Computer and Information Science
www.ccsenet.org/journal.html
Vol. 1, No. 1
February 2008

The Social Dynamic of Health Disclosure

Who Do Patients Tell and When?

Nasriah Zakaria
School of Computer Sciences, Room 726 Building DG31
Universiti Sains Malaysia, 11800 Minden, Penang, Malaysia
Tel: 6(019)4106826 E-mail: nasriah@cs.usm.my
Jeffrey M. Stanton
School of Information Studies, Hinds Hall 316
Syracuse University Syracuse, NY USA 13244-4100
Tel: 1(315) 443-2879 E-mail: jmstanto@syr.edu

Abstract

This paper focuses on social dynamics among disclosure communities in terms of balancing disclosure and privacy. Why does a man tell his mother but not his father when facing a medical crisis? This is an example of the core question in this study. To better understand these situations, we need to identify the disclosure activities that take place within the patient and their disclosure community when dealing with illness, and explore the different ways patients balance the need to disclose and the need to be private. The outcome of this study is the development of a conceptual framework (in the form of conceptual map) that describes the social dynamic of health disclosure for chronically ill patients. Concepts like balancing act, which is being closed (private) and at the same time being open (disclosure), timing of disclosure, and role of disclosure emerged as three patterns that emerge during the disclosure process.

Keywords: Disclosure, Health Information, Health Communication

1. Introduction

1.1 The Concept of Self-Disclosure

"The concept of disclosure is clearly related to notions of privacy and secrecy. If privacy concerns keeping things hidden, and secrets are the specific messages chosen not to be shared, then disclosure is the process that grants access to private things and to secrets" (Rosenfeld, 2000, page 6).

The interrelationship between privacy and disclosure is at the heart of this study. The main assumption is that patients balance the need for disclosure and the need for privacy when dealing with health information relative to their disclosure communities (DC). Petronio (1991) developed the boundary metaphor to describe how humans build protective walls around their sensitive information and how they balance disclosure and privacy.

2. Literature Review and Background Theory

2.1 Self Disclosure

Self-disclosure is defined as "any message about self that one communicates to another" (Cozby, 1973). The topic has attracted scholars from diverse fields – communications, information studies, social psychology, sociology, and psychology. Northouse and Northouse (1998) presented five variables in health communication, where disclosure is one of the central variables that determine the effectiveness of communication. The authors discussed disclosure as a variable since the presence (or absence) of disclosure facilitates (or impedes) effective health communication among patients and medical teams.

Self-disclosure is a communication process whereby people transmit personal information to others; in exchange they may receive feedback or help from others. These messages about self may consist of facts or of personal thoughts, feelings, and experiences, and may refer to the present or the past. Empirical studies on the nature of the self-disclosure

message (Cozby, 1973; Wheeles & Grotz, 1976) identified five attributes: intention, amount, valence, honesty and depth. Intention is concerned with an individual's willingness to disclose to others. Amount refers to the quantity of information exchanged. Valence indicates the positive or negative content of the message; if a person discloses positive content, the valence was positive, and the valence is negative when the content is perceived to be negative. Honesty refers to the factual accuracy of the message while depth refers to the level of intimacy of the message conveyed. (As an example, prognosis information has more depth than general health information).

Most of the earlier works on self-disclosure were in the form of reviews and lacked a theoretical framework (Berg & Derlega, 1987, page 2). However, in recent years, researchers have begun to develop theories that attempt to predict and/or explain self-disclosure behaviors. Among these theories are Communication Boundary Management and Communication Privacy Management (Petronio, 2002), and Uncertainty Reduction Theory (Berger & Calabrese, 1975). These theories looked at disclosure under three major themes: (a) the role of self-disclosure in treating psychological distress (Berg & Derlega, 1987), (b) the role of self-disclosure in building, maintaining or destroying relationships, and (c) self-disclosure as a personality/intrapersonal trait. This study takes the second approach, exploring the formation, maintenance, and disintegration of relationships (specifically, disclosure of health information among patients and other people). Before venturing into a discussion of the role of self-disclosure in relationships, however, a brief description of the body of empirical studies that have been done in the therapy and personality areas is in order, since these works provide background in the overall disclosure research.

Early research in self-disclosure focused on the benefits of self-disclosure to well-being and health – mainly psychological or mental health. Sydney Jourard, a psychologist who studied self-disclosure in the context of mental health conditions (1964, 1968, and 1977), found strong indications that self-disclosure promotes healthy interpersonal relationships. A great deal of Jourard's research looked at the self-disclosure variable from a relational perspective, wherein he examined how disclosure helps individuals in general. He found that the process of self-disclosure is linearly related to an individual's mental health. Without disclosure, individuals feel lonely and estranged from the social world; with it they can interact and become close with others. However, several other studies (Chaikin & Derlega, 1974a, 1974b; Cozby, 1973) challenged Jourard's conclusions, postulating a curvilinear relationship between self-disclosure and mental health condition: both extremely low and extremely high levels of self-disclosure correlated with a low level of personality adjustment. In other words, people with problems reveal either a great deal more, or a great deal less information about themselves than "normal" people, a finding which has contributed to treatment of psychological distress.

Derlega and Chaikin (1974, 1977) proposed two factors that mediate between self-disclosure and health conditions: the nature of the relationship, and situational context. The nature of the relationship comes into play because research indicates that people tend to disclose to those with whom they have a close relationship, such as spouse, immediate family and close friends. People also evaluate the situational context in deciding whether and what to disclose to others. For example, a person who knows that he will need a great deal of time off for chemotherapy will disclose his medical state to his manager and immediate subordinate so someone can take over his responsibilities at work. However, he may not disclose to his employers if his medical condition is mild and under control. In a later compilation of self-disclosure work, Rosenfeld (2000) suggested four factors that influence a disclosure decision: nature of relationship, risk-to-benefit ratio, situational context and reciprocity. Nature of relationship and situation have already been described. The risk to benefit ratio refers to an individual's assessment of the benefits of self-expression, self-clarification, and catharsis as compared to the risk of rejection, humiliation, and possible avoidance by other people. Reciprocity proposes that once a sensitive disclosure is made, the recipient is expected to respond by providing some piece of sensitive information of his own to the discloser, either then or at a later time.

The research that views self-disclosure as a personality trait assumes that self-disclosure is an individual choice. Under this assumption, people constantly reassess the risk-to-benefit ratio before making a disclosure. Research in this area has identified various specific benefits and risks and suggests that individuals do make their own decisions on what information to disclose and what information to withhold from others (Wenburg & Wilmot, 1973). In the context of health communication, benefits of self-disclosure are catharsis, receipt of feedback from others, and help with problem solving (Cozby, 1973; Northouse & Northouse, 1998). It can also improve patient care: Petronio and her colleagues (2004) found that family members who accompanied patients during medical interviews disclosed patients' personal information in order to clarify, correct or refute the physician's statements. Identified risks of inappropriate disclosure include maladjustment (Chaikin & Derlega, 1974a; Wortman et al., 1976), social stigma of showing weakness and vulnerability (Petronio, 2000), and the loss of personal relationships (Northouse & Northouse, 1998). For example, Cline and McKenzie (2000) found that HIV patients who disclosed their status faced embarrassment and humiliation because of HIV's perceived association with illegal drug use and homosexuality. Block (2000) found that some cultures regard certain medical conditions (particularly mental disorders) as taboo, and patients who disclose such illnesses to other people usually get negative reactions.

Researchers who studied self-disclosure as an interpersonal or social relationship aspect found several ways in which self-disclosure can enhance social relationships. Altman and Taylor's (1973) Social Penetration Theory (SPT) explains the relationship between self-disclosure and intimacy by proposing that a high level of disclosure increases the intimacy level between discloser and recipient. In addition, SPT also explains the formation, maintenance, and disintegration of relationships. Uncertainty Reduction Theory, on the other hand, proposes that the function of disclosure is to reduce human uncertainty under various circumstances. For an example, when the victim of sexual assault discloses the identity of the culprit, it reduces the uncertainty for her family and friends.

Disclosure reciprocity is an important concept in understanding why and how people in a relationship disclose to each other. As stated above, reciprocity means that the recipient of a disclosure is expected to exchange similar information about himself, either immediately or at some later (but not too distant) time. This reciprocity may serve to express liking for and trust in the discloser, to accord with social norms, or to follow or imitate the behavior of discloser. Dindia (2000) performed research in existing work on self-disclosure in social relationship aspects and found that reciprocity occurs at all stages of a relationship, from the beginning or introductory stages to more intimate phases.

Scholars such as Westin (1967, 2003) and Altman (1977) studied self-disclosure from the other side, in terms of privacy. In fact, Altman's work linked the privacy concept closely to self-disclosure and his work was followed by extensive research by Derlega & Chaikin (1977) and by Petronio (1991, 2000). Petronio relied on the "boundary" metaphor originated by Altman and from there developed her Communication Boundary Management (CBM) theory. CBM offers a new perspective on self-disclosure in two ways. First, Petronio (1991, 2000) defined the concept of "boundary" as the border surrounding private information. The boundary is actually a psychological construct created by human beings in order to manage their information. Many previous research studies viewed self-disclosure as simply revealing information about oneself to others (Berg & Derlega, 1987), but Petronio's work looked at both disclosure (revealing) and privacy (not revealing) at the same time. The second important contribution of CBM was the dialectical perspective of self-disclosure and privacy, wherein humans constantly try to balance openness with privacy in order to achieve, respectively, relational intimacy or autonomy.

In sum, then, the literature lays out three approaches to studying self-disclosure: the role of self-disclosure in psychotherapy, the role of self-disclosure in social relationships, and the personality or intrapersonal aspect. Self-disclosure has been shown to benefit physical health, mental health, interpersonal communication, and social relationships. Because the main focus of my research is on social relationships (second aspect), we look at the roles of each party – the transmitter of information and the recipient – rather than at the personality trait or mental health aspect. The social relationship aspect of disclosure can shed light on how disclosure can create, maintain or disintegrate social bonds among individuals. We wanted to see how disclosure activities contribute to the balancing act of openness versus privacy about health information. In a social relationship perspective, disclosure occurs based on what other people think, say and do. For example, one person may decide to disclose her problem when she is surrounded by people who are talking about their problems. Another person may choose to disclose to her friends because her friends ask her to clarify gossip that they have been hearing.

Many theories have been advanced to explain how disclosure functions in relationships as well as how individual disclosure decisions are made. We selected Communication Boundary Management Theory (CBM) as the foundation for this study in order to help guide the exploration of disclosure dynamics among three stakeholder groups: patient, disclosure community and medical team. The reasons for our choice of CBM as the basis for this study are that it deals extensively with the issue of balancing disclosure and privacy in relationships, and has been used to explain various contemporary health communication issues.

2.2 Self-Disclosure in Health Care Situations

Numerous studies have examined disclosure of health information. These studies looked at the content, frequency and consequences of self-disclosure in different medical situations and raised different issues of disclosure, but frequently ignored the balance between disclosure and privacy issues (Cozby, 1973; Petronio, 1991). Wiener et al. (1996) explored the process of disclosure and consequences among HIV patients and their support network. It examined the caregiver-patient dyad it did not discriminate between the different roles of caregivers during the coping period, thus we are unable to conclude what specific roles are crucial for effective communication with the dyad. Another study (Baird, McConachie & Scrutton, 2000) explored how family and caregivers cope with cerebral palsy, and found that support network members were dissatisfied with the information disclosure activities. That study also determined that factors such as the age of the child, the timing of diagnosis and the severity of physical disability influenced information disclosure. The study suggested "best practice" guidelines for disclosing the diagnosis of an illness to the support network. Contro et al. (2002) showed that some family members such as siblings were often not included during the information disclosure process; this in turn caused the siblings to feel "left out" of the coping process.

A few studies pointed out the lack of empirical work in understanding self-disclosure among medical teams and family in chronic illness situations (Bradley et al., 2001; Contro et al., 2002). Families also made it clear that they wanted more

information from the medical teams in order to be able to provide the appropriate support for the patient (Bradley et al., 2001; Holroyd, Turnbull, Wolf, 2002). Other recent research on self-disclosure in healthcare examined different situations, contexts and issues as well as the nature of relationships. Topics examined include the process of disclosure (e.g. content and frequency) and its consequences (Holroyd, Turnbull, Wolf, 2002), the dyad relationship during disclosure (Wiener et al., 1996, Nielsen. 1998), practices for disclosing illness (Baird, McConachie & Scrutton, 2000), disclosure of chronic illnesses (Bradley et al., 2001; Contro et al., 2002), functional perspectives on health disclosure (Derlega, Winstead, Folk-Barron, 2000), privacy and disclosure (Welch & McKenzie, 2000), and the influence of illness, relationship and information-seeking on disclosure (Brann, 2003). Recently, self-disclosure research in healthcare has begun to pay attention to the larger group of people involved in patient care – friends, employers, spiritual groups and self-help groups. Petronio and her colleagues (2004) explored the role of these "informal advocates" by examining the self-disclosure behavior of family and friends when they were present during a patient's visits with the physician and/or medical team.

All the empirical work mentioned above informs the question of disclosure in various medical situations. However, it is clear that little work has been done on the social dynamics in disclosure communities when facing illness: as such, it is a good candidate for exploration using grounded theory, which is ideal for discovering conceptual model in areas about which little is known.

3. Method

This study explored the dynamics of disclosure communities by examining data from patients, medical team members, and disclosure community (family, sexual partners, neighbors, spiritual advisors, etc). Semi-structured interviews were conducted to gather stories regarding patients' experiences in deciding on communication rules for the disclosure process during important health events. Semi-structured interviews provide a beneficial and productive method of gathering data for this research because of the sensitivity of the topic, the likely complexity of the social dynamics, and the absence of structured interviews protocol to this topic area. Because of the need to speak with individuals who recently experienced an important health event, we employed the snowball-sampling technique which asks one respondent to refer another person who might also be willing to share his or her past disclosure experiences in a health care context.

The sampling was helpful in locating individuals who met the eligibility criteria: i.e., centered on a patient who had been admitted to the hospital for treatment of an illnesses, and who were thus likely to have encountered HIPAA-driven privacy policies while receiving treatment. These patients could also share their experiences in interacting with their disclosure communities during those times. We also conducted semi-structured interviews with medical team members – doctors and nurses – to elicit their experiences managing patients' disclosure needs and preferences. Finally, the third group of respondents comprised individuals who shared and managed a patient's health information when the patient faced illness. These individuals included family members, friends, sexual partners, non-profit organization members, and other support group members. The results of this study describe the social dynamics of the disclosure communities and provide understanding of how patients decide whether or not to tell their health information to others.

The overall goal was to develop a new conceptual model that explicates social dynamics of disclosure communities through the use of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990). One of the best methodological approaches to building such explanations is "grounded theory." Grounded theory is a systematic approach to data collection and analysis that aids the researcher in seeing emergent patterns in narrative data (Glaser & Strauss, 1967; Strauss & Corbin, 1990). Currently, there are two modes of thinking in doing grounded theory: "Glaserian" and "Straussian." The difference between the two lies in how each of them views the source data.

Glaser believed in developing emergent theory from the data itself, while Strauss questioned the data initially, before conceptualizing or abstracting it to a higher level. Glaser's positivist background makes him objectivist toward data; he is a neutral observer. Strauss brought his social science background, wherein he gave voice to the respondents. He emphasized the interaction between researcher and respondent and added an interpretive stance when building data.

In this study, we viewed the disclosure topic using the dialectic view of disclosure vs. privacy. This means that we had some preconceived ideas about the subject matter, so whenever we had data at hand, we had some biases. In addition, our overall conceptual framework was influenced by the constructs offered in CBM theory. For these reasons we chose to use Strauss and Corbin's version of grounded theory approach, which admits of the presence of an existing theory.

From the data, we developed a conceptual model able to explain the social dynamics of disclosure derived from what respondents say about the situations they had experienced. During data collection, we simultaneously performed various data analysis activities such as writing memos and creating conceptual labels or codes. Codes coalesced into categories which eventually became concepts that fit the situation and helped to explicate the process that respondents were going through (Glaser & Strauss, 1967). The final product is a conceptual model which explains the emerging concepts and the relations among them, illuminating the social dynamics of disclosure communities.

4. Results

The respondents for this study comprised medical patients, medical survivors, physicians, nurses, social workers, family members and clergy. All twenty-three people have been directly involved in patient care either in hospitals, nursing homes or residential. Table 1 shows the overview of the respondents sample for this research.

One of the important tasks in grounded theory approach is to reduce the conceptual findings to one core category, which represents the main storyline of the research. The storyline for this study revolves around the social dynamics in disclosure communities. The conceptual map (Figure 1) explains and describes two important factors – stages of illness and role of disclosure community (DC) – and shows how they influenced the balancing act between disclosure and privacy of health information

The map is divided into three sections. The arrows indicate the flow of disclosure reported by patients, supported by DC responses. The first box on the left, "Balancing act," represents an individual's decision process in choosing to be open or closed about his health condition. In this research, the data demonstrated that individuals make this decision by considering both respondent's and receiver's social interactions.

Four arrows flow from the balancing act. Three of them lead into boxes that represent the three stages of illness (diagnosis/checkups, treatment/surgery, and post-treatment), indicating the influence that illness stage has on disclosure behavior. For example, a person chooses to disclose her illness when she is the recovery stage because she accepts her illness then, when she did not before. Other individuals choose to be private even in the recovery stage because they are still distressed with their current situation. The fourth arrow leads to the role of disclosure community (DC), indicating the influence of the three possible roles found in members of the DC: social support, advocate and medically literate.

From each of these four factors that influence a patient's disclosure decisions – the three stages of illness and the role of DC – one or two arrows lead out, to typical open behaviors associated with that factor (e.g., asking for prayers), and/or to typical closed behaviors (e.g. refusing to talk about it). Note that "Special Roles" leads only to open behaviors, indicating that those roles only served to encourage open behavior

The other important dimension in this conceptual map is the time factor (arrow at the bottom of the Figure 1). Chronic illnesses span a long period of time and this time span influences the evolution of an individual's disclosure process. For instance, the OPEN and CLOSED disclosure behaviors indicated by the boxes on the far right change across time as the individual is constantly balancing being open or closed to others The outcomes of these disclosure decisions (e.g., negative reaction from boss) feed back into the system, thus influencing future decisions; this iterative process is represented by the feedback arrows from these behaviors into the balancing act box.

The three stages of illness – diagnosis and checkups (T1), treatments (T2), and post-treatment (T3) – occur across time (time). Based on the limited data, the post-treatment stage comprises of several possible outcomes: recovery, still suffering ("battling") or dying. For example, some of the respondents suffered their illness for more than twenty years, and most of that time they were in the treatment stage, while other respondents suffered for 10 years, mostly in the post-treatment stage. Even though each person suffered illness for a different length of time, they went through each of the three stages at least once during the disease course.

The conceptual map gives an overview of typical disclosure behaviors. Overall, during the first stage of illness – diagnosis and checkups – respondents discussed their medical diagnosis in detail with others. Most respondents reported that they were open to people who were sympathetic and supported them emotionally, or to those who helped them with decision-making and who provided them with information. A few respondents, however, felt upset and confused with the situation, and so tried not to discuss their health issue with many people during this stage. In the second or treatment and surgery stage, some respondents were compelled to disclose their health condition at work and in other social settings. Some had to take time off for treatment, some had to quit their job and some asked for the community to pray for them during this critical stage. Others remained silent, avoided seeing others and/or provided only minimum information to others as a way to keep their health information private.

The third stage could be recovery, still suffering ("battling") or dying. In this stage, many respondents felt a responsibility or desire to use their first-hand experiences, to tell others about their illness in order to educate and give social support. Some of them even became advocates for new patients by accompanying them to doctor's appointments and dealing directly with the medical team. Others chose to remain private about certain aspects of their illness, either because they were still upset or felt they didn't have enough information about their prognosis. All three stages of illness can yield either open or closed behaviors, indicating that individuals each perform their own balancing act in choosing open and closed behavior.

The special roles played by members of the DC indicate the social interaction that takes place between patient and DC and which influences the disclosure behavior. Four broad categories of DC roles emerged (see "Special Roles in DC" at upper left in Figure 1). Note that these special roles of DC only influence "Open" behavior; the special roles only appeared as factors that enhance the disclosure activities. There was not enough data to build up categories of "negative

roles" that might encourage closed behavior. This is indicated by an arrow from Special Roles to open behavior, but no arrow from Special Roles to closed behavior. On the right side of the diagram, bubbles inside the categories of "Open" and "Closed" summarize the different behaviors found in the data. Feedback arrows from these open and closed behaviors to the balancing act box indicate the constant reevaluation of disclosure decisions, as mentioned above in the discussion on Time as a factor.

The essence of the conceptual map is to show that disclosure processes occur across time and that an iterative balancing between disclosure (open) and privacy (closed) takes place, in which decisions are made not once but again and again. The balancing for each individual occurs across time, and is influenced by each stage of illness that they pass through.

The researcher's (first author) role as an interviewer fits into this map. The qualitative nature of this study means that the researcher is involved in the social dynamics of the disclosure process, since the respondents had to disclose to the researcher (first author) about their disclosure behaviors with others. Through snowball sampling technique, trust is established through the use of a mutual social network; this allowed the respondents to accept the interviewer as part of their disclosure community at that point in time. In addition, given the sensitive and emotional nature of the topic, the researcher becomes a social supporter to the respondents for the duration of the interview (for example, the researcher made sure that she listened carefully and showed sympathy). The researcher, then, by being an active, respectful listener genuinely interested in the respondent's experience, falls into the "Special Roles" category, specifically the "social supporter" subcategory. The relationship is admittedly brief, but nevertheless clearly present. The researcher also has developed friendship relationship with a few of the respondents and asked their well being from time to time.

5. Conclusion of study

Information privacy is a term that has many meanings to people. Most people will say they are open about their situation and that they have nothing to hide, but in reality individuals make conscious decisions which information to share (or not to share) with others. For medical patients, health information lets them understand what is going on and helps them feel more confident about informing selected individuals. Patients gained a positive outcome when they disclosed to others suggesting that the importance of a disclosure community to patient well-being. The lessons learned from this study support the idea that patients need to be able reach out to others by sharing their information so that others know how and when to provide help to patients.

The medical teams also play an important role in the disclosure process, which is to provide timely and accurate information to their patients without discrimination. The medical team must be aware that the information that they provide can help to inform, clarify and provide assurance to patients and their DC. In addition, the medical team needs to know how to explain the medical situation in general terms so that patients are able to fully understand their health situation and explain it to others.

Finally, this study emphasizes that awareness of health communication among the three parties is a crucial aspect of quality health care. The medical team who serve as the information broker can foster an atmosphere of openness by providing good information to patients so that the patient can disseminate information to their DC. This way, DC will be able to provide the appropriate support to patients. In addition, the medical team also can be proactive, giving ideas and guidelines to the DC on how they can directly and indirectly help patients in order to improve the quality of care.

References

Altman, I. (1977). Privacy regulation: Culturally universal or culturally specific? *Journal of Social Issues,* 33 (3), 66-84.

Altman, I. & Taylor, D. (1973). *Social Penetration: The Development of Interpersonal Relationships*. NewYork: Holt, Rinehart and Winston.

Baird, G., McConachie, H., Scrutton, D. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of disease in childhood,* 83(6), 475-480.

Berger, C. & Calabrese, R. (1975). Some explorations in initial interaction and beyond: Toward a developmental theory of interpersonal communication. *Human Communication Research,* 1, 99-112.

Berg, J.H., Derlega, V.J. (1987). Chapter 1: Themes in the Study of Self-Disclosure. In V.J. Derlega & J.H. Berg (Eds), *Self Disclosure: Theory, Research, and Therapy* (pp. 1-7). Plenum Press, NY.

Block, S.D. (2000). Assessing and Managing Stress in the Terminally Ill Patient. *Annals of Internal Medicine,* 132,209-218.

Bradley, E.H., Hallemeier, A.G., Fried, T.R., Johnson-Hurzeler, R., Cherly S., Kasl, S.V., Horwitz, S.M. (2001). Documentation of discussions about prognosis with terminally patients. *The American Journal of Medicine*, 111(3), 218-223.

Brann, B.M.S. (2003). Assessing the influence of illness, relationships, and information-seeking strategies on physicians' disclosure of confidential health information to relatives of patients. *Dissertation Abstracts International. 64*(07A), 2309. (UMI No. AAI3097381.

Chaikin, A.L. & Derlega V.J. (1974a). Liking for the norm-breaker in self-disclosure. *Journal of Personality,* 42, 117-129.

Chaikin, A.L. & Derlega V.J. (1974b). Variables affecting the appropriateness of self-disclosure. *Journal of Consulting and Clinical Psychology,* 42s, 588-593.

Contro, N., Larson, J., Scofield, S., Sourkes, B., Cohen, H. (2002). Family Perspectives on the quality of pediatric palliative care. *Archives of pediatrics & adolescent medicine,* 56(1), 14-19.Cozby, P.C. (1973). Self-disclosure: A literature review. *Psychological Bulletin,* 79(2), 73-91.

Derlega, V.J., Chaikin, A.L. (1977). Privacy and self-disclosure in social relationships. Journal of Social Issues, 33(3), 102-117.

Dindia, K. (2000). Chapter 2: Sex Differences in Self-Disclosure, Reciprocity of Self Disclosure, and Self-Disclosure and Liking: 3 Meta Analyses Reviewed. In S. Petronio (Ed.), *Balancing the secrets of Private Disclosures* (pp. 21-35). Mahwah, NJ: Lawrence Erlbaum Associates.

Glaser, B.G., Strauss, A.L. (1967). *Discovery of Grounded Theory: Strategies for Qualitative Research*. Aldine.

Holroyd, S., Turnbull, Q., Wolf, A.M. (2002). What are patients and their families told about the diagnosis dementia? Results of a family survey. *International journal of geriatric psychiatry,* 17(3), 218-221.

Nielsen, S.E. (1998). Confidentiality in the nurse-patient relationship (Ethics). *MAI, 36*(04), 1067(UMI No. AAG1388817).

Jourard, S.M. (1964). *The transparent self.* Princeton, NJ: Van Nostrand Reinhold.

Jourard, S.M. (1968). *Disclosing man to himself.* Princeton, NJ: Van Nostrand Reinhold.

Jourard, S.M. (1977). *The transparent self* (2nd ed). Princeton, NJ: Van Nostrand Reinhold.

Northouse L.L, Northouse, P.G. (1998). *Health Communication: Strategies for Health Professionals* (3rd ed). Appleton & Lange.

Rosenfeld, L.B. (2000). Overview of the Ways Privacy, Secrecy and Disclosure Are Balanced in Today's Society. In S. Petronio (Ed.), *Balancing the secrets of Private Disclosures* (pp. 3-17). Mahwah, NJ: Lawrence Erlbaum Associates.

Petronio, S. (1991). Communication Boundary Management: a theoretical model of managing disclosure of private information between marital couples. *Communication Theory,* 1,311-335.

Petronio, S. (2000). Chapter 3: The Boundaries of Privacy: Praxies of Everyday Life. In S. Petronio (Ed.), *Balancing the secrets of Private Disclosures* (pp. 37-49). Mahwah, NJ: Lawrence Erlbaum Associates.

Petronio, S. (2002). *Boundaries of Privacy: Dialectics of Disclosure.* SUNY series in communication studies.

Petronio, S. Sargent, J., Andea, L. Reganis, P. Cichoki, D. (2004). Family and friends as healthcare advocates: Dilemmas of confidentiality and privacy. *Journal of Social and Personal Relationships.*21 (1):33-52.

Strauss, A., Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques.* Sage Publications Inc.

Welch Cline, R.J., McKenzie, N.L. (2000). Chapter 5: Dilemmas of Disclosure in the Age of HIV/AIDS: Balancing Privacy and Protection in the Health Care Context. In S. Petronio (Ed.), *Balancing the secrets of Private Disclosures* (pp. 71-82). Mahwah, NJ: Lawrence Erlbaum Associates.

Wenburg, J.R., Wilmot, W.W. (1973). *The personal communications process*. New York: Wiley.Westin, A.F (1967). *Privacy and Freedom*. New York: Atheneum.

Westin, A.F. (2003). Social and Political Dimensions of Privacy. *Journal of Social Issues,* 59(2), 431-453.

Wortman C.B., Adesman, P., Herman, E. & Greenberg, R. (1976). Self-disclosure: An Attributional Perspective, *Journal of Personality and Social Psychology,* 33, 256-266.

Wheeles, L.R. & Grotz, J. (1976). Conceptualization and Measurement of reported self-disclosure. *Human Communication Research,* 2(4), 238-246.

Wiener, L.S., Battles, H.B., Heilman, N., Sigelman, C.K., Pizzo, P.A. (1996). Factors associated with disclosure of diagnosis to children HIV/AIDs. *Pediatric AIDS and HIV infection,* 7(5), 310-324.

Table 1. Overview of Respondents

Research Respondents (Total: 23 people)	
Medical Patient/Survivor (9)	Patients (5) Diabetes (1) Chronic Obstructive Pulmonary Disease (1) Heart Disease and Depression (1) Renal Failure (1) Chronic Fatigue Syndrome (1) Survivors (4) Breast Cancer Survivor (3) Thyroid Cancer Survivor (1)
Disclosure Community (8)	Family (6) Daughter (5) Daughter and Legal Guardian (1) Non-family (2) Spiritual (2)
Medical Team (6)	Medical Professionals (5) Physicians (4) Nurse (1) Other (1) Social Worker (1)

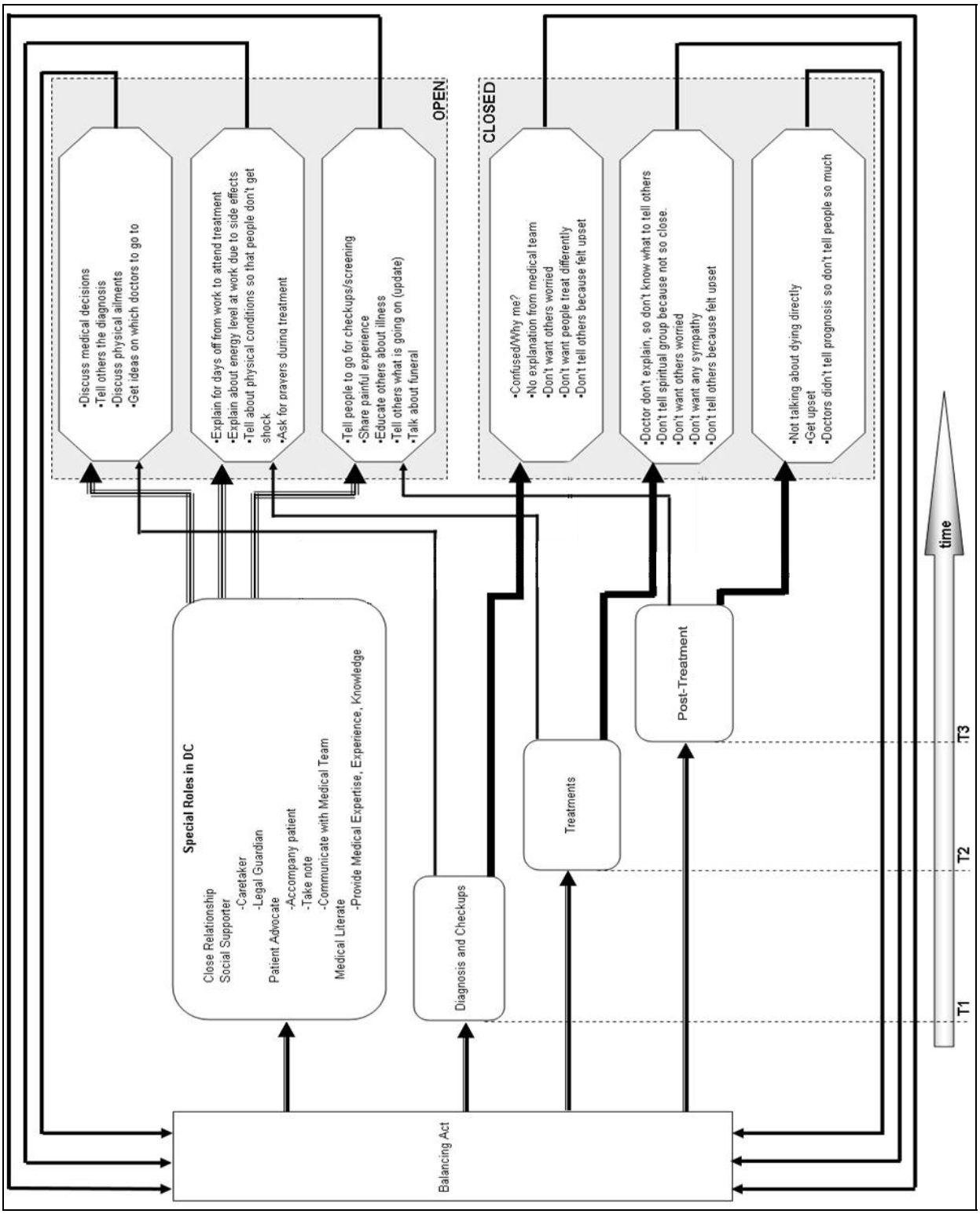

Figure 1. Conceptual Map for Social dynamics in disclosure communities