also caused by sexual promiscuity, and focused on a small number of scientific studies about that, and not the wider breadth of knowledge available about these conditions. Furthermore, medical information was lost in the story, making readers have a difficult time extracting and comprehending it. In the end, Kilgore concluded that newspapers were not an efficient medium for providing medical information about cancer affecting the female reproductive system.

Perspectives like these have lead some health educators to shift gears to models based more on health promotion, media advocacy, and community empowerment (Seale, 2002), with these subjects comprising the field of media health. In 2002, Clive Seale published an overview of media health which is comprehensive in describing its forms and applications to television and newspaper media. His research, however, has a large gap in that it does not reference how health promotion is displayed in what is rapidly becoming the largest medium: the Internet. Health blogs, health advice sites, and virtual health communities have both a large audience and presence online. Seale’s 2004 book, *Health and the Media*, is a compilation of articles by other researchers which do reference the Internet.

Seale’s theories of media health can be applied to online information. Using ideas of community activism and empowerment, these models differ from traditional information-delivery like that of newspapers in that they focus on engaging and empowering people to use the media as a source of power. Virtual health communities foster this more radical approach to health education, with a shift from “educating the

masses” about healthy behavior, to the creation of a peer-to-peer model that fosters both education and social support.

The emergence of the Internet has allowed patients greater “informed choice,” with an expansion of medical information and knowledge available to them (Henwood, et. al, 2004). Quality information provides an empowerment tool for patients, but can also be overwhelming, as patients must sift through several different sources of information and distinguish between what is quality and what is subpar. Eyesenbach (2002, as cited in Henwood, et. al, 2004) notes that the increasing availability and interactivity of information from places like the Internet has given consumers a desire to take more responsibility for their health. Information technology and consumerism thus create an “information age healthcare system,” where consumers use information found online to control their own health care.

Burrows (2000) term, “virtual community care” describes the self-help and social support found on the Internet. Burrows found that the internet has caused an increase in “lay knowledge,” based on experience and over the “expert knowledge” provided by healthcare professionals.

Camerini et al.(2010) provide a comprehensive view of the advantages and disadvantages of virtual health communities by reviewing past research and discussing the relationship between persons’ identity and the networks they belong to. The article also points to research showing that the internet is considered by most to be the most trusted place for health information . Camerini tries to give meaning to the term “community” by looking at it from a semiotic perspective.

Most of these communities arise originally as discussions about topics of interest; in these communities, boundaries are not defined by geographical proximity, but rather from shared interests and self-identification of belonging to a group (Camerini 89).

The “semiosphere” serves not only as a place for discussion, but as an establishment of how and what members are allowed to discuss. The researchers argue that the structure of each community and the users that take part in it is unique and therefore defines the dialogue and information that is on the site. They emphasize the importance of understanding the power structure of the site one is researching in order

to understand who is presenting the information and who is the “lurker” who is not actively participating but is instead taking in the dialogue.

The researchers also give a history of online communities, which started in the days of early internet. According to them, informal health communities, like the Web site analyzed in this report, share three characteristics: they are rooted in offline communities that share a therapeutic goal, they use the internet to “overcome geographical boundaries,” and they are hierarchically structured with predefined leaders. This hierarchical structure is important in determining the quality of the information within the community. Without a monitor, anyone could post opinion and state it as fact.

Also useful was the typology of virtual health communities. The researchers explain that stakeholders of virtual communities can be health care professionals, patients, companions or researchers. The “patient and caregiver peer-to-peer applications” category, which describes the community in this case study, allows for direct communication between different areas in the community. The goals of the community, according to Camerini, are informative, clinical, and communicative.

Researchers have also codified discussions in virtual health communities. Klemm et al (1999) identified categories of information exchange in forums about cancer. This included information-seeking, encouragement and support, personal opinions and experiences. A differentiation between lurkers and supporters was also made, as posters are the ones who determine the pattern of discussion.

Camerini also discussed the benefits and pitfalls of virtual health communities. The most widely discussed benefit is “the ability to communicate 24 hours a day with anyone in the world with a high level of anonymity (Camerini 93).” Camerini notes that users of online health communities already belong to a community by having whatever health condition they are on to learn about. “They are therefore bonded to the community. The virtual community thus serves as a reinforcement of this identity and does not overcome it (Camerini 95).”

A person’s level of a participation also defines their experience of a site. In Camerini’s study of a virtual health community found that out of the 194 users who

posted at least once in discussions, 2 individual posters made up 30 percent of the posts and the eight “most prolific users” contributed more than half of the posts (Camerini). “This result clearly indicates how the community, although supposedly horizontally structured, is indeed hierarchical, in that only a few members take the lead in the discussion (Camerini 95).” Camerini notes that most virtual communities take on a “90-9-1” rule that has been created to show the “participation inequality” in communities.

In online communities, usually 90% of users are lurkers (i.e. read or observe, but do not contribute); 9% of users contribute from time to time, but other priorities dominate their time; and 1% of users participate a lot and account for the most contributions (Nielson 2006)

Preece et al. (2004) studied the reasons behind lurking and found that the top reasons for lurking were: not needing to post, needing to find more information about the group before posting, thinking they were being helpful by not posting, and not being able to make the software work. The researchers cited a need for web site developers to encourage participation and support lurkers by, among other things, providing encouragement to post, rewarding quality and quantity of postings, providing support for how to browse the site, and creating a “greeter” to welcome newcomers into the group.

### **Similar Studies**

Two studies are similar to this case study in that they discuss infertility and computer-mediated social support.. In 2008 Malik and Coulson wrote an exploratory study of online experiences in infertility support groups using open-ended questionnaires. The researchers found that answers had five recurrent themes: ‘improved relationships with partner,’ ‘reduced sense of isolation,’ ‘unique features of online social support,’ ‘information and empowerment,’ and ‘negative aspects of online communities.’ The study concluded that there were a range of valuable benefits to online communities, like finding a network of people with similar situations and having 24-hour support, but also cited downsides to online communication including becoming depressed at reading stories of people’s grief and jealousy over reading about other people’s success. Still, the researchers concluded that online support groups can provide

a tool for healthcare providers to further understand the psychosocial needs of patients going through fertility treatments.

Malik and Coulson (2010) also examined self-help mechanisms used by persons with infertility issues in online support groups with a content analysis of 3,500 messages. The study found that the most frequently used support mechanisms were: support or empathy (45.5%) and sharing personal experiences (45.4%), followed by the provision of information and advice (15.9%), gratitude (12.5%), friendship (9.9%), chit-chat (9.4%), requests for information or advice (6.8%) and universality (4.8%). The researchers concluded that online support groups feature many of the self-help mechanisms that face-to-face support groups have, with very little negative communication. The key functions of the support group analyzed were found to be support and empathy with encouragement for others to share their personal experiences.

Steuber and Solomon (2008) also looked at the discourse in online infertility forums and blogs to gain insight into the relationships of couples with infertility issues. The researchers used the forums as data for studying the relationships but did not study the online medium itself.

### **Contributing to existing literature**

Research into the interpersonal dynamics of online health communities requires a thorough study of social networking, new media, computer-mediated communication, and social support and comforting communication theories. While these areas are distinct research fields, they share many commonalities and often overlap to form the field of virtual health.

Online health communities have existed for only a little over 20 years, but the foundations of the social interaction, networking, and communication that takes place within them has existed in scholarly research for hundreds of years. Still, debate over how to define the internet and the communication within it is constant and the debate over whether to treat online interaction in the same manner as face-to-face communication is heated. Furthermore, as uses of the Internet change, so does the research and literature supporting it. There is constant revision of research and theories



as well as a large number of case studies that are only 5-years-old and already out-of-date.

This thesis serves to fill a proven gap in current research: the study of how empathy is expressed on-line. This literature review has provided background on how people network and communicate both offline and online with networking and social support tactics.

## **Overview of the Field**

Camerini et. al point out that the first academic reference to virtual health communities was made in 1993, when the early internet consisted of text-based bulletin boards with several sub-topics. The Whole World 'Lectronic Link (TheWELL), a Web site of on-line forums, was developed in 1985 and has been cited as “the birthplace of the virtual community.”<sup>5</sup> The site began as a dial-up bulletin board and has since expanded to an on-line social networking site. In the early 1990s, as internet usage began to grow, so did the number of virtual communities, with one of the most popular being Classmates.com, founded in 1995. In 1999, WebMD went public as one of the first Web sites focusing solely on health.

Since those early days of online communities, thousands of sites have been developed with both a communicative goal and a health goal. Some, like Facebook.com, serve the broad focus of allowing people to build online networks of already existing social networks through shared links, photos, videos and commentary. Other communities, like shadowedrealm.com, an online forum designed for medieval history aficionados, serve a specific niche. Virtual health communities also serve both broad and specific audiences. Healthcommunities.com, DailyStrength, and HealingWell are three examples of communities which offer one large site and several sub-communities based on specific health conditions. Breastcancer.com, WrongPlanet (Autism), and cysticfibrosis.com offer communities focused specifically on one ailment.

DailyStrength, the site which is further analyzed in this report, differs from traditional forums in that it offers users many ways to express themselves. The site has

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<sup>5</sup> <http://www.well.com/aboutwell.html>

hundreds of “Support Groups” for mental and physical health conditions as well as over 500 member-created groups with even more specific definitions like, for example, “Narcissistic Victim Syndrome Supporters” and “Divorce after 20 years together.” Users can join as many support groups and user-created groups that they want and can also use the site to create private or public journals, set and monitor goals, post photos, indicate their mood, and send private messages.

A unique feature of Daily Strength is the “Hugbook,” which allows users to send virtual hugs, trophies, four-leaf clovers, and other symbols to users. Users send a virtual hug attached to a message of encouragement (See Figure 1).

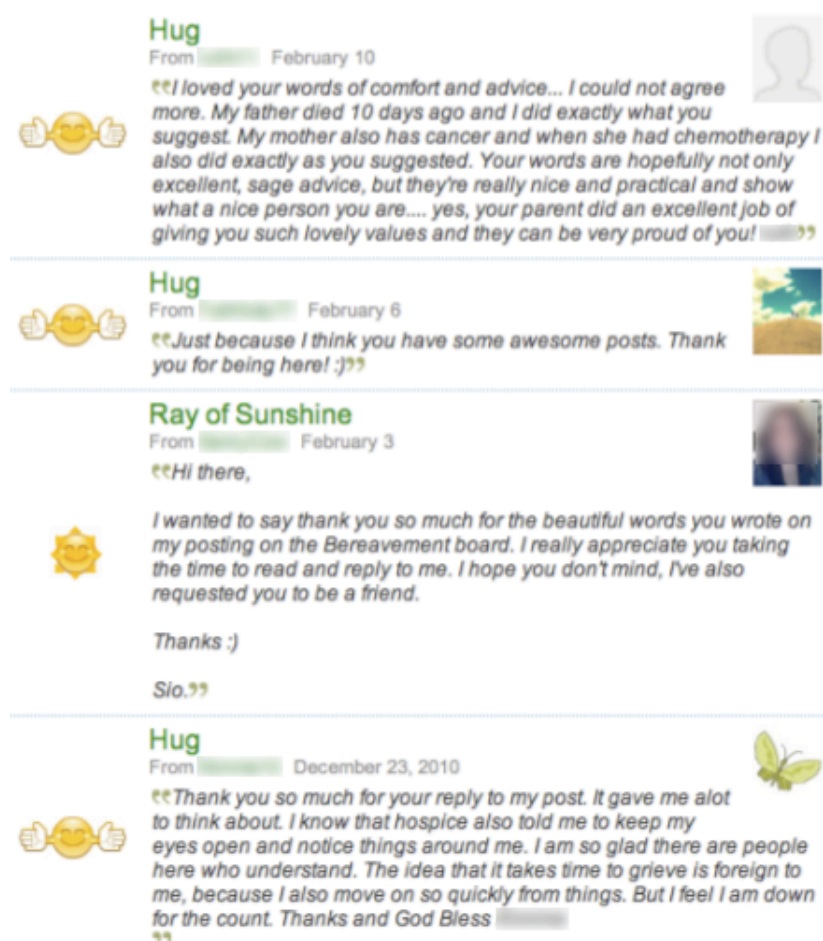


Figure 1: Sample Hugbook from user in “Caring for Aging Parents” support group

Users also have the option of sending “group hugs” to entire support groups, virtual prayers, and virtual chicken soup as a way of encouragement.

Goal planning (See Figure 2) is also a feature of the site. Users set goals for themselves and track their progress via a “percent completed” icon. Other users can rate

the goal as “inspirational,” “moving,” “helpful,” or “creative,” and can support the goal by sending a virtual “Thumbs Up,” “Shout Out,” or “Gold Star.”



Figure 2: Example of goal progress tracking

According to a Web site traffic information site<sup>6</sup>, 62 percent of visitors to DailyStrength are from the United States, followed by 12.5 percent from India and 4.1 percent from the United Kingdom. Compared with the overall population of Internet users, DailyStrength's audience tends to be female and consists of more higher-income people between the ages of 35 and 65 who browse from home and have no postgraduate education. Users, in the period from January-March 2011, spent an average of 9.3 minutes on the site during each visit. The number of pageviews<sup>7</sup> per visit in the same time period was seven.

<sup>6</sup> <http://www.alex.com/siteinfo/dailystrength.org#>

<sup>7</sup> Pageviews are the number of pages within a Web site that each user will visit

# Methodology

## A Case Study Approach

This project takes a case study approach towards examining a larger issue, with one internet support group serving as an example of how people communicate about stigmatizing health conditions online. Robert E. Stake argues that case studies in the social sciences can be used to show complex descriptions, involving “a myriad of not highly isolated variables; data that are likely to be gathered at least partly by personalistic observation; and a writing style that is informal, perhaps narrative, possibly with verbatim quotation, illustration and even allusion and metaphor (Stake, 2007:24).”

The methodology for this report includes semi-structured interviews as well as analysis of public forum conversations and on-line journals. In following the case study approach, the data has been gathered by the researcher’s observations of life in on-line support groups. Through this observation, the researcher has, as Stake puts it, proliferated rather than narrowed the field, with the data adding to existing experience and human understanding. Quotations about how women use online support groups to feel less isolated and lonely serve to open up more questions about why women with infertility issues feel isolated in the first place and why they can not find company offline.

Robert Donmoyer (2007) offers three advantages which case studies have over direct experience from the reader. First, They allow researchers to go where most wouldn’t have the opportunity to by giving them a look into a world which was previously unavailable. Persons who have never experienced infertility would not be able to understand the emotions involved in the process. “Case studies also allow us to experience vicariously, unique situations and unique individuals in our own culture (Donmoyer, 2007:62)”.

Case studies also allow readers to see the world through the researcher’s eyes and see things they might not have noticed before. This doesn’t mean that the reader sees the world through the researcher’s personal views, but rather through the theories and perspectives which the researcher is presenting (Donmoyer, 2007). Case studies

can add refinement to perspectives on existing theories and “add depth to theoretical understanding (Donmoyer, 2007:63).”

Lastly, case studies allow readers a “vicarious experience” which is less likely to produce defensiveness and resistance to learning. A readers’ direct exposure to individuals with infertility issues might make them uncomfortable, as many interview subjects in this study cited that even their friends and family were embarrassed and afraid to talk about infertility with them. Subjects themselves might also be cautious discussing their issues with strangers who aren’t familiar with and haven’t experienced infertility. The researcher is of course also a stranger who has not had direct experience with infertility. Still, through several conversations and emails with subjects the researcher was able to gain a rapport with subjects and make them comfortable enough to speak anonymously about their feelings for the purpose of a study in a way in which they would not speak about them to strangers.

### **Virtual Methods and Interviews in Qualitative Research**

The goal of this project is to illustrate how people show empathy when discussing issues related to infertility in on-line communities. For this purpose, it is necessary to learn more about people’s individual emotions, motivations and thoughts about *why* and *how* they communicate online, rather than look at numbers and statistics about their actual site usage. Uwe Flick states that the overall goal of qualitative research is to concentrate on “the subjects’ points of view and on the meanings they attribute to experiences and events, as well as the orientation towards the meaning of objects, activities and events (68).” With this in mind, a qualitative approach is taken in this study.

Research shows that people behave differently online compared to offline, disclosing more about themselves in an online setting than offline, and “much of that disclosure is more candid (Joinson 2005, 27.)” By looking at interviewee’s forum posts one can see the differences between their behavior and dialogue publicly on-line compared to that of their discussions on the phone and by private email. Shani Orgad (2005) discusses the implications of moving from on-line to off-line interactions in research by quoting Bakardijieva & Smith (2001) in saying that there is a need to use

offline methods in online research because it captures “developments on both sides of the screen” and allows the researcher to investigate the real-life actions and context of users and their activities in cyberspace. This was important when looking at how users turned the advice and support they received online about managing their health toward their personal problems with infertility offline.

For example, from my interviews I was able to see how using certain site features made users feel, something that does not come across in their forum postings. One person shared the downsides to using online communities:

**Sandra:** Journal posts and private messages are different in that a journal post is a comment or support or something you are writing about and honestly most private messages are about other users who may be annoying us. This is a site all about support and there are a few users who are not always supportive.

This message shows both how Sandra uses the site, what she doesn’t like about the site, and how she communicates with her online friends. All of this information would not be available by simply looking at her forum posts, especially given that private messages can’t be seen by the researcher.

Joinson says that there is a lack of “ethnographic immersion” into context about how statements are made when interpreting what people say online about their offline lives, which justifies the need for conducting offline interviews. “It’s important to remember that all ‘internet research’ takes place in an embedded social content. To understand Internet-based phenomena you need to understand that broader context. Consequently most ‘online research’ really also should have an offline component (Joinson, 2005:22).” While in-person interviews may be a better offline component to see individual personalities and visual cues, this was not possible given time and budget constraints involved with this project. Still, the telephone interviews showed the “offline” personas of users and email interviews conducted privately gave a more intimate look at the “behind-the-scenes” thinking behind posts on the forums.

Orgad said it is important for the researcher to ask whether or not offline interactions would reveal something significant about a person’s experience of the Internet which could not be obtained online and how offline interaction would enhance the interpretation of data found online. For this report, offline interviews and email interviews served to find more information about how users saw themselves as using the sites and a reflection on how the site has helped them to feel comforted and supported

as well as how they showed empathy and support to others. Ideas of how they were inspired or motivated to make changes are not as obvious in their forum posts as in their spoken thoughts on the phone.

In short, at the heart of this inquiry are the connections between users' online and offline experiences, how patients' online participation affects their life offline, and vice versa, how their offline world shapes their online experiences. (Joinson 53)

In one telephone interview, a woman spoke of the differences between talking to her on-line friends on DailyStrength and talking to her family and friends:

**Sharon:** You can almost hide around the fact that you're on an online site. You say it and vent and you don't have any repercussions. You can't be angry, mean and nasty and with a family member or friend. Online you can go vent and everyone will forget about it.

This information tells a lot about why Sharon chose to find support online and why her emotions come across as stronger on-line than they do off-line. By looking at her forum posts, it is impossible to tell her motivations for "venting" or choosing to display her emotions. Her on-line posts show what her emotions and feelings are, but her telephone interview reveals why she acts the way she does on-line.

Respondents were also offered the option of email interviews, after requests for telephone communication yielded a low response rate. Email interviews were approached differently than telephone interviews. Joelle Kivits notes that email interviewing involves "a strong commitment towards the subject under study and the interviewing process, lasting long after the first email exchange (Kivits, 2005:35)," but adds that repetitive email exchanges and the one-to-one relationships between the researcher and the respondent make emailing interviewing "a personal and thoughtful form of communication."

One of the main issues of email interviewing focuses on whether text-based communication enables the intimacy that in-person conversations hold. Kivits suggests a connection of trust through mutual disclosure and repeated interaction (Kivits, 2005:38). This involves being open about research methods, objectives, and privacy issues. For this study, participants were told that this was a study about how women with infertility issues communicate and give and receive support online. They were told, and signed a release agreeing to, the fact that they would remain anonymous in the

report and that the report would be published. Original email inquiries had a casual tone that mimicked the conversation style observed on the site:

**Stephanie:** Hello! I am a graduate student in Sweden working on a research project about how women use the internet to get support with issues of infertility. I'm hoping to look at how online communities like this one help people to talk about things that may be difficult to bring up with family and friends. Would you be willing to be interviewed by phone or email for about 15 minutes about your use of the site and how it has helped you? Interviews are completely anonymous and real names won't be used in the final report. Any help is appreciated. Thanks in advance for your time!

Kivits also suggests that the researcher discloses information about her interests, hobbies, age, etc. This creates a more comfortable and friendly environment for the subject. For this study, the researcher created a DailyStrength profile with her age, gender, and location and ended each email with an off-topic remark:

**Stephanie:** I hope all is going well with you. We are finally getting some warm and sunny weather over here - hopefully you are over there too!

Responses were met with similar candidness, along with answers to the actual research questions being asked:

**Sherry:** The sun is shining but it is really cold here - like 32 fahrenheit! Spring starts Saturday so it's not supposed to be that cold right now. Wish me luck that in one week a BFP (big fat positive) pregnancy will be shown!

It is also important to understand others' expressions without physical cues. The researcher must adapt her own language to better fit that of the subject with emoticons, punctuation, and abbreviation. The researcher mimicked the abbreviations used by users on the site, wording questions with terms like "BFP"<sup>8</sup> and "IVF"<sup>9</sup> as well as casual punctuation, ie. the use of exclamations and capital letters.

The time period of an email interview also varies, as participants have as long as they want to respond to questions. Thus researchers must constantly be prepared to change their study schedule to accommodate the needs of the subjects, and it is important to preserve the participant's initial interest in the research by sending reminders and notifications in a relaxed way (Kivits, 2005). There is a large risk of respondents suddenly not responding to messages when conducting email interviews, as

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<sup>8</sup> "BFP" is an abbreviation for a "Big Fat Positive" pregnancy test result.

<sup>9</sup> "IVF" is an abbreviation for In Vitro Fertilization, a major treatment for infertility



sudden withdrawals can lead to incomplete data (Kivits, 2005). Some respondents to this study delayed their responses because of the emotional effects of a negative pregnancy test or because they were going through fertility treatments like IVF, and there was one withdrawal in the study. Data from the withdrawal was not included in the study.

## **Methods Used**

The methodology of this project consists of analysis of individual users' posts, journal entries, and virtual expressions of sympathy and empathy within online health communities as well as interviews with some of these users. Interviews were semi-structured, with the interviewer having a theory, hypothesis, and research problem in mind when approaching the interview and a broad outline of theory-based questions on hand. Semi-structured interviews were chosen over structured interviews to emphasize the subject's broader viewpoints.

Subjects were found by sending private messages to random participants who listed infertility as one of their health issues. Originally, subjects were only given the option of a phone interview, but after this method yielded a very low response rate subjects were offered an email interview. It was assumed that subjects were comfortable expressing themselves on-line, given that they were members of an on-line health community and communicate on-line every day.

Approximately 100 people were contacted, and 11 agreed to be interviewed for the study. Two of these individuals chose a phone interview while 8 of them opted for questions to be asked over email. One respondent agreed to be interviewed but did not reply to questions asked. By email, participants were asked 11 preliminary questions and follow-up questions were asked for clarification and elaboration of original answers. Phone interviews centered around similar questions, but were less structured to accommodate the natural conversation taking place.

Questions centered around how respondents used the site, how they communicated with others, how others communicated with them, and how that communication made them feel. A pilot test showed that questions were focusing too much on how others were supporting the respondent, and not enough on how the

respondent was supporting others, which is a key part of empathy. Therefore, questions were restructured to focus more on the reciprocal act of providing and receiving social support. Interview respondents were also given an opportunity to a free-response for additional thoughts and comments.

Given that the health issue being studied is infertility, all respondents were of childbearing age (25-42) and female. This demographic represents the majority of women in the forum, as only 141 out of nearly 12,000 members of the infertility support group list their age as over 45-years-old. While men can also experience infertility issues, only a small number record it as a health issue on the site. Of 11,841 members citing infertility issues, 86 were men. All respondents had also completed higher education and all but one lived in the United States.

Individual forum posts and overall site usage by interview subjects were also looked at. For those who agreed to be interviewed, emphasis was placed on their “profile” as a user. The analysis used not only their responses to interview questions, but also the text in their journal entries, postings in support groups, goals, and virtual hugs messages. The analysis notes the medium in which each statement was made. Quotations from users who agreed to be interviewed are noted using false names, while public forum posts by other users are noted using a numbering system (User 1, User 2, etc.).

Analysis which involved the “Infertility Support Group” forum as well as its sub-categories (Secondary Infertility, Ovulation Predictor Kits, Infertility and PCOS, etc.) was made from posts by all users participating in the site. Forum posts from February 1 - April 1, 2011 were used, and all quotes are recorded with original spelling, punctuation, and grammar.

### **Defining Empathy**

In order to properly code and analyze the data from interviews and individual Web site postings, it is important to define empathy and the researcher’s interpretation of the term. As noted in the literature review, empathy has taken on many definitions and meanings since the term was first used in the early 1900s, and is further defined in an online context.

For the purpose of this report, empathy will be defined as a human trait and a caring mechanism, such as Kunyk and Olsen described in 2000. The researchers state that as a human trait, empathy offers a natural ability to feel and understand others through the expressions of aesthetics, experience, maturity, awareness, and creativity. As caring, empathy is described as a compulsion to act to understand others. This includes engrossing in the experiences of others and experiencing another person's feelings. Empathy can also develop as a "special relationship," where both parties reciprocate emotions and support and form a friendship or common bond (Kunyk and Olsen, 2000.). Similarly, Preece (1997) explains that empathy is the ability to identify with and understand another's situation, feelings and motives.

With this definition, examples of empathy were sought in postings on support groups, journals, and public messages on DailyStrength. Interviews served as a way to better understand *why* users were expressing empathy and in which contexts they did this. The following excerpt from a forum posting serves as an example of empathy found in DailyStrength's infertility forums:

**User 1:** guess it's on to IVF. The orange underwear, sweet potatoes and red raspberry leaf tea<sup>10</sup> did not help my 3rd IUI chances. I can't believe I'm not pregnant again! This is really driving me crazy! I'm scared about starting the IVF process, but also very ready for it at the same time. I had a gut feeling that this was the route we would have to go:(

**User 2:** I'm sorry that this wasn't the month and the IUI that worked for you. I have been through 2 and I don't know that I'm emotionally ready for another so I can understand how you feel. \*\*HUGS\*\*

In following Kunyk and Olsen's definition, this example shows an empathic response from User 2. She shows experience by noting that she has been through a similar experience as well as awareness of the difficulty in getting the result and expressing sorrow and sympathy over the experience of another person. The key difference between sympathy and empathy, as explained in the literature review, is that empathy requires a person to understand another's situation based on his/her past experiences, rather than just being sympathetic and feeling sorry for them. It is important that

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<sup>10</sup> Users often cite the color orange as a good luck charm, adding that orange is seen as a color that empowers the reproductive system. Sweet potatoes and raspberry leaf tea are also believed to be helpful in fertility.

empathy and sympathy are distinguished when looking at the data. The following serves as an example of sympathy:

**User 1:** As most of you know, this is our last time with IF. I told the nurse and doctor that we aren't going to try any more and they agreed to go aggressive this time...but low and behold, they went conservative. . . I am upset right now....well lets hope that this is the week for my IUI and that one follicle produces a good viable egg that attracts the wee little sperm! Thanks for letting me vent

**User 2:** Keeping you in good thoughts and prayers. May this be your one good egg that brings you a beautiful baby.

User 2's response is sympathetic in that she feels *for* User 1, but makes no indication that she has past experience with or understands what what she is experiencing. A further discussion of both sympathetic and empathetic emotions appears in the analysis section.

### **Coding and Categorizing**

Data has been coded into four categories focusing around empathy: Information, Friendship, Emotions, and Anonymity. These codes were inductive codes, and were developed while looking at the data. Many more categories were later distinguished via Open Coding, with the aim of expressing data in the form of concepts, and were narrowed down with Axial Coding, which refined and differentiated those categories (Flick, 2006). Mostly, interview text was coded paragraph-by-paragraph, although some was coded sentence- by-sentence if it appeared there were two or more categories in the text.

The axial categories of Information, Friendship, Emotions, and Anonymity served to provide a basis for *how* empathy was expressed when discussing infertility online. They were chosen because they were deemed best fit for further elaboration and interpretation (Flick, 2006) and fit with the vast majority of the data collected. Within those categories, other subcategories emerged like, for example, the discussion of extreme emotions and the repeated use of the word “roller coaster” to describe the infertility journey. These sub-categories served both to break down the data into separate themes and to show how these themes fit together with the rest of the data.

Axial coding was followed by selective coding, which put all data into what Flick describes as a *story line*, or “a concept attached to the central phenomenon of the story and related to other categories.” The data’s story line is the following:

*Conditions of anonymity allow women to more openly discuss the issues and emotions of infertility on-line with strangers, whereas they are not as open to discuss these issues offline with friends and family.*

This central phenomenon goes with the central category of empathy, which encompasses all other sub-categories in the data and thus allows theoretical saturation to be reached. This breakdown of data allowed for a more focused analysis and deeper understanding of the meaning of my data beyond a simple summary (Flick, 2006).

### **Limitations**

As with any study, there are limitations to the methodology used in this report. A qualitative case study approach can deliver great description and insight into a subject, but it can not provide as much objectivity and generalization. Statistical analyses allow more “black and white” facts and a more comprehensive view of a larger sample of people. It was thus not possible to make assumptions about *all* women with infertility who communicate online or to compare them with each other. Still, the goal of a case study is to show the *how* and *why* things happen (Andersen, 1993). It is not intended to look at the entire population, but rather at one particular issue (Noor, 2008), in this case the online expression of empathy amongst women with infertility issues in one particular support group. Therefore, while the case study method does limit the number of people one has access to and the statistical significance of their response, it provides much that a statistical analysis cannot provide.

Email interviews were also used because the response rate was too low when phone interviews were offered. Lack of in-person interviews meant that verbal cues were missed and the offline persona of a person was not able to be captured. This could be argued as a limitation, with responses less candid and more rehearsed over email. Still, it can be assumed that women who talk about their personal lives to strangers on the internet every day are comfortable answering questions by email, most likely more

so than on the phone or in person. The responses were deeply personal and candid despite their electronic medium.

Lack of time and resources also added limitations. In five months, a single researcher cannot conduct a statistical analysis with a sample size big enough to represent the hundreds of thousands of people discussing infertility online. Lack of time and funding also made in-person interviews with people in other countries impossible. This is another reason why a case study approach was appropriate. It allowed for in-depth understanding of a particular issue from the viewpoint of *one* set of people using *one* support group. While generalizations can't be made about the entire population, information and anecdotal evidence can be added and applied to existing theories and research.

## **Findings and Analysis**

Infertility is a condition which has few outward physical effects but a host of inner emotional effects. According to a Harvard University publication, 1.3 million Americans receive infertility advice or treatment (Harvard Mental Health Letter, 2009), and research has shown that psychological effects from infertility treatments can cause as much stress, anxiety, and depression as for those who have been diagnosed with cancer or are recovering from a heart attack.

Women who learn that they can not conceive a child naturally can experience emotions similar to those who experience loss with feelings of shock, grief, depression, anger and frustration (Harvard Mental Health Letter, 2009). These emotions are exacerbated by the fact that infertility is a stigmatic condition, which makes discussing it publicly difficult. Moreover, medical side effects include hormonal changes and psychological effects, and in countries where infertility treatments are not covered by health insurance, the financial cost of treatment can cause even more stress. While these treatments often help accomplish the overall goal of having a child, they can be unsuccessful, which causes a renewed cycle of grief (Harvard Mental Health Letter, 2009). As one infertility support group user described it:

**User 1:** My body is not meant to conceive, cannot conceive, will not conceive. I have wanted children my whole life and am now prepared to live with this huge hole in my life, this unfulfilled dream. I have been strong for so long, fighting the

depression and frustration to the best of my ability, but I am giving up the fight. It is time to break down, to stop being strong, to accept what is and is not possible.

Online support groups like those found on DailyStrength offer a confidential place for people with similar problems to discuss their health conditions. I have found that an online infertility support group can offer women a chance to discuss these emotions by gaining informational support, a new social network, and social and emotional support while feeling relatively anonymous. These forms of support are received via expressions of empathy as other users validate and verify feelings and emotions expressed by people in similar situations to theirs. The result is an empathetic environment which is drastically different to that of users' offline lives, where they say that family and friends often don't understand what they are experiencing.

### **Informational Support**

While online support groups offer ways to express emotion and understanding, participants said one of their original reasons for joining them was for medical information and advice which could be used to help them become pregnant. This form of support is defined as *Informational Support* by Caplan and Turner (2007) and is given in the form of practical advice, information, and feedback, such as when women ask about the side effects of in vitro fertilization treatments or the effectiveness of the drug Clomid.

The public is increasingly turning to the Internet as a place to find health information, and people's personal experiences are becoming as trusted as medical advice from health professionals. Many infertility forum posts are also aimed to find health information about drugs or treatments, and interview participants said they used the boards for advice on which steps to take toward getting pregnant.

**Jessica:** I find the forum very useful because it is a wonderful source of information. You can compare how certain medications are making you feel and share in other members experience both physically and emotionally.

**Amanda:** When I went through IVF treatment in October I was really scared and had no idea what I was doing. Giving myself injections each day was so awkward. I would ask others on DS for advice. We exchange helpful tidbits of information all the time - things your doctors and nurses NEVER tell you. For example: if you ice the location of your shot for 1 minute before you won't feel the needle. Or if you use a heating pad to warm up the progesterone in the vial before injecting it will be less painful and spread quickly.

Information-seeking forum posts on the infertility support group discuss ways to increase sperm count, the side effects of the fertility drug Clomid, and irregular menstrual cycles. Many cited the advice of their own doctors as well as their personal experiences, and a comparison with health care professionals' advice and the information found from other users on the web was often made:

**User 1:** I had my IUI last week. DH's post wash numbers were 23 million and 95% motility. It wasn't broken down into very active etc. I was really concerned about the count because I have seen MUCH higher numbers from other posts on DS. But, my RE said the numbers were great, he was very positive.

Monitors hired by DailyStrength post reminders that the forum should not be used for medical advice, and that posters should not rely solely on the medical information given by other users on the site.

The question of whether online forums are the best place for sound medical advice is a topic for a different academic study. What is instead important for this study is that the offer of information can also serve an important supportive role. While questions are information-based, responses often offer both informational and emotionally supportive responses. The result is an expression of empathy, where the user acknowledges that she understands where the other person is coming from and offers advice and encouragement for the next steps like this response to a question about drug side effects:

**User 1:** I had headaches the first cycle and no side effects the second. Unfortunately it caused me not to ovulate- I had regular cycles, still not sure why I was on it? But hopefully it will work for you as it should!!! Good luck!

Users act as both senders and receivers of information on the site. As one respondent noted, "That is the beauty of DS. You are constantly learning and then sharing back what you have learned." While Walther and Boyd (2002) note that CMC does not carry a "reciprocal obligation," where one feels a burden to help out someone who has helped them, it appears that help is naturally reciprocated as users gain more knowledge and thus share that with the rest of the community. This process is voluntary and there isn't any pressure to respond, users seem to feel naturally empathetic to those starting fertility treatments, and thus end up "returning the favor" of providing advice and personal experience.



### **Anonymity and Confidentiality**

One of the biggest advantages cited to using on-line communication, as opposed to talking with family and friends, was the ability to communicate in an anonymous environment. Interview subjects repeatedly discussed the benefits of being able to talk about complex and intimate issues involved with infertility without having to meet in person. One of the greatest benefits was the ability to not be “judged” or looked at differently after being emotional.

**Sandra:** There’s safety in anonymity. They don’t know me or my husband so I can share the raw pain and frustration without worrying about them looking at my husband or me differently the next time they see us.

**Sherry:** It’s refreshing to be able to discuss things about something so personal but not be judged because you are somewhat anonymous.

**Sharon:** You don’t have to impress anyone or carry on an aura of who you are. You can almost hide around the fact that you’re on an online site.

While the word “anonymous” was repeatedly used by interview subjects, it was found that the environment to which they were referring to wasn’t actually anonymous.

Persons interviewed had public profiles which included a variety of personally defining data like their photo, age, first name, location, and interests. This certainly doesn’t fit Merriam-Webster’s definition of anonymous in “lacking individuality, distinction, or recognizability.”

The same was true with Kennedy’s (2006) case study study of women who were making their own Web sites. In that study, Kennedy stated that there is a difference between *being* and *feeling* anonymous online. One can feel anonymous by not needing to display their name/age/gender, etc. but doesn’t have to actually be anonymous in what they post about themselves, as Kennedy found that aspects of her subjects’ offline identities were still prevalent throughout their individual Web sites.

Like Kennedy’s subjects, the women interviewed for this study placed importance on *feeling* anonymous in the sense of being removed from their offline social networks of family and friends. Online support groups aren’t likely to have what Granovetter describes as “bridges” linking those in the online network to offline contacts. Many said that this kind of environment allowed them to be more honest and

forthcoming about their feelings. On-line there wasn't a need to fake happiness for the sake of being with family or friends, or to avoid the subject of wanting to have children.

**Sharon:** You say it and vent and you don't have any repercussions. You can't be angry, mean and nasty with a family member or friend. Online you can go vent and everyone will forget about it.

**Lorry:** My best friend has struggled with infertility and I am able to talk to her about it all, but having a resource that is anonymous allows me to post things and ask questions that I wouldn't to my family and friends. It is always a risk to bring up infertility with my family and friends because they are bound to say unknowingly insensitive things, without meaning to

**Jessica:** My husband and I did not share the fact that we were doing infertility with too many people. Majority of our family and friends do not know what we are trying to do. We knew our struggle was not going to be easy and we didn't want everyone asking us how things were going only to have to relive the negative outcomes over and over again. Plus we just didn't want to have to answer a ton of questions. DS have given me the outlet I need to discuss with people that understand it all. No matter how I feel it is ok on DS. I don't have to explain myself nor feel like I have disappointed anyone.

Caplan and Turner's theory of Online Comforting Communication states that the internet allows for a non-threatening environment which provides a safe and secure place for people to discuss personal and upsetting experiences. Computer-Mediated Communication (CMC) requires less personal and social risk than Face-to-Face (FtF) conversations, leading Caplan (2003) to argue that lonely and socially-anxious people may be especially fit to use online social interaction because "they feel safer, more efficacious, more confident, and more comfortable with online interpersonal interactions and relationships than with traditional FtF social activities (Caplan and Turner, 2007: 989)." Thus, the internet is an appropriate place for women to escape the loneliness and anxiety of dealing with infertility by talking with others about how it affects them. Infertility is what Caplan and Turner (2007) describe as a "stigmatized condition," like AIDS, cancer, and physical disabilities (Caplan and Turner, 2007). As with women dealing with infertility, people with stigmatized conditions are often reluctant to reveal their condition to others and therefore have anxiety when using FtF interaction. Compared to FtF interaction, online comforting provides weaker social ties, greater control over self-presentation and a less anxiety-provoking environment (Caplan and Turner, 2007).

This environment makes for an easier time discussing topics which might be perceived as taboo. Some users discuss how they secretly hate the arrival of Spring, because it means that they have to watch neighborhood children playing outside, and in

several posts users also talk about hidden jealousy towards friends and family members who are pregnant:

**User 1:** So I thought I was going to make it through planning this baby shower without losing it, but I finally broke down today. I went shopping for the gifts yesterday and wrapped them today and it's just too much. Maybe I'm selfish, but I want the cute stroller and cradle and tiny sleepers. Has anyone felt this?

**User 2:** Absolutely!!! At my best friends baby shower I felt as if I crying every hour. I just told everyone it was happy tears for my BF. I was bummed out wondering why it had not happened to me yet. It's hard to stay positive when everyone around you is popping out a baby left and right. Hang in there and be strong!!!

**User 3:** . . . it has really made me feel like less of a woman not being able to have a babe... I do get jealuse of my friends and sisters..and it makes me so sad.. to see so many people who shouldt have kids get pregnant or have kids... i dunno.. today is a really bad day for me..

**User 4:** Knowing others who are pregnant is like being kicked in the face several hundred times.

The anonymous environment of the Internet allows users to discuss these private feelings without having to worry about confronting each other in person or having secrets leak back to their offline networks of family and friends, and even spouses, who are often referenced in posts.

### **Social Networking and Shaping of Technology**

Data also shows that strong friendships are formed when women meet people with similar conditions online, and these friendships involve the sharing of empathy. While forum posts on the Infertility Support Group page tended to focus on medical information, most data gathered from interviews showed that users join the groups for social support and online friendships. Interviewees repeatedly talked about how online support groups allowed them to meet people who were experiencing the same feelings as theirs and could understand what they were going through.

**Sherry:** I can only assume it will be a "sisterhood" of sorts that will continue as infertility is a condition that doesn't go away and IVF is typically not successful the first time plus people want to have more than one child. . . .It's good - it's like a whole new network of friends that you can tell your innermost secrets to about your body and/or questions about your body that will help you.

**Erin:** It is easier to get the emotions out and advice are better to obtain as the site is joined by ladies with the same interest. Other individuals' stories are uplifting and also bring about the locked up emotion within yourself when they feel down, alone, sad etc.

**Jessica:** When I read about other people's struggles we often share so many of the same feelings so it makes me feel like I am not alone and also not going crazy. . . Sometime I have a very hard time putting how I feel into words and

some of the women here express it all so eloquently. I feel like they help give me a voice. I am also a very optimistic person so I do like to share that optimism with other in hopes I can lift their spirits some.

While online relationships begin with what Granovetter describes as “weak ties,” they quickly resemble the strong-tie characteristics of friendship and support. As Haythornwaite said, users of on-line media may form weak ties, but they are forced to use “strong tie behavior” to make initial contact by offering frequent communication, self-disclosure, and negotiation of communication norms. The effort usually reserved for strong kinship and social relationships is extended to these weak ties online, as internet users make their interactions more closely match conversations found in the real world, says Haythornwaite. The result is a weak tie with strong-tie behavior. Online friendships are formed with a casual acquaintance, like most weak ties are, but can develop into relationships which make it discuss personal and intimate details, another characteristic of a strong tie.

Haythornwaite said that this behavior can be reinforced by using emoticons and acronyms, which provide “code” for personal exchanges. This creates norms and standards which are reinforced by continued use. Users’ infertility support groups have a host of acronyms for fertility treatments. One fertility Web site<sup>11</sup> lists a dictionary of “Newsgroup-specific Acronyms and Abbreviations,” which includes about 200 abbreviations commonly found in fertility support groups and forums. Newcomers are referred to that site when they first join. It is observed that users who have been on the site for a long time often use several acronyms and abbreviations in their posts, while new users have longer sentences with little use of shorthand. For example, user 1 is a new user to the site while user 2 has been on the site for 14 months.

**User 1:** Hi - I am new here. I had a miscarriage in September, and have not been able to get pregnant since. So, we went to the fertility doctor to see what was going on. It ends up I have a slightly elevated prolactin level, and my HSG reveled a possible blockage in my left tube. I am going to have a laposcopic procedure to see if they can clear that up - anyone have any experience with that??

**User 2:** My husband and I just recently found out that he has low morphology (first test showed 0% on the strict Kruger scale, second test showed 1%). Our RE has recommended IVF with ICSI, which I have read a lot about and chatted with many women here and elsewhere about not only being the most recommended,

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<sup>11</sup> "Acronyms & Abbreviations - Fertility Plus." FertilityPlus: Information Written by Patients, for Patients. Web. 19 Apr. 2011. <<http://www.fertilityplus.org/faq/acronyms.html>>.

but often most successful method in this situation. My RE said that being that all of my numbers and test results seem "really good," we have about a 60% chance at success.

User 2 uses several abbreviations and acronyms in her post while user one only uses one. User 1 also doesn't use common abbreviation for miscarriage (m/c) that most seasoned users use on the site.

The use of common acronyms and abbreviations argues in agreement with Lievrouw's Social Shaping of Technology theory, which states that technologies not only create social effects, but are affected by outside social forces themselves. Lievrouw argues that sociologists do not need to restrict themselves to studying the effects of technologies, and should instead look at how technologies are shaped by the people who use them. Women with infertility issues had a need to communicate in a precise and common language, free of lengthy terms for treatments like "Antiphospholipid Antibodies" (abbreviated on forums as APA) and "Activated Partial Thromboplastin Time" (abbreviated on forums as APTT). Abbreviated norms help users understand each other and focus on goal of the message instead of being intimidated by scientific words within it. There are four aspects, or "moments" of the Social Shaping of Technology theory, all of which are present in DailyStrength's online support groups.

First, Lievrouw describes *Actors* as anyone who makes choices which affect new media development. While site creators are the first actors in the shaping of technology, individual users are important actors as well. Users can shape the development of new media by deciding which aspects of a Web site are important (and thus generate the most traffic) and how these aspects are used. Women discussing infertility on DailyStrength decide which topics are discussed and how much emphasis is placed on each topic, with a moderator providing little guidance aside from removing posts deemed inappropriate.

As actors interact and technology evolves, *dynamics* are formed. Dynamics involve the movement and momentum of an idea, expression, and its adoption. DailyStrength's users have further shaped the technology by creating their own support groups on the site. Those whose needs are not fulfilled by the general infertility support group can form their own "user groups" within DailyStrength. Member groups include

“IVF buddies,” “adoption after infertility,” and “I’m Pregnant!!!” These dynamics lead to greater *choice*, a third “moment” in the Social Shaping of Technology theory. Choice is characterized by contingency and determination in both the direction and design of technology. Social dynamics, like those found in online support groups, lead to a wide variety of choice, and contingency to these dynamics allows for more choice while determination with a fixed plan limits choice.

These ideas are spread through *Distributive Mechanisms*. As with formal properties, site usage of virtual health communities have the distributive mechanisms of word of mouth and popularity. Users decide how to better and more easily use DailyStrength and thus the technology is shaped around the majority’s needs and desires.

*Consequences* are the effects, impacts, and other outcomes of technology. The friendships formed through this technology are the consequences of creating an environment which fosters discussion amongst like-minded individuals. Thus the friendships are not only shaped by the technology but serve to further shape the technology for future audiences.

### **Emotions and Social Support**

Embedded within the friendships found online are the expressions of the feelings and emotions which come about when dealing with infertility. Several participants described infertility as a “roller coaster” of emotions, citing the highs of finding a new treatment and the lows of learning about a miscarriage or negative pregnancy test. Interview data and forum posts showed that infertility treatments and the worry over being able to become pregnant can become an obsession. Participants talked about how the process of getting pregnant and the emotions that went along with the successes and failures encompasses a large part of their daily lives and is very stressful.

**Sherry:** Right now, it seems to have taken over b/c your thoughts are consumed by it. I am giving myself 3 shots a day and going to the dr every morning for 10 days straight for bloodwork and ultrasound. It is very exciting but also very time consuming. There are many women on this site that have gone through 3-10 rounds of IVF for various reasons - some miscarried several times due to a chromosome issue or disease of sort. It's very sad.

**Forum User:** How many more roadblocks will there be? I'm so tired. There is no more anxiety or a need to conquer it anymore. I am sad to think that it may not ever happen. Don't get me wrong, I won't give up as long as there is hope, but I just feel so beat up. Infertility is like Chinese water torture! I feel like there's this invisible child around me who I can't touch, see, or hear, and fear that I will never meet.

Forum members often encourage each other not to “give up” and to continue with treatments. The phrase, “miracles can happen” appears often in response to posts where users express defeat and failure. This empathetic response comes from other users who have either had success getting pregnant or are going through the same situation. Participants said that finding network of other women with infertility issues online not only helped them to express their emotions, but also helped them feel like they were less alone in their struggle.

**Sandra:** If you spend any time on the IF<sup>12</sup> pages you will see that there are a roller coaster of emotions. Hope, optimism, despair. The hormones you have to take don't help. But as you go into a new cycle you believe that “this will be the time it works” and as you go through the cycle you start to waiver. And when it doesn't work you plunge into darkness.

**Sherry:** right now I am half way through the 2 week wait period. . . They transferred all four on Sunday 3/20 and I will know in a week if I am pregnant. One think is it is quite an amazing rolling coaster. Many woman have tried various IVF techniques 2,3,4,5 etc times. This is only my first. So far, it's cost us \$24,000 USD. I couldn't imagine finanacially, or emotionally doing this that many times.

Users provided each other social support - or the exchange of verbal and nonverbal messages of emotion, information, or referral (Walther and Boyd 2002) designed to reduce stress and show that a person is cared for and about. Walther and Boyd (2002) uses Cutron and Suhr's (1992) classification system of the forms social support, most of which are found in DailyStrength's infertility support group. As discussed earlier, the site offers *Informational Support* in the form of practical advice, information, and feedback, like when women ask about the side effects of in vitro fertilization treatments or the effectiveness of the popular fertility drug Clomid. *Social Network* support is also used when referring users to other support groups or friends, which happens occasionally on the forums.

The three most prevalent forms of social support found in the online support group studied were emotional support, esteem support and group support.

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<sup>12</sup> Abbreviation for Infertility

*Emotional support* involves the expression of empathy, sympathy, caring and concern, like when a person shows emotional understanding of another's situation. Interview participants said one of the greatest advantages of using online support groups was meeting someone who had "been there" and could help them get through the "roller coaster" of emotions which was repeatedly described.

**Jessica:** IF is such an emotional rollercoaster that it is reassuring to know that you are not alone in the way you feel. When you see other members who have struggled and finally succeeded it can give you hope.

**Amanda:** DS is really just a way for me to communicate with others who are going through the same sticky situation I am. . . .Most women are told to stop stressing as if they are creating the problem themselves. This lack of support can cause additional stress and depression as women start to feel guilty, ashamed and hopeless. Each month they go through a roller coaster of emotions waiting for see if they are pregnant.

Expressions of emotional support helped Amanda feel like her feelings were normal and reassured Jessica that there was "hope" in being able to have a child. This reassurance comes in the form of both reading other success stories and empathetic support from peers on the site. Participants often cited being "up" and "down" emotionally. They said that getting emotional support helped bring out those emotions.

Giving women hope and encouragement can also be classified as *esteem support*. These expressions involve admiration and understanding of another's worth (Walther and Boyd, 2002). Interview participants said that this type of support often came from women who struggled with infertility and were eventually able to get pregnant. Many of these users are still active in the forums, encouraging other women to try what they did and not to lose hope. Still, users acknowledge that the feeling of seeing others with children, even those who have had difficulty conceiving, can be difficult.

**Sandra:** I stayed in touch with many of my friends after they got pregnant and had babies. I was finally successful at one point. I have a 15mo son. So a lot of us have moved onto the newborn/toddler boards together. Most do continue to support their friends who are still trying.

**Lorry:** It's a double edged sword. I feel very happy for them that they have achieved their goal of pregnancy, but it's also another reminder that I am still not pregnant and am left behind..... There have been some ladies who still get online even after having their babies to support others going through infertility.

**Jamie:** I have quite a few friends that we still chit chat and comment on each others journals. It's hard when all of a sudden you are the only one out of the group still trying to conceive. But, you gain new friends to run with along the journey and just move forward.



**Jessica:** Being newly pregnant myself (I am almost 9 weeks) I still go onto DS and post updates on my pregnancy and I keep in touch with other friends. Since this is my first pregnancy after many, many years of trying I am sure I will keep in touch with my DS sisters for awhile.

Many of the participants, both in interviews and in forum posts, refer to other users as their “sisters” and talk about forming a “sisterhood” with users on the site. Some refer to other users as “friends” and form private groups on Facebook and DailyStrength, while others who live close to one-another meet in person. Still, membership in on-line groups involves a constant reconstruction of relationships and social ties as ties are reinforced by closer contact or lost altogether when users permanently sign off, which leads to the additions and deletions of online relationships (Haythornwaite).

Group support is another element of social support found online (Walther and Boyd, 2002). Self-help groups both offline and online share some characteristics: all members of the group often experience the same problem and are looking to provide and receive help, and members draw validation from one another (Walther and Boyd, 2002). Interview participants said they were able to have their spirits lifted when they visited the online group on a bad day and help others when they had a good day.

**Erin:** Other individuals' stories are uplifting and also bring about the locked up emotion within yourself when they feel down, alone, sad etc

**Sharon:** By using my own experiences. there might be days where you're up others are down, and you help them by picking them back up. You have no control over it, something you want cant control it. So there's a lot of emotions.

**Lorry:** When you feel like you can't do another treatment cycle, both because you are emotionally exhausted and financially strained, you get the needed encouragement and hear success stories that allow me to be able to try one more month with the hope that this could be my month where I conceive

**Sandra:** It let me know I wasn't alone. I could be raw, open and honest here and wouldn't be judged. . . I could never have survived our battle with IF with out my friends here. They cried with me with every BFN and celebrated when I finally got my BFP. What was most important was talking me "off the ledge" during the dark days. Letting me know there was still hope.

The examples of group support cited by users of DailyStrength help to verify the disadvantages Walther and Boyd argued of Face to Face (FtF) communication in terms of providing and receiving social support. The researchers said that close ties are likely to offer unqualified acceptance of a friend or family member with a problem and can be less forthcoming and have less knowledge of the actual problem, given that they do not

have personal experience from it. Interview participants said that their parents and siblings didn't understand what they were going through, which made conversations about infertility awkward. They also said it was nice not to have to feel like they were a burden on their family, and Walther and Boyd noted that receiving social support from a close relation carries the disadvantage of a reciprocation obligation of having to provide social support in return. Computer-mediated communication doesn't have these disadvantages, as in online forums it is expected that a person is seeking support and "relational dependency and obligation" to reciprocate support isn't as much of a factor (Walther and Boyd, 2002). Instead, users can choose when and how much support they provide to other users, with the reassurance that if they don't help someone there are thousands of others on the forum who can.

## **Conclusion**

This study shows that with the onset of the Internet, people with stigmatic conditions have a safe place to discuss their emotions and journeys and feel less isolated. Furthermore, the anonymous environment of these online support groups helps people to more freely express their emotions and ask questions that they wouldn't ask in person.

The qualitative data collected for this report shows how one online support group provided women with informational support, a new social network, and emotional and social support from when they first decide to get pregnant to when they have a child or decide to stop trying. This support is strengthened by the ability of women to choose how much or how little they disclose about themselves, thus giving a feeling of anonymity.

Lievrouw's Social Shaping of Technology theory argues that while technology has a role in shaping society, society also has an equal role in shaping technology. I found that women are shaping the technology they use to discuss infertility by creating text-friendly language, online methods of showing support, and a flexible level of anonymity. The users, not the site's creators, are the ones in control of how technology is used and perceived. In shaping this technology to fit their needs, women adapt

“strong-tie” social networking behavior usually reserved for family and friends to better understand strangers online. The technology, over time, thus adapts to fit the users’ needs.

This technology is not perfect. As women become pregnant, they become less active or leave the group altogether, causing other users to have to find new connections. Those who stay online to help others after they become pregnant are also met with mixed feelings from other users, who said talking to them made them both jealous and hopeful. Informational support from peers can also be confusing, as it is difficult to distinguish whether medical information posted by another user is valid or not.

The advantages of online support groups instead lie in the hope and encouragement provided by other users in the form of empathetic social support. Empathy, defined in this study to be the understanding and legitimization of others by someone who has been in a like-situation. Empathy was cited as one of the most important outcomes of being a member of an online support group. Those interviewed for this study cited their online friendships as being useful in helping them feel less isolated and more normal. Furthermore, an empathetic environment made women more eager to share their private feelings. This open outlet for talking about things they wouldn’t speak about offline was said to be a form of relief, and fills a gap that the traditional doctor-patient relationship cannot provide.

Social media can therefore be used as a tool by healthcare providers in understanding and treating the psychological effects of fertility treatments. Healthcare providers can use online support groups and social networking tactics in the following ways:

- By acting as “lurkers,” doctors can read forum posts and gain better understanding into the thought patterns of patients dealing with infertility issues.
- Healthcare professionals can refer couples dealing with fertility issues to online support groups for more information and to find peers going through similar issues. This is especially useful in rural areas, where it may be more difficult to find an offline group.

- This study shows that anonymity makes women more forthcoming about their feelings and emotions. Using online social media, doctors can create their own social media platform, where women can ask questions anonymously.
- Healthcare professionals can use their patients' online journals and goal-tracking as a way to further understand their individual fertility process. Taking 10 minutes to read a month of journal entries may prove more beneficial than asking a patient to remember and explain, in ten minutes, what they have done and felt in the last month.

Further research could also be made into how users deal with the changing population of support groups and how this technology is used after a person is able to get pregnant. While this study does discuss this, a larger quantitative study would give better insight into the constantly changing population of online support group users and their motivations for joining and leaving the site. With statistics on the extent to which users leave online groups and their motivations, it is easier to further address the needs of the users who are still on the site and help them to retain a stable support system despite the group's changing population.

This case study shows battles with infertility can be stressful, emotional, and lonely. Women have cited being reluctant to speak to close family and friends about the process which can cause physical, emotional, and economic pain. While the traditional doctor-patient relationship can provide medical advice and information, there is a void in its ability to provide women with the social and emotional support that is vital when suffering from infertility. Women have, since the beginning of time, dealt with these emotions through denial and ignorance - until now. With the development of the Internet, online support groups offer a way to fill the need women with infertility issues have for emotional support and empathy, and thus make their struggles with infertility a little easier.

## Works Cited

- "Anonymous - Definition and More from the Free Merriam-Webster Dictionary." Dictionary and Thesaurus - Merriam-Webster Online. Web. 18 Apr. 2011. <<http://www.merriam-webster.com/dictionary/anonymous>>.
- Anderson, G., 1993. *Fundamentals of Educational Research*. Falmer Press, London, pp: 152-160.
- Bandura, Albert. "Social Cognitive Theory of Mass Communication." *Media Psychology* 3.3 (2001): 265-99.
- Baym, Nancy K. "Interpersonal Life Online." *Handbook of New Media: Social Shaping and Social Consequences of ICTs*. London [u.a.: SAGE, 2006. 35-54.
- Beniger, J. R. "Personalization of Mass Media and the Growth of Pseudo-Community." *Communication Research* 14.3 (1987): 352-71.
- Burrows, Roger, Sarah Nettleton, Nicholas Pleace, Brian Loader, and Steven Muncer. "Virtual Community Care? Social Policy and the Emergence of Computer-mediated Social Support." *Information, Communication, and Society* 3.1 (2000): 95-121.
- Canfield, John V. "The Self and Emotions." *Emotions and Understanding: Wittgensteinian Perspectives*. Basingstoke [England: Palgrave Macmillan, 2009. 102-13. Print
- Caplan, S., and J. Turner. "Bringing Theory to Research on Computer-mediated Comforting Communication." *Computers in Human Behavior* 23.2 (2007): 985-98.
- Caplan, S. "Problematic Internet Use and Psychosocial Well-being: Development of a Theory-based Cognitive-behavioral Measurement Instrument." *Computers in Human Behavior* 18.5 (2002): 553-75.
- Cerulo, Karen A. "Reframing Sociological Concepts for a Brave New (Virtual?) World." *Sociological Inquiry* 67.1 (1997): 48-58.
- Diani, M. "Simmel to Rokkan and Beyond: Towards a Network Theory of (New) Social Movements." *European Journal of Social Theory* 3.4 (2000): 387-406.
- Dijk, Jan Van. *The Network Society Social Aspects of New Media*. Los Angeles [u.a.: SAGE, 2009.
- Flick, Uwe. *An Introduction to Qualitative Research*. London: Sage, 1998.
- Granovetter, Mark S. "The Strength of Weak Ties." *American Journal of Sociology* 78.6 (1973): 1360.
- Haythornthwaite, Caroline. "Strong, Weak, and Latent Ties and the Impact of New Media." *The Information Society* 18.5 (2002): 385-401.
- Kennedy, H. "Beyond Anonymity, or Future Directions for Internet Identity Research." *New Media & Society* 8.6 (2006): 859-76.
- Kivits, Joelle. "Online Interviewing and the Research Relationship." *Virtual Methods: Issues in Social Research on the Internet*. Oxford: Berg, 2005. 35-50. Print.

- Klemm, Paula, Melanie Hurst, Sandra Dearholt, and Susan Trone. "Cyber Solace: Gender Differences on Internet Cancer Support Groups." *Computers in Nursing* 17.2 (1999): 65-72.
- Knapp, Mark L., and John A. Daly. "Cues Filtered Out, Cues Filtered In." *Handbook of Interpersonal Communication*. Thousand Oaks, CA: SAGE Publications, 2002.
- Kraut, Robert, Sara Kiesler, Bonka Boneva, Jonathon Cummings, Vicki Helgeson, and Anne Crawford. "Internet Paradox Revisited." *Journal of Social Issues* 58.1 (2002): 49-74.
- Kunyk, Diane, and Joanne K. Olson. "Clarification of Conceptualizations of Empathy." *Journal of Advanced Nursing* 35.3 (2001): 317-25.
- Lievrouw, Leah A. "New Media Design and Development: Diffusion of Innovations v Social Shaping of Technology." *Handbook of New Media*. London: SAGE, 2006. 246-63.
- Malik, Sumaira, and Neil Coulson. "Coping with Infertility Online: An Examination of Self-help Mechanisms in an Online Infertility Support Group." *Patient Education and Counseling* 81.2 (2010): 315-18. 9 Feb. 2010. Web. 13 Apr. 2011
- Malik, S., and N. Coulson. "Computer-mediated Infertility Support Groups: An Exploratory Study of Online Experiences." *Patient Education and Counseling* 73.1 (2008): 105-13.
- McMillan, Sally J. "Exploring Models of Interactivity from Multiple Research Traditions: Users, Documents, and Systems." *Handbook of New Media*. London: SAGE, 2006. 205-30.
- Preece, J. "The Top Five Reasons for Lurking: Improving Community Experiences for Everyone." *Computers in Human Behavior* 20.2 (2004): 201-23.
- Preece, Jenny. "Empathic Communities: Balancing Emotional and Factual Communication." *Interacting with Computers* 12.1 (1999): 63-77.
- Resnyansky, Lucy. "Online Identity as a Semiotic Phenomenon." *2010IEEE International Symposium on Technology and Society* (2010): 253-59. Web.
- Rice, Ronald E., and Caroline Haythornthwaite. "Perspectives on Internet Use: Access, Involvement and Interaction." *Handbook of New Media*. London: SAGE, 2006. 92-113. Print.
- Seale, Clive. *Media and Health*. London: SAGE Publications, 2002.
- Shapiro, Andrew L. *The Control Revolution: How the Internet Is Putting Individuals in Charge and Changing the World We Know*. New York: PublicAffairs, 1999.
- Sproull, L., and S. Kiesler. "Reducing Social Context Cues: Electronic Mail in Organizational Communication." *Management Science* 32.11 (1986): 1492-512.
- Stake, Robert E. "A Case Study Method in Social Inquiry." *Case Study Method Key Issues, Key Texts*. Los Angeles [u.a.: Sage, 2007. 19-25. Print.
- "Testing the Strength of Weak Ties Theory in Small Educational Social Networking Web Sites." Proceedings of the ITI 2009 31st International Conference on Information Technologies. Dubrovnik. 7 Aug. 2009. Speech.
- Trout, J. D. *Why Empathy Matters: the Science and Psychology of Better Judgment*. New York: Penguin, 2010.

- Turkle, Sherry. "Virtuality and Its Discontents." *The American Prospect* 24 (1996): 50-57.
- Turnage, Anna K. "Email Flaming Behaviors and Organizational Conflict." *Journal of Computer-Mediated Communication* 13.1 (2008): 43-59.
- Turner, Jonathan H. "Émile Durkheim's Theory of Social Organization." *Social Forces* 68.4 (1990): 1089-103.
- Van Dijk, Jan. "A Framework for Digital Divide Research." *University of Twente - University of Twente*. Web. 24 Feb. 2011. <[http://www.utwente.nl/gw/vandijk/research/digital\\_divide/Digital\\_Divide\\_overigen/a\\_framework\\_for\\_digital\\_divide.doc/](http://www.utwente.nl/gw/vandijk/research/digital_divide/Digital_Divide_overigen/a_framework_for_digital_divide.doc/)>.
- Walther, J. B. "Computer-Mediated Communication: Impersonal, Interpersonal, and Hyperpersonal Interaction." *Communication Research* 23.1 (1996): 3-43.
- Walther, J. B. "Interpersonal Effects in Computer-Mediated Interaction: A Relational Perspective." *Communication Research* 19.1 (1992): 52-90.
- Walther, J. "Selective Self-presentation in Computer-mediated Communication: Hyperpersonal Dimensions of Technology, Language, and Cognition." *Computers in Human Behavior* 23.5 (2007): 2538-557.
- Walther, J.B., and M.R. Parks. "Cues Filtered Out, Cues Filtered In: Computer-mediated Communication and Relationships." *Handbook of Interpersonal Communication*. Thousand Oaks, CA: SAGE Publications, 2002.
- Walther, Joseph, and Shawn Boyd. "Attraction to Computer-Mediated Social Support (Walther & Boyd)." *Michigan State University. Est. 1855. East Lansing, Michigan USA*. Web. 17 Feb. 2011. <<https://www.msu.edu/~jwalther/docs/support.html>>.
- Walther, Joseph B. "Group and Interpersonal Effects in International Computer-Mediated Collaboration." *Human Communication Research* 23.3 (1997): 342-69.
- "The WELL - Learn About The WELL." *The WELL - the Birthplace of the Online Community Movement*. Web. 07 Mar. 2011. <<http://www.well.com/aboutwell.html>>.
- Wellman, Barry. "Physical Place and Cyberplace: The Rise of Personalized Networking." *International Journal of Urban and Regional Research* 25.2 (2001): 227-52.
- Wright, E. "Review Article: Our Computers, Our Selves: Sherry Turkle," *The Second Self: Computers and the Human Spirit*. Cambridge, MA: MIT Press, 2005.
- Wyatt, Sally, Angie Hart, and Julie Smith. "Health Information and the 'informed Patient'" *Health and the Media*. Malden, Mass. ; Oxford: Blackwell, 2004.

## Appendix 1: Interview Transcripts

Sandra

Age: 41

State/Country: VA/USA

Marital Status: MARRIED

Education: College Graduate

### 1. How did you first hear about DailyStrength?

Google. I googled infertility support when I found out we weren't going to get pregnant the old fashion way.

### 2. What do you use DailyStrength for (virtual hugs, journal, forums, etc)?

Initially support after suffering a miscarriage, then support through my fertility treatments, pregnancy, birth, breastfeeding, newborn and now toddler information. For infertility it was really about support, questions and information on drugs, side effects, possibly treatments, and what test results mean. I've learned more from the women here than from my RE. I learned what questions to ask. Now I use DS for information on my child. I also have made so many friends here I use it like a social network to check in on them too

### 3. Which of the site's features do you find most useful and why?

The specific boards, great information. Hugs are nice too

### 4. How has DailyStrength helped in your battle with infertility?

It let me know I wasn't alone. I could be raw, open and honest here and wouldn't be judged. The information from the other women was invaluable. I could never have survived our battle with IF with out my friends here. They cried with me with every BFN and celebrated when I finally got my BFP. What was most important was talking me "off the ledge" during the dark days. Letting me know there was still hope.

### 5. How does it make you feel to communicate with others online about infertility?

It was so amazing to have support and understanding from others who were facing similar issues. None of my friends really understood what we were going through.

### 6. Have you also used the site to help other people with their infertility issues?

Yes, that is the beauty of DS. You are constantly learning and then sharing back what you have learned.

### 7. Have you made friends on the site? Do you only talk to them online, or are there others you see in person or talk to on the phone?

I've made so many friends here. There are few I speak with on Facebook too, and there are two that are now friends in my "real" life. Soon to be three.

### 8. How often do you visit the site and how long do you spend on it when you are there?

My company would probably fire me, but I'm on DS every week day. Maybe an hour total. But when I know a friend is expecting test results I check back all the time.

### 9. Are there ways in which going to online communities like DailyStrength that differ from talking to family/friends?

There are two answers to that question. One is the anonymity. You can be brutally honest and share things here you wouldn't necessarily tell close friends or family. Especially the strain it can put on your marriage and some of the nastier side effects of the drugs. The second is that these women are going through it with you and understand in a way that friends/family can't.

### 10. Can you describe for me a typical visit to the site ("I log on, check my messages, update my journal . . . etc.)?

I log on and check the main page to see who is up to what, I check any hugs that I may have gotten, any messages and then I check the boards. The IF, Parenting Infants, Parenting Toddlers, Breastfeeding and the Donor Egg board



**11. How did you talk about your issues with infertility before you found DailyStrength?**

I didn't really. Some friends new when we were in treatment but it was something we didn't really share. Daily Strength gave me an outlet to share all of the emotions etc that come with IF.

*Follow-up Questions:*

**1. Can you tell me what these acronyms mean? I think I know, but I want to make sure we're both thinking the same definitions: RE, BFN, BFP**

RE- Reproductive Endocrinologist  
BFN- BIG FAT NO  
BFP- BIG FAT POSITIVE

**2. Can you tell me more about the friends you have made on this site? How do you communicate with them and what do you talk about? How are these friends different from your regular "offline" friends?**

I USUALLY COMMUNICATE VIA PRIVATE MESSAGES, JOURNALS AND HUGS. THEY ARE DIFFERENT BECAUSE THEY COMPLETELY UNDERSTAND WHAT THE BATTLE WITH IF MEANS. UNLESS YOU HAVE BEEN THROUGH IT, YOU CAN'T UNDERSTAND IT.

**3. You mention that two people you have met on DS are now your friends in real life. How did these relationships come about and in what way are you friends with them now? Do they live near you, do you talk on the phone, etc.?**

NOW WE ALL HAVE CHILDREN SO WE DO PLAYDATES, HAVE LUNCH ETC. WE JUST SHARE A SPECIAL BOND KNOWING WHAT WE WENT THROUGH TO HAVE OUR CHILDREN

**4. You mention that "hugs are nice too." What do virtual hugs mean to you and how do you use them? How does it make you feel to receive them and how are they different from receiving a private message or a comment on your journal or forum post?**

HUGS ARE FUN, BUT THEY CAN BE INCREDIBLY HELPFUL WHEN YOU ARE HAVING A BAD DAY. JOURNAL POSTS AND PRIVATE MESSAGES ARE DIFFERENT IN THAT A JOURNAL POST IS A COMMENT OR SUPPORT ON SOMETHING YOU ARE WRITING ABOUT AND HONESTLY MOST PRIVATE MESSAGES ARE ABOUT OTHER USERS WHO MAY BE ANNOYING US. THIS IS SITE IS ALL ABOUT SUPPORT AND THERE ARE A FEW USERS WHO ARE NOT ALWAYS SUPPORTIVE

**5. You also talked about how none of your friends understood what you were going through. How are people you meet on DS different from your family/friends and how is your relationship with them different? THERE IS SAFETY IN ANONYMITY. THEY DON'T KNOW ME OR MY HUSBAND SO I CAN SHARE THE RAW PAIN AND FRUSTRATION WITHOUT WORRYING ABOUT THEM LOOKING AT MY HUSBAND OR ME DIFFERENTLY THE NEXT TIME THEY SEE US.**

**6. How does it feel for you to now see others struggling with IF issues that you struggled with before? How do you respond to them? I WANT TO WRAP MY ARMS AROUND THEM AND LET THEM KNOW THEY ARE NOT ALONE. THAT IS ONE OF THE WORST PARTS WHEN YOU HEAR FROM YOUR RE THAT GETTING PREGNANT THE OLD FASHION WAY ISN'T GOING TO WORK FOR YOU. I TRY TO RESPOND WITH HONESTY AND SUPPORT.**

**7. You said DS gave you an opportunity to share all the emotions that come with IF - can you explain what some of those emotions are?**

IF YOU SPEND ANY TIME ON THE IF PAGES YOU WILL SEE THAT THERE ARE A ROLLER COASTER OF EMOTIONS. HOPE, OPTIMISM, DESPAIR. THE HORMONES YOU HAVE TO TAKE DON'T HELP. BUT AS YOU GO INTO A NEW CYCLE YOU BELIEVE THAT "THIS WILL BE THE TIME IT WORKS" AND AS YOU GO THROUGH THE CYCLE YOU START TO WAIVER. AND WHEN IT DOESN'T WORK YOU PLUNGE INTO DARKNESS.

**How did it feel when others got pregnant before you did? Did you stay in touch with them?**

Honestly it depends on how close you were. It was definitely a double edged sword when it happened. You were so happy for them but sad for you. But I stayed in touch with many of my friends after they got pregnant and had babies. I was finally successful at one point. I have a 15mo son. So a lot of us have

moved onto the newborn/toddler boards together. Most do continue to support their friends who are still trying.

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**Sherry**

**Age:** 40

**State/Country:** IL, USA

**Marital Status:** Single-engaged

**Education:** Bachelor of Science

1. **How did you first hear about DailyStrength?** googled Invitro support groups
2. **What do you use DailyStrength for (virtual hugs, journal, forums, etc)?** A forum to meet others in the same/similar situation to ask questions, learn from their experiences, make friends.
3. **Which of the site's features do you find most useful and why?** Everything - the support groups perhaps in particular.
4. **How has DailyStrength helped in your battle with infertility?** Helped to understand more of what to expect and also give me an outlet to discuss feelings/medications. Sometimes it feels like it has taken over your life.
5. **How does it make you feel to communicate with others online about infertility?** Making new friends. I have noticed some weirdo men on IM that want to talk. I don't like that and am only allowing my info to be read by my "friends"
6. **Have you also used the site to help other people with their infertility issues?** Yes, I recommended to a friend.
7. **Have you made friends on the site? Do you only talk to them online, or are there others you see in person or talk to on the phone?** So far just online as many are across the country or world however, I met someone local and we plan to meet. She is pregnant with triplets and we are all thrilled for her. I want to help her anyway I can.
8. **How often do you visit the site and how long do you spend on it when you are there?** a couple times a day - maybe 15 min/time
9. **Are there ways in which going to online communities like DailyStrength that differ from talking to family/friends?**  
Again, these are people going through very very similar situations and there is much empathy for each other. Sometimes it seems like a burden to family. They don't make me feel this way but I don't want it to be a burden.
10. **Can you describe for me a typical visit to the site ("I log on, check my messages, update my journal . . . etc.)?** Log on, check messages, look at support group updates and possible journal addition.
11. **How did you talk about your issues with infertility before you found DailyStrength?**  
I didn't really talk to anyone other than "I cannot conceive naturally"

*Follow-up Questions:*

1. **At what stage of infertility did you decide to look for invitro support groups online?**

This is my first round, and this is first time I searched out a support group. I heard on Today Show (am show here in the states) that if you join one and talk about your experiences, your likelihood of getting preggers goes up from 20% to over 50%!!

**2. You mention that the support groups are particularly helpful, why is that? How have they helped you?**

There are a lot of things your body is experiencing on all the medications you have to take. Emotionally, physically and spiritually it is helpful. It gives you an outlet and open forum to discuss things. There are many different support groups within. For ex, I am 40 years old, and there is one just for "older" women trying to conceive.

**3. You say, in question two, that sometimes "you feel as if though it has taken over your life." What do you mean by this?**

Many people going through fertility issues really want to be parents. It is a dream to be able to see your eyes in your babies eyes or that cute little dimple your husband has in your daughters cheeks. Right now, it seems to have taken over b/c your thoughts are consumed by it. I am giving myself 3 shots a day and going to the dr every morning for 10 days straight for bloodwork and ultrasound. It is very exciting but also very time consuming. There are many women on this site that have gone through 3-10 rounds of IVF for various reasons - some miscarried several times due to a chromosome issue or disease of sort. It's very sad.

**4. You say that you have made new friends on DailyStrength - What kind of friendship is it? Do you talk about Infertility, or other things as well? How are they different from your non-online friends?**

It is strictly a supportive online friendship that we discuss our processes we are going through to become pregnant. It is a very long process so you will find people in many different situations - maybe some like me going through their first round of IVF, someone having gone through it multiple times (fresh or frozen), miscarried etc.

**5. Do you help other people on DailyStrength with their infertility issues? How? Yes, by reading their journal of experiences, sending a hug, letting them know people are out there feeling empathy and compassion for them. Inspire them by sharing an experience, show them support by encouraging them to stay strong if they just miscarried or to not give up if they did not get pregnant this time around. One lady on here tried 13 times (variety of ways) IUI, IVF, shots and just got pregnant!**

**6. How is keeping a journal on DS useful? Keeps track of medications, feelings, emotions**

**7. You said that you didn't really talk about infertility with people before DS. How does DS make it easier to talk about things and what did it feel like when you first started using the site and talking about your issues?**

Well, I was unmarried previously so I wasn't trying to conceive so no reason to talk about it. Once I met my fiance, we met, moved in, getting married and began IVF all within a year of meeting. As I mentioned previously, joining a support group increases your chances more than double of getting pregnant b/c you are not suppressing your feelings but talking about them which is healthy. It's refreshing to be able to discuss things about something so personal but not be judged because you are somewhat anonymous.

*Third Follow-up*

**Is there anything you would like to add or that you feel I have left out?**

right now I am half way through the 2 week wait period. We were lucky enough to get 11 embryos and 4 got to the 8 cell stage which is good. They transferred all four on Sunday 3/20 and I will know in a week if I am pregnant. One thing is it is quite an amazing roller coaster. Many women have tried various IVF techniques 2,3,4,5 etc times. This is only my first. So far, it's cost us \$24,000 USD. I couldn't imagine financially, or emotionally doing this that many times.

**What happens when one of your DS friends gets pregnant and has a baby? Does communication usually stop after that or does she continue to support her other friends who are still trying to conceive? How does that make you feel?**

I just joined a few months ago but see ladies on there that conceived a couple years ago via IVF or IUI and they offer advice and help those that are new. I can only assume it will be a "sisterhood" of sorts that will continue as infertility is a condition that doesn't go away and IVF is typically not successful the first time plus people want to have more than one child. Also, there are many reasons for it for there are so many different viewpoints to help ladies.

It's good - it's like a whole new network of friends that you can tell your innermost secrets to about your body and/or questions about your body that will help you.

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**Amanda**

**Age:** 31

**State/Country:** Ohio / USA

**Marital Status:** Married

**Education:** Masters Degree

- 1. How did you first hear about DailyStrength?** I found it on a google search
- 2. What do you use DailyStrength for (virtual hugs, journal, forums, etc)?** Support for infertility
- 3. Which of the site's features do you find most useful and why?** The forum posts - they allow you to ask questions and get advice from those who have been through this before. The journals - as they allow you to share personal experiences with your close group of DS buddies
- 4. How has DailyStrength helped in your battle with infertility?** Well, it has been a rock for me. I am now 21 weeks pregnant, and went through IVF to get here. My husband is a carrier for Cystic Fibrosis, which causes infertility issues for affected men. DS was a place that allowed me to talk with other women who have been through this and see how many had success.

When I went through IVF treatment in October I was really scared and had no idea what I was doing. Giving myself injections each day was so awkward. I would ask others on DS for advice. We exchange helpful tidbits of information all the time - things your doctors and nurses NEVER tell you. For example: if you ice the location of your shot for 1 minute before you won't feel the needle. Or if you use a heating pad to warm up the progesterone in the vial before injecting it will be less painful and spread quickly.

DS is really just a way for me to communicate with others who are going through the same sticky situation I am. Infertility has a shame stigma that's really unfair. Unlike cancer patients, we can't talk about our problems with friends or family. Most of the time they don't understand and brush it off as unimportant. Most women are told to stop stressing as if they are creating the problem themselves. This lack of support can cause additional stress and depression as women start to feel guilty, ashamed and hopeless. Each month they go through a roller coaster of emotions waiting for see if they are pregnant. Many infertility patients have been dealing on their own for YEARS.

- 5. How does it make you feel to communicate with others online about infertility?**  
Mainly I feel not alone.

- 6. Have you also used the site to help other people with their infertility issues?**  
I try to support others and give them hope.

- 7. Have you made friends on the site? Do you only talk to them online, or are there others you see in person or talk to on the phone?**  
Yes, several. We mainly talk through DS. Although I am friends with one through Facebook.

- 8. How often do you visit the site and how long do you spend on it when you are there?**  
I visit everyday, maybe a few times a day to check on friends, especially if they are waiting to see the results of a pregnancy test.

- 9. Are there ways in which going to online communities like DailyStrength that differ from talking to family/friends?**  
Yes - we support each other completely. Friends and family mean well, but don't always have the most comforting words or advice. They tend to simplify everything, and to change the subject when we do feel like talking. They are uneducated in infertility and the process of adoption. They make outrageous suggestions.

**10. Can you describe for me a typical visit to the site ("I log on, check my messages, update my journal . . . etc.)?**

I check my homepage - which lists my friends status updates. I will check the infertility boards, and the BFP After IVF board. If I have messages or hugs waiting I will answer them if I have time. Every few weeks I update my journal with progress of my pregnancy and I only give access to my DS friends, as I try to keep somethings private.

**11. How did you talk about your issues with infertility before you found DailyStrength?**

I spoke to my mom, my aunt a few close friends and of course, my husband. I still do this, but I know they don't quite get where I am coming from all the time.

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**Jamie**

**Age:** 40

**State/Country:** USA

**Marital Status:** Married

**Education:** MBA

- 1. How did you first hear about DailyStrength?** Found it while internet searching after my first miscarriage.
- 2. What do you use DailyStrength for (virtual hugs, journal, forums, etc)?** All of the above. Initially it was for advice and support after miscarriage but now is for everything to do with infertility.
- 3. Which of the site's features do you find most useful and why?** Journals, Hugs, and Support Groups
- 4. How has DailyStrength helped in your battle with infertility?** Made me realize while I may be alone in this journey among my local freinds there are so many women and couples living through what we are and it makes you feel better knowing you are not alone and there are people that understand your emotions, fears, hopes, and dreams.
- 5. How does it make you feel to communicate with others online about infertility?** Easier and more inclined to be completely honest and not hold back. Sometimes you put on a brave face to people you see all the time. On DS you don't have to wear that mask ever.
- 6. Have you also used the site to help other people with their infertility issues?** BLANK
- 7. Have you made friends on the site? Do you only talk to them online, or are there others you see in person or talk to on the phone?** I have made many friends on this site. I tlak to them online through DS and through Facebook.
- 8. How often do you visit the site and how long do you spend on it when you are there?** daily and depending upon the day between and hour or two. Maybe more depends on comments and what is going on in my infertility journey. Sometimes it helps when you arehaving a rough day to try and help others. For me it makes me feel better and more in control.
- 9. Are there ways in which going to online communities like DailyStrength that differ from talking to family/friends?** It is easier to more open and honest since you don't see these people everyday. Also, most of these friends have been or will be where I am and can completely understand how I feel and the emotions intertwined in each procedure and each step on the fertility journey.
- 10. Can you describe for me a typical visit to the site ("I log on, check my messages, update my journal . . . etc.)?** I log on to site. Check any new messages, hugs, friends. Check my journal to read comments. Check my weight watchers group posts, check infertility support group posts. Then go to friends and check individual friends. Send hugs tot hose I know are in the 2WW or those that are having one thing or another done. Then I will usually start the whole process again in a few hours or in the afternoon.

11. **How did you talk about your issues with infertility before you found DailyStrength?** I talked to my husband but outside of that I didn't. There was no one that understood what we were going through. In fact most people steered the conversation in a different direction when it ever came up.

*Follow-up Questions:*

1. **Can you expand on why you find journals, hugs and support groups useful? What is it about these site features that you find have helped you with infertility?**  
i just find it helpful to have so many friends that have been or are in the same situation I am. They understand, give advice and support when needed.
2. **Why are you more inclined to be completely honest and not hold back when you talk to people online, as opposed to when you see people face-to-face?** There is no need to be a certain way since most of these friends you will never see. With people you see all the time you may or may not be comfortable showing your true feelings.
3. **What kind of things do you talk about with your DS friends? How does it make you feel to hear their stories about their personal experiences with infertility?** The whole infertility journey. From cycle problems, to husband and family problems and challenges. It makes you feel not so alone to know that other people in similar situations are going through similar problems or successes.
4. **You said sometimes it helps when you're having a bad day to try to help others - what do you mean by this?** By reading journals and discussion posts and offer others advice and support helps me to realize that life isn't as bad as it seemed. Makes me realize all my problems will also find solutions given time and patience.
5. **You mention that you use the "virtual hugs" feature of the site. What does a "virtual hug" mean to you and how does it feel to both send and receive them?** Reminds me of all the support and cheerleaders I have out there. Makes you feel like you are not alone and there are many many women that care about you and what you are going through.
6. **What happens when one of your DS friends gets pregnant and has a baby? Does communication usually stop after that or does she continue to support her other friends who are still trying to conceive? How does that make you feel?** Sometimes yes and sometimes no. depends on the connection. I have quite a few friends that we still chit chat and comment on each others journals. It's hard when all of a sudden you are the only one out of the group still trying to conceive. But, you gain new friends to run with along the journey and just move forward.

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**Mary**

**Age:** 27

**State/Country:** Alabama/USA

**Marital Status:** Married

**Education:** Medical Assistant

1. **How did you first hear about DailyStrength?** Google
2. **What do you use DailyStrength for (virtual hugs, journal, forums, etc)?** Getting information from the other ladies! Alot of things you can't search for, you have to know someone who has been through it to get answers!! There are alot of ladies here so pretty much ever topic has been studied!
3. **Which of the site's features do you find most useful and why?** Support Groups because that is were you can get the encouragement and I have never had a question not answered. The Journals are great too because I have go back and read what happened the last cycle and if its different this time!
4. **How has DailyStrength helped in your battle with infertility?** It helps have so many women in one spot to answer all the question! Everyone is so nice and understands what you are going through so its like a safe place to come and talk!
5. **How does it make you feel to communicate with others online about infertility?** I love it :)

6. **Have you also used the site to help other people with their infertility issues?** I have given friends some advice that I received on here!
7. **Have you made friends on the site? Do you only talk to them online, or are there others you see in person or talk to on the phone?** I haven't really made any "friends" we just answer each others bloggs and such!
8. **How often do you visit the site and how long do you spend on it when you are there?** I visit a couple times a day! I stay one 1-60min each time just depending on why I logged on to start with.
9. **Are there ways in which going to online communities like DailyStrength that differ from talking to family/friends?** yes I feel that i can open up more online then with friends and family
10. **Can you describe for me a typical visit to the site ("I log on, check my messages, update my journal . . . etc.)?** Log on, check any messages I have then go to the support groups.
11. **How did you talk about your issues with infertility before you found DailyStrength?** I really didnt because no one in my family has ever had to deal with this! They still dont understand

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Lorry  
 Age: 28  
 State/Country: Kansas/United States  
 Marital Status: Married  
 Education: Bachelor's degree in Psychology and Master's degree in Social Work

1. **How did you first hear about DailyStrength?** Found it after doing a Google search for support groups.
2. **What do you use DailyStrength for (virtual hugs, journal, forums, etc)?** Love the journaling aspect of the site as I use it to chronicle the treatment protocols I'm using and how this very difficult journey is affecting me. I enjoy the forums because I feel like I am giving support, encouragement and every once in awhile, I am providing valuable information I have gathered about whatever topic is being posted. I know I have posted a lot of questions on the forum that I know no one else would be able to answer, unless the person was going through infertility.
3. **Which of the site's features do you find most useful and why?**  
 I love getting email notifications about journal updates from my friends. It helps me to stay connected to what they are going through and helps me provide support when they need it.
4. **How has DailyStrength helped in your battle with infertility?** It is, quite honestly been the only place I know I can go and get real support from people who truly understand. I honestly don't know if I would still be functioning in my daily life, if I didn't find this site and the awesome women who give me hope. When you feel like you can't do another treatment cycle, both because you are emotionally exhausted and financially strained, you get the needed encouragement and hear success stories that allow me to be able to try one more month with the hope that this could be my month where I conceive.
5. **How does it make you feel to communicate with others online about infertility?** It makes me feel supported and gives me hope that I don't think I would have otherwise.
6. **Have you also used the site to help other people with their infertility issues?** Yes. I am on the Infertility forum almost daily, looking through posts and reading about other women's struggles.
7. **Have you made friends on the site? Do you only talk to them online, or are there others you see in person or talk to on the phone?** I have made quite a few friends on this site. Unfortunately I'm not able to meet any of them outside of this site, since they are all in other states.

8. **How often do you visit the site and how long do you spend on it when you are there?** I visit it almost daily and can spend well over an hour at a time looking through posts and reading my friends journals and updates.
9. **Are there ways in which going to online communities like DailyStrength that differ from talking to family/friends?** I think that there are significant differences. My best friend has struggled with infertility and I am able to talk to her about it all, but having a resource that is anonymous allows me to post things and ask questions that I wouldn't to my family and friends. It is always a risk to bring up infertility with my family and friends because they are bound to say unknowingly insensitive things, without meaning to. People on this site, know what not to say (ex. "Just relax" "Why don't you adopt?")and sometimes that is more important than knowing what to say.
10. **Can you describe for me a typical visit to the site ("I log on, check my messages, update my journal . . . etc.)?** I usually check my email first, which sends me alerts when a friend of mine has posted a journal entry. I then read the journal entries, comment on those entries and then search and respond to infertility forum postings, then I get write my own journals/updates.
11. **How did you talk about your issues with infertility before you found DailyStrength?** I didn't talk about them very much. I kept them to myself and internalized a lot things which made me very depressed and anxious. Since this site, I feel more empowered and more in control of my treatment options and decisions, because I have gotten advice from people who have been there and who have had failure and success with different treatment protocols.

*Follow-up Questions*

**1. When in your infertility journey did you decide to look for online support groups, and why did you decide to look for one?**

I decided to look for one when I found out that I wasn't ovulating like I should have been. It was a pretty big emotional blow to hear that you are not normal and that you may not be able to do what should be so natural....to have a baby.

**How does it feel when one of your online friends gets pregnant?**

usually have mixed feelings when one of my DS friends gets pregnant. It's a double edged sword. I feel very happy for them that they have achieved their goal of pregnancy, but it's also another reminder that I am still not pregnant and am left behind.... There have been some ladies who still get online even after having their babies to support others going through infertility.

**2. How does it feel to see others' experiences with infertility?**

It makes me feel very sad a lot of the time, to know that so many women have to go through this living hell, but it also makes me feel not so alone.

**3. You said talking to others online gives you hope you didn't think you would have otherwise. Can you explain more about this?**

When I see others who are using the same treatment protocol as I am or did and actually got pregnant, it makes me feel hopeful that I could actually get pregnant too.

I also feel very supported and that my fellow infertility sisters completely understand what I am going through when I have a treatment cycle fail and I don't get pregnant.

**4. How does it make you feel to be able to help other women with their infertility issues?**

Makes me feel like I am contributing hope to them, because that is what I feel like I have been given by them.

**5. Do you use the "virtual hug" feature? What does giving/receiving a virtual hug mean to you?**

I sometimes use the virtual hug feature, but not often. I usually give hugs when I have noticed what a bad day someone has had. It seems more personal when I get a hug from someone, it feels like they really care because they have taken the time to send the hug.



**Jessica**

**Age:** 39

**State/Country:** Illinois/USA

**Marital Status:** Married

**Education:** Bachelor's degree

**1) How did you first hear about DailyStrength**

Found DS online while I was doing a search on infertility and poly cystic ovary syndrome.

**2) What do you use DailyStrength for (virtual hugs, journal entries, etc.)?**

I mainly use DS to read forums, journal, and keep in touch with the new friends I have made on DS. I use the hug function on occasion.

**3) Which of the site's features do you find most useful and why?**

I find the forum very useful because it is a wonderful source of information. You can compare how certain medications are making you feel and share in other members experience both physically and emotionally.

**4) How has DS helped you with your battle with infertility?**

IF is such an emotional rollercoaster that it is reassuring to know that you are not alone in the way you feel. When you see other members who have struggled and finally succeeded it can give you hope.

**5) How does it make you feel to communicate with others online about infertility?**

My husband is wonderful and we can openly discuss our fertility issues and provide each other endless support so I am very fortunate in that aspect. DS gives me the extra support and understanding that I need to stay positive about this journey. It is nice to be able to talk to others going through the same thing and not have to explain yourself because the DS members just know.

**6) Have you also used the site to help other people with their infertility issues?**

I have spoken with others on DS to share my experience and provide some emotional support whenever possible. It is so easy to get down that I try to encourage people to stay positive and miracles do happen.

**7) Have you made friends on the site? Do you only talk to them online, or are there others you see in person or talk to on the phone?**

I have made some friends on DS but we only communicate online. At this time I don't have any desire to reach out to anyone outside of the DS site.

**8) How often do you visit the site and how long do you spend on it when you are there?**

I visit the site almost once a day. I would say at least 5 days a week at certain times. Sometimes I do take a break and I may only check out the site once a week. I seem to be more active when I am getting ready for a cycle, actively in a cycle and for the few weeks following a cycle. When I am actively on the site I spend maybe 20 to 30 minutes on the average.

**9) Are there ways in which going to online communities like DailyStrength that differ from talking to family/friends?**

My husband and I did not share the fact that we were doing infertility with too many people. Majority of our family and friends do not know what we are trying to do. We knew our struggle was not going to be easy and we didn't want everyone asking us how things were going only to have to relive the negative outcomes over and over again. Plus we just didn't want to have to answer a ton of questions. DS has given me the outlet I need to discuss with people that understand it all. No matter how I feel it is ok on DS. I don't have to explain myself nor feel like I have disappointed anyone.

**10) Can you describe for me a typical visit to the site ("I log on, check my messages, update my journal . . . etc.)?**

I usually check the updates I get via email (If my DS friends create a journal entry I receive email notification) and I respond to my DS friends if I want. Then I check the daily newsletter that DS sends out and check my messages and respond. I only update my profile or journal if I have something going on.

**11) How did you talk about your issues with infertility before you found DailyStrength?**

I have 2 friends (1 that has been through IF and 1 that is a great person to talk to) that I would discuss infertility and I would talk to my mom and husband. They are pretty much the only ones since like I mentioned before we really didn't tell very many people.

*Follow-up Questions:*

**1. You say that you share in other's experiences both physical and emotionally on site forums - how does it make you feel to read about others' struggles?**

When I read about other people's struggles we often share so many of the same feelings so it makes me feel like I am not alone and also not going crazy. Between all the hormones and the heart ache and hoping and everything else you really test your strength. Sometime I have a very hard time putting how I feel into words and some of the women here express it all so eloquently. I feel like they help give me a voice. I am also a very optimistic person so I do like to share that optimism with other in hopes I can lift their spirits some.

**2. Do you use the virtual hug feature of the site? What does sending/receiving a virtual hug mean to you?**

I use the virtual hugs a little bit. I don't use them often. It is nice to receive them and a nice way to feel like someone is thinking about you. I look at them a just a quick not to say hi or offer quick words of encouragement. They put a smile on my face when I receive them.

*Third Follow-up*

**Is there anything you think I missed out or you would like to add?**

I don't think I have very much to add. I guess I would just add that dealing with infertility is so difficult and hard to put into words. It is impossible for someone who does have to deal with it to understand. Obviously people can have allot of empathy but it isn't the same. You really go through so many emotions that only someone going through the same thing could understand. For me it is totally unlike any other emotion I have had to deal with so being able to share this with people who understand it just invaluable.

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**Emma**

**Age:** 31

**State/Country:** Illinois, USA

**Marital Status:** Married (2years)

**Education:** masters in education

**1. How did you first hear about DailyStrength?**

I was looking on-lilne for any type of support group out there to help me get through this trying time in my life. I found it on accident and I'm so happy that I did!

**2. What do you use DailyStrength for (virtual hugs, journal, forums, etc)?**

I use it to see what other topics that women with infertility are having. It's nice to be in a group that is going through the same journey. I love that I can journal and vent my worries, thoughts and questions. The virtual hugs and responses to questions or topics that I have brought up make me feel like I'm not alone. It's really nice to have such and amazing support group.

**3. Which of the site's features do you find most useful and why?**

I like the journal becuase I am able to vent to anyone or just keep it personal. I think it's wonderful when other women read my journal and comment and I like reading what other women are going through in their journals.

I also love the message/topic/question board where anyone can ask a question or talk about what they are going through. I have only been on the website since the beginning of March, but I already has helped me so much.

**4. How has DailyStrength helped in your battle with infertility?**

The support and knowledge that I'm not alone dealing with this is so comforting. I felt so alone last year going through with all of my infertility issues, and even though I've only been on the website for a few weeks, I already feel like I'm a part of something.

**5. How does it make you feel to communicate with others online about infertility?**

It makes me feel like I'm not going crazy. It's maddening to try and deal with all of the thoughts, worries and questions that you have when your dealing with infertility, so having a place that I can go anytime to feel like I'm not alone is so wonderful.

**6. Have you also used the site to help other people with their infertility issues?**

No, because I'm new and I'm the only one of my friends going through this.

**7. Have you made friends on the site? Do you only talk to them online, or are there others you see in person or talk to on the phone?**

Since I'm so new to the site, I've only made a few friends. I would be happy to talk to anyone on the phone or meet up if they wanted to talk.

**8. How often do you visit the site and how long do you spend on it when you are there?**

I'm on the website for an average of an hour a day (on and off)

**9. Are there ways in which going to online communities like DailyStrength that differ from talking to family/friends?**

Yes, it's hard to tell the people in your life that you are going through something so difficult and unexplainable if they have never experienced any of the same problems. I know that my friends and family want me to be happy but their advice to "relax" and "it will happen someday" just make me frustrated (eventhough I know they are trying to be helpful)

I feel like it's so my easier to vent and be real about what questions and thoughts I'm having, because everyone on this site is or has been going through the same problems.

**10. Can you describe for me a typical visit to the site ("I log on, check my messages, update my journal . . . etc.)?**

I log in, check if I have any messages, check the support group infertility group discussions/questions. I've journaled 3 times in the three weeks that I've been on the site.

**11. How did you talk about your issues with infertility before you found DailyStrength?**

I tried to talk some select friends and family about it, but that was really isolating. Now that I have this website I don't have to talk to them about it if I don't want to, and on a typical day I don't want to talk about it with anyone that doesn't understand how it feels to not be able to get pregnant as easily as others.

*Follow-up Questions:*

**How do you use the journal function of this site? Is it for you personally or so that you can communicate your journey to others? Or both?**

You can journal on the website and keep it as personal, or just let your friends on the site see it, or you can make it public. There are boxes that you can click by each choice after you journal, so it's up to the individual.

I have told other women going through infertility about this website and I think they are going to try it. I just started going to a support group on Monday night about infertility and that's when I told the ladies about this site.

I encourage other women on this site and receive the same encouragement back. I just found out yesterday that I am not pregnant again this month:( It will be nice to have the support of my friends on this site when I tell them today.

*Third Follow-up*

**Is there anything you would like to add or feel is important?**

if there is one word I could say to describe this website it would be lifesaving. Even with the support of my wonderful loving husband and amazing family and friends, I felt so alone before I found this website. It has helped me so much and I will be forever grateful to the person who started it.

**Sharon**

**Age:** 38

**State/Country:** Wisconsin

**Marital Status:** Married

**Education:**

**How did you first hear about DailyStrength?**

I had a miscarriage 3 years ago, I had tried for four months to get pregnant and I was 35. During the week I took off to heal physically from it I was on the computer a lot. I came upon it looking up medical things about miscarriage. Three years later from when I started trying and I'm still not pregnant. I am not a regular, but I pop in and out of there. I just met a girl on there from my home state and we met up a month ago. You get kinda hooked into it because you can always share with your friends. (Infertility is) embarrassing not because you have it but because you don't want to deal with it yourself so you don't want sympathy. It is one less thing to worry about how people will react to it.

**What do you use DailyStrength for (virtual hugs, journal, forums, etc)?**

I post updates on how things are going, where things are at. I'll post medical questions, or help other people. Its more of a non-medical resource. I work as a nurse, and it is just a chance for other people who don't understand lab results and don't know what it means for me to help them. I don't give real medical advice because if i'm wrong it could be malpractice. There are a couple people you establish relationships with and you say things you wouldn't in your everyday life.

**Which of the site's features do you find most useful and why?**

The messaging board, and they let you have friends groups so you can see how people you talk to are doing. You can make it a private or public group.

**How has DailyStrength helped in your battle with infertility?**

It has helped with a lot of it, like if you're going in for procedures or tests, you learn what you're going in for. You know what you're going to expect, because its people who went through it. If I didn't ask questions, someone has already asked them.

**How does it make you feel to communicate with others online about infertility?**

It's really easy to get into self pity but by going on here you can see how people have it worse than you or better so you have hope. When you have your close group of friends its people going through that.

**So, you get sympathy from it, or you feel empathetic?**

It is not sympathy, but empathy. You might feel sympathy with friends/family, you feel you have to put on a pretense because they are also hurting. The women on the site have the experiences and offer support and empathy. Family and close friends tend to offer sympathy and support

**How have you also used the site to help other people with their infertility issues?**

By using my own experiences. there might be days where you're up others are down, and you help them by picking them back up. You have no control over it, something you want cant control it. So there's a lot of emotions.

**Have you made friends on the site that you see offline?**

Met one of the girls who I've gotten to know in the last month or two. We send emails, pictures, and have met in person. It was weird at first, because you want to make sure she's not a serial killer, but once you see the person is normal, it's fine. We talked for about 1.5 hours.

**How often do you visit the site and how long do you spend on it when you are there?**

I check in about 15-20 minutes a day. A lot of people are on a lot more. It's kinda like Facebook, where you check in and check out.

**Do you use any other virtual communities?**

No, there aren't any other sites I go to.

**Are there ways in which going to online communities like DailyStrength differ from talking to family/friends?**

There are some things you don't want them (family) to know. You don't talk about addiction or infertility or financials with your family. its things they are private. You don't have to impress anyone or carry on an aura of who you are. You can almost hide around the fact that you're on an online site. You say it and vent and you don't have any repercussions. You can't be angry, mean and nasty and with a family member or friend. Online you can go vent and everyone will forget about it.

A lot of insurance companies dont cover infertility treatments, so its a financial issue as well. You can get treatment for everything else, but infertility isn't considered a medical issue. Something like this helps where you put up recsources likr certain drugs prescribed and coupons.

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**Erin**

**Age:** 30 years

**State/Country:** South Africa

**Marital Status:** Married

**Education:** M.A. Industrial Psychology

**1. How did you first hear about DailyStrength?**

Googled support groups and found it as one of the first hits.

**2. What do you use DailyStrength for (virtual hugs, journal, forums, etc)?**

Forum to discuss infertility topics and answer questions. Community with similar interests and understanding away from family and friends.

**3. Which of the site's features do you find most useful and why?**

Discussion areas. Different ideas and advice available. Respect and support.

**4. How has DailyStrength helped in your battle with infertility?**

I can vent in private without being judged. Uplifting stories of success when ladies fall pregnant after long difficult roads of infertility.

**5. How does it make you feel to communicate with others online about infertility, and to hear other people's stories?**

It is better than talking to friends and family that do not have the knowledge or the need to understand. On-line communication makes it easy in that you can stay anonymous and only reveal your identity to those you choose to befriend. It is easier to get the emotions out and advice is better to obtain as the site is joined by ladies with the same interest. Other individuals' stories are uplifting and also bring about the locked up emotion within yourself when they feel down, alone, sad etc.

**6. Have you also used the site to help other people with their infertility issues?**

Not necessarily. I made one friend and will meet her for coffee this Friday for the first time. I am very excited about this.

**7. Have you made friends on the site? Do you only talk to them online, or are there others you see in person or talk to on the phone?**

As per the above response. Made one friend and will meet her this Friday for the first time

**8. How often do you visit the site and how long do you spend on it when you are there?**

Once a day and sometimes stay for an hour.

**9. Are there ways in which going to online communities like DailyStrength that differ from talking to family/friends?**

Yes, it is far easier to communicate online and also, family and friends sometimes do not want to support you - it is too difficult for them to understand.

**10. Can you describe for me a typical visit to the site ("I log on, check my messages, update my journal . . . etc.)? I log on, see what the latest discussion points are, update my journal, write a new discussion point if I have one that particular day, log off.**

**11. How did you talk about your issues with infertility before you found DailyStrength? Tried friends and family with some disastrous outcomes.**

**12. Is there anything else you want to add or feel I have left out? No.**