Disclosure of Chronic Illness Varies by Topic and Target: The Role of Stigma and Boundaries in Willingness to Disclose

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Research continues to increase at a critical juncture between the fields of communication and health care, particularly disclosures of illnesses. As the number of patients with chronic illnesses such as AIDS and cancer continues to increase, more people must decide how to balance decisions to reveal or conceal their illnesses. Disclosure is widely recommended by health care practitioners, in part due to the link between disclosure and physical and mental health. Decisions to disclose chronic illness, however, are threatening and problematic for many patients. Stigma surrounding illness has contributed to the unwillingness to disclose. People must balance competing needs to obtain benefits from disclosure yet avoid negative consequences from sharing.

The goal of this chapter is to explore patients' willingness to disclose a diagnosis of chronic illness to members of their family. This study will examine if the topic of the illness (e.g., AIDS or cancer), the potential target or recipient of the information (e.g., mother or brother), or some combination of the two best explains willingness to disclose. Research on stigma and self-disclosure is reviewed. The effects of stigma on balancing disclosure are examined first.

STIGMA

Decisions to disclose can be inhibited by negative images of the information or stigma. Goffman (1963) described stigma as a deeply discrediting attribute, deviating from a prototype. Stigma is not mere prejudice; it indicates a
preference for avoidance and carries a mark of shame or discredit (Herek & Glunt, 1988). Stigma originates in shared reactions of groups of people that are inherently comparative (Leary & Schreindorfer, 1998). Deviance is often labeled as illness, and certain illnesses carry meanings other than biomedical, such that the illness becomes a metaphor for characteristics attributed to the person (Sontag, 1989). Originally, cancer fit this definition for stigma, but cancer is perhaps not currently stigmatized in this way. HIV/AIDS fits all of these qualifications for stigma, though that also may be lessening.

Stigma and HIV/AIDS

AIDS has been socially defined as a disease of marginalized groups (Herek & Glunt, 1988). HIV/AIDS itself is stigmatized, but there are things that intensify stigma, including assignment of blame (see Leary & Schreindorfer, 1998). Sexual activity and drug use are more stigmatized than perinatal transmission or transfusion as modes of contracting HIV. Thus, the AIDS stigma has been layered upon preexisting stigma. J. A. Kelly and associates (J. A. Kelly, St. Lawrence, Hood, Smith, & Cook, 1988; J. A. Kelly, St. Lawrence, Smith, Hood, & Cook, 1987) had physicians, medical students, and nurses read vignettes describing how a patient contracted HIV/AIDS. The results of the studies by Kelly and associates indicate a clear prejudice against AIDS and homosexuals, with most specific findings for unwillingness to interact with people with AIDS (see Crawford, 1996). More recently, a meta-analysis by Crawford reported (based on 21 published studies) more stigma towards AIDS than other illnesses, with more stigma among college students than among health professionals.

Stigma functions differently for various groups, likely based on blame or perceptions of control over infection. Being homosexual is stigmatized even without adding HIV-positive status (see Derlega, Lovejoy, & Winstead, 1998), but some people with HIV/AIDS must deal with the double stigma of AIDS and homosexuality. Group perceptions/stereotypes of HIV/AIDS as a White gay male disease has isolated HIV-infected persons who do not fit this description (e.g., women or black men). Stigma is also a problem for HIV-positive women and for children, two groups who have not been widely addressed by media images of HIV/AIDS.

The effects of stigma can be widespread. People with HIV/AIDS “must bear the burden of societal hostility when they are most in need of social support” (Herek & Glunt, 1988, p. 886). For interpersonal relationships, there is potential for physical withdrawal, avoidance, and fear of rejection (Leary & Schreindorfer, 1998). In psychological terms, stigma can lead to a sense of alienation, lost social support, anxiety and depression, and decreased self-concept (look, e.g., at the suicide rate). For health consequences, stigma could lead people to resist HIV testing (see Serovich et al., 1992) and may also lead to nondisclosure, thus further increasing the possible spread of HIV/AIDS. To manage stigma, many HIV-infected persons report “passing” or deliberately concealing their stigmatized attribute (infection). Clearly, stigma has effects on willingness to disclose HIV infection.

Crawford’s meta-analysis (1996) revealed more stigma towards AIDS than other illnesses. For example, St. Lawrence, Husfeldt, Kelly, Hood, and Smith (1990) compared AIDS and leukemia. They explained that many diseases are as lethal as AIDS, yet few have created the level of fear and irrational hysteria associated with AIDS, including proposals to quarantine and tattoo people with AIDS/HIV.

Stigma and Cancer

In the past, cancer evoked the same intense negative reactions now associated with HIV/AIDS. Bolund (1990) pointed out that “There is only one disease, AIDS, that has a similar strong attribution of dread” (p. 13). The blaming or labeling associated with HIV/AIDS stigma, however, does not generally occur with cancer, although different types of cancer are viewed differently. For example, compare perceptions of breast cancer with those of leukemia, and cancer associated with sexually transmitted diseases (STDs) or smoking is viewed still differently. The continuum of “deserving” versus “being innocent” has not been applied to the public perception for cancer. Public stigmatization of persons diagnosed with cancer has decreased. Although disclosure of a cancer diagnosis may still be risky in terms of potential loss of health insurance and employment due to missed workdays, disclosure to intimates, such as family members, may not be as threatening now as it was in the past.

Clearly, stigma can function to inhibit self-disclosure for both AIDS and cancer victims. If stigma is intense, the potential consequences could overwhelm any possible disclosure. This could result in potential lost social support and possible health precautions through failure to disclose.

SELF-DISCLOSURE

Several theories of disclosure have been proposed, but Communication Boundary Management (CBM) theory (Petronio, 1991) has the possibility to incorporate variables such as topic and target to explain disclosure decisions. Petronio’s (1991) theory of boundary management describes how people control potential risk to self when disclosing. Individuals regulate disclosure of private information in their relationships to attain a balance between disclosure and privacy, and between intimacy and autonomy (Petronio, 1991).
Individuals erect a metaphorical semipermeable boundary to protect themselves and reduce their chances of losing face. The risks associated with disclosing chronic illness are tremendous, perhaps leading to more rigid boundaries (little or no disclosure). Clearly, disclosure is a double-edged sword: it is possible to lose social support through disclosure, yet potential support can also be eliminated through failure to disclose (Hays, Turner, & Coates, 1992).

There are benefits from self-disclosure, and people struggle with decisions to disclose in order to receive support while avoiding negative consequences associated with stigma (see Greene & Serovich, 1996; Yeo, 1993a). Potential benefits from disclosing include feeling loved and accepted, gaining information, and possibly making safer sex decisions (for HIV).

There are risks for people who disclose their chronic illness, and decisions to disclose are likely fraught with fear and anxiety (Marks et al., 1992; Yeo, 1993a). Risks can include potential rejection and discrimination, and emotional distress for others. The potential impact is wide ranging, from ostracism in interpersonal relationships to self-identity crises, from threats to basic survival (loss of employment, housing, insurance or health care) to loss of social support. A person must see benefits (and how they outweigh risks) before being willing to expose themselves by disclosing (Hays et al., 1992).

Disclosure may be a means of obtaining social support, and social support may serve a significant role in mediating between stress and health (e.g., Albrecht & Adelman, 1987; Greenblatt, Beccera, & Serafinides, 1982; Kulik & Mahler, 1989). Disclosure of traumatic experiences has been reported to reduce stress (e.g., M. A. Greenberg & Stone, 1992; Pennebaker, 1990) and physical and mental health problems (e.g., Pennebaker, 1990; Susman, 1988). In addition, satisfaction with social support increases both psychological (J. J. Kelly, Chu, & Buehler, 1993; Zich & Temoshok, 1987) and physical well-being (Hays et al., 1992; Zich & Temoshok, 1987).

Researchers have also established that the target of self-disclosure constrains how people reveal information about themselves (see Stokes, Fuehrer, & Childs, 1980; Tardy, Hosman, & Bradac, 1981). The factors in decisions to disclose to one target (e.g., mother) are likely different from another (e.g., partner; see Simoni et al., 1995). An important step in the coping process for people with chronic illness is the disclosure of this information to others; however, at present, there is a lack of clarity about who is considered an appropriate recipient of that information. Next, specific research on disclosure of HIV/AIDS and disclosure of cancer will be reviewed.

Self-Disclosure and HIV/AIDS

There is a small but growing body of research on how people decide who to tell about their HIV infection (see Derlega et al., 1998; Greene et al., 1993; Greene & Serovich, 1995, 1996; Hays et al., 1992; Marks et al., 1992; Serovich et al., 1992; Serovich & Greene, 1993; Serovich, Kimberly, & Greene, 1998; Yeo, 1993a). Findings indicate that people disclose their HIV/AIDS status very selectively. These disclosure decisions are based, in part, on the degree to which others are expected to respond in a positive way.

The target or recipient of HIV information is significant in explaining how people balance disclosure decisions. Members of the marital subsystem (lovers, spouses, ex-spouses, friends) have been viewed as the most appropriate targets for disclosure of HIV infection, with the nuclear family (e.g., parents, siblings, children) rating next highest (Greene & Serovich, 1996; Marks et al., 1992; Serovich & Greene, 1993; Simoni et al., 1995), extended family and the general public rating lowest.

Serovich et al. (1992) looked at the potential recipient of HIV testing information. Individuals overall reported most desire to restrict access to HIV testing information to the general public, less to the community, and least to the marital subsystem. Serovich and Greene (1993) expanded this work by looking at potential family targets for release of HIV testing information. Overall, participants reported most support for access to HIV testing information for members of the marital subsystem (e.g., lovers, spouses), moderate support for access for the nuclear family (e.g., mother, son), and least support for access for the extended family (e.g., aunt, mother-in-law).

Greene and Serovich (1996) replicated these studies and reported that HIV-infected persons have clear distinctions in perceptions of appropriate recipients of information about HIV infection. In addition, HIV-infected persons reported less desire (compared with other groups) for disclosure of HIV infection to members of all subsystems. Marks et al. (1992) similarly reported that HIV-positive men were highly selective in choosing targets of disclosure and tended to inform significant others (parents, friends, and lovers) more than nonsignificant others (employers, landlords, and religious leaders). Next, we review research on disclosure to various family targets, including partners, parent(s), siblings, children, and friends.

Disclosure to Partner(s). Disclosure to partners is not just done to obtain social support, as there is an added benefit of possible safer sex practices. The partner of an HIV-positive person is in a significantly different position from others in that he or she may be at substantial risk for exposure to HIV. Nondisclosure could also affect the health of an HIV-infected person. An infected person is at risk for reinfection with a possibly more drug-resistant strain of HIV; additionally, other STDs are dangerous to HIV-infected persons. Therefore, decisions to disclose to partners are defined by different senses of obligation, both moral and legal. There is concern that some HIV-infected individuals continue to put others at risk for infection, and Perry and Markowitz (1988) reported that significant numbers of HIV-positive gay men (30% to 63%) continued to engage in unprotected anal inter-
course with multiple partners after their diagnosis. Similarly, Marks et al. (1992) reported that for HIV-positive gay men, disclosure decreased with number of sexual partners.

Rates of reported disclosure of HIV infection to sexual partners have varied and range from 31% of a sample of homosexual HIV-positive men (Stempel, Moulton, Bachetti, & Moss, 1989) to 89% of an HIV-positive sample (Mansergh, Marks, & Simon, 1995). Perry, Ryan, Fogel, Fishman, and Jacobsberg (1990) reported that 53% of HIV-positive gay men had disclosed to all present sexual partners, but only a lower rate had disclosed to past or casual sexual partners. Clearly, some people who know themselves to be infected with HIV/AIDS fail to inform their sexual partners of this fact, but these figures indicate that reported disclosure to partners may be increasing.

Disclosure to Parent(s). People who test HIV positive report great distress over decisions to tell parent(s) (Kimberly, Serovich, & Greene, 1995). HIV-infected persons may fear parents’ rejection, and perhaps withdrawal of financial or emotional support (Gard, 1990). HIV-infected persons cite health, age, and lack of education or sophistication as reasons for not disclosing to parents (Gard, 1990; Kimberly et al., 1995). One problem with disclosing HIV-positive status to parents is that it may also provide information about an HIV-infected person’s associated behavior (e.g., sexual or drug using). Gard labeled this phenomenon a “double coming out” (p. 254). In fact, virtually no one in Marks et al.’s (1992) study revealed HIV infection to parents if parents did not already know about their gay/bisexual orientation. Reports of disclosure to parents vary. Marks et al. (1992) reported that 23.8% of the HIV-positive people in the sample had disclosed to their mothers, compared with 8.1% who had disclosed to fathers, but Simon et al. (1995) reported moderate disclosure, with 59% to mothers and 31% to fathers. This is in sharp contrast to a sample where 82% of mothers and 78% of fathers had knowledge of a child’s HIV infection (Greene & Serovich, 1996). (These figures were also adjusted for people without target mothers or fathers.) Regardless of the discrepancy in numbers, results of these studies indicate that disclosure of HIV infection to fathers is significantly lower than to mothers.

Disclosure to Siblings. There is less information available about disclosure of HIV infection to siblings. For example, Marks et al. (1992) reported that 34.4% of their HIV-positive sample had disclosed to their sisters compared with 30.7% to brothers, and these levels are higher than disclosure to parents. Mansergh et al. (1995) also reported moderate disclosure (49%) to brothers and (53%) to sisters. HIV-infected persons may also choose to disclose incrementally, first to siblings to get support for disclosing to parents and possibly to obtain additional information about how parents might respond.

Disclosure to Friends. Studies of disclosure have often added “friend” as a target person. Reports that individuals disclose most to friends are not surprising, because a friend is a voluntary relationship, likely marked by similarity. Perry, Ryan et al. (1990) reported 68% disclosure to a friend, but Marks et al. (1992) reported 58% disclosure to a male friend and 43% to a female friend. This is in contrast to Hays et al. (1992), where 95% had disclosed to a gay friend.

Disclosure and Cancer

Although several researchers are currently examining the process of disclosing HIV infection, less is known about disclosing a cancer diagnosis. Some researchers assumed that patients disclosed a cancer diagnosis (e.g., Pruyn, Van den Borne, & Stringer, 1986; Weir, Deans, & Calman, 1985). Years ago, over 90% of physicians reported that they never told patients of their illness, revealing it only to the families (Oken, 1961), but more recently, more than 95% of doctors surveyed informed patients directly of their cancer diagnosis (Novack et al., 1979). Thus, there have been clear changes in the process of how a cancer diagnosis is revealed.

A diagnosis of cancer is often accompanied by emotional responses such as fear of death, pain, vulnerability, loss of control, guilt, isolation, and hopelessness (Bolund, 1990; L. R. Martin, 1982; Revenson, Wollman, & Felton, 1983). Cancer patients speak of themselves as lepers and speak of fear of being rejected by others (Severo, 1977), much like reports from those infected with HIV. In addition, Funch and Mettlin (1982) found that women recovering from breast cancer reported feelings of being overprotected and misunderstood when seeking support. Dunkel-Schetter, Feinstein, Taylor, and Falke (1992) investigated coping in cancer patients and reported that those who attended support groups used more and a wider variety of social support. Interestingly, in this study, coping was measured by items such as “talked to someone,” and “let my feelings out somehow,” and these clearly tap self-disclosure as well. Thus, we still need to understand more about disclosure and cancer.

Research Question

The role of stigma in willingness to disclose chronic illness cannot be overlooked. For both AIDS and cancer, stigma has potential effects but it is not known if disclosure is different by topic. It is also possible that the target or recipient of the information is a crucial factor in the decision to disclose illness. The topic of the information and the potential target of the infor-
mation might also work together to explain willingness to disclose. Based on this, the following research question is posed:

RQ: Is the topic (cancer or AIDS), the potential target (specific family member), or some combination of topic and target most important in predicting a person’s willingness to disclose chronic infection?

METHOD

Participants

Participants (N = 168) in the present study were drawn from a larger study (N = 826) of disclosure and attitudes toward AIDS conducted in 1994 (the smaller final sample included only those participants who responded to all six target family members). Participants were overwhelmingly Caucasian (64%) or African American (32%). Participants ranged in age from 18 to 74 years (M = 30.6), and the sample was 45% male and 54% female.

Participants were recruited by students trained in an undergraduate research methods course. This project is part of a larger study of relationships and disclosure. Student researchers completed a mock interview with the author before collecting data, and each researcher had to sample participants meeting specific criteria. Random call-backs were conducted (25% contact) to ensure participation. Each participant was given the questionnaire and instructions, and the surveys were returned sealed.

The instructions on the questionnaire stated: “We are going to ask you to think about specific people in your family and your relationships with them. We will ask you to think about things happening to you that might cause you to volunteer information to members of your family. Next, we will ask you if you think you would, indeed, tell members of your family if these things happened to you.”

Measurement Instruments

The primary goal of this study was to examine if the topic (cancer or AIDS) or the potential target (specific family member) was more important in predicting a person’s willingness to disclose. Likert-type items were developed by the author, following the format for disclosure of AIDS items developed previously (Greene & Serovich, 1996; Serovich et al., 1992). The instructions asked participants to think about disclosing to family members. The first item stated: “Think about your [target such as mother]. How likely would you be to tell [him/her] if you had [AIDS/cancer]?” Responses ranged from “Absolutely” (1) to “Never” (5). The second item substituted “cancer” for “AIDS.” Participants then thought about various targets and how willing they would be to disclose to each target person. Target family members included: mother, father, partner, sister, brother, and best friend. Thus, the primary variable of interest in the present study, likelihood of disclosing illness, was composed of 12 items: six targets for two diseases.

RESULTS

Data were analyzed using factor analyses, confidence intervals, and MANOVAs. Analyses were conducted to explore both target and topic effects, as well as a combination of target and topic effects. The level of significance was set at p < .05 for all tests.

The factor analysis indicated a three-factor solution accounting for 65% of variance using varimax rotation. Thus, it is clear that neither topic nor target alone can account for differences in disclosure in these data (the solution was neither one nor two factor). The factors did, however, tend to group according to target rather than topic. Primary factor loadings were all above .60, with no secondary loadings above .4 except for the sister disclosure items. The first factor was labeled “friend/sibling” (eigenvalue = 4.97; 41% variance) and included friend/AIDS (.76), friend/cancer (.69), brother/AIDS (.75), brother/cancer (.70), sister/AIDS (.65), and sister/cancer (.67). (However, the loadings for the sister items were also above .5 on the second factor, indicating the sister items split loaded.) The second factor was labeled “parent” (eigenvalue = 1.47; 12% variance) and included mother/AIDS (.80), mother/cancer (.59), father/AIDS (.86), and father/cancer (.68). The third factor was labeled “partner” (eigenvalue = 1.39; 11% variance) and included partner/AIDS (.73) and partner/cancer (.83). Thus, there were some differences by target in these data. Mean score comparisons using 95% confidence intervals were also calculated to explore these differences (see Table 9.1).

Participants did distinguish between disclosing cancer and disclosing AIDS. Participants were generally more willing to disclose cancer than AIDS (the confidence intervals for that disclosure of AIDS and cancer generally did not overlap for a particular target person), but participants reported that disclosing both AIDS and cancer was likely. This difference did not hold for the partner item, however, as participants reported they would tell partners equally (as often) about either AIDS or cancer diagnosis. Thus, there were some differences by topic in these data.

To better explore the nature of the target and topic disclosure differences, a MANOVA was performed. The 12 likelihood-of-disclosing items were the dependent measures, with two within-subject factors, topic (AIDS or cancer) and target (six family members). The design included tests for main effects of topic and target as well as the interaction of topic by target. The MANOVA for disclosure items indicated statistically significant main effects.
TABLE 9.1
95% confidence intervals (CIs) for 12 disclosure items

<table>
<thead>
<tr>
<th>Disclosure item</th>
<th>Mean*</th>
<th>SD</th>
<th>CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner AIDS</td>
<td>1.18</td>
<td>.59</td>
<td>1.14-1.22</td>
</tr>
<tr>
<td>Partner cancer</td>
<td>1.18</td>
<td>.60</td>
<td>1.14-1.22</td>
</tr>
<tr>
<td>Mother AIDS</td>
<td>1.83</td>
<td>1.08</td>
<td>1.75-1.91</td>
</tr>
<tr>
<td>Mother cancer</td>
<td>1.46</td>
<td>.87</td>
<td>1.31-1.53</td>
</tr>
<tr>
<td>Father AIDS</td>
<td>2.21</td>
<td>1.31</td>
<td>2.09-2.33</td>
</tr>
<tr>
<td>Father cancer</td>
<td>1.63</td>
<td>1.03</td>
<td>1.54-1.72</td>
</tr>
<tr>
<td>Sister AIDS</td>
<td>1.83</td>
<td>1.08</td>
<td>1.74-1.92</td>
</tr>
<tr>
<td>Sister cancer</td>
<td>1.59</td>
<td>.96</td>
<td>1.51-1.67</td>
</tr>
<tr>
<td>Brother AIDS</td>
<td>2.05</td>
<td>1.16</td>
<td>1.95-2.15</td>
</tr>
<tr>
<td>Brother cancer</td>
<td>1.71</td>
<td>1.00</td>
<td>1.63-1.79</td>
</tr>
<tr>
<td>Friend AIDS</td>
<td>1.66</td>
<td>.94</td>
<td>1.59-1.73</td>
</tr>
<tr>
<td>Friend cancer</td>
<td>1.40</td>
<td>.72</td>
<td>1.35-1.45</td>
</tr>
</tbody>
</table>

*Lower score indicates more likelihood of disclosing

for both topics (Wilks’s Λ (1, 167) = .554, p = .002) and target (Wilks’s Λ (5, 163) = .606, p < .001). Follow-up analyses for the topic effect indicated that participants were more willing to disclose cancer than AIDS. Follow-up analyses for the target effect indicated that participants were more willing to disclose to partner than to friend, mother, or sister and even less to brother or father. There was also a significant interaction between topic and target (Wilks’s Λ (1, 167) = .763, p < .001). This effect was more difficult to explain, but the most notable effect was for partners. For most family targets, there were differences in disclosure by topic, with disclosure of cancer more likely, but participants reported equal likelihood of disclosing AIDS and cancer to partners. Thus, the MANOVA revealed effects for both topic and target, but the interaction between target and topic cannot be ignored.

DISCUSSION

Results of the present study indicate that both topic and target explain willingness to disclose chronic illness. The assumptions proposed by Petronio’s (1991) CBM theory and the balance of privacy have utility in explaining these findings. Petronio focuses on the permeability of informational boundaries, and these data do show differences in informational boundaries or by target. Previous researchers have reported that people create boundaries in willingness to disclose AIDS (e.g., Greene & Serovich, 1996; Marks et al., 1992; Serovich et al., 1992). The order of the means in likelihood of disclosing (see Table 9.1) is the same for both AIDS and cancer. For both diseases, partner and friend were most likely, mother or sister next most likely, and brother or father least likely disclosure recipients. The differences by target alone imply that people do balance competing needs in disclosure decisions. People clearly make distinctions in how they balance private information and to whom they choose to disclose chronic illness.

Theories of stigma indicate that people might be more likely to disclose cancer than AIDS, and this was supported by these data. The stigma surrounding AIDS is clearly more intense than for cancer today. Examination of stigma will be crucial, as it has been shown to affect social support, decisions to disclose, coping, and identity (see Derlega & Barbee, 1998). Unfortunately, not many relational theories incorporate stigma explicitly in their models. Stigma is based on assumptions about cancer and HIV/AIDS status, and, at times, about mode of transmission.

Interestingly, these topic differences between AIDS and cancer did not hold for the partner items, and this should be explored further. Participants reported equal likelihood of disclosing AIDS or cancer to a partner. The implications are significant, because people clearly underestimate the difficulty of disclosing HIV/AIDS to their partner. For AIDS but not cancer, the partner is at significant risk for infection. Others (e.g., Perry, Ryan et al., 1990; Stempel et al., 1989) confirm that an astonishingly low number of HIV-infected people do in fact tell their partners. Thus, this partner disclosure is an area researchers should continue to explore.

LIMITATIONS

There are several limitations to this study worth noting. First, the sample was not comprised of people with cancer or HIV (to the best of our knowledge). Thus, items tapped only individual perceptions of likelihood of disclosing infection. Previous research (Greene & Serovich, 1996), however, has shown remarkable similarity between HIV-positive and non-HIV-positive people’s formation of groups of (or boundaries for) disclosure recipients even further, they show how willingness to disclose infection and actual disclosure patterns were significantly correlated. The format used to measure disclosure in this study was an improvement over previous research because it was specific to a target person and by disease. It would be useful, however, to have multiple item measures, but this would be difficult to obtain without rather obvious redundancy. Only one perspective was taken into account where obtaining responses from target family members would provide valuable additional information (though only one perspective is a major factor in a decision to disclose). The operationalization here also involved an intent to perform a hypothetical behavior, and the hypothetical situation did not include how they contracted the disease, if significant other was aware of risk behavior, and so on. An additional limitation was the design; a longi-
tudinal design, studying the process of disclosure through the course of disea

Implications

There are implications in these data for people working with patients and their families, for message design, and for theory.

Implications for Health Care Workers. The data presented here may be useful for people who work with persons diagnosed with cancer and HIV/AIDS and/or their families. The value of disclosing disease information to family members has been well documented (cf. Berg & Derlega, 1987; Pennebaker, 1990). However, for those who are not willing to disclose, or for those who have reservations about doing so, sensitivity to these disclosure differences must be respected.

Health care workers may develop programs (or incorporate the information into social support groups) to help individuals with difficult decisions about disclosure. Specific discussion of disclosure problems could be useful, perhaps with role-plays. Although only cancer and HIV/AIDS were examined in this study, it is reasonable to assume that other illnesses may have stigma associated with them that could decrease likelihood of disclosure. Health care workers should continue to be sensitive to differences in willingness to disclose, and the means in this study indicate that brothers and fathers may be especially problematic recipients for this type of disclosure. It may be that people are more comfortable disclosing health information to women.

Implications for Message Design. Clearly, stigma is still a problem that inhibits disclosure. Specific campaigns portraying how HIV (or cancer) affects families and the support families can provide might be useful in reducing this stigma and labeling. More messages with positive portrayals of people with cancer and AIDS might serve to reduce stigma and increase likelihood of disclosing. Campaigns also need to be specific about how and why to disclose chronic illness, in particular to partners.

Implications for Theory. Additional work to test Petronio's CBM theory and Yep's (1993a) application to HIV/AIDS would be fruitful. There is also a need for more information on decision-making criteria and disclosure strategies (Petronio et al., 1996; Yep, 1993a). Because disclosure is a relational event, variables associated with both the sender and the receiver need to be examined (Yep, 1993a). Social exchange theory has been used to describe relationships, but it has also been used to describe disclosure decisions in relationships. People balance positive and negative potential consequences of disclosure before being willing to make decisions about illness. For some, the sheer relief of not keeping a secret and anticipation of support outweigh fears of negative consequences. Derlega and Barbee (1998) indicate that HIV-infected persons have some level of awareness of the positive and negative consequences of disclosure, much like the anticipated response variable in Petronio's (1991) boundary management model.

Future Research. Research such as this study can contribute to understanding how people deal with chronic illness. Insight into how people live with diseases will become increasingly important as treatments progress. Balancing the need to disclose infection to obtain social support with avoiding stigma is a part of this process. Researchers examining disclosure must continue to do so within a theoretical framework, for example, a boundary management, social exchange, or uncertainty reduction model. Examination of other variables that predict likelihood of disclosing infection would be useful (e.g., gender, relationship with target, expected response). It would also be helpful to understand if disclosure functions in the same way for those outside the nuclear family (e.g., grandparents, in-laws, etc.) or for nonfamily members (e.g., teachers, employers). Clearly, asking people with cancer or HIV about their disclosure patterns over time would prove beneficial, and this would be a way to study actual message strategy selection for disclosure. At present, very little information is available about the content of disclosure messages, especially regarding chronic illness. The present study makes a significant contribution to explaining how people balance decisions to disclose chronic illness, and more research would be useful.

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