

Information Seeking and Avoiding in Health Contexts

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Information management is an important component of coping with illness and illness-related uncertainty. Normative theory and research on information seeking and avoiding in health contexts can help explain why some information management activities are more adaptive than others. Challenges and dilemmas of information management include relational demands (e.g., the need to coordinate the behaviors and goals of the participants) and contextual features (e.g., cross-cultural considerations or channels available for information seeking and providing). Issues that need to be addressed in a normative approach include (a) how information management goals can be accomplished while still accounting for other goals (e.g., identity management or relational maintenance), (b) what roles interpreters can play to facilitate effective cross-cultural information exchange (e.g., as cultural informants), and (c) how information seekers can best manage conflicting or overwhelming information when confronted with messages from multiple channels.

Recent research and theory highlights information management as one possible response to illness-related uncertainty (Mishel, 1988, 1990). For example, people with acute or chronic illnesses often seek information to understand their diagnosis, to decide on treatments, and to predict their prognosis. People wanting to maintain good health seek information to understand risk factors and to learn preventive measures. For both understanding illness and its prevention, information sources include health care providers, peers (e.g., others with the illness),

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friends and family social networks, media, government agencies, and health services organizations (Brashers, Haas, Neidig, & Rintamaki, in press). Channels for information seeking and providing include face-to-face encounters (e.g., personal conversations, support groups, and health care interactions) and mediated communication (e.g., television, internet websites, email, pamphlets, self-help books, and health magazines).

Our contribution to this colloquy draws from current research and theory on information seeking and avoiding in health contexts (specifically, in social support networks, provider-patient interactions, and mediated contexts) and suggests directions for future investigation. We combine our own theories of uncertainty management (Brashers, 2001; Goldsmith, 2001) to develop a normative perspective (Goldsmith, 1992; Goldsmith & Fitch, 1997) on information seeking and avoiding. In contrast to a research agenda developed to predict when and how people will seek information, the objective of our normative approach is to understand what challenges and dilemmas are involved in information management in order to explain why some information management activities are more adaptive than others. Our specific aim is to suggest a research agenda that would provide a basis for proposing normative recommendations for information management in health contexts. We begin with a brief overview of information seeking and avoiding processes. Following that, we describe challenges and dilemmas faced by those who seek, avoid, and provide information. Finally, we offer research questions derived from a normative agenda for information management in health and illness contexts.

INFORMATION MANAGEMENT IN HEALTH CONTEXTS

Information can be defined as stimuli from a person's environment that contribute to his or her knowledge or beliefs. As communication scholars, we are especially interested in the content of messages (e.g., facts or opinions) that are communicated by and with others. *Information management* includes communicative and cognitive activities such as seeking, avoiding, providing, appraising, and interpreting those environmental stimuli. For example, information can be used to decrease uncertainty that is distressing, to increase uncertainty that allows for hope or optimism, and to invite reappraisal of uncertainty. Information can also increase stress-producing certainty or uncertainty. Avoiding information allows people to maintain their current state of knowledge or beliefs (Brashers, Neidig, Haas, et al., 2000).

Information seeking has been studied in the context of individuals' networks of interpersonal relationships (e.g., family, friends, and health

care providers). Information that facilitates coping with life stresses, including illness, is one form of social support that may be exchanged among members of a support network. Research on informational support has focused on the effects of receiving information and advice. People may go to friends and family to identify symptoms or possible treatments. Health care providers (e.g., physicians, nurses, pharmacists, social workers) also are sources of information for people with chronic or acute illnesses. At diagnosis, people may want information about the etiology of a disease, their prognosis, or treatment options. Procedural (i.e., "What will happen to me?") or sensory (i.e., "How will it make me feel?") information helps them make sense of medical procedures and treatments (Garvin, Huston, & Baker, 1992). Prevention and risk information (e.g., how to reduce the threat of illness) also can be solicited from health care providers.

Mediated sources offer additional opportunities for mass and interpersonal communication aimed at health information seeking and providing. Television programs and magazine and newspaper articles on health topics are common (Johnson, 1997). The World Wide Web supports information accumulation, storage, and dissemination through websites sponsored by individuals or health care organizations and allows people to use the Internet to seek health information from the privacy and comfort of their homes (Borzekowski & Rickert, 2001). Listserves, newsgroups, and chatrooms provide information and help with interpreting and appraising it. People who benefit from these online support groups include those with stigmatized illnesses (because they might find it difficult to attend a face-to-face group) or people with relatively rare diseases (because they don't know others in their community with the illness) (Davison, Pennebaker, & Dickinson, 2000). Email connects people to distant friends and relatives, which allows them to develop and maintain larger social networks. Email also provides "on demand" service from health care providers (Spielberg, 1998). Telemedicine (e.g., medical consultations by closed-circuit television) provides opportunities for patients to consult with providers that would have been inaccessible prior to the advent of the technology (Mun & Turner, 1999).

Although the study of information management in health contexts traditionally has focused on individuals' sources and patterns of information seeking, recent research indicates that information avoiding is also an important element of information management. People who are ill or who believe themselves to be at risk for disease may avoid information when it is distressing (Brashers, Neidig, Haas, et al., 2000; Leydon et al., 2000) or when it conflicts with beliefs with which they are comfortable (Babrow, 2001). People avoid diagnostic information that might help them determine the meaning of symptoms (e.g., people delay seeking treat-

ment for myocardial infarction despite warning signs; see Alonzo & Reynolds, 1998). A person who is "healthy" (without signs or symptoms of illness) may avoid information to prevent anxiety if risk awareness calls into question the person's health or potential for disease (Brashers, 2001), such as in the case of genetic testing to determine disease likelihood or carrier status (Fanos & Johnson, 1995). Thus, information seeking and avoiding may be a balancing act for individuals who need to achieve multiple goals (e.g., reducing uncertainty, improving or sustaining health, and maintaining optimism).

Challenges and Dilemmas of Information Seeking and Avoiding

Developing a normative model of information management necessitates understanding the challenges and dilemmas associated with those processes. There are numerous sources of complexity (e.g., situational, conversational, and cultural features) inherent in information exchange. Our purpose is not to provide an exhaustive list of these features, but instead to introduce some topics that might be fruitful directions for research. The focus is on understanding when and how some information strategies will be more adaptive than others.

The collaborative nature of information management. One set of challenges for information management arises from the collaborative nature of the activity and the need to coordinate the goals and behaviors of both participants. For example, in the typical health care encounter, doctors and patients are both seeking and providing information to diagnose and treat illness. Physicians elicit information from patients about symptoms and potential causes of illness, and patients elicit information from physicians about the meaning of illness and treatments. Often this has been characterized as an asymmetrical information exchange: Physicians ask most of the questions and patients provide most of the information (e.g., McNeilis, 2001). A variety of reasons has been offered for this disparity. Studies have shown that physicians respond to individual communication and personal characteristics of patients (Beisecker, 1990; Waitzkin, 1985). Geist and Hardesty (1990) discovered that patients' cues that signal a lack of understanding about their medical care (i.e., uncertainty) tend to inhibit, rather than promote, communication. Street (1991) found that more information was given to younger and more educated patients; less educated patients were "doubly disadvantaged" because of their passive communication styles and because of doctors' misperception of their informational needs and desires" (p. 546). Others have suggested that physicians misjudge patients' wants and needs. Waitzkin (1985) discovered that "doctors spent little time informing their patients, overestimated the time they did spend, and underestimated patients' desire for information" (p. 81). Physicians may overestimate the amount of information that patients

have (Guttman, 1993); patients and providers may have different ideas about what kind of information is needed (Hines, Babrow, Badzek, & Moss, 2001); and providers may have difficulty explaining things in a way that is clearly understood by patients (Bogardus, Holmboe, & Jekel, 1999).

Another challenge involves recognizing when information is desired. For example, although receiving information from members of one's social network can have positive effects on health, psychological well-being, and coping, there are also instances in which informational support is unhelpful or even harmful to recipients (for a review, see Albrecht & Goldsmith, in press). Emotional support (e.g., expressions of empathy, caring, and concern) is seen as helpful in a wide variety of situations, yet the helpful effects of informational support are much more contingent (Burlison & Goldsmith, 1998; Cutrona, Cohen, & Igram, 1990; Dakof & Taylor, 1990). One factor that affects the usefulness of information offered by network members is whether a recipient of informational support sought information or wished to avoid it (and how he or she goes about communicating these desires to others). Goldsmith (2000) found that advice about everyday problems was seen as more respectful and caring when it was delivered in response to a request for advice than when it was given unsolicited. However, some ways of "soliciting" advice were indirect, so that network members might be uncertain whether advice was desired. Studies comparing direct versus indirect ways of seeking support, including informational support, suggest there are both advantages and disadvantages to each type of support-seeking strategy (see Goldsmith, 1995, for a discussion).

Indirect methods of seeking information occur in health care encounters as well. Some have argued that patients do little to seek information in health care encounters (e.g., Beisecker, 1990). Cegala, McClure, Marinelli, and Post (2000) noted that this may be a result of researchers' failure to identify the range of possible information-seeking behaviors. They found that requests for information may be more or less obvious, including direct questions ("Will you tell me about this medicine?"), assertive questions ("I want you to tell me about this medicine"), and embedded questions ("This medicine seems to work, but I don't know why"). Patients' use of indirect strategies may reflect deference to the authority of the physician (i.e., indirect strategies may be evaluated as more appropriate and effective, especially with higher status persons; see Goldsmith, 1992). Norms about politeness or deference to authority may be why it *seems* that patients fail to enact a more participative or collaborative role (Brashers, Haas, Klingle, & Neidig, 2000), even when they express a desire for greater participation (e.g., Bilodeau & Degner, 1996).

Patients' use of indirect strategies, however, may contribute to less information being passed from physician to patient. Research on physician-

patient encounters has demonstrated that patients' use of indirect requests for information can result in minimal answers (Weijts, Widdershoven, Kok, & Tomlow, 1993). If health care providers do not recognize indirect requests, they may differ from patients in their perceptions about the patients' information-seeking preferences. If providers fail to respond to patients' requests for information, patients may be frustrated and experience increased uncertainty about their illness and treatments. Distress of information seekers may stem from the frustration of not receiving the information they want, either because they are unable to elicit the information from their physician or because the physician seems unable (or unwilling) to provide them with that information.

Yet another set of dilemmas arise from the ways in which illness may create needs for information not only for the person who is ill, but also for his or her social network. Members of an ill person's social network face the prospect of changes in roles and responsibilities, increases in caregiving activities, the threat of losing a loved one, and, for some illnesses, increased risk of contracting the same illness (e.g., some illnesses are transmitted through intimate contact, whereas other illnesses have a genetic risk component that is shared by other family members). This suggests a need to understand how relational partners seek and avoid information and how patients and partners coordinate (or fail to coordinate) their information needs and information management strategies. For example, in their study of people with HIV or AIDS and members of their social network, Brashers, Neidig, and Goldsmith (2000) found supportive others served as sources of information, as collaborators in information gathering (also see Miller & Zook, 1997), as evaluators of information, and as buffers against information. Whether the partners' information management activities were appreciated or not was contingent on whether they were matched to the patients' own desires for information. Some patients and partners collaborated in seeking or avoiding information while others found their information management strategies worked at cross purposes (e.g., a patient who wished to take a vacation from information received unwanted news clippings or suggestions from well-meaning others).

Ill persons and their relational partners face challenges not only in coordinating their information management efforts but also in handling the implications of information management for valued identities and relational definitions. In their study of persons with AIDS, Miller and Zook (1997) found that direct contact between care providers and physicians could provide information that was invaluable in providing home care for the patient, monitoring the patient's symptoms, and advocating for the patient. However, because the normative model for medical care is one in which functional adults see their physicians unaccompanied, care partners seeking information directly from the physician had undesir-

able implications for the patient's identity and undermined both the patient's and partner's attempts to normalize the patient's condition or forestall recognition of disease progression. Partners were more likely to have direct access to information from physicians when patients were hospitalized or faced difficulties in functioning independently. This finding is consistent with McIntosh's (1974) observations about how physicians and family members may conceal information about cancer diagnosis from the patient. Patients may also resist family members' attempts to solicit information directly from themselves. For example, Rees and Bath (2000) found that when mothers with breast cancer withheld information from their daughters, it often was motivated by a desire to protect the daughters. Thus, the pattern of information seeking and avoiding in a family or social network has implications for relational definitions of autonomy and paternalism (Cicirelli, 1991).

Contextual features of information management. Researchers also have noted that social support (Goodwin & Plaza, 2000), doctor-patient communication (Pachter, 1994), and uncertainty management (Goldsmith, 2001) occur within a sociocultural context that may shape how specific behaviors are understood and interpreted. For example, cross-cultural considerations may further complicate the relational demands of information seeking and avoiding (Baldwin & Hunt, this issue; Goldsmith, 2001). Studies have shown that in some cultures (i.e., family-centered cultures such as the Chinese, Vietnamese, Cree, and Ethiopian cultures) the responsibilities of information control (information seeking, giving, and withholding) and decision making often are assumed by family members rather than individual patients (Beyene, 1992; Blackhall, Frank, Murphy, & Michel, 2001; Kaufert, Putsch, & Lavallée, 1999; Muller & Desmond, 1992). When individuals from these cultures are involved in health care interactions in the United States, information seeking or avoiding involves a complex coordination between health care providers, patients, patients' family, and, sometimes, interpreters. When a patient has a poor diagnosis, not only do family members see information and treatment seeking as their responsibilities (Kaufert & Putsch, 1997; Kaufert et al., 1999), but patients also see those as the responsibilities of their family members (Beyene, 1992; Blackhall, Murphy, Frank, Michel, & Azen, 1995). In some cases, family members have informed care providers about their unwillingness to discuss the diagnosis with the patients (Beyene, 1992), explicitly declined the use of interpreters (Muller & Desmond, 1992), emphasized that direct communication with the patient being diagnosed was unacceptable (Kaufert & Putsch, 1997; Kaufert et al., 1999), or simply distorted the doctor's diagnosis when acting as interpreters for the patients (Kaufert & Putsch, 1997).

If a health care provider's sense of ethics (e.g., respecting the patient's

autonomy to make informed decisions about their medical care) conflicts with values held by a non-English speaking patient's family members, the health care provider may rely on professional interpreters to circumvent the family and to establish a communicative channel with the non-English-speaking patient. Interpreters, although traditionally regarded as neutral parties (Hsieh, 2001), often actively interfere with the content of conversations, deciding what should be said and heard (Bolden, 2000; Hsieh, 2001; Kaufert & Putsch, 1997). As a result, in situations in which health care providers and patients (or patients' family members) have conflicting cultural values, interpreters may edit information as they deem appropriate without any explicit explanation (Bolden, 2000), overtly refuse to interpret specific information (Kaufert & Putsch, 1997), or be trapped in dilemmas about whether to side with the health care provider or the patient (Beyene, 1992; Kaufert et al., 1999). In some cases, direct communication with patients about their diagnoses through interpreters has even led to patients' negative evaluations of the health care services they received (Beyene, 1992; Kaufert et al., 1999). As a result, the services provided by interpreters do not necessarily facilitate patients' autonomy, make patients better informed, or provide better health care services.

Another important contextual feature is the channels of communication available for information seeking and providing. Because of the saturation of the media environment, it may be difficult for individuals to avoid information about some health topics. News reports of illnesses and direct-to-consumer advertising place health and illness at the forefront of public consciousness. Additionally, despite the potential for communication technology to improve systems of information delivery in health care, it can be underutilized or utilized in ineffective ways. Individuals with the greatest need for health information may lack the technology to use Internet resources. When they do have access to the technology, individuals may find the information confusing or contradictory, and the volume of information overwhelming. Moreover, many credible sources provide website information that may be written in technical language and present minimal information, which may contribute to increased uncertainty about illnesses and treatment options (Berland et al., 2001). Other, less credible sources may offer miracle cures or alternative theories about disease processes. Often individuals seeking information for health care decision making need help interpreting what they find on websites and resolving inconsistencies between discrepant "facts" about illness and treatments.

When information is provided, other contextual barriers to understanding may inhibit information acquisition and processing. Cognitive capacity might be diminished when people experience extreme stress or anxiety because of illness or medical procedures (Brashers, Neidig, Haas, et

al., 2000; Mishel, 1988). For example, in a study of people who had undergone spinal surgery, Holmes and Lenz (1997) found that over half of their respondents reported difficulty remembering postoperative care instructions either because they still felt sedated when receiving the instructions or because they were in so much pain at the time. Their results led to suggestions for the timing and method of presenting postoperative information: Opportunities for questions should be given when patients are less distressed (including follow-up phone calls 2 to 3 days after discharge), and the oral instructions should be supplemented with written materials.

Summary. Information seeking and avoiding are collaborative activities that require negotiation and coordination among participants. A person might attempt to manage uncertainty by talking to his or her health care providers, friends, and family—all of whom are trying to manage their own uncertainty while they help the person with his or her information seeking and avoiding. Babrow, Hines, and Kasch (2000) have noted that people facing dialysis decisions often avoid uncertainty reduction with the cooperation of family and health care providers. They argued that “although denial may violate norms regarding full disclosure of a patient’s condition, patients, families, and health care providers may collectively choose to reduce stress by avoiding conversation about severe illness or approaching death” (p. 62; also see Hines, 2001). Moreover, information seeking and avoiding (i.e., uncertainty management) goals of individuals and their health care providers, friends, and families may be matched or mismatched, which may be either problematic or beneficial for the individual concerned, depending on the circumstances. Identifying goals and methods of achieving them is central to coordinating the efforts of all parties; however, information-seeking and information-avoiding behaviors may be more or less direct, which may confuse other participants about the goals associated with those behaviors. Different perceptions about an individual’s desire for information between the individual and potential information providers (e.g., health care providers or supportive others) may result in behaviors that seem unresponsive or intrusive. Finally, contextual features help shape information management activities, including the cultural (or cross-cultural) context and the information environment (channels or situational levels of stress and anxiety). These features suggest important directions for developing recommendations for effective information management.

Responding to Challenges and Dilemmas

The final goal of a normative model is to identify ways of addressing challenges and dilemmas of communication. We propose a number of research questions and directions needed to develop normative recommendations. For example, although it might appear that a match between

patient's and partner's information needs and strategies would be optimal, there are instances in which a mismatch may actually result in better outcomes. Johnson (1991) found that some heart patients engaged in information avoiding when they began to experience precursors to or symptoms of a heart attack, and it was only the urging of concerned others that led the patient to seek the necessary diagnostic information and life-saving treatment. A similar pattern exists for people with HIV who wish to avoid the information provided by a test, but who change their preferred strategy in response to persuasion from significant others (Brashers, Neidig, Haas, et al., 2000). To understand how patients and partners coordinate information seeking and avoiding and with what effect, we must consider not only the match between patients' and partners' needs and preferences for information management, but also the risks and benefits of obtaining and avoiding information. In addition, there is also almost certainly variability in the skill with which patients and partners are able to communicate about their needs. Thus, coordinating information management is likely to be a type of interaction in which multiple goals are present (e.g., for information, for optimal treatment, for preservation of autonomy and reciprocity, for displaying caring) and in which some ways of interacting are more successful for responding to multiple goals than others (Brashers, Neidig, Haas, et al., 2000; Cicirelli, 1991; Goldsmith, 1999). Questions within this domain might concern (a) what goals are present in information management situations, (b) how goals can be effectively communicated, and (c) how participants can effectively manage conflicting goals.

Similarly, provider-patient interactions can benefit from a normative perspective on communication. Interventions for improving patients' information-eliciting skills are being tested (Cegala et al., 2000), which may improve patients' ability to gather information from health care providers. Asking direct questions and expressing concerns does seem to stimulate information giving by providers (Street, 1991). However, to design effective interventions, it will be important to determine if information seeking is reduced by a lack of skills (e.g., a need to understand the ways in which directness and indirectness can impact another's responses), a lack of motivation (e.g., a preference to avoid threatening information), relational and identity concerns (e.g., a desire to respect the authority and face needs of the physician), or some combination of these factors. Research in this domain might be directed toward answering questions about (a) how and why information-seeking behaviors vary in directness and (b) how information management goals can be accomplished while accounting for other goals (e.g., identity management or relational maintenance)?

Cross-cultural considerations likewise are an important domain for re-

search. For example, although patients in some family-centered cultures may be reluctant to assume responsibilities for information seeking, act in ways that are labeled "information avoiding," and allow family members to take charge of their treatment, they should not typically be viewed as in "denial" (Muller & Desmond, 1992) or passive about their treatment. Often in family-centered cultures, the patients' family members express reasons why they handle information in such a manner (e.g., telling a patient negative information would make it true or make the patient lose hope) and are very active in communicating with health care providers and seeking information. Shifting the responsibility of information seeking to family members is not interpreted as information avoiding by the patient. It is in these circumstances that a normative approach to examining the information-seeking and information-avoiding behaviors can provide valuable information, such as (a) what information seeking and information avoiding mean to patients and their family members, (b) how patients negotiate autonomy and connectedness with family members, (c) how interpreters mediate the conflicting goals of information giving of health care providers and information control of patients' families, and (d) what roles interpreters can play to facilitate effective cross-cultural information exchange (e.g., as cultural informants).

Characteristics of the information provider may also influence the likelihood that an individual will seek informational support and the reaction to information provided. For example, cancer patients reported that informational support was most valued from health care professionals and fellow cancer patients or survivors rather than from family and friends, who might be well meaning but less expert (Dakof & Taylor, 1990). Adelman, Parks, and Albrecht (1987) suggested that "weak" network links (i.e., supporters who lie beyond the primary network of family and friends and with whom one typically has less frequent or intimate interaction) may be especially useful as sources of informational support because they extend access to new information, promote social comparison with dissimilar others, facilitate low risk discussion of high risk topics, and foster a sense of community. Mediated sources may be particularly useful because of characteristics such as convenience of use, ability to communicate anonymously or privately, use of asynchronous capabilities, and the ability to develop extended social networks (Street, Gold, & Manning, 1997). Questions that arise from these considerations include (a) what preferences information seekers and providers have for communication channels, (b) what channels provide the most efficient and effective modes of information dissemination, and (c) how information seekers can best manage conflicting or overwhelming information when confronted with messages from multiple channels.

CONCLUSION

Information management is an important component of coping with illness and illness-related uncertainty. People seek information from supportive others, health care providers, and mediated sources. There are challenges to information seeking and avoiding, which include coordinating the multiple goals and expectations of the interactants. These considerations give rise to important directions for research on information management in health contexts.

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