

## Patients' and Partners' Perspectives of Chronic Illness and Its Management

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This study is framed in theories of illness uncertainty (Babrow, A. S., 2007, Problematic integration theory. In B. B. Whaley & W. Samter (Eds.), *Explaining communication: Contemporary theories and exemplars* (pp. 181–200). Mahwah, NJ: Erlbaum; Babrow & Matthias, 2009; Brashers, D. E., 2007, A theory of communication and uncertainty management. In B. B. Whaley & W. Samter (Eds.), *Explaining communication: Contemporary theories and exemplars* (pp. 201–218). Mahwah, NJ: Erlbaum; Hogan, T. P., & Brashers, D. E. (2009). The theory of communication and uncertainty management: Implications for the wider realm of information behavior. In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty and information regulation in interpersonal contexts: Theories and applications*, (pp. 45–66). New York, NY: Routledge; Mishel, M. H. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research*, 17, 269–294; Mishel, M. H., & Clayton, M. F., 2003, Theories of uncertainty. In M. J. Smith & P. R. Liehr (Eds.), *Middle range theory for nursing* (pp. 25–48). New York, NY: Springer) and health information management (Afifi, W. A., & Weiner, J. L., 2004, Toward a theory of motivated information management. *Communication Theory*, 14, 167–190. doi:10.1111/j.1468-2885.2004.tb00310.x; Greene, K., 2009, An integrated model of health disclosure decision-making. In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty and information regulation in interpersonal contexts: Theories and applications* (pp. 226–253). New York, NY: Routledge) and examines how couples experience uncertainty and interference related to one partner's chronic health condition. Specifically, a model is hypothesized in which illness uncertainty (i.e., stigma, prognosis, and symptom) and illness interference predict communication efficacy and health condition management. Participants include 308 dyads in which one partner has a chronic health condition. Data were analyzed using structural equation modeling. Results indicate that there are significant differences in (a) how patients and partners experience illness uncertainty and illness interference and (b) how appraisals of illness uncertainty and illness interference influence communication efficacy and health condition management. We discuss the findings and implications of the study.

**Keywords:** illness uncertainty, illness interference, efficacy, chronic illness, health management

Nearly one of every two adults has at least one chronic disease (Centers for Disease Control and Prevention [CDC], 2011a; see also Wu

& Green, 2000; Yorgason et al., 2010), indicating that many people are managing a disease on an ongoing basis. A chronic disease<sup>1,2</sup> is a non-communicable illness that is prolonged in duration, does not resolve spontaneously, and is rarely cured completely. Chronic health conditions (CHCs) such as cardiovascular disease (primarily heart disease and stroke), diabetes, and arthritis are among the most prevalent of all

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<sup>1</sup> Chronic illness, chronic disease, health condition, and chronic health condition are used interchangeably.

<sup>2</sup> Greene's (2009) health disclosure decision-making model (DD-MM) argues that individuals assess health information in terms of five aspects including preparation, prognosis, relevance to others, symptoms, and stigma.

health problems in the United States (CDC, 2011b).

Many people who are managing a CHC are also managing chronically high uncertainty (Mishel, 1999). Uncertainty is a key feature in individuals' illness experiences (Babrow, Kasch, & Ford, 1998; Mishel & Clayton, 2003) and in their health information management (Brashers, 2007; Greene, 2009). Unlike uncertainty in acute illness, which tends to be localized in issues of diagnosis, treatment, and recovery, uncertainty in chronic illness involves broader aspects of a person's life (e.g., home, work) and influences daily routines and activities (Bayliss, Steiner, Fernald, Crane, & Main, 2003; Mishel, 1999; see also Yorgason et al., 2010).

A sizable body of research exists on how couples cope with the stresses associated with managing a chronic illness (Revenson, Kayser, & Bodenman, 2005) and how chronic illness influences other aspects of a person's life such as relational quality (e.g., Berg & Upchurch, 2007), marital satisfaction (Burman & Margolin, 1992; Kiecolt-Glaser & Newton, 2001), and communication (Brashers, 2007; Goldsmith, Miller, & Caughlin, 2007; Pisrang & Barker, 2005). Yet, to date, we still have few quantitative tests of how uncertainty in chronic illness is experienced and managed in relationships (for exception, see Checton & Greene, 2012). Chronic illnesses impact not only the life of the ill individual, but the relationships of the individual as well. By taking a *relationship* perspective, we can better understand how individuals adapt their lives to their own or their partners' chronic illness (Badr & Acitelli, 2005). However, knowing more about how couples cope with chronic illness (cf. Bodenmann, 2005 on dyadic coping) requires consideration of how multiple sources of illness uncertainty are interrelated (see Goldsmith, 2009) and how patients and partners differ in their illness experiences.

It is important to note, however, that there are numerous cultural, socioeconomic, and developmental (e.g., couple life-stage) factors influencing illness experiences, communication, and health condition management. Western cultures, in general, tend to view uncertainty as something to be eliminated or managed (Babrow & Matthias, 2009; Hogan & Brashers, 2009; Smithson, 2006), but this may not be

consistent across cultures. Socioeconomic factors influence people's self-management of certain CHCs. For example, Halm, Moro, and Leventhal (2006) found that inner-city adults with asthma managed their illness by treating the symptoms and not the chronic nature of the illness (i.e., "No symptoms = no disease"). Illness uncertainty may change the way partners communicate such that even couples in long-term, satisfactory relationships may avoid discussing certain topics (Goldsmith, 2009). The purpose of this study, then, is to examine how patients' and partners' perspectives of chronic illness (i.e., illness uncertainty and illness interference) differ in terms of perceived management of one partner's CHC.

### Illness Uncertainty

The prolonged course of illness from chronic conditions such as diabetes, arthritis, and cardiovascular diseases often results in extended pain and decreased quality of life for millions of Americans (CDC, 2011b). Although improved capabilities in diagnosis and treatment of such diseases may benefit patients and families, such improvement also "sets the stage for numerous sources of uncertainty" (Goldsmith, 2009, p. 209). Uncertainty exists when details of situations are ambiguous, complex, unpredictable, or probabilistic (Babrow, Hines, & Kasch, 2000; Brashers, 2001). As Brashers (2001) noted, uncertainty "is primarily a self-perception about one's own cognitions or ability to derive meaning, a person who believes himself or herself to be uncertain is uncertain" (p. 478).

Illness uncertainty is complex and stems from many sources such as the nature of the illness, an unknown future, perceived stigma, a lack of information or social support, conflicting diagnoses from health care providers, and the development of new symptoms (Babrow & Matthias, 2009; Brashers et al., 2003; Hogan & Brashers, 2009; Mishel, 1999). People also experience various types of uncertainty simultaneously (Babrow, 2007; Brashers, 2007). The experience of uncertainty may focus on the self (e.g., "Can I manage this condition?"), others (e.g., "Can my partner help manage my condition?"), and relationships with others (e.g., "Will my health condition affect my relationship with my partner?") (Brashers, 2001; Greene, Derlega, & Mathews, 2006). Uncer-

tainty is an underlying feature of Greene's (2009) disclosure decision-making model (DD-MM), which posits that prior to disclosing health information people appraise the information in terms of five areas: preparation, prognosis, relevance to others, symptoms, and stigma. The five components may be weighed in progression or simultaneously, or it may be that only one or two components are relevant for a particular piece of information being shared. For example, individuals may be uncertain about the implications of new information (e.g., new symptoms) and avoid sharing the information with a partner, disclose it immediately, or delay relaying the new information. The current study focuses specifically on uncertainty regarding symptoms, stigma, and prognosis as they relate to managing a CHC. Individuals with chronic obstructive pulmonary disease (COPD), for example, may experience uncertainty regarding disease *prognosis* (e.g., expected course of illness, chance of recovery, fears about the future), *symptoms* (chronic, relapsing, visibility), and *stigma* (e.g., perceived blame for being a smoker). Because patients and partners are likely to appraise illness uncertainty differently, it is also likely that such appraisals influence their communication and health condition management in different ways.

Although there are many forms and meanings of uncertainty (Hogan & Brashers, 2009), theorists concur that uncertainty is neither good nor bad, but rather, like any other object or event, it must be appraised as either a threat or an opportunity (Babrow et al., 1998; Mishel, 1999). People manage uncertainty and the emotions associated with it in various ways (Afifi & Weiner, 2004; Babrow & Matthias, 2009; Brashers, 2007). A considerable body of research suggests that uncertainty in relationships undermines people's confidence in their ability to communicate with a partner (Knobloch & Satterlee, 2009) and is empirically linked with avoiding discussion of sensitive topics within cross-sex friendships (Afifi & Burgoon, 1998), dating relationships (Knobloch & Carpenter-Theune, 2004), family relationships (Afifi & Schrodt, 2003), and marital relationships (Knobloch, Miller, Bond, & Mannone, 2007).

In relation to chronic illness, uncertainty may generate a desire to talk to one's partner; yet, the changes patients are experiencing may make them unsure about how to communicate (Gold-

smith, 2009). In a study of elderly patients managing heart-related conditions, prognosis uncertainty was positively associated with communicating with a partner about a range of topics, but symptom uncertainty was negatively associated with frequency of talk about one's heart condition (Checton & Greene, 2012). Thus, patients' appraisals of prognosis and symptom uncertainty influenced communication with their partner in different ways.

Less is known about (a) how *partners'* uncertainty appraisals influence their communication with the patient and (b) the relationship between communication and managing a CHC. For example, scholars have argued against an "ideology of openness" in communication (Caughlin, Mikucki-Enyart, Middleton, Stone, & Brown, 2011, p. 410; see also Afifi, Caughlin, & Afifi, 2007; Petronio, 2002). That is, people are not constant disclosers, and topic avoidance is a common and functional relational event (Afifi et al., 2007; Goldsmith, 2009). Regardless, it is expected that the more uncertain individuals are about a CHC, the less perceived ability to share information with a partner about the condition. Illness uncertainty may also be linked sequentially with perceptions of illness interference. For example, individuals who are managing a chronic illness such as fibromyalgia may experience uncertainty about a prognosis that may then influence their beliefs that the illness is interfering in their life.

### Illness Interference

About one fourth of people with CHCs have one or more daily activity limitations (CDC, 2011a; see Anderson, 2004). Devins (2009) suggested that illness intrusiveness results from disease- and treatment-induced disruptions to lifestyles, activities, and interests and is a common, underlying factor in quality of life for people managing CHCs. Similar to the numerous sources of uncertainty in illness (Babrow & Mathias, 2009; Hogan & Brashers, 2009; Mishel, 1999), illness interference stems from a myriad of stressors associated with the disease itself, including symptoms such as pain, fatigue, and disability and/or treatment side effects, which influence subjective well-being indirectly through their effects on illness intrusiveness (Devins, 2009). Theories of information management provide frameworks for understanding

how people cope with chronic illness, including how people (a) evaluate and incorporate an illness into their lives (Babrow & Matthias, 2009; Mishel & Clayton, 2005), (b) manage illness uncertainty (Hogan & Brashers, 2009), and (c) seek information to manage uncertainty-related anxiety (Afifi & Morse, 2009). From this perspective, goals are not necessarily a tool to eliminate illness-related anxiety or uncertainty, but rather a method to manage increases or decreases in uncertainty (Afifi & Weiner, 2004; Brashers, 2007), while acknowledging that co-existing with or “being with” uncertainty is a basic feature of human existence (Babrow & Matthias, 2009).

More specific ways of coping with or managing a CHC may involve seeking information (e.g., from a partner, family members, health care providers, or media), setting goals (e.g., lose weight, reduce stress, quit smoking), and developing action plans for achieving those goals (see Leventhal, Halm, Horowitz, Leventhal, & Ozakinci, 2004). Berger (1997, 2008) posited that people are goal-directed. Goals are desired end-states (e.g., “maintain a good relationship with my partner”) that motivate action. Plans guide actions (e.g., “talk to my partner each day”) and are derived from either long-term memory or current information sources. Individuals use communication as one strategic plan to accomplish their goals (Berger, 1997, 2008). Couples who discuss their daily activities over breakfast each morning (i.e., a plan) may be accomplishing a goal of maintaining intimacy. When goals are interrupted, however, people may be forced to alter their plans or build contingencies into their plans (Berger, 1997, 2008). A couple’s established morning routine may be interrupted or changed when one partner is diagnosed with diabetes and must check a blood sugar level before breakfast each day. Moreover, perceived illness interference is likely to interrupt individuals’ ability to share health information with a partner. For example, a person with diabetes may be comfortable discussing general information (e.g., “I talk to my husband about things like diet and exercise”), but may be less confident talking about sensitive topics (e.g., “I don’t talk about my lack of interest in sex”). Although interference from one partner’s illness may render partners less able to talk to each other about the CHC, it may also be that they avoid specific topics out of

concern for the other (e.g., to appear positive, to avoid saying the wrong thing, or to provide protection from worry). Some couples engage in “protective buffering” in which they hide their concerns from their partner to avoid upset or conflict (Goldsmith, 2009; see also Coyne & Smith, 1991; Suls, Green, Rose, Lounsbury, & Gordon, 1997). Regardless of the reason for avoiding certain topics, patients’ and partners’ perceptions of an illness interfering in their lives are likely to influence their perceived ability to talk about the illness.

### **Communication Efficacy**

Communication efficacy concerns individuals’ confidence in their ability to communicate some kind or type of information (Afifi & Steuber, 2009; Afifi & Weiner, 2004; Checton & Greene, 2012) and has been empirically linked with willingness to directly discuss organ donation with family members (Afifi et al., 2006), willingness to reveal a secret (Afifi & Steuber, 2009); breadth, depth, and frequency of sharing heart-related information with a partner (Checton & Greene, 2012); and likelihood of disclosing health information (Greene et al., 2012).

Individuals disclose personal/private information to people with whom they are close, whom they can trust, and from whom they will receive support (Greene, 2009; Kelly, 2002; Petronio, 2002; Vangelisti, Caughlin & Timmerman, 2001). Disclosure serves a key role in the development and maintenance of relationships (Derlega, Metts, Petronio, & Margulies, 1993) and is associated with greater satisfaction for marital (Fincham & Bradbury, 1989; Finkenauer & Hazam, 2000) and cohabiting couples (Lippert & Prager, 2001). In health contexts, women with breast cancer who shared concerns, feelings, and problems with their husbands enjoyed better psychological adjustment (Lichtman, Taylor, & Wood, 1987) and enhanced social and emotional adjustment and self-esteem (Zemore & Shepel, 1989; see also Goldsmith, Miller, & Caughlin, 2007). For patients who recently experienced a heart attack, talking with a partner about lifestyle changes can be empowering in terms of taking control of one’s life (Goldsmith, Lindholm, & Bute, 2006). Further, low levels of disclosure for patients with gastrointestinal cancers predicted lower relationship functioning and psychological distress



(Porter, Keefe, Hurwitz & Faber, 2005). Additionally, a large body of research exists on the health benefits of disclosure (for a review, see Frattaroli, 2006).

Sharing information with a partner about a chronic health condition may facilitate coping with illness uncertainty, interference, and the complexities and unpredictability of managing the condition. Because positive benefits (e.g., physical, psychological, emotional) are associated with disclosing personal information (Frattaroli, 2006), it is expected that perceived ability to share health information with a partner will positively influence health condition management.

### Health Condition Management

Relationships play an important role in helping people maintain their physical and psychological well-being (Uchino, 2004). Being in a supportive relationship is one explanation for why marital partners live longer and enjoy better health than do unmarried individuals (Burman & Margolin, 1992; Kiecolt-Glaser & Newton, 2001). Spousal emotional support (perceived as emotionally responsive) was associated with better well-being for women with lupus (Fekete, Stephens, Mickelson, & Druley, 2007). Partner support (e.g., instrumental, emotional, or informational) is particularly important for people with coronary artery disease in terms of managing depression (Bosworth et al., 2000; Shen, McCreary, & Myers, 2003), promoting health (Franks, Wendorf, Gonzalez, & Ketterer, 2004; see also Goldsmith et al., 2006), and preventing accelerated disease progression (Wang, Mittleman, & Orth-Gomer, 2005).

Appraisals of illness uncertainty also influence how people evaluate and incorporate an illness into their lives (Babrow, 2007; Babrow & Matthias, 2009; Mishel, 1999; Mishel & Clayton, 2003). Reports from people who have transitioned through illness uncertainty, for example, reveal themes such as “new ways of being in the world,” “reevaluating what is worthwhile,” “redefining what is normal,” and “building new dreams” (Mishel & Clayton, 2003, pp. 38–39). Although numerous factors predict how people manage CHCs, less research has focused on whether patients and partners experience illness and management of one partner’s CHC differently.

### Hypothesized Model

Based on the preceding rationale, the following model is hypothesized (and tested for both patient and partner health condition management; see Figure 1). First, patients’ and partners’ perceptions of their own illness uncertainty (i.e., symptom, stigma, and prognosis) about the patient’s CHC are positively correlated (H1a, H1b). Both patients’ and partners’ perceptions of symptom, stigma, and prognosis uncertainty about the patient’s CHC negatively predict communication efficacy such that higher illness uncertainty predicts lower communication efficacy (2ab, 3ab, 4ab). Both patients’ and partners’ perceptions of the degree to which the patient’s CHC interferes in their everyday activities negatively predict communication efficacy such that higher illness interference predicts lower communication efficacy (H5ab). Additionally, communication efficacy positively predicts health condition management (H6ab). Finally, one research question is proposed: Does stigma, symptom, or prognosis uncertainty predict illness interference (RQ1)?

### Methods

#### Participants

Participants ( $N = 616$ ) were couples (in a committed relationship for at least six months), where *one* partner ( $n = 308$ ) has a nonvisible (physical or mental) CHC.<sup>3</sup> CHCs excluded all cancers and included the following: cardiovascular (32.8%), endocrine (25.3%), psychiatric

<sup>3</sup> Several factors guided our decision to recruit people with nonvisible chronic health conditions. First, this study examines the notion of (self) disclosure in which individuals intentionally or deliberately share personal or private information with another person that the individual would not necessarily know by looking at the person, such as a diagnosis (“I have diabetes”) (Greene, 2009) or a secret (“I was unfaithful and contracted hepatitis C”) (Afifi & Steuber, 2009; Kelly, 2002). Second, the notion underlying disclosure is that the other person does not have access to the information unless shared. That is, we specifically chose to focus on nonvisible health conditions that require sharing. Finally, although our participants are couples where one partner has a nonvisible chronic health condition (i.e., both partners *already* know about the CHC) we were interested in illness perception factors influencing partners’ communication about the CHC, as well as their perceptions of managing the health condition.

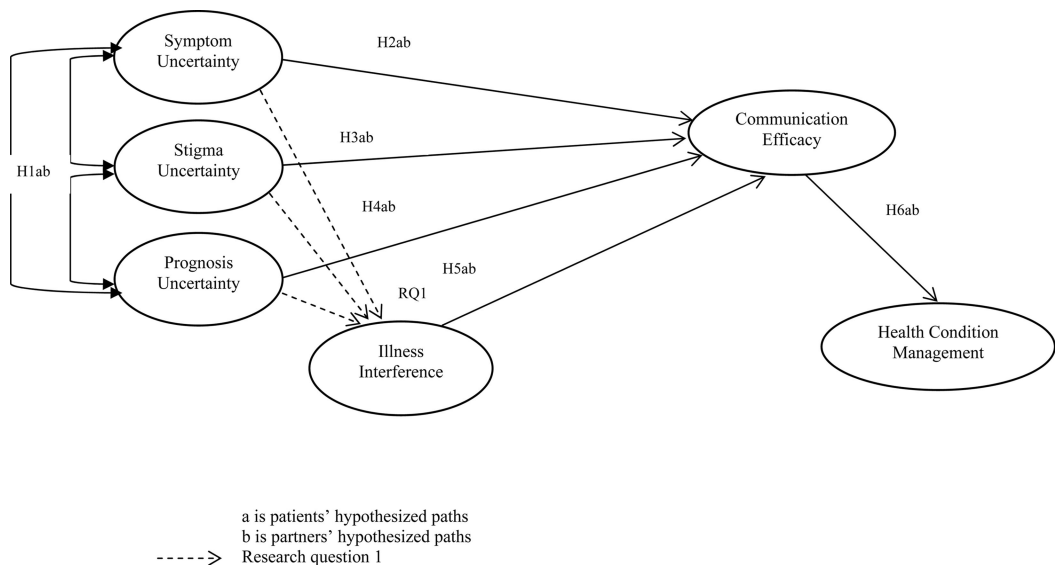


Figure 1. Hypothesized model.

(9.4%), rheumatologic (5.8%), digestive (5.8%), pulmonary (4.9%), neurologic (3.2%), hematologic (2.9%), and other (5.5%). Of partners with the diagnosed CHC (hereafter referred to as “patient”), 121 (39%) were women and 187 (61%) were men. Participants ranged in age from 28 to 87 years ( $M = 52.33$ ,  $SD = 10.79$ ; seven did not report age). Among participants who reported ethnicity ( $N = 600$ ), 70% were Caucasian, Asian (11.7%), African American (7%), Hispanic/Latino (5.7%), and other (3%). The time since the patient’s CHC diagnosis ranged from <1 year to 53 years ( $M = 11.22$ ,  $SD = 10.45$ ).

## Procedure

A network sampling technique was used. As part of the research component of a course, undergraduate researchers in an upper-level communication research methods class recruited couples to complete surveys individually and privately (e.g., in couples’ own homes/with partners separated). All undergraduate researchers received institutional review board certification, and the research protocol was approved by a university institutional review board. Researchers conducted an extensive training session with the undergraduate researchers. Undergraduate researchers explained

the purpose of the study to couples during pre-arranged face-to-face meetings. After signing consent forms, the couples *individually* completed a survey (~15 min), placed the survey in an envelope, sealed it, and returned the envelope. Undergraduate researchers returned the signed consent forms and sealed envelopes (separately) to the researchers. Finally, to verify consent to participate and to ensure participation of only those couples managing a CHC, participants were asked to provide their phone number for random callbacks. Researchers conducted verification callbacks (23% contact), and all data from one undergraduate researcher were deleted.

## Measures

Variables measured for both patients and partners included stigma, symptom, and prognosis uncertainty, illness interference, communication efficacy, and health condition management. Because of the limited prior quantitative measurement for most constructs, we developed measures grounded in prior research and theory. The measures were pilot-tested and underwent several revisions, and extensive analyses were conducted to ensure adequate psychometrics. We conducted exploratory factor analysis using principle com-

ponents analysis, varimax rotation to evaluate the dimensionality of the measures. Criteria for factor retention included eigenvalues  $>1$ , scree plot examination, and parallel analysis (Hayton, Allen, & Scarpella, 2004). Items with factor loadings below .6 were deleted; only factors with three or more items were retained. Composite scores were created by averaging responses to the individual items separately for patients and partners. Reliability was estimated by Cronbach's alpha.

**Illness uncertainty.** The degree of perceived stigma, symptom, and prognosis uncertainty regarding one partner's CHC was measured with 15 five-point Likert items created by the authors based on prior research (Greene, 2009; see also Knobloch & Solomon, 1999, 2002). Responses ranged from 1 (*very uncertain*) to 5 (*very certain*). All items were reverse-scored. The instructions began with the stem, "These questions ask you about how *certain* or *uncertain* you are about the following items. Please complete the following sentence: How certain am I about . . ."

*Symptom uncertainty* is the perceived degree of uncertainty regarding the visibility of symptoms of a CHC. Results indicated a single factor for patients (eigenvalue = 3.10, 62% var., five items loading above .59) and partners (eigenvalue = 3.10, 62% var., five items loading above .71). A sample item for patients included "whether or not people notice symptoms of my health condition," and a sample item for partners included "whether or not symptoms of my partner's health condition are noticeable." A higher score indicated more symptom uncertainty. Reliability was good for patients ( $\alpha = .85$ ,  $M = 2.40$ ,  $SD = .88$ ) and partners ( $\alpha = .85$ ,  $M = 2.35$ ,  $SD = .91$ ).

*Stigma uncertainty* is the perceived degree of uncertainty regarding the potential stigma or negative attention the patient is likely to experience as a result of a CHC. Results indicated a single factor for patients (eigenvalue = 3.06, 61% var., five items loading above .60) and partners (eigenvalue = 3.40, 68% var., five items loading above .63). A sample item for patients included "what others think about my health condition," and a sample item for partners included "whether or not people view my partner's health condition negatively." A higher score indicated more stigma uncertainty. Reliability was good for patients ( $\alpha = .84$ ,

$M = 2.91$ ,  $SD = .88$ ) and partners ( $\alpha = .88$ ,  $M = 2.76$ ,  $SD = .99$ ).

*Prognosis uncertainty* is the perceived degree of uncertainty regarding a patient's CHC prognosis. Results indicated a single factor for patients (eigenvalue = 2.93, 59% var., five items loading above .60) and partners (eigenvalue = 3.04, 61% var., five items loading above .69). A sample item for patients included "my prognosis with this health condition," and a sample item for partners included "my partner's future with this health condition." A higher score indicated more prognosis uncertainty. Reliability was good for patients ( $\alpha = .82$ ,  $M = 2.91$ ,  $SD = .88$ ) and partners ( $\alpha = .85$ ,  $M = 2.76$ ,  $SD = .99$ ).

**Illness interference.** The extent to which patients and partners perceive that the patient's CHC interferes with everyday activities was measured with three 5-point Likert items created by the authors based on prior research on interference from a partner in a relationship (Solomon & Knobloch, 2004). Responses ranged from 1 (*strongly disagree*) to 5 (*strongly agree*). Results indicated a single factor for patients (eigenvalue = 2.26, 75% var., three items loading above .85) and partners (eigenvalue = 1.99, 67% var., three items loading above .71). A sample item for patients included "My health condition interferes with the things I like to do every day," and a sample item for partners included "His or her health condition does not get in the way of my day-to-day activities" (R). Higher scores indicated more illness interference in everyday activities. Reliability was good for patients ( $\alpha = .84$ ,  $M = 2.62$ ,  $SD = 1.11$ ) and partners ( $\alpha = .74$ ,  $M = 2.05$ ,  $SD = .89$ ).

**Communication efficacy.** The extent to which patients and partners perceive the ability to share information with each other about the patient's CHC was measured with five 5-point Likert items adapted from literature on revealing secrets (Afifi & Steuber, 2009; Kelly, 2002) and disclosing a health condition (Checton & Greene, 2012; Greene et al., 2012). Responses ranged from 1 (*strongly disagree*) to 5 (*strongly agree*). Results indicated a single factor for patients (eigenvalue = 2.93, 59% var., all items loading above .70 after discarding one item) and partners (eigenvalue = 3.26, 66% var., all items loading above .80 after discarding one item). A sample item for patients included "I am confi-

dent that I can share information about my health condition with my partner when I want to," and a sample item for partners included "I have difficulty sharing information about my partner's health condition with him/her" (R). Higher scores indicated more communication efficacy. Reliability was good for patients ( $\alpha = .81$ ,  $M = 4.40$ ,  $SD = .58$ ) and partners ( $\alpha = .86$ ,  $M = 4.26$ ,  $SD = .63$ ).

**Health condition management.** The extent to which patients and partners perceive that they are managing the patient's CHC was measured with four 5-point Likert items created by the authors with responses ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Results indicated a single factor for patients (eigenvalue = 2.39, 58% var., all items loading above .72 after discarding one item) and partners (eigenvalue = 2.91, 73% var., all items loading above .82 after discarding one item). A sample item for patients included "I am handling my health condition," and a sample item for partners included "I can cope with his or her health condition." Higher scores indicated better health condition management. Reliability was good for patients ( $\alpha = .74$ ,  $M = 3.96$ ,  $SD = .72$ ) and partners ( $\alpha = .87$ ,  $M = 3.87$ ,  $SD = .93$ ).

## Results

Data were screened for normality and outliers, and no transformations were needed nor were any data removed. Table 1 presents bivariate correlations. Independent-samples  $t$  tests were conducted to evaluate differences in patients' and partners' perspectives for study variables.<sup>4</sup> One-way ANOVAs were conducted to evaluate differences in study variables by health condition.<sup>5</sup> Gender differences were examined in a multilevel model.<sup>6</sup> Next, we tested hypotheses using maximum likelihood structural equation modeling (AMOS 18). The strategy accounts for measurement error and makes it possible to assess hypothesized associations. Three goodness-of-fit indices were used to evaluate the models.  $\chi^2/df$  adjusts the  $\chi^2$  statistic for sample size (Kline, 1998). Comparative fitness index (CFI) calculates the ratio of the noncentrality parameter estimate of the hypothesized model to the noncentrality parameter estimate of a baseline model (Bentler, 1990). Root mean square error of approximation (RMSEA) ac-

counts for errors of approximation in the population (Browne & Cudeck, 1993). It was determined that the model fit the data if  $\chi^2/df$  was less than 3, CFI was .90 or greater, and RMSEA was less than .10 (Browne & Cudeck, 1993; Kline, 1998).

**Model for patients.** The first step required calculation of the error variance ( $1 - \alpha$ ) ( $\sigma^2$ ) to account for measurement error (Stephenson & Holbert, 2003). Initial results indicated the hypothesized model (see Figure 1) did not adequately fit the data,  $\chi^2/df = 11.07$ ,  $p < .001$ ;

<sup>4</sup> We conducted  $t$  tests to explore differences in patients and partners. Results of independent-samples  $t$  tests revealed a significant difference between patients and partners on illness interference, such that patients perceived more illness interference in everyday life ( $M = 2.62$ ,  $SD = 1.11$ ) than did partners,  $M = 2.05$ ,  $SD = .89$ ;  $t(289) = 6.99$ ,  $p < .001$ , and communication efficacy, such that patients perceived more communication efficacy ( $M = 4.40$ ,  $SD = .58$ ) than did partners,  $M = 4.26$ ,  $SD = .63$ ;  $t(289) = 2.87$ ,  $p < .01$ . We also wanted to examine demographic differences in study variables (i.e., stigma, prognosis, and symptom uncertainty, illness interference, communication efficacy, and health condition management) for patients and analyzed by time since diagnosis ( $\leq 9$  years and  $> 9$  years), relationship length ( $\leq 25$  years and  $> 25$  years), and gender using median splits for continuous variables. Results indicated that patients diagnosed  $\geq 9$  years ago reported significantly better management of their health condition ( $M = 4.08$ ,  $SD = .66$ ) than did patients diagnosed  $< 9$  years,  $M = 3.84$ ,  $SD = .74$ ;  $t(285) = -2.88$ ,  $p < .01$ . Thus, there were no systematic differences in study variables by demographic variables. Due to the number of tests conducted, modified Bonferroni adjustments were used.

<sup>5</sup> One-way ANOVAs were conducted to test for mean differences in health condition for study variables. One significant effect was found for *illness interference* for both patients,  $F(6, 268) = 7.86$ ,  $p < .01$ ,  $\eta^2 = 0.15$ , and partners,  $F(6, 267) = 2.22$ ,  $p < .05$ ,  $\eta^2 = 0.05$ . Post hoc tests for patients revealed that those with rheumatologic health conditions ( $n = 18$ ;  $M = 3.83$ ,  $SD = 1.15$ ) and mental health conditions ( $n = 28$ ;  $M = 3.17$ ,  $SD = 1.03$ ) reported significantly higher illness interference than did patients with heart-related ( $n = 101$ ;  $M = 2.16$ ,  $SD = 1.04$ ), pulmonary ( $n = 15$ ;  $M = 2.63$ ,  $SD = 1.25$ ), endocrine ( $n = 78$ ;  $M = 2.63$ ,  $SD = 1.05$ ), and digestive ( $n = 18$ ;  $M = 2.44$ ,  $SD = 1.33$ ) disorders. Post hoc tests for partners revealed no significant mean differences in illness interference for the health conditions. These two differences overall were less than would be expected by chance, and data for health conditions were collapsed for subsequent analyses.

<sup>6</sup> Data for men ( $n = 288$ ) and women ( $n = 302$ ) in the study were examined in a multilevel model. The  $\chi^2$  difference statistic showed no significant difference between the unconstrained model and the equal-constrained model; therefore the model has measurement invariance across both males and females,  $\chi^2(12) = 30.641$ ,  $p < .01$ ;  $\chi^2/df = 2.53$ ,  $GFI = .98$ ,  $CFI = .96$ ,  $RMSEA = .05$ .



Table 1  
Bivariate Zero-Order Correlation Matrix for Study Variables

	1	2	3	4	5	6	7	8	9	10	11	12
1. StigUncert-Pt	1.00											
2. ProgUncert-Pt	.35**	1.00										
3. SymUncert-Pt	.51**	.36**	1.00									
4. Interfer-Pt	.13	.20**	.14	1.00								
5. CommEff-Pt	-.18**	-.09	-.30**	-.27**	1.00							
6. Manage-Pt	-.13	-.15**	-.16**	-.49**	.33**	1.00						
7. StigUncert-Prt	.19**	.14	.10	.06	.03	-.03	1.00					
8. ProgUncert-Prt	.09	.14	.15**	.15**	-.06	-.08	.25**	1.00				
9. SymUncert-Prt	.14**	.11	.16**	.15	-.05	-.08	.53**	.35**	1.00			
10. Interfer-Prt	.06	.07	.12	.35**	-.15**	-.22**	-.24**	.17**	.12	1.00		
11. CommEff-Prt	-.10	-.07	-.12	-.22**	.27**	.19**	-.11	-.17**	-.12	-.38**	1.00	
12. Manage-Prt	-.03	-.01	-.03	-.08	.12	.06	-.06	-.08	-.07	-.25	.28**	1.00

Note. StigUncert-Pt = Patient stigma uncertainty; ProgUncert-Pt = patient prognosis uncertainty; SymUncert-Pt = patient symptom uncertainty; Interfer-Pt = patient illness interference; CommEff-Pt = patient communication efficacy; Manage-Pt = patient health condition management; StigUncert-Prt = Partner stigma uncertainty; ProgUncert-Prt = partner prognosis uncertainty; SymUncert-Prt = partner symptom uncertainty; Interfer-Prt = partner illness interference; CommEff-Prt = partner communication efficacy; Manage-Prt = partner health condition management.

\*\*  $p < .01$ , two-tailed.

$CFI = .75$ ,  $RMSEA = .18$ . First, a path was added to the model based on the magnitude of the modification indices and theory, such that suggested paths with the largest values were added first. The addition of a path from illness interference to health condition management resulted in a model that adequately fit the data,  $\chi^2/df = 2.64$ ,  $p = .02$ ;  $CFI = .97$ ,  $RMSEA = .07$ . As predicted in H1a, stigma, symptom, and prognosis uncertainty were positively correlated (see Figure 2). H2a was supported as symptom uncertainty negatively predicted communication efficacy such that the more uncertain patients were about visibility of their symptoms the less perceived communication efficacy. H3a and H4a were not supported because stigma uncertainty and prognosis uncertainty were not significantly related to communication efficacy. Illness interference negatively predicted communication efficacy, supporting H5, such that the more an illness interfered in a patient's life, the less perceived ability to talk to a partner about the CHC. As H6a hypothesized, communication efficacy significantly predicted health condition management, because a greater ability to share information with a partner about one's CHC predicted better health condition management.

**Model for partners.** Initial results indicated the hypothesized model (see Figure 1) did not adequately fit the data,  $\chi^2/df = 3.37$ ,  $p = .001$ ;  $CFI = .93$ ,  $RMSEA = .09$ . The addition of

a path from prognosis uncertainty to illness interference resulted in a model that adequately fit the data,  $\chi^2/df = 1.89$ ,  $p = .08$ ;  $CFI = .98$ ,  $RMSEA = .06$ . As predicted in H1b, stigma, symptom, and prognosis uncertainty were positively correlated (see Figure 2). H2b, H3b, and H4b were not supported because symptom, stigma, and prognosis uncertainty did not significantly predict communication efficacy. However, illness interference significantly predicted communication efficacy, supporting H5b in that the more a patient's illness interfered in the partner's life, the less perceived ability the patient had to talk to the partner about the health condition. As hypothesized, in H6b, communication efficacy significantly predicted health condition management such that the greater ability to share information with a partner about the patient's CHC predicted better management of the health condition.

### Discussion

Rather than focusing on how patients and partners manage chronic illness, per se, the present study explores how patients and partners experience illness uncertainty and illness interference in the management of one partner's CHC. The findings suggest that there are significant differences in how patients and partners experience illness uncertainty and

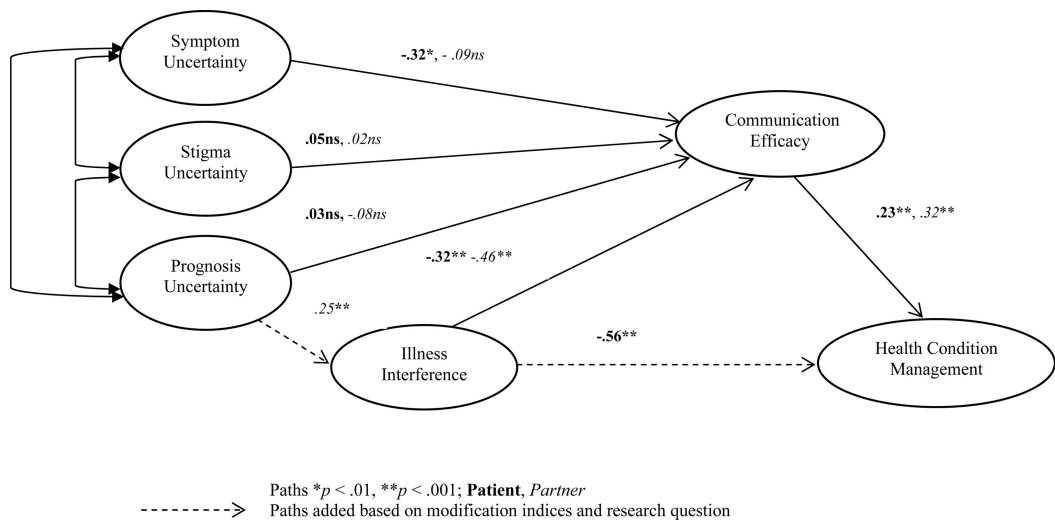


Figure 2. Results for patients and partners.

illness interference and how appraisals of illness uncertainty and illness interference influence communication efficacy and health condition management.

### Similarities Between Patients and Partners

There are several important similarities between the models. First, in terms of illness uncertainty only *prognosis* and *symptom* uncertainty (not *stigma* uncertainty) played significant roles in patients' and partners' perceptions of managing one partner's CHC. However, the ways that prognosis and symptom uncertainty influenced their health condition management differed. Theories of uncertainty in illness support the findings such that people evaluate their illness experiences (Babrow, 2007; Mishel, 1999) and manage myriad types of illness uncertainty in various ways (Brashers, 2007).

Another similarity in patients' and partners' illness experiences is that *illness interference* was negatively associated with communication efficacy for both patients and partners. That is, both patients' and partners' perceptions that the patient's CHC interfered in their lives was negatively associated with their perceived ability to share information with their partner about the health condition. Berger's (1997, 2008) planning theory of communication provides support for this finding, as the theory asserts that people

use language to accomplish goals. When their goals are interrupted (e.g., an illness interferes) people may be forced to alter their plans for achieving goals. Thus, patients and partners may perceive less ability to talk about certain issues such as the patient's prognosis. Avoiding sensitive topics such as death, dying, and infidelity in relationships is common, however, and people have legitimate reasons for avoiding them (Affi et al., 2007; Dailey & Palomares, 2004; Greene et al., 2006).

Finally, the paths from communication efficacy to health condition management were consistent for both patients and partners. Patients and partners who perceived the ability to share information with one another about the patient's CHC were more likely to report that they were managing the health condition. This finding is important as prior research indicates that perceived ability to manage a chronic illness results in better health outcomes (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Leventhal Brissette, & Leventhal, 2003; Leventhal et al., 2004). Thus, it is important to focus on patients feeling confident about their ability to share and communicate to improve overall health management.

### Differences Between Patients and Partners

How people respond to uncertainty is shaped by appraisals and emotional reactions to the experience (Babrow, 2007; Brashers, 2007;

Mishel, 1999). Indeed, several key differences are noted between patients' and partners' illness experiences. First, the more uncertain partners were about the patient's prognosis, the more partners perceived that the patient's CHC interfered in their lives (RQ1). Illness interference, in turn, negatively influenced partners' communication efficacy. In other words, prognosis uncertainty for partners preceded illness interference sequentially, whereas for patients, illness interference acted independently.

Second, symptom uncertainty was a significant negative predictor of communication efficacy for patients, but not partners. That is, the more uncertain patients were regarding symptom visibility (e.g., "Do I look like a diabetic?" or "Do others notice symptoms of my illness?"), the less perceived ability to share information with a partner about their CHC. The finding is consistent with the notion that illness uncertainty influences communication such that people perceive the ability to talk about certain topics (e.g., treatment decisions), but may avoid discussing sensitive issues (Goldsmith, 2009; Goldsmith et al., 2007). It is interesting to note that although we recruited individuals with *non-visible* health conditions (and their partners), the findings suggest that patients are concerned regarding visibility of symptoms. In turn, patients' concerns played a role in their communication efficacy.

A third difference in the models is that in addition to predicting communication efficacy, illness interference for patients, unlike partners, directly predicted management of the patient's CHC. That is, the more patients perceived that their CHC interfered in their lives, the lower their perceived management of the health condition, regardless of their communication efficacy. The intrusive nature of a chronic illness disrupts people's lives, activities, and interests (Devins, 2009; Townsend, Wyck, & Hunt, 2006), and therefore it is not surprising that greater illness interference would render patients less confident about managing their CHC. That illness interference was not a significant predictor of *partners'* perceptions of their partner managing the health condition is an interesting finding and warrants continued research. Gender differences in health condition management may be one avenue to explore. In the current study, partners of patients with a CHC were predominantly women. Because women

have traditionally been the primary caregivers in their families, they may be less likely to perceive illness interference as a factor in managing a partner's CHC. This explanation should be explored further.

### Practical Implications

The results of this study have practical implications for both patients and partners in terms of managing a CHC and managing their relationship. Although the notion that "we're in this together," can be an empowering perspective for couples managing chronic illness (Goldsmith, 2009; Kayser, Watson, & Andrade, 2007; Rohrbaugh, Mehl, Shoham, Reilly, & Ewy, 2008), patients and partners may diverge in the way they think about the illness (Heijmans, Ridder, & Bensing, 1999). Our findings suggest that, although a CHC concerns both partners simultaneously, patients and partners are experiencing the impact of one partner's CHC differently in their relationships, and the features of individuals' illness experiences, including prognosis and symptom uncertainty and illness interference, may be potentially more helpful or damaging. For example, concerns about prognosis negatively influenced partners' perceptions, but did not impact patients' perceptions of the CHC interfering in their lives. An assumption of dyadic coping is that both partners should be motivated to help one another manage stressful situations and to engage in a joint effort to manage those stressors (Bodenmann, 2005). In order to help each other manage a CHC, however, both partners must be aware of perceived differences in their illness experiences.

Although patients and partners appraised illness uncertainty and illness interference differently, our findings also indicated that perceived ability to talk to a partner about a CHC was related to perceptions of better health condition management for both patients and partners. Thus, communication efficacy seems to be a key feature in perceptions of managing a CHC. Moreover, prior research indicates that relational quality and partner support are significant predictors of disclosure efficacy (Greene et al., 2012) and communication efficacy (Checton & Greene, 2012). Whether people discuss their concerns openly or avoid certain topics, being in a supportive relationship with perceived abil-

ity to share information may allow partners to better manage not only their relationship, but also the CHC.

Taken together the findings of the current study suggest that researchers and health care providers need to direct more attention to the quality of patients' and partners' relationships and to treat different aspects of health management for patients than for partners. A lack of congruence in disease beliefs is one of the major relationship characteristics associated with chronic disease processes and outcomes (Fisher, 2006). Research on the features of individuals' illness experiences and how those experiences influence communication and management of a CHC may be translated into couple-based interventions that maximize the support partners can provide for each other. Fekete et al. (2007) highlighted the importance of perceived emotional responsiveness as part of the social support process, especially for patients and partners coping with a chronic illness. It is not always easy for couples to support each other. Understanding how partners' illness experiences differ may be one step toward maximizing support, communication efficacy, and better management of CHCs and relationships.

### **Strengths, Limitations, and Future Research**

Fisher (2006) noted the absence of studies addressing adults with chronic disease and their families. This study addresses that gap by exploring factors influencing how couples manage a CHC. A strength of this study is quantitative measurement of both patients' and partners' chronic illness experiences. Specifically, our measures of symptom, stigma, and prognosis uncertainty and illness interference contribute to understanding how these features relate to people's management of a CHC. Continued research should strive to improve these quantitative measures. Surprisingly, stigma uncertainty did not play a significant role in the current study. The belief that some CHCs are attributable to the patient's behaviors is quite powerful. For example, a patient with lung cancer (or COPD) may feel stigmatized by family and friends regardless of smoking history (Caughlin et al., 2011). Future research should explore perceptions of stigma in the management of various CHCs, such as the relationship between

obesity and diabetes or cardiovascular diseases. Additional strengths are sample diversity in terms of types of CHCs and that the sample proportions approximate the most prevalent chronic illnesses (CDC, 2011a).<sup>7</sup> We recognize however, that there are contextual constraints of specific illness conditions (e.g., sudden onset vs. progressively declining; constant vs. relapsing) that likely influence people's perceptions of illness uncertainty and interference that should be explored in future research (cf. the developmental-contextual model of Berg & Upchurch, 2007).

The predominantly Caucasian sample limits generalization to other ethnic groups. There are likely differences in how various cultural groups experience chronic illness and its management (Halm et al., 2006). Cultures also differ in how uncertainty is conceived and expressed. For example, metaphors regarding uncertainty typically have a negative connotation (Smithson, 2008), with Western culture giving less recognition to the positive aspects of uncertainty. Even the notion of "managing uncertainty" is a Westernized concept implying control (Smithson, 2008; see also Babrow & Matthias, 2009; Brashers, 2007). Cultural norms also influence disclosure and intimate conversations in various types of relationships such as with strangers, close friends, and romantic partners (Derlega, Winstead, & Greene, 2008). The concepts of total sharing or individual privacy are deeply rooted in cultural ideals about groups and relationships. Future research should strive for more culturally diverse samples in which to explore illness experiences, communication, and health condition management.

Focusing on a relational perspective (e.g., *we*) is important for partners managing a CHC. However, continued research regarding how patients and partners *individually* experience chronic illness is also necessary because patients' and partners' appraisals have implications for how they individually manage not only the CHC but also their relationship. Such research may also inform health practitioners in developing evidence-based interventions ad-

<sup>7</sup> Participants reported predominantly cardiovascular (32.8%) and endocrine (e.g., diabetes) (25.3%) illness conditions.

dressing differences in illness perceptions for the many people managing both chronic illness and chronic uncertainty, including couples, extended family members, and other social network members.

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