12 An Integrated Model of Health Disclosure Decision-Making[1]

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People receiving a health diagnosis experience a range of emotions, including uncertainty and fear, and may average 1 hour a day or more dealing with illnesses such as diabetes (Braitman et al., in press) or cancer. Most patients are overwhelmed by the sheer amount of health information they receive (Epstein & Street, 2007). They will face challenges in adhering to regimens, deciding on treatment, and may require social support. Researchers need more sophisticated understandings of how people manage information in these situations, especially how they manage the tension surrounding disclosure or sharing the information with others.

Scholars recently sought reconceptualizations of uncertainty and information management. Brashers (2001) called for scholars to abandon the assumption that uncertainty produces anxiety and focus on *how* people manage uncertainty. Several recent theories, including uncertainty management theory (UMT; Brashers, 2001), problematic integration theory (PI; Babrow, 2001), the revelation risk model (RRM; Afifi & Steuber, in press), and the theory of motivated information management (TMIM; Afifi & Weiner, 2004), advance conceptualizations in the information management arena. Some of these theories focus on information-seeking behaviors, yet people with health diagnoses must also manage sharing the information. Thus, we need to explore how disclosure decision-making unfolds in situations of health uncertainty.

Individuals presume a right to privacy (Petronio, 2002) or believe they have a choice in what information they share, when they share it, and with whom. Initial conceptualizations of the process of disclosing information involve confounding dilemmas about whether to reveal highly intimate personal information to significant others. That is, people balance the risks inherent in disclosure along with the benefits they might gain. A health disclosure decision involves coping with these dialectical dilemmas (Greene, Derlega, & Mathews, 2006) and attempts to reconcile these needs in a comparative weighting process for self, other, and relationships (see Afifi, Olson, & Armstrong, 2005; Derlega, Sherburne, & Lewis, 1998; Derlega, Winstead, & Folk-Barron, 2000). What is less clear are the factors that people weigh in these disclosure decision processes, and the model presented in this chapter addresses this gap.

Information regulation has been explored in literatures such as disclosure, avoidance, privacy, and secrets. Widespread scholarly interest has been devoted to examining these phenomena, but there are relatively few integrating frameworks or overarching theories that guide operationalization of these processes and generate testable hypotheses. Generally rooted in catharsis principles (see Stiles, 1987), much of this research assumes that people will purge troubling information. The crucial question is what underlies the decision processes and creates conditions for likely disclosure that are relatively consistent across situations, goals, and individual differences (Omarzu, 2000).

Much disclosure research has focused on reasons or motivations for disclosure but not always on the decision process. Reasons for disclosure are multifaceted and vary in complexity, and people generally pursue multiple goals simultaneously (Caughlin & Vangelisti, this volume; Dillard, 1990; Goldsmith, 2004; O'Keefe, 1988). Afifi and Caughlin (2006) describe a clash of motivational forces leading to a complex picture of when people are likely to disclose or not. Some reasons spring from common processes, yet others pertain to specific situations and cannot be generalized (Goldsmith, Miller, & Caughlin, 2007). Thus, these relevant decision factors are unclear in form and number, and the solution does not lie in typologies. Instead, researchers need a model to explain steps in the process leading to a decision to disclose. A clearer articulation of the sequence of the decision process will enable a more complex understanding of it, especially what variables interact to produce disclosure decisions (and the outcomes thereof). Consequently, the proposed model advances research by integrating and providing a framework to predict decisions to disclose. At the foundation of this new model are disclosure uncertainty, managing uncertainty regarding the information, the relationship, and efficacy in evaluating whether or not to share.

Model Overview

The first model presented in this chapter is an overview of the global process of a disclosure decision-making episode (see Figure 12.1). According to this model, explicated in greater detail by Greene, Derlega, Yep, and Petronio (2003) and Greene et al. (2006), a number of features are taken into account when a potential discloser assesses information and recipients for possible sharing. If a decision is made to disclose, the discloser carefully considers message features (e.g., setting and timing). Finally, the disclosure episode includes outcomes affecting the self, other, and relationship as well as subsequent disclosures. Portions of the model have been elaborated and tested previously, although there are many available avenues for future research.

The model depicted in Figure 12.2 addresses the call for a better understanding of decisions to manage uncertainty through disclosure (explicating the first component of the model in Figure 12.1) and possible moderators of disclosure decisions. This is conceptualized as a process including both direct and indirect effects (prior to the disclosure enactment). The first part
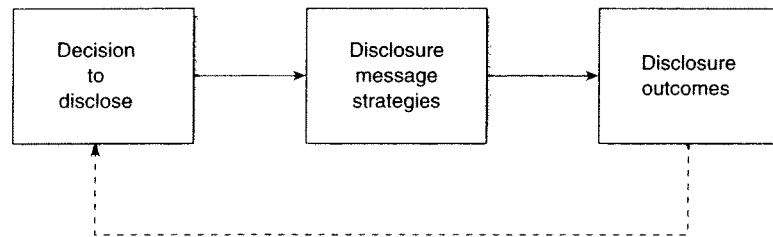
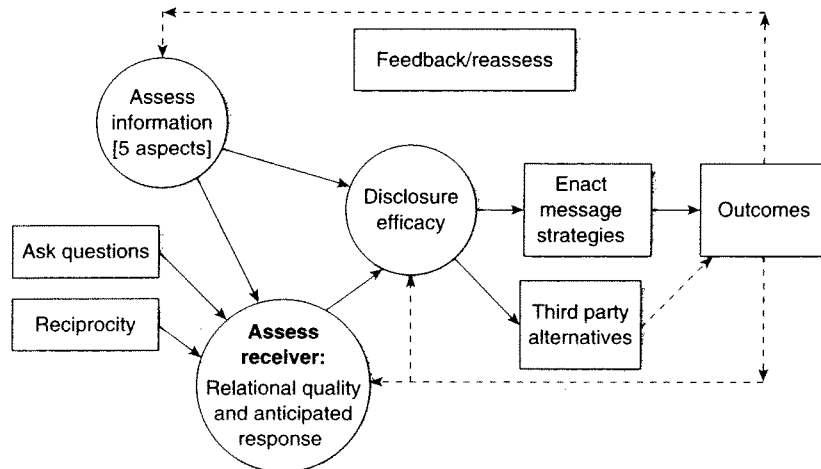Figure 12.1 Simplified Disclosure Process Model

Figure 12.2 Health Disclosure Decision-Making Model

of this process is to assess the diagnosis or information (Propositions 1–5), followed by an evaluation of a potential receiver (Propositions 6–7), and finally exploration of perceived disclosure efficacy (Proposition 8) in predicting willingness to disclose. What is argued is that disclosures are encouraged or discouraged by the relative assessment of these factors. Interruptions to the most predictable decision patterns are also included (Propositions 9–10), along with potential feedback loops. Propositions are included to allow for testable hypotheses and to examine more complex associations accounting for moderation and interruptions in the general decision-making process.

The Proposed Disclosure Decision-Making Model (DD-MM)

The DD-MM separates the disclosure decision-making process into several components perceived by the discloser. Initially, the person assesses the information or diagnosis; this process is repeated for various targets, but it is also cycled through in the disease process when new pieces of information become available. The DD-MM illuminates how people evaluate information as one part of this complex initial process of information management. The assessment of information includes weighing five components that are likely interrelated: stigma, preparation, prognosis, symptoms, and relevance to others. These five aspects are not intended to represent an ordered process; each could occur in a different progression, simultaneously, or not be relevant for a particular piece of information. In an instance such as a sexually transmitted infection (STI), a person might evaluate stigma and relation to others initially, but with another situation a prognosis assessment might come first. Based on the evaluation of information, if the evaluated risk is not too great and the process lends itself to continued consideration of revealing, the discloser will then move to consider the specific potential receiver. A potential discloser can also exit the disclosure process at this point by not disclosing or waiting to potentially disclose in the future when some aspect of the information is reconsidered.

The second component of the DD-MM is consideration of the potential receiver, and this variable includes two factors: relational quality and anticipated response. First, the discloser considers the quality of the relationship (including intimacy or closeness and anticipated contact). Anticipated response is the second factor and includes the discloser's subjective assessment of how the receiver might respond or react to the shared information. If, after consideration of these two receiver factors, this part of the decision process is still favorable for sharing, the discloser will then examine his or her disclosure efficacy. The discloser can also exit the process at this point by not disclosing to this person and potentially reassess the decision at a later point in time.

The last portion of the model, disclosure efficacy, has not received a great deal of attention, although it has been included as a reason for nondisclosure or reported as a disclosure concern. Disclosure efficacy is a person's perception of his or her ability to share the message to produce the desired results (Bandura, 1977), and this is a narrower conceptualization than communication efficacy that spans varied situations and communication behaviors. The initial disclosures of a piece of information may be especially salient in people's assessment of their efficacy. One aspect that has not been fully considered is the use of intentional third party disclosures and alternate message strategies (see Greene et al., 2003, p. 116f). If people do not perceive that they have the ability to disclose, they may enlist another to disclose or choose other options. If disclosers do not perceive efficacy or

select another strategy to disclose the information, they may decide not to disclose at the current time (and exit the model).

Finally, in the DD-MM, if disclosers perceive adequate efficacy and all other components of the model lead to a disclosure decision, they will enact the message. This part of the process includes the discloser planning the setting, timing, channel/mode, and the message features, which may also include practice or rehearsal. The aspects of the process that are not explicated in this chapter due to space limitations include disclosure enactment and disclosure outcomes, but some of these components have been articulated elsewhere (e.g., Afifi & Caughlin, 2006; Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Caughlin, Afifi, Carpenter-Theune, & Miller, 2005; Greene et al., 2003, 2006).

Outcome variable. One question to address is the nature of the outcome variable, which is the intention to disclose or likelihood of disclosure in the DD-MM. The most commonly utilized measure, disclose/not disclose, has a number of limitations beyond its dichotomous nature, including the inability to separate goals from behavior. Utilizing intention or willingness to disclose allows for more focus on planning and the process of disclosure, with consideration of interruptions. Similar to behavior change models such as the theory of reasoned action (TRA; Ajzen & Fishbein, 1980), the DD-MM also recognizes that intentions, although highly correlated with behavior in certain circumstances, do not always lead to the planned disclosure behavior.

Scope

The DD-MM focuses on interpersonal contexts, including face-to-face or mediated interaction, but it would not include public disclosure or announcing information to a large group. The DD-MM is best suited for conditions where people have a personal relationship, rather than, for example, considering disclosure to a medical professional who may be visited based on the information in question (e.g., getting a scan to track cancer progression or X-rays to follow arthritis progression). However, there is research available on the disclosure of HIV to medical professionals (e.g., Jeffe et al., 2000) or workplace disclosure (Munir, Leka, & Griffiths, 2005).

Certain communication interactions are more planned or mindful, and this may be the case with health disclosures. The decision to disclose important information is generally preceded by considerable effort in strategically planning the disclosure (Afifi, Dillow, & Morse, 2004). Similar to other information management models, the DD-MM assumes we strategically manage our information, yet it is likely that different parts of this process are more automatic (e.g., oft-repeated disclosures), while others are more cautiously planned (Omarzu, 2000). We must grapple with the reality that the entire disclosure process is rife with unpredictability, and this is revealed in numerous predicted interruptions in the model.

Self-disclosure and private information. Knowing how people define, assess, and manage their private information is crucial in coping with

disease. This chapter adopts Derlega, Metts, Petronio, and Margulis's (1993) focus on self-disclosure as an interaction between at least two individuals where one intends to deliberately divulge something personal to another. There is less agreement about "what" people do or do not disclose. Mathews, Derlega, and Morrow (2006) asked people to identify their personal information, and many of their reported personal topics had negative valence (see also Vangelisti's or T. Afifi's research on secrets). When participants are asked to describe secrets, most are negatively valenced. Health "issues" are also often negatively valenced, with positive disclosure moments in the progression such as "The biopsy was negative" or "My PSA is still low." The influence of the level of perceived privacy of a piece of information remains a question for future research (see Venetis, Greene, Banerjee, & Bagdasarov, 2008a), but it is clear that perceptions of the intimacy of secrets vary and affect disclosure decisions. For example, having an eating disorder is secret to some, private to some, and open to others. The assessment of information is present in the DD-MM but not most disclosure models (for exception see valence in RRM; Afifi & Steuber, in press).

The DD-MM is conceptualized to include both disclosure and privacy and can address secrets and avoidance. Nondisclosure is different from avoidance because people fail to introduce topics, such as not discussing new symptoms or treatment options with a person even after sharing the initial diagnosis. We know little about conditions in which avoidance of health information is productive or functional for relationships (see Goldsmith et al., 2007, for review with cancer). There is a growing body of research on secrets that may also illuminate nondisclosure decisions (see Kelly, 2002; Vangelisti, 1994). Keeping secrets is an active process that uses cognitive resources (Kelly & McKillop, 1996; Wegner & Lane, 1995), compared to privacy. This research points to how potential disclosers view the information, as private or secret (see Venetis et al., 2008a), and assessment of information is a crucial first step in the DD-MM.

Definition of health. The DD-MM explains the health information decision-making process; most traditionally this would apply to physical or psychological health topics. Thus, it can be applied to health, yet disclosing divorce (family health) or infidelity (relational health) could be considered using the DD-MM, but a physician sharing a diagnosis with a patient or disclosure to a therapist would not fit the model as well because of the situational demands as well as the nature of the information and relationship. The DD-MM may not have the same applicability for traumas such as a car crash, breaking a bone, or receiving stitches. For example, "I was in the hospital" could in some situations be a health disclosure of an ongoing illness or condition. Recent topics of disclosure studies have ranged widely, from epilepsy (Santosh, Kumar, Sarma, & Radhakrishnan, 2007) to rape (Ahrens, Campbell, Ternier-Thames, Wasco, & Sefl, 2007), from genital herpes (Green et al., 2003) to psychiatric disorders (Corrigan & Matthews, 2003), demonstrating the range of potential applicability of the DD-MM.

One additional question is whether the information is about the self, other, or the relationship. There are genetic diseases where siblings might consider testing (family information), or a parent has Alzheimer's, and this information could be considered relational in nature. The focus of the DD-MM is generally on health information about the self, yet "We are pregnant" can be relational news and fit within the DD-MM. Sharing others' health information is labeled *third party* or *gossip* and is also discussed in the DD-MM, but this is not considered disclosure because it is not personal information revealed by the discloser.

Process. The interactive nature of the disclosure process is not captured well by current disclosure models, although several models, like the DD-MM and RRM, contain variables similar to relational quality. Disclosure is an iterative process where people share and then incorporate perceived responses to disclosure into their future disclosure decisions as feedback mechanisms. The DD-MM is designed to proceed through the decision-making process with exits for nondisclosure. Disclosure itself is cumulative (of a diagnosis) in that, for one piece of information, disclosers increase the number of people who know (or are told), yet nondisclosure decisions may be reassessed (disclosure decisions can only be regretted and perhaps new information not shared). People can and do reevaluate receivers not told and decide whether or not they want to share further. There is little research to date on the order of disclosure or who people tell first (and last) and how initial reactions—positive and negative—affect subsequent sharing (see Afifi & Steuber, 2008). People also do not simply disclose about an illness diagnosis (the initial consideration of the DD-MM). Rather, there is a continual disclosure process regarding treatment options, coping, and disease progression. People are constantly in a process where decisions have to be made about sharing updates, not simply the initial diagnosis. Thus, the process is complex, and people can simultaneously disclose some aspects yet avoid sharing other information.

Assessing Information

The DD-MM proposes that the first stage of disclosure decision-making involves assessing the diagnosed information. How a person appraises the information is crucial, as there are many responses to the same diagnosis (PI theory; Babrow, 2001). Aspects of assessing the diagnosis include stigma, preparation, prognosis, symptoms, and relevance to others, conceptualized globally in other work as valence (e.g., Afifi & Steuber, in press).

Stigma

Disclosure involves vulnerability and potential risk, and this risk is elevated when the information is viewed as stigmatized. Depending on perceptions of the topic and stigma, there may be more pressure to conceal. Goffman's

(1963) initial conceptualizations of stigma and spoiled identity underlie most research in this area, but the most complete treatment of health-related stigma is Leary and Schreindorfer's model (1998; see also Greene et al., 2003). Recent research on stigma has centered on HIV, but there are also many investigations with cancer and sexual orientation. For some people, attribution of responsibility for a disease is a critical facet of both disclosure and response, perhaps related to labeling such as with mental illness. Recent studies of stigma and disclosure have ranged from obesity (Brown, Ueno, Smith, Austin, & Bickman, 2007) to erectile dysfunction (Rowland, Thornton, & Burnett, 2005), among others.

Stigma literature has developed extensively to incorporate health, yet we still know little about the effect on disclosure intentions, particularly how relational quality might moderate this association. If a person has a good relationship with the potential recipient, she or he may be willing to disclose even highly stigmatized information. Research consistently reports negative correlations between perceived stigma and willingness to disclose (and negative outcomes of disclosure). However, despite all these possible drawbacks or risks, people do choose to selectively share stigmatized information. We know little about the conditions under which some variable, such as anticipated response, "overcomes" stigma and leads to a disclosure decision. If a person believes that she or he will receive a positive response to a disclosure (likely correlated with relational quality), she or he may be willing to disclose even highly stigmatized information. With this information in mind, the first propositions are set forth:

> Proposition 1A: Perceptions of stigma decrease intentions to disclose.
>
> 1B: The effect of stigma on intention to disclose is partly moderated by anticipated response and relational quality.

Preparation

Preparation addresses the discloser's expectations prior to receiving the information. People may anticipate a diagnosis if they are aware of symptoms and this leads to visiting a physician. It is possible, however, that a routine exam (or an unrelated test) uncovers cancer, for example, leaving a person less prepared for a diagnosis. Age may also influence preparation, given that as people age they may become more prepared for certain types of health diagnoses. Another component of preparation is whether the person has any prior knowledge of the disease. A person may have some general awareness of arthritis but not his or her particular type. Family history or group membership may also prepare a person for a diagnosis if the disease is hereditary or genetically linked, such as for diabetes.

The relation of preparation to disclosure decisions is complex. On one hand, if the person was prepared to some degree and expected the diagnosis, she or he may have already considered the disclosure decision process

and waited to share the news (or selected one close confidant for initial disclosure). According to Berger (1997), increased time for planning leads to more complex plans (and perhaps greater success). Alternatively, it is possible that, without having preparation or readiness, a person unprepared for the diagnosis might disclose immediately to relieve distress (see Stiles' 1987 fever model). In this case, emotions may overcome a more rational model of disclosure decision-making, and people may vent in search of expressive social support (or instrumental support if they need assistance such as research on the Internet). The association between preparation and disclosure may also be influenced by relational quality and anticipated response, such that we seek out a target with good relationship features accompanied by a positive anticipated response, especially if we are unprepared for the diagnosis. Therefore, the next set of propositions suggests that associations exist among these variables, but their direction remains unclear:

2A: What is the association between preparation and intention to disclose?

2B: Is the association between preparation and intention to disclose partly moderated by the assessment of the receiver (relational quality and anticipated response)?

Prognosis

There is a great deal of variability in prognosis and intrusiveness by disease stage. Goldsmith et al. (2007) argue that we need to theorize about these relations and not simply control for or sample by disease features, as addressed by this portion of the DD-MM. When receiving a diagnosis, a person may subjectively evaluate the disease prognosis. Is the disease chronic, treatable, or terminal? What are the treatment options? This is a classic case where having additional information (the diagnosis) decreases one form of uncertainty yet increases another. Assessing the prognosis may include considering the relative probability of various outcomes (see PI; Babrow, 2001). One of the greatest concerns for breast cancer patients is the uncertainty of progression and recurrence (e.g., Gill & Babrow, 2007). Patients may need to transition to coping with death, which could include disclosure decisions and preparing social networks. The topic of death "inspires some of the greatest variability in communication" (Goldsmith et al., 2007, p. 72), including disclosure decisions. Death may be an especially ominous topic, and people may find it easier to share treatments or facts rather than feelings, especially if they are uncertain of how the other might react. A terminal prognosis may also create greater interaction urgency (see Berger, 1997) where people feel pressure to disclose. In the final weeks, people may openly discuss death (Hinton, 1998) or conversely they may discuss death initially at diagnosis and then drop the topic.

Although clinicians report that they are discussing illness prognoses with patients, patients and caregivers do not generally confirm these reports (Fried, Bradley, & O'Leary, 2003), and patients may not desire prognostic information or probability information in assessing risk (Beresford, Seymour, Vincent, & Moat, 2001). Terminal cancer patients may want to know less information (Jiang et al., 2007). For instance, Fujimori et al. (2007) reported that 30% of Japanese cancer patients did not want life expectancy information. Desire for prognosis information may need to be addressed for a patient before she or he proceeds with disclosure decisions. In addition, receivers may ask about the disease prognosis ("How long do you have?" or "How bad is it?"), thus the discloser must prepare for possible disclosure outcomes such as varied responses.

Differences in the desire for prognosis information are best explained theoretically by Babrow's (2001; Babrow & Matthias, this volume) PI theory that describes uncertainty as a central feature of illness experience. According to PI theory, people form probabilistic and evaluative orientations to the world, and these two features are interdependent and affect how people integrate an illness experience. According to this perspective, more information may not reduce uncertainty (or lead to disclosure): "many uncertainties cannot be resolved by more information" (Babrow, 2001, p. 563). PI explains why some people may avoid not only prognosis information but may more extensively avoid through strategies such as not seeing a doctor or declining offers for testing (e.g., genetic testing; Lerman et al., 1999). Some of these strategies may be more active than others: Avoid seeing a doctor or not returning a phone call are more passive, yet telling a physician that you do not want surgery or information about treatment options are more active. Finally, PI theory proposes that people can "cognitively reappraise" and reassess information, and thus they can potentially abort the disclosure process and decide not to share. For example, people can reframe even definitive diagnostic information as "preliminary," choosing as well to await results of surgery, initial chemo or other therapy, before disclosing their condition. Therefore, the following propositions are proposed:

3A: Is the relation between prognosis and disclosure intention curvilinear?

3B: The effect of prognosis on disclosure intention is moderated by anticipated response.

3C: Prognosis uncertainty will lead to delay in disclosure intentions.

Symptoms

There are risks of complications and visible symptoms associated with the progression of many diseases that vary over the illness trajectory. However, there have not been many studies of the relationship between disclosure and disease progression except in the context of HIV. Most HIV studies report

that disclosure is positively associated with physical symptoms, including CD4 count and illness severity (e.g., Greene et al., 2003, pp. 99–100; Vallerand, Hough, Pittiglio, & Marvicsin, 2005; for exception see Klitzman et al., 2007). Some people do refrain from disclosing a disease until they are symptomatic or too ill to care for themselves. For example, Asians disclosed HIV status to relatives only when necessitated by declining health (Yoshioka & Schustack, 2001).

People who are symptomatic may disclose more than those who are in the earlier stages of their illness. We still need a better understanding of the disclosure process with other diseases, such as those progressing rapidly or with few or no external symptoms. With longer-course illnesses, it might be a matter of time before some people share (Emlet, 2006; Zea, Reisen, Poppen, Echeverry, & Bianchi, 2004), or people may feel a sense of inevitability about others' knowing. Some people feel that circumstances will reveal the information anyway and cite this as a reason for disclosure (e.g., Greene et al., 2003; Vangelisti, Caughlin, & Timmerman, 2001).

Noticeable symptoms may affect the timing of disclosure or interrupt plans, perhaps leading receivers to ask questions about an illness (discussed later in the chapter). Some people feel the process of disclosure is forced on them because of declining health status (e.g., Vallerand et al., 2005) and need for social support. Symptoms or disease progression may force changes in routine, which can result in people trying to hide symptoms (see Leary & Schreindorfer, 1998, p. 26). As health begins to decline, others may begin to notice changes in a person's normal activities, such as eating patterns or not going out in public (due to compromised immune system). This leads to the next set of propositions below:

> 4A: Disease progression and symptom visibility are associated with increased disclosure intentions.
>
> 4B: What is the association between progression and disclosure intentions for diseases with few visible symptoms?

Relevance to Others

One last part of assessing the decision to disclose is consideration of the diagnosis in relation to the potential recipient of the information: Are others directly or indirectly affected by the diagnosis? Most research in this area has been conducted with STIs, where people consider the possible risk of transmission to their sexual partners. In this context, a partner may seek an explanation for changes in safer sex practices, such as the introduction of condoms (see Mattson & Roberts, 2001). Public health recommendations include STI disclosure to all sexual partners, yet data indicate that this particular decision is complex with STI information not shared with all or even most sexual partners (e.g., Ciccarone et al., 2003; Simbayi et al., 2007). These decisions

are complicated by perceptions of stigma and potential anticipated responses; if people fear loss of the relationship or view the information as stigmatized, they are less likely to disclose, even if the information is relevant to the other or they believe the other "has a right to know."

Several related topics are also worthy of consideration. Noncommunicable diseases that may still affect others are unaddressed in the disclosure literature. First, consider disclosure of illnesses with genetic links such as cystic fibrosis, Huntington's syndrome, or hemophilia. People receiving such diagnoses may want to share the information with siblings, children, or other family members. Second, there may be environmental issues, such as being exposed to lead poisoning, where people would be motivated to tell others at the workplace (yet an employer may or may not share this motivation to reveal the information). In cases such as rape (see Ahrens et al., 2007) or sexual abuse, where the perpetrator might place additional others at risk, a survivor might feel compelled to disclose to protect others and/or prevent future crimes. Finally, even a person losing a job may directly or indirectly affect the family (e.g., their financial health). Thus, it is suggested that:

> 5A: The perceived relevance of a diagnosis to others' health increases intentions to disclose.
>
> 5B: This association is moderated by stigma and anticipated response.

Assessing the Receiver

If, after evaluating the information, people continue to consider disclosing, the next portion of the DD-MM involves assessing the receiver. Two receiver variables, relational quality and anticipated response, are factors people use when they consider whether or not they should disclose. These two variables are likely positively associated (e.g., Afifi & Olson, 2005). That is, the closer people feel toward the respondent, the more likely they will be to expect a positive response (see also Afifi & Steuber, 2008).

Who is told. Much attention has been paid to comparisons of who is told a specific piece of information. This research, however, has confounded relational role or type with relational quality and is thus limited conceptually. People have varying levels of intimacy with a particular "role" such as a sibling. Some researchers sum the number of people told to create a "disclosure measure," and this operationalization confounds family or network size with the proportion of possible persons told, leading to inflated measures for those with large networks.

Disclosure involves a pattern of selective sharing or target selection. Target selection in rare cases is determined by the situation; most often we have a range of options for choosing disclosure targets (Omarzu, 2000). People often begin the disclosure process by assessing their social network, or answering the question, "Who might I tell (or not tell)?" People are

relatively selective about who they choose as recipients (Vangelisti et al., 2001), especially with important information, and thus select confidants to minimize risk. An illness takes a tremendous toll on families/partners who are available and willing to provide support. Consequently, we need more information about when and why some disclosers choose not to share their health status, perhaps due to the quality of these relationships or characteristics of the information/diagnosis.

Relational Quality

Disclosure plays a critical role in the kind of relationships people have with each other (Greene et al., 2006; Harvey & Omarzu, 1997; Prager, 1995), and the quality of a relationship with a recipient is associated with the likelihood of disclosure (e.g., Altman & Taylor, 1973; Chaiken & Derlega, 1974). Some research, however, confounds relational quality or intimacy and disclosure both conceptually and operationally (Altman & Taylor, 1973; Sullivan, 1953). Current views of intimacy are broader, separating the disclosure process from the relationship development process (see Morr & Petronio, 2007), yet even discussing private topics increases intimacy (see Derlega et al., 1993), making it important to consider the reciprocal nature of this relationship.

Generally, better relational quality is related to increased intentions to disclose and may even overcome the suppressive effect of stigma, yet there are situations where people disclose to those with whom they have poor relationships. We need to better understand the conditions under which people choose to disclose to recipients where the relationships are poor or conflictual (and the consequences of such disclosures), as these particular disclosure events are likely to have heightened uncertainty. Factors that might predict disclosing based on poor relational quality include telling a former lover that she or he should be tested, feeling a duty to inform, or perhaps to make amends before dying. Caughlin and Afifi (2004) and others reported a lack of closeness as a reason for avoiding.

Despite the centrality of relational quality in research on disclosure over the past 40 years, there are a number of unanswered questions regarding relational quality, including measurement and sampling. Relational quality may also be confounded with variables such as anticipated contact. A discloser could easily delay sharing (e.g., disclosure of pregnancy) for months if she or he would not be seeing a potential recipient face-to-face in contrast to a case where a person is surrounded daily by potential disclosure recipients (Afifi & Steuber, 2008). We also need to consider social changes in modes of contact including e-mail, IM, and mobile phones, rather than simply face-to-face contact (see Greene et al., 2003, p. 85f). A lack of contact is also cited as a reason for not sharing (e.g., Golish & Caughlin, 2002).

Research to date has not been well designed to assess the impact of relational quality in disclosure decisions or how relational quality moderates

associations. If there is not enough variance in measurement (e.g., why bring a friend with whom you have a poor relationship to a lab study, but also how could a person have a close relationship with a stranger?) this will attenuate associations in model testing, perhaps underestimating the role of relational quality. This leads to the following:

6A: Better relational quality will be associated with increased disclosure intentions.

6B: Relational quality moderates the association between perceived stigma and disclosure.

Anticipated Reactions

People often consider what would happen if they did reveal to a specific person (Greene & Faulkner, 2002; Vangelisti et al., 2001) and make estimates about the likely reaction of a receiver before deciding whether to share the information, including the relative probability of the outcome or reaction from the receiver (see Babrow, 2001). An unresponsive reaction is cited as a reason for topic avoidance (e.g., Caughlin & Afifi, 2004). Kelly and McKillop (1996) proposed that prior to disclosure people should evaluate three qualities of a recipient that could be captured under the umbrella of anticipated response: Is the person discreet, nonjudgmental, and able to help them? Alternately, Reis and Shaver's (1988) interpersonal process model of intimacy (IPMI) emphasizes the role of partner responsiveness, and Manne et al. (2004a) reported a very strong association between perceived responsiveness and intimacy among couples (range .72–.88). This research suggests the need for more tests of the role of response using models like the DD-MM.

Generally, a discloser must anticipate a positive (not negative or neutral) response before being willing to disclose (Altman & Taylor, 1973; Greene & Serovich, 1996), although exceptions have been reported and are not well understood. A rejecting response will decrease the likelihood of additional disclosure and could be viewed as feedback. We know little about situations where a discloser is neutral or uncertain about a receiver's likely response (for exception, see Greene & Faulkner, 2002), and these may be the source of greatest uncertainty. In these ambiguous situations, disclosers may focus additional attention on maximizing either recipient or relational goals (see Sunnafrank, 1986) in deciding whether to disclose. People can also test reactions by observing others (Kelly & McKillop, 1996) or use incremental disclosure to gauge reactions before fully disclosing (e.g., Greene et al., 2003; Petronio, Reeder, Hecht, & Mon't Ros-Mendoza, 1996).

Research to date has failed to consider the discloser's confidence in the potential receiver's reaction. If a partner might leave the relationship, being "nearly certain" that this will not occur may not be sufficient to overcome fear and result in nondisclosure. For example, less than half of women with

epilepsy in India disclosed their illness prior to marriage, fearing breakup of marriage negotiations (Santosh et al., 2007). Other specific relational challenges with anticipated response include sharing with elderly people or those who are ill where a discloser may not want to burden someone or increase his or her stress. A potential receiver may also be seen by the discloser as "unsophisticated" or might not know much about the disease, thus limiting disclosure.

Gossip and PRPs. As one possible outcome from disclosure, recipients may repeat information to others, even if specifically asked not to do so. Thus, people consider the discretion of the potential recipient (Kelly & McKillop, 1996) and choose recipients who will respect their privacy requests. According to communication privacy management (CPM; see Petronio, 2002; Petronio & Reierson, this volume), recipients are viewed as shareholders or co-owners of the information, even though the recipient does not always treat the information with the same caution as the discloser. Some people feel a great deal of ownership of their health information (DeMatteo et al., 2002), but there are no quantitative tests of this phenomenon, including whether ownership perceptions are shared by the receiver and how this affects the receiver's subsequent disclosure decisions and perceived responsibility for the other's information. If a receiver does share the information despite a discloser's request to remain private (Greene & Faulkner, 2002, labeled this gossip), this may affect the subsequent disclosure decisions such that a discloser will share with fewer people.

The area of gossip and third party disclosure has received some attention, but only two studies to date have examined prior restraint phrases (PRPs). PRPs mark the disclosed information for others and signal how the discloser wants the information to be managed (e.g., "Please don't tell anyone else, but ..."). According to Petronio and Bantz (1991), people who receive PRPs do not necessarily keep the information secret. Even the discloser recognizes that the information will likely be shared—but hopefully only to select others, such as the receiver's partner. Nevertheless, the discloser intends the PRP to result in the receiver sharing with few others (but not zero others). Venetis, Greene, Banerjee, and Bagdasarov (2008b) described how both implicitly and explicitly stated privacy rules generally serve to safeguard disclosed information from further revealing, but they differ based on the participant's role as recipient or discloser, motivations to not further reveal, and the type of information disclosed. How disclosers' expectations about privacy responses are communicated to—and perceived by—receivers is deserving of future research.

Prior reactions. One component of the DD-MM that forms the basis of anticipated response is prior reactions. People may consider the target's previous responses in deciding whether to reveal (Afifi & Caughlin, 2006). Past histories with potential disclosure recipients form the basis for expectations (positive or negative). If the respondent has responded positively to prior revelations, this may increase the likelihood of sharing again, but if

prior responses were negative this may delay disclosure or result in not sharing. In a longitudinal study of family secrets, people were less likely to reveal (and reported decreased closeness) if they expected negative reactions (Afifi & Steuber, 2008). A related phenomenon was labeled the *chilling effect*, where partners withhold relational complaints if they believe a partner will respond negatively such as with anger or aggression (see Afifi & Olson, 2005; Cloven & Roloff, 1993; Roloff & Cloven, 1990). It is also likely that perceived prior response is positively associated with relational quality, or we tend to like those who respond positively (or vice versa).

Biased perceptions? Evaluating anticipated consequences assumes individuals are able to accurately predict outcomes or others' responses, yet people have biased perceptions (Caughlin et al., 2005). People may expect negative reactions to sharing and delay their disclosure as a result; then when they finally do disclose and receive a negative reaction, is the negative reaction atttributable to the delay in sharing or to the information itself (see Afifi et al., 2005)? There are few studies that untangle these questions, especially with regard to health information.

There may also be bias in retrospective reports where the discloser considers that "telling was not as bad as I thought" with the passage of time. Greene and Faulkner (2002), however, reported unexpected gossip and threats of violence (toward the source of HIV infection) as unanticipated reactions from recipients. Measures of targets' responses, however, are based on disclosers' perceptions rather than on the receivers' actual or reported reactions. Kelly (2002) argues that the discloser's perception of a receiver's response is more crucial than actual recipient behaviors or responses. There are few studies measuring both the discloser and the receiver that could help address this gap (see Caughlin et al., 2005). Both perspectives can assess the congruence of views, even if both are biased, despite the fact that it is the discloser's view that is pivotal in information-sharing models.

Actual reactions. We may expect the worst outcomes to disclosure. Actual reactions to disclosure may be far less dramatic than anticipated reactions (Rutledge, 2007), although some extremely negative reactions are reported (e.g., Greene et al., 2003; Greene & Faulkner, 2002). Caughlin et al. (2005) found that people were generally relieved that their partner's reactions were more positive than expected, yet Ahrens et al. (2007) found that only about half of their sample reported receiving positive responses to first disclosures of rape. Greene and Faulkner (2002) reported that five categories captured perceived reactions to HIV disclosure (three that would be labeled *negative*) including treated differently, negative emotional reactions, provided support, told others, and treated no differently. Thus, actual reactions to disclosure may be more positive than expected, with crucial negative instances being evaluated as people assess the relative risk of disclosing.

Even well-intentioned people may respond in unsupportive or distressing ways (see Barbee, Derlega, Sherburne, & Grimshaw, 1998; Ingram, Betz, Mindes, Schmitt, & Smith, 2001; Wortman & Lehman, 1985). People can be

surprised by close others' reactions, both positively and negatively. This is best explained by expectancy violation theory (Burgoon, Buller, Dillman, & Walther, 1995), where uncertainty is increased when expectations are not met, such as when a discloser expects a positive response and receives a negative or ambiguous one. A person may overreward a receiver if she or he receives a more positive—or less intensely negative—response than expected, yet negative responses likely decrease future disclosure to others and may have negative effects on relational quality. Thus, the same behavior some-times increases and decreases uncertainty, depending on what the discloser expected prior to sharing (see Afifi & Olson, 2005). Positive violations will likely increase perceived efficacy and future disclosure. Disconfirming responses will lead to tighter boundaries (CPM; see Petronio, 2002; Petronio & Reierson, this volume). Consequently,

7A: If the anticipated response is positive, people are likely to disclose to this receiver, even if the information is assessed as stigmatized.

7B: There is a positive association between relational quality and anticipated response.

7C: If the perceived actual response is more negative (or less positive) than expected, this will result in less future disclosure intentions.

7D: If a PRP is perceived to be violated, there will be decreased relational quality and decreased future disclosure intentions.

7E: Gossip or unsolicited third party disclosure will decrease future disclosure intentions.

Disclosure Efficacy

If, after evaluations of the information and potential target, people continue to consider disclosing the information, they must evaluate their ability to send this message to this specific person. Both confidence and skills are needed to share a difficult message such as a health diagnosis, although at times disclos-ers do share with trepidation, apprehension, and considerable uncertainty. Efficacy is the perception of one's ability to perform an action or produce an outcome (Bandura, 1977; Makoul & Roloff, 1998; see also Afifi & Weiner, 2004). People can design message strategies but know that "in the moment" they would not be able to articulate or enact the message. Thus, people may not act upon a disclosure plan unless they are confident in their ability (see Afifi et al., 2005), and this efficacy is also affected by the information assessed. In fact, the strongest path in the RRM is between risk assessment and efficacy (Afifi & Steuber, in press; see also Afifi et al., 2005).

Does repetition or practice affect disclosure efficacy? Afifi and Steuber (in press) reported that decreased communication efficacy was related to increased rehearsal (and incremental disclosure). For some people, disclosure

becomes easier after the first few times, yet others retain their anxiety throughout each disclosure. Miller and Rubin (2007) reported that some people discuss disclosure strategies with a trusted person to facilitate plan-ning, and this could potentially include choosing words ("I'm sick" vs. "I have cancer"; see Greene et al., 2003; Hosek, Harper, & Domanico, 2000) and other message features, akin to creating a script (see Afifi et al., 2005). Many disclosure recommendations encourage practice or preparing details, including choosing time, phrasing, and location for disclosure to maximize confidence in skills.

One framework that is useful for considering the efficacy component is impression management, or people's desire to decrease potential loss of face and protect their identity (Afifi & Caughlin, 2006). People have complex identity needs that affect disclosure decisions, often motivated by the need to avoid negative impressions (Afifi & Guerrero, 2000; Rosenfeld, 1979). Some information is assessed as more face threatening, such as the fear of being seen as weak, thus one would expect that increased relational quality and perceived anticipated response would be required in addition to per-ceived efficacy to share this type of message. A discloser could also perceive that his or her efficacy might be higher at a later time and wait to disclose, perhaps when there is more pressure due to symptoms or the receiver notices and asks.

If people feel unable to share yet are still motivated to disclose, they may resort to alternate message strategies to accomplish sharing the informa-tion. That is, they could ask another person to share the information (see third party disclosure). Options for disclosure enactment also include send-ing an e-mail or letter if the discloser feels unable to verbalize the message or experience the verbal/nonverbal reactions in person (see Greene et al., 2003; Petronio et al., 1996). Correspondingly, it is argued that:

8A: Increased stigma will lead to decreased disclosure efficacy (and this may be partially moderated by relational quality and anticipated responses).

8B: Decreased relational quality and anticipated negative responses will lead to decreased disclosure efficacy.

8C: Perceived negative outcomes of disclosure will result in decreased efficacy and decreased future intentions to disclose to others.

Third Party

One phenomenon worthy of additional scrutiny is when people share infor-mation that is not their "own." Although this is not self-disclosure per se, it captures some information management strategies utilized. This phenom-enon has been labeled third party (intentional or not) disclosure, using intermediaries, and gossip.

Several studies report intentional third party disclosure as a vehicle for HIV disclosure (see Greene et al., 2003). Miller and Rubin (2007) describe intermediation where some people selected a relative with whom they were close (often a cousin or sibling) and "sent this person with explicit instructions to inform those in the family who needed to know the diagnosis" (p. 593). Schrodt and Afifi (2007) also report how disclosure may place a person in the role as messenger of information in divorced families. Although this third party strategy is practical in some cases and may serve to protect the person from the stress and burden of retelling, there may be side effects such as placing the third party in the middle or lack of clarity about who this person can tell. Third party disclosure could also result in the recipient feeling betrayed or not respected by receiving the information indirectly (from another person). However, recipients may appreciate knowing, even if the delivery is not directly from the diagnosed person. Given the lack of research in this area, research questions are presented:

9A: What is the effect of intentional third party disclosure on perceived reactions to disclosure?

9B: Does intentional third party disclosure result in increased sharing by recipients?

9C: Use of intentional third party disclosure will increase relational quality for the intermediary but decreased perceptions of relational quality for the recipient.

Interruptions in the Model

At times the disclosure process is nonlinear and foundationally unpredictable. Despite having a clear disclosure plan, circumstances may alter intentions, or a context may create an unanticipated opening for spontaneous disclosure. This section examines two conversational events that can interrupt an overall disclosure plan: asking questions and reciprocity. The fever model (Stiles, 1987) assumes that disclosure tension is an internal state, yet these are external pressures (Afifi & Steuber, in press) that are brought to the discloser (see also PI; Babrow, 2001). The DD-MM conceptualizes these interruptions as occurring prior to evaluation of the receiver. That is, depending on who asks the question or discloses first, a potential discloser may still lie, avoid, or choose to disclose depending on evaluation of the specific person.

Questions. Asking questions impedes the normal disclosure decision process, and plans (including setting, order, timing, etc.) can be bypassed by both direct and indirect questions. Invitations to disclose are recognized by others (Caughlin & Golish, 2002). Even a general question can be interpreted as an opportunity for disclosure (Petronio et al., 1996), with the inquiry taken as permission to share. For example, a general question such

as "How was your break?" could receive the response, "Well, I had surgery to explore a suspicious growth." Petronio et al. described how sexual abuse survivors look for cues that signal tacit permission to disclose, similar to Greene et al.'s (2003) reports for people with HIV. It is unclear whether asking questions is related to relational quality, or whether those closer to us tend to ask more questions or perhaps wait to give the discloser time and space to share on their own terms. In addition, if the question askers are relationally close, are they more likely to receive full disclosures?

Asking questions has been included as a reason for disclosure (e.g., Agne, Thompson, & Cusella, 2000; Vangelisti et al., 2001). Ahrens et al. (2007) reported that, of first disclosures of rape, one third were not initiated by the survivor but rather were "initiated by others" to explain why the survivor was acting strangely or the survivor was asked, "What's wrong?" (see Allagia, 2004). The person asking questions may already have some information: The discloser had a doctor's appointment or she or he may be present when a medical office calls with test results. In these situations, disclosure may be difficult to avoid without directly lying. In situations where someone asks or implies interest, however, the potential discloser has a wider range of options, such as avoiding, lying, or partial disclosure (see Berger & Kellerman, 1989). If people see an opportunity to share, they may choose to disclose, even without a clear anticipated response. With this in mind, the next set of propositions are set forth:

10A: The potential recipient asking questions increases disclosure.

10B: What are the consequences of unplanned disclosure in response to a question?

10C: What is the association between relational quality and question asking?

10D: Does the directness of the question predict the disclosure response?

Reciprocity. Another feature that interrupts the planned disclosure decision process may be reciprocity. People report that they generally share if they receive equivalent disclosure. Many communication behaviors are reciprocated: We respond to disclosure with disclosure, especially if the topic is shared (Dindia, 1982, 2000; Gouldner, 1960; Jourard, 1971).

There is little systematic research on this reciprocity phenomenon in health, yet it is reported as a reason for disclosure in some studies (e.g., Greene et al., 2003; Vangelisti et al., 2001) with low occurrence. Thus, it does not account for a great deal of variance in disclosure, but it is a phenomenon that interrupts the regular/planned process and is recognized by participants as such (e.g., "I hadn't planned to talk about it, but she was talking about her violent boyfriend and it just seemed right to share"). One example of research on health disclosure reciprocity is Manne et al. (2004b)

who reported that reciprocal self-disclosure during videotaped discussions between partners (where one had breast cancer) was associated with lower overall levels of distress. Additional dyadic studies such as Manne et al.'s using the IPMI would increase understanding of this phenomenon. This research begs the questions below:

> 11A: What level of initial disclosure must occur before reciprocity is enacted?
>
> 11B: What are the perceived consequences of unplanned reciprocal disclosure?

Future Research

This chapter presents the DD-MM to integrate existing frameworks and research on disclosure processes. The chapter has noted a number of under-explored areas and unanswered questions, and this section elaborates on areas for future research. There are few studies of dyads interacting in the health disclosure context (for exception, see Manne et al., 2004b). Studies generally rely on individual data to examine dyadic relationship processes and draw relationship conclusions (Caughlin & Golish, 2002). We need studies generalizing across diseases or illness states and replications across samples and topics. Increased longitudinal research would also allow exploration of decision processes, order of disclosure, and consequences, among other factors. Studies including outcomes for the relationship and for the health of the discloser and recipient would be beneficial. Research often purports that disclosure is unilaterally beneficial, but we know much less about situations where sharing is harmful and concealment is healthy.

Self-disclosure is a social action that must be accomplished in interaction, and this emphasizes message enactment and efficacy. Beach and Anderson (2003) suggest that conversational analysis is a tool for studying how families "interactively accomplish" cancer communication. Researchers know little about how disclosure messages are processed, including how receiver reactions are viewed and integrated into future decisions. Why does disclosure fail to produce desired outcomes (Hines, Babrow, Badzek, & Moss, 2001)? Is this related to disclosers' expectations, or are receivers unprepared to support disclosers?

What information is disclosed is also worth exploring. A person may disclose the health diagnosis but not update the receiver on treatments or progression, perhaps based on the receiver's initial response. The DD-MM examines one point in time, yet people constantly reassess disclosure decisions, especially with those receivers who were not told. The order of who was told (and why) is likely linked to relational quality, anticipated response, and confidence in keeping the secret, which could be explored further. In addition, we need to include culture as a factor, as there may be fundamental differences in perceptions of privacy and expectations for relational openness. Privacy could also be a relational choice managed by the couple (Goldsmith et al., 2007).

Different reactions to disclosure and outcomes are difficult to compare across studies because the methodology is difficult to replicate (e.g., focus groups or interviews) or different variables are measured. Operational definitions vary widely, including measuring disclosure as "Did you tell X?" instead of "Does X know?" to assess third party disclosure or other information discovery modes such as guessing or reading a person's e-mail (see Caughlin, Scotts, Miller, & Hefner, 2008, putative secrets). In addition, disclosure is secondary to some investigations, measured by one or two items (exceptions are HIV and recent studies of breast cancer), which poses a significant limitation in understanding disclosure as a process. Other measures are even less nuanced. For example, reaction to disclosure is a complex phenomenon operationalized in some studies (e.g., Jonzon & Lindblad, 2005) as positive or negative, often based on one primary code that obscures multiple goals. The present chapter encourages quantitative measurement of variables that are weighed in each part of the disclosure decision process.

This chapter has presented an integrated model of health information sharing, the DD-MM, focusing on the decision process prior to revealing/concealing. The DD-MM proposes evaluation of uncertainty related to information, relationship, and efficacy and describes a possible sequence that can cut across contexts. The model was developed to integrate and organize lines of research, as well as lay a foundation for future examinations. The disclosure process outlined by the DD-MM includes a nuanced selection of disclosure recipients based on relative assessments of identified components. The DD-MM emphasizes the process of disclosure decision-making, and a next step will be to test these relations and link these variables to the type of disclosure made (e.g., breadth, depth, and duration, Omarzu, 2000; directness, Afifi & Steuber, 2008). The model has heuristic potential, with a wide range of applicability including health contexts.

Note

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