

### Coping as a Coordinated Activity:

#### Situating Health Literacy and Social Support in the Management of Diabetes

Several surveys have indicated that low health literacy is a prevalent problem in the United States, where more than one-third of the English-speaking population and half of the Spanish-speaking population struggle with health literacy (Gazmararian et al., 1999; Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005; Kutner, Greenberg, Jin, & Paulsen, 2006). Health literacy has been defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S. Department of Health and Human Services, 2000, p. 20). Researchers have noted that health literacy is critical to individuals’ illness experience: Low health literacy is linked to negative impacts on individuals’ health status, treatment adherence, health outcomes, and communication with health care providers (Michielutte, Alciati, & el Arculli, 1999).

Researchers, however, recently have urged a paradigm shift in conceptualizing a patient’s illness experience and his or her coping strategies (Zubialde & Aspy, 2001; Zubialde & Mold, 2001). Specifically, they have argued that past research has failed to recognize the complexity of the illness experience by viewing patients as isolated individuals (Edwards & Elwyn, 2001) with fixed skills (e.g., coping strategies and health literacy) that do not evolve over time in an illness event (Berkman et al., 2004). Illness is always a contextualized experience coordinated between multiple individuals (e.g., the patient, the provider, and the patient’s support network) (see Gallant, 2003; Lyons, Mickelson, Sullivan, & Coyne, 1998; Zubialde & Mold, 2001; Zubialde, Shannon, & Devenger, 2005). Several researchers have highlighted the need for longitudinal studies that investigate how a patient’s health literacy and illness-related needs may change throughout the course of an illness event (Berkman et al., 2004; Cegala, 2003; Weiner & Long,

2004; Zarcadoolas, Pleasant, & Greer, 2003b). Other researchers have emphasized the importance of examining social support as a moderator of patients' health literacy (Lee, Arozullah, & Cho, 2004). This theory paper is a response to these concerns: We propose a theoretical model that situates a patient's changes in and management of health literacy and social support during the progression of an illness event. Based on the theoretical model, we will also provide directions for future research.

### *Diabetes, Health Literacy, and Social Support*

We choose to use patients with type 2 diabetes as the target population to illustrate our theoretical model. Several characteristics of type 2 diabetes make it a particularly fitting illness for this model. First, type 2 diabetes is an adult-onset chronic illness that requires lifelong management. The patients are old enough to be expected to assume responsibility for managing their illness (Parsons, 1951); yet, they will need to develop health literacy and effective coping styles to manage their diabetes successfully (Schillinger et al., 2002; Zauszniewski, McDonald, Krafcik, & Chung, 2002). Because the timeframe for illness management is long, the patients' health literacy and coping styles may change as a result of changes in other factors (e.g., complications, age differences, marital status, and other contextual factors), which will provide valuable opportunities for researchers to examine the interrelationship between health literacy and other social factors. Second, diabetes is an illness for which individual experiences of uncertainty may differ greatly (Drivsholm, de Fine Olivarius, Nielsen, & Siersma, 2005). These patients may experience a wide range of uncertainty about their symptoms (e.g., asymptomatic diabetes vs. symptomatic diabetes), treatment options (e.g., diet vs. insulin injections), and illness management (e.g., easily controlled vs. multiple complications). The patients' diverse illness experiences provide rich resources to investigate how these variables influence a patient's social interactions with others. Third, social support is an important factor to the successful

management of diabetes (Barrera, Toobert, Angell, Glasgow, & Mackinnon, 2006; Gallant, 2003; Gerstle, Varenne, & Contento, 2001; Littlefield, Rodin, Murray, & Craven, 1990; Skinner, John, & Hampson, 2000). The necessary changes in diet and exercise patterns provide important insights into the relationship between patient health literacy and social support (Barrera et al., 2006; Skinner et al., 2000). Fourth, patients with diabetes often experience other types of chronic illnesses and face the threats of various (and serious) complications, such as cardiovascular, renal, and nerve diseases (A. Lloyd, Sawyer, & Hopkinson, 2001). In addition, compared to patients with type 1 diabetes, patients with type 2 diabetes experience more complications (Eiser, Riazi, Eiser, Hammersley, & Tooke, 2001). As a result, the management of health literacy for different types of illness and illness symptoms and coordination with the social support network become an on-going process that is particularly important for these patients. Finally, diabetes provides an excellent opportunity to examine the between-group differences in (a) various aspects of health literacy, (b) the complexity and meanings of social support, and (c) the preferences of coping strategies (Daniulaityte, 2004; DeCoster, 2003; M. Stone, Pound, Pancholi, Farooqi, & Khunti, 2005). Researchers have noted gender and cultural differences in the understanding and importance of social support for patients' coping styles and health outcomes (Chesla & Chun, 2005; DeCoster & Cummings, 2004; Ilias, Hatzimichelakis, Souvatzoglou, Anagnostopoulou, & Tselebis, 2001; Segall, 2001; Taylor et al., 2004). In addition, because persons from minority ethnic groups suffer disproportionately from type 2 diabetes and its complications (Dagogo-Jack, 2003; Okosun, Glodener, & Dever, 2003), researchers have the opportunities to examine the cultural differences between groups in areas of health literacy, social support, and coping strategies.

### *Health Literacy, Social Support, and Coping*

Health literacy is critical to a patient's ability to manage the uncertainty of an illness

event, as it reflects “the evolving skills and competencies needed to find, comprehend, evaluate, and use health information and concepts to make educated choices, reduce health risks, and improve quality of life” (Zarcadoolas et al., 2003b, p. 119). Researchers have noted that health literacy is critical to an individual’s health status, treatment adherence, health outcomes, and communication with health care providers (Michielutte et al., 1999): In two large scale reviews, researchers concluded that people with inadequate health literacy have poorer health, less knowledge about their medical conditions and treatment, and less understanding and use of preventive services (Berkman et al., 2004; Nielsen-Bohlman, Panzer, & Kindig, 2004).

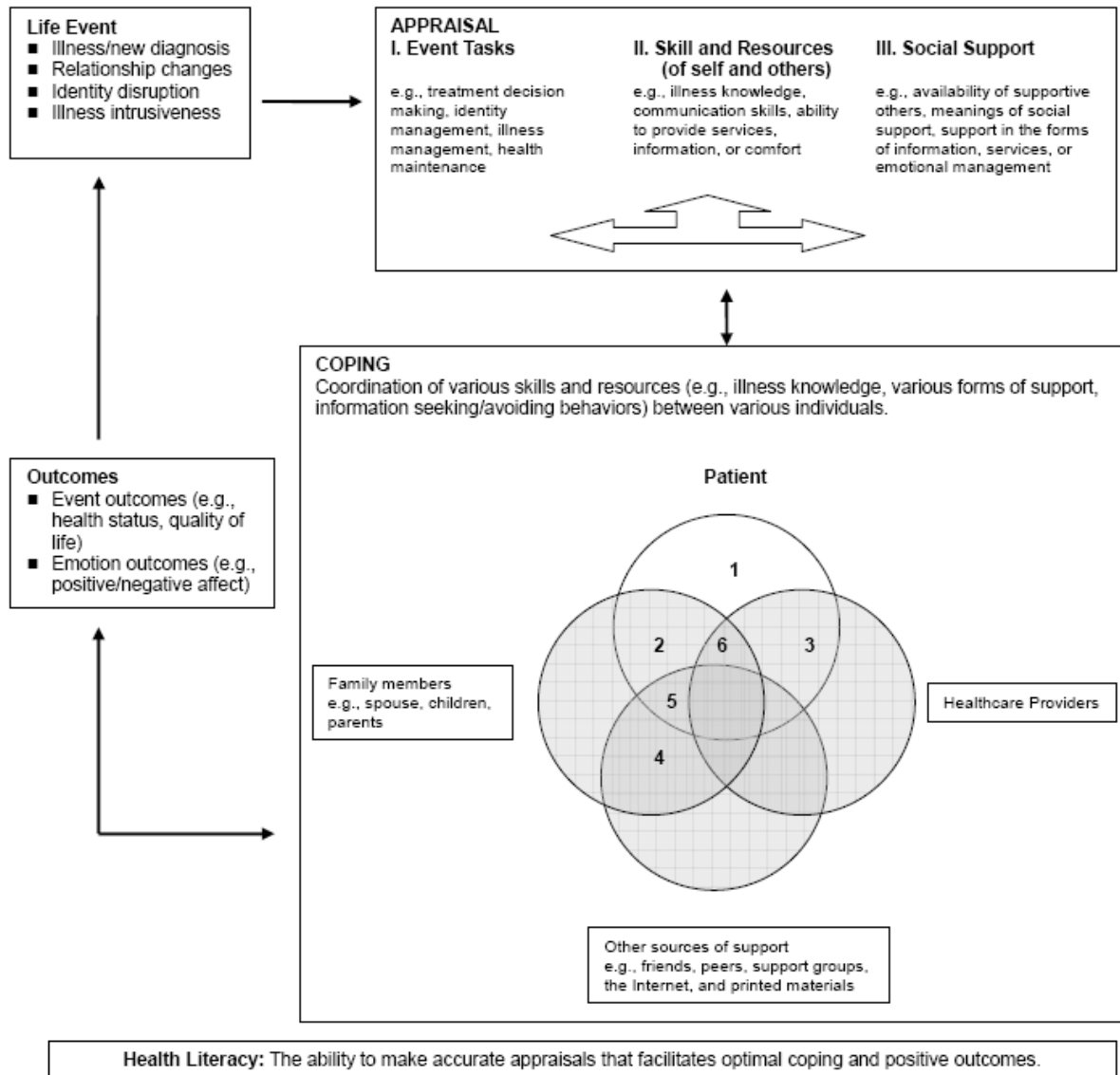
Although research in these areas often centered on the patients’ (lack of) health literacy and its corresponding impacts (e.g., Endres, Sharp, Haney, & Dooley, 2004; Howard, Gazmararian, & Parker, 2005), research on uncertainty and self-management for chronic illness has suggested that illness events often require the patient and members of his or her social support network (e.g., caregivers, family members, and friends) to coordinate their management of information and resources (Brashers, Neidig, & Goldsmith, 2004; Gallant, 2003). Brashers and colleagues argued that supportive others “*can be sources of information (e.g., peers or coworkers who share similar experiences with the support seeker), collaborators in information gathering, and evaluators of information, or they can serve as buffers against information* [italics added]. They also facilitate information management by encouraging development of information-seeking and decision-making skills” (Brashers et al., 2004, p. 324). The knowledge and ability to manage the illness event, thus, is coordinated between various individuals rather than independently possessed by an isolated patient. We propose that the level of the patient’s health literacy and its corresponding effects on the treatment process and coping strategies is best understood in the context of the patient’s supportive network and the coordination of resources among members of that network, specifically those resources related to the illness management.

In Figure 1, we present a coping model that highlights features of interest in this paper. This model is informed by past research on uncertainty (Brashers et al., 2003), coping (Folkman, 1997), and social support (Brashers et al., 2004). This coping model is for both the patient and the supportive others. Our model aims to show that (a) life events facilitate the (re-)appraisal process, which may lead to changes in coping strategies; (b) appraisal of event tasks, skill and resources, and social support influences coping strategies; and (c) coping is a coordinated activity between various individuals involved in the illness event (Brashers et al., 2004; Gallant, 2003).

In our model, health literacy is conceptualized as the evolving ability to make accurate appraisals that facilitate optimal coping and outcomes. In other words, high health literacy means that a patient is able to accurately appraise the event task, the skills and resources needed, and the individuals (e.g., self or members of the support network) who are available to provide the needed skills and resources (i.e., a cognitive process). In addition, the patient needs to coordinate with his or her supportive others effectively and appropriately to achieve optimal coping and outcome (i.e., problem solving and social interaction). This definition highlights some other areas that were not incorporated in the previous conceptualizations of health literacy. For example, the definition from the U.S. Department of Health (i.e., “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”) (U.S. Department of Health and Human Services, 2000, p. 20) views health literacy as a fixed skill (i.e., it does not recognize the evolving and changing nature of health literacy) and it assumes that the value of health literacy is to make “appropriate” health decision (i.e., it fails to situate illness events in a social context). Research has noted that individuals’ management of their identities, social relationships, and work often take priority over their illness management (C. E. Lloyd, Smith, & Weinger, 2005;

Smith, 2002). Individuals may make health-related decisions that may not be appropriate but are critical to other areas in life (e.g., a person may choose to keep a demanding job although it interferes with the treatment regimen because he or she needs the money). Zarcadoola et al.'s (2003b, p. 119) definition ("the evolving skills and competencies needed to find, comprehend, evaluate, and use health information and concepts to make educated choices, reduce health risks, and improve quality of life.") focuses on individuals' management of health information and concepts, whereas our model includes the interpersonal aspects of health management. As a result, high health literacy is not a set of skills and competencies of an isolated patient, but a set of different skills (e.g., the ability to make accurate appraisals in different areas and communicative competence to coordinate with various members of the support network) and resources (e.g., medical knowledge and financial resources) that can be coordinated between various individuals in an illness event. For example, a person may be too distressed to obtain illness-related information and rely on his or her relational partner to learn the latest treatment options and make treatment decisions. Finally, by conceptualizing health literacy as the *general* skills and abilities to make accurate, effective, and appropriate appraisals and coping, our theoretical model can be extended to management of illness in general (as opposed to diabetes). Health literacy, from this perspective, is about *problem-solving*: Individuals with abilities to accurately identify the problem (i.e., appraisal) and generate adaptive strategies (i.e., coping) to meet the challenges will manage their illness successfully (Glasgow, Toobert, Barrera, & Strycker, 2004; Hill-Briggs, 2003).

Figure 1: Coping Model for Patients and Their Supportive Others



This coping model also provides a new perspective to consider individuals' coping strategies. In past literature on individuals' appraisal and coping in illness events, researchers have argued that individuals appraise illness-related uncertainty as danger or opportunity (Brashers et al., 2000; Lazarus & Folkman, 1984; Mishel, 1990). When uncertainty is appraised as danger (e.g., when not knowing treatment options can lead to problematic decisions), individuals attempt to reduce it as an adaptive response. When uncertainty is appraised as opportunity (e.g., when knowing about disease progression undermines hope), individuals attempt to maintain or increase it as an adaptive response. This approach highlights the individual differences in an illness event because what would be perceived as danger by one patient may be interpreted as opportunity by another. The challenge faced by this theoretical approach is that it is difficult to anticipate how the illness-related uncertainty or stress would be appraised by a patient and thus, present a challenge to providing a group-based intervention. In contrast, our model emphasizes the patients' ability (a) to make accurate appraisal to identify the skills, resources, and social support available to accomplish the event task and (b) to appropriately and effectively coordinate with supportive others for optimal coping and outcomes. Instead of focusing on individuals' internal evaluation (e.g., uncertainty appraised as danger vs. opportunity), we offer a skills-based model that emphasizes behavioral outcomes and explores how various individuals can coordinate different skills (e.g., ability to seek information and provide emotional support) and resources (e.g., medical knowledge and financial resources) in an illness event for optimal coping and outcomes.

We also highlight some aspects of interdependence in our model. First, the three appraised elements are intrinsically linked to each other. We will explore this interdependence as we explain these concepts in the following sections. Second, the appraisals made by the patients and their supportive others may not be the same and may require negotiation from both sides.

For example, even with the same event task of maintaining a healthy diet, a patient may view the task as a matter that requires family participation, whereas a spouse or partner of the patient may feel that it is the patient's personal responsibility and should not interfere with other family members' lifestyles. Third, coping strategies are interdependent with the appraisal process. When people share incompatible appraisals, they may find that conflicting goals inhibit their ability to cope with the illness. These are undoubtedly complex relationships (e.g., note the reciprocal arrows between the elements of Figure 1). Our goal in the paper (and future studies) is to illuminate processes that connect these variables.

### *Situating Patients' Health Literacy in the Illness Events*

To understand what constitutes effective healthcare communication, researchers need to understand "what patients need to know, when during the course of care, and from whom they receive this information" (Rutten, Arora, Bakos, Aziz, & Rowland, 2005, p. 250). Researchers who study health literacy and provider-patient communication have advocated for longitudinal research because a patient's event tasks, skills and resources, and social support may change throughout the course of an illness event (Berkman et al., 2004; Cegala, 2003). Current research on health literacy is heavily weighted toward studies with limited or no longitudinal component, assessing the participants' health literacy through one-time survey/measurement (Berkman et al., 2004); however, health literacy is not a fixed ability, but rather one that may evolve throughout a patient's illness experience (Zarcadoolas, Pleasant, & Greer, 2003a).

Life events facilitate the appraisal process in the two ways. First, life events (e.g., changes in health status, psychosocial status, symptom development, and interpersonal relationships) in the illness experience can trigger the need for (re)appraisal (Brashers, 2001; Folkman, 1997). For example, the illness experience (e.g., changes in health status or experience with side effects) can prompt a patient to reevaluate the importance, availability, credibility, and

authority of different sources of social support in managing the illness event. Researchers have noted that a patient has different informational needs and relies on different individuals at different phases of an illness event (Rutten et al., 2005). For example, at the diagnosis and treatment phase, cancer patients in one study relied most on printed materials and health professionals (physicians in particular), but at the post-treatment phase, they then relied most on health professionals (physicians, nurses, and other health care professionals were viewed as equally important) and interpersonal contacts (Rutten et al., 2005).

Second, as patients become more familiar with their illness experiences, they may become more accurate and effective in their appraisal and coordination of event tasks, social support, and skills and resources. Researchers have noted that patients' coping strategies evolve over time and shift from less adaptive to more adaptive coping strategies (Reeves, Merriam, & Courtenay, 1999) and that patients with chronic illnesses develop the ability to appraise uncertainty (e.g., ambiguous physical symptoms and/or side effects of medication) and trust different individuals for different needs (Brashers et al., 2000). Several studies have suggested that one to two years of longitudinal study is necessary to observe the changes in health status and self-care management for patients with diabetes. In one large-scale study, researchers found that patients have clinically significant improvements in HbA<sub>1c</sub> levels, systolic and diastolic blood pressures, aspirin use, and weight occurred within 1 year of a new diagnosis of diabetes (O'Connor et al., 2006). However, some studies suggest that there may be other factors that may lead to patients' deterioration in illness management. In another large-scale study, in a two-year period, 10.8% of the patients who originally had good diabetes control crossed over to poor control and 38.7% of the patients who originally had poor control crossed over to improved control (Weiner & Long, 2004). In the same study, compared with whites, blacks were 1.76 times as likely to switch from good to poor control and only 0.56 times as likely to switch from

poor to good control. Because these changes take place in a short timeframe (i.e., 1 to 2 years), the research design on health literacy needs to have frequent evaluations to examine the subtle changes and various social factors that may influence these behavioral and health outcomes. To develop effective interventions, researchers need to identify the factors that may make patients become more (or less) appropriate and effective in assessing their needs, identifying the skills and resources needed, and soliciting support from the person that best meets their needs.

Past literature has suggested that stressful life events influence individuals' diabetes control (C. E. Lloyd et al., 2005). Although researchers have suggested that minor stressors and hassles (a) can be an integral part of living with diabetes, and (b) are related to both work and family life (e.g., identity and relational management), which often takes priority over illness management (C. E. Lloyd et al., 2005; Smith, 2002), there has been no study that systematically examines how patients with diabetes negotiate these minor stressors and hassles with their support network in their everyday life. By situating a patient's health literacy in the everyday life of an illness event, researchers can focus on the specific effects of health literacy on individuals' illness experiences. In this paper, we view health literacy as a contextualized, evolving skill that a patient may or may not learn to master during the course of an illness event. By situating the illness event in a timeline, researchers can examine how a patient learns to be more appropriate and effective in coordinating with multiple individuals (e.g., providers, family members, and fellow patients) to obtain various resources (e.g., information, emotional, and tangible support) needed to navigate through the illness event.

In summary, our approach highlights the two aspects of health literacy that rarely have been discussed in past literature. First, health literacy is an evolving skill that a patient develops throughout the course of illness event. Researchers should explore the various factors and mechanisms that influence a patient's development of health literacy in the illness event. Second,

the level of a patient's health literacy should be understood in a social context. Because an illness event often involves the coordinated management of skills and resources between a patient and his or her support network, the meaning and the influence of a patient's health literacy cannot be viewed as an isolated skill. From this perspective, we should examine how the coordinated activity between the patient and his or her support network influences a patient's health literacy and communication with the supportive others.

*Appraisal Process: Event Task, Skills and Resources, and Social Support*

Patients rely on various individuals (e.g., providers, family members, and fellow patients), resources (e.g., individuals who are able to provide information, instrumental, or emotional support) and strategies (e.g., information seeking and avoiding) to navigate through the uncertainty of an illness event (Babrow, 2001; Babrow, Kasch, & Ford, 1998; Brashers et al., 2000; Lyons et al., 1998; Mishel, 1997, 1999). As a life event (e.g., new diagnosis, new complications of the illness, identity disruption, or illness intrusiveness) presents new challenges in the management of the illness event, *the patient and his or her supportive network* may (re)appraise (a) the event task, (b) the skills and resources needed, and (c) the type of social support needed for optimal coping. It is important to point out that the appraisal and coping are theoretically distinct concepts: Appraisal is about the cognitive process aim at evaluation and coping focuses on the cognitions and actions meant to manage the illness and its effects (i.e., problem solving and social interaction).

Event tasks. Life events create disruption to the patients' illness management (Charmaz, 2000; Ruggiero, Spirito, Coustan, McGarvey, & Low, 1993). Appraising event tasks can be challenging. First, a life event may cause crises in multiple areas. For example, an increase in illness intrusiveness (i.e., the disruptions of valued activities and interests due to constraints imposed by the illness, such as worsened symptoms, new complications, and increased

complexity of treatment regimens) may lead to uncertainty (Lohri-Posey, 2006), emotional distress (Talbot, Nouwen, Gingras, Belanger, & Audet, 1999), identity loss (Jeanfreau, 2005), and noncompliance with the treatment (Connell, O'Sullivan, Fisher, & Storandt, 1988). As a result, a patient is faced with different tasks that may include uncertainty, emotion, identity, and/or treatment management. A patient will need to accomplish the different (and possibly competing or conflicting) tasks. For example, a patient with diabetes may wish to maintain a spontaneous, carefree identity but having diabetes means that his or her diet needs to be carefully monitored and planned. Second, the same task (e.g., healthy dietary practices) may have different meanings for different patients (and their supportive others). Depending on the meanings associated with the task, a patient may choose to utilize different forms or sources of social support, and different skills and resources. For example, one study demonstrated that female patients with diabetes viewed food consumption as an individual concern, whereas male patients viewed it as a family matter (Peel, Parry, Douglas, & Lawton, 2005). As a result, compared to female patients, male patients may have greater expectations for support and participation from family members in maintaining their dietary practices. From this perspective, it is important for researchers to examine patients with type 2 diabetes and their supportive others to determine their (a) evaluation and management of the various event tasks over a period of time and (b) understanding of the meanings of the event tasks.

Skills and resources. Once an event task is identified, the next step is to appraise (a) the skills and resources needed and (b) the types and sources of social support available to accomplish this task. The appraisal of skills and resources is interdependent with the appraisal of social support. As a patient identifies the event task, he or she will need to evaluate his or her own available skills and resources and those of supportive others to decide the most effective and appropriate means of coping. For example, a patient may wish to obtain more information about

his or her illness. However, if his or her relational partner is too distressed to learn additional information about the illness (i.e., appraisal: the spouse is not able to provide informational support), and subsequently chooses to seek information independently (i.e., coping: go to the medical appointments alone so that sensitive questions can be asked). In other words, the appraisal of skills and resources requires individuals to consider the appropriate and effective strategies to achieve optimal coping (i.e., coordination between various individuals) and outcomes (e.g., emotional and health outcomes).

A patient may find that the most available (or accessible) skills and resources would be those that are possessed by himself or herself. For example, a patient with a high level of skills may be someone who can independently seek information, make informed treatment choices, and maintain diet and exercise regimens. A patient with high level of resources may be someone who is knowledgeable about diabetes-related information (i.e., knowledge as a resource), is able to purchase pre-made meals for persons with diabetes (i.e., finance as a resource), or has control over their time so that he or she can exercise regularly (i.e., time as a resource). A patient may be motivated to develop his or her own skills and resources to meet the demands of illness management because they are easily accessible and do not require coordination with others. Although a person with a high level of skills and resources may be perceived as an ideal patient (i.e., high self-advocacy and self-efficacy), it is unlikely that he or she will be able to maintain that high level of skills and resources over time. First, individuals may be limited in their initial skills and resources. For example, individuals' low education level may present challenges when they try to read academic papers about diabetes. Second, the on-going process of illness management may reduce a patient's ability to seek information, make treatment choices, or maintain diet and exercise regimens independently. For example, if a patient develops new complications, needs to meet a project deadline at work, or experiences emotional distress, he or

she may not be able to maintain the usual exercise routine or information-seeking pattern. As a result, the patient may need to seek help from the supportive others.

A patient needs to accurately identify the supportive others who are able to provide the skills and resources needed to cope with the illness events. For example, when individuals make treatment decisions, they often need information and/or advice to assist in this process.

Developing decision-making and information-seeking skills may be necessary for individuals unfamiliar with health care settings (e.g., newly-diagnosed individuals). Strategies that they might learn include (a) eliciting information from multiple sources (e.g., health care providers, peers, friends, family, and media sources); (b) constantly monitoring for updated information; or (c) interacting in information-rich environments (e.g., illness-related organizations or support groups) (Brashers, Haas, Neidig, & Rintamaki, 2002; Brashers et al., 2000). A patient and members of his or her supportive network need to *learn* these skills. At the early stage, patients may need to rely on health care providers' medical knowledge to make decisions (Rutten et al., 2005); however, as the patients become more experienced with the illness symptoms and develop abilities for seeking information from more reliable or credible sources (e.g., peers or latest publication on medical journals), they may assume the role of self-advocates or solicit support from the trusted sources (Brashers, Hsieh, Neidig, & Reynolds, 2006).

A patient also needs to be aware of the possible changes in his or her supportive network member's ability and willingness to provide the skills and resources needed for the coping process. For example, in the initial diagnosis period, a caregiver may actively seek to enhance his or her health literacy on the specific illness, while the patient is protected from this tedious information-seeking process (see Parsons, 1951); however, in the post-treatment or health maintenance phase, the patient may be expected to assume most health-maintaining responsibilities and thus, to have higher health literacy.

We believe that the progression of an illness requires the patients to respond to the changes in skills and resources of self and supportive others in order to achieve optimal coping and positive outcomes. From this perspective, researchers should examine the patients' (a) learning process of developing accurate appraisal of skills and resources available to them and (b) variables that influence their decisions to rely on themselves or the supportive others.

Social support. Social support is an umbrella term for various social factors that may influence physical and psychological well-being, including the size and diversity of an individual's network of social relationships, the perception that support would be available if needed, the amount of support actually received during some time period, and satisfaction with one's support resources. Both theory and findings from previous research on individuals coping with various kinds of life stresses suggest that these different social factors may have different kinds of effects (e.g., Cohen, 1988; Cohen & Wills, 1985; Dunkel-Schetter & Bennett, 1990; Schwarzer & Leppin, 1991; Vaux, 1988). For example, perceived available support is likely to be positively associated with positive behavioral outcomes and with physical and psychological well being. The belief that others will be available to provide comfort, reassurance, information, resources, and companionship during times of need has been demonstrated to buffer individuals from the otherwise negative effects of life stresses (for a review, see Cohen & Wills, 1985). On the other hand, the degree to which received social support protects against stress depends upon the match between the support that is received and an individual's needs and expectations (for reviews, see Cohen & McKay, 1984; Cutrona & Russell, 1990).

We believe that the appraisal of social support is multi-dimensional. First, social support is a generic term for a wide variety of illness-specific and general support behaviors. Researchers have noted that support in the areas of emotion, services (i.e., instrumental, tangible, and coping support), information (e.g., information seeking, avoiding, giving, and shielding), and

relationships (e.g., ego/identity support and companionship) is important to a patient's illness management (Brashers et al., 2004; Gerstle et al., 2001; Orford et al., 1998; Seeman & Syme, 1987). It is important for a patient to accurately identify the type of support needed to accomplish the task. To reduce anxiety, a patient may actively seek information by himself/herself or to ask a spouse or partner to buffer potentially distressing information (Brashers, 2001). However, if a patient experiences loss of identity (e.g., is no longer able to work, so loses the role of "bread winner" for the family), an empathetic listener is critical in the coping process (Frank, 1998). Failure to match the event task with the type of support needed may lead to unsuccessful coping and negative outcomes.

Second, a patient needs to appraise the availability of his or her support network (e.g., family members, friends, health care providers, support groups) to decide who can best to provide the specific type of support needed for the event task. For example, a health care provider may be a good source of informational support to enhance a patient's medical knowledge but not a good source of relational support to reduce a patient's feeling of loneliness. On the other hand, a close friend who is a health professional or has significant experience with health concerns may be able to provide both informational and relational support.

Third, the meanings and experience of social support can be gender- and culture-specific (Burlinson, 2003). Researchers have noted that men and women may require different types of support when coping with illness. For example, in a weight loss program, female patients did better when treated with their spouses, whereas male patients did better when treated alone (Wing, Marcus, Epstein, & Jawad, 1991). Another study of patients with asthma or diabetes found that female patients experienced worse physical health when their husbands hide their concerns whereas male patients benefited when their wives did not discuss their worries (de Ridder, Schreurs, & Kuijer, 2005). Researchers also have noted that cultural differences account

for different needs and utilization of support (Dressler, 1994; Taylor et al., 2004; van Dam et al., 2005). For example, in family-centered cultures, when a patient has a poor diagnosis, both the patient and his or her family members see information and treatment seeking as the family members' (rather than the patient's) responsibility (Beyene, 1992; Blackhall, Murphy, Frank, Michel, & Azen, 1995; Kaufert & Putsch, 1997; Kaufert, Putsch, & Lavalley, 1999). In these cultures, a patient who actively seeks to obtain health-related information will be viewed by his or her community as being abandoned or neglected by his or her family members. In other words, informational support in these cultures is not only management of information but also the management of identities and relationships (i.e., identity and relational support).

From this perspective, researchers should examine (a) the patients' evolving ability to appraise and solicit social support, and (b) the patients' and the supportive others' construction of the meanings of social support. In addition, it is important to examine how different variables (e.g., culture and gender) may influence these processes.

#### *Coping as a Coordinated Activity*

Researchers have emphasized the interactive and collaborative nature of the coping process in an illness event (Brashers et al., 2004; Lyons et al., 1998). For example, researchers have noted that a patient may intentionally avoid information to manage illness-related uncertainties but passively receive information provided by supportive others (Brashers, 2001; Brashers et al., 2000). Researchers also have noted that patients may utilize their interpersonal network to enhance their well-being and coping through the exchange of tangible and symbolic support during interactions (see Albrecht & Goldsmith, 2003, for a review). Miller and Zook (1997) elaborated the ways in which caregivers adopt various information-seeking behaviors to facilitate the patient's coping with illness events. Finally, researchers have found that a patient's social network assumes a greater role and has stronger influence over a patient's illness event as

the patient's level of literacy decreases (Davis et al., 1996; Davis, Williams, Marin, Parker, & Glass, 2002). In short, coping requires individuals involved in an illness event to coordinate their skills and resources to achieve optimal outcomes.

In Figure 1, we have used a Venn diagram to illustrate how coping activities may be coordinated between various individuals. For example, a patient's maintenance of proper diet when eating alone can be an example for area (1). Area (2) represents coordinated efforts between family members and the patient (e.g., the whole family changes their dietary habits to accommodate the patient's needs) and area (3) represents coordinated efforts between the patient and health care providers (e.g., joint decision making for the treatment). Family members' efforts to seek information from the Internet can be considered an example of area (4), whereas attending support groups with the patient can be an example of area (5) and going to medical appointments with the patient can be an example of area (6). We believe that optimal coping occurs when the patient and the support network (a) share similar or compatible appraisals, (b) have the necessary skills and resources to meet task needs, and (c) successfully coordinate their activities through effective and appropriate communication.

The coordination of these activities may be more or less successful. For example, earlier, we pointed out that some studies have argued that social support may be unhelpful or even have negative effects (see Goldsmith, 2004 for a review). Researchers have noted that patients experience "unhelpful" (or the lack of) support when others' supportive behaviors seem intrusive, insincere, dismissive, or avoidant (Barbee, Derlega, Sherburne, & Grimshaw, 1998; Dyregrov, 2003; Goldsmith, Lindholm, & Bute, 2006a, 2006b; Trief et al., 2003). However, we believe that the usefulness of support is contingent upon the patient's and the supportive others' ability to appraise and to coordinate event tasks, support needs, and skills and resources with the supportive others. In other words, unsuccessful coping can be caused by (a) problematic

appraisals and (b) failure in coordinating with others. *Problematic appraisal*, which focuses on the cognitive process, can be flawed, mistaken, or inaccurate assessments of event tasks, social support, and skills and resources of self and others. For example, a patient may seek emotional support from a family member without knowing that the family member is struggling to cope with his or her own issues of distress (Lyons et al., 1998). In other words, the patient made an inaccurate assessment about the skills and resources available from the family member. *Failure in coordinating with others*, which focuses on the communicative process (i.e., social interaction), can be the miscommunication or ineffective collaboration between the patient and supportive others. In one study, a patient noted that his mother's supportive behavior included unreasonable demands, such as when she "insisted I eat, and expressed frustration when I'd throw up" (Hays, Magee, & Chauncey, 1994, p. 388). The challenges of coordinating activities increases when the patient and his or her supportive others share different (or even incompatible) appraisals. For example, if a patient wishes to reduce anxiety by avoidance, having supportive others to solicit their stories can be undesirable (Gurowka & Lightman, 1995). Alternatively, if a patient wishes to reduce anxiety through sharing traumatic experiences, telling stories to supportive others who exhibit avoidant behaviors can be stressful (Dyregrov, 2003). Researchers have noted that the dilemma of managing their own and others' anxiety may make individuals actively discourage others from talking about the traumatic experiences and inhibiting their own conversations, even though they report a continuing desire to discuss their own experiences (Pennebaker & Harber, 1993; L. D. Stone & Pennebaker, 2002). Although (a) problematic appraisal and (b) failure in coordinating with others are theoretically distinct concepts, the relationship between them is still unclear. A careful investigation of the relationship between (a) and (b) will allow researchers to develop better interventions that target the patients' cognitive processes (i.e., appraisal) and communicative skills (i.e., coping). From this perspective, we

believe future research should examine how individuals (a) manage the coping process through collaboration between multiple individuals, (b) learn from their experiences of problematic appraisal and failure in coordinating with others, and (c) improve health literacy during the coping process.

### Conclusion

Health literacy has been an area that has received great attention from both the research community and health care industry in recent years (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs American Medical Association, 1999; Speros, 2005). The challenge faced by researchers, however, is to move beyond a general discussion of health literacy and to situate the functions and meanings of health literacy in an illness event (Zarcadoolas, Pleasant, & Greer, 2005). We've proposed a coping model that is build on the past literature on social support, uncertainty management, and health literacy. Our coping model highlights the interpersonal perspectives of illness management and situates illness experiences in a timeframe. Our objectives are to generate a theoretical model that synthesizes past research and to provide future directions for research on illness management.

We have focused our discussion on patient's coping process (e.g., life event followed by appraisal and coping); however, it is important to point out that the coping model views coping as a coordinated activity between *all* individuals involved in the illness event (i.e., the model can be used to examine how a patient's family members develop their coping strategies). A successful illness management requires *all* individuals involved to coordinate and negotiate their appraisals and coping strategies. Because this theoretical model is behavior-oriented and skill-based, researchers will be able to develop effective interventions to improve the coping strategies in illness events for different parties (e.g., patient, family member, and providers).

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Figure 1: Coping Model for Patients and Their Supportive Others

