

ARTICLE

Out of the shadow: Partners managing illness together

Alexandra C.H. Nowakowski¹ | J.E. Sumerau²¹Florida State University College of Medicine²University of Tampa**Correspondence**

J. E. Sumerau, Department of Government,
History and Sociology, University of Tampa,
401 West Kennedy Boulevard, Tampa, FL
33606, USA.

Email: jsumerau@ut.edu

Abstract

In this manuscript, we critically review existing studies of managing chronic illness within the context of intimate relationships to reveal future paths for this line of inquiry. Building on the combination of insights from previous studies and our own collaborative experiences managing chronic conditions together as relationship partners to one another, we outline some ways that intersectional analyses may broaden contemporary understandings of chronic illness management, and the ways people accomplish such management individually and collectively within varied concrete situations and social locations. Further, we reveal gaps in existing knowledge concerning, for example, sexual, gender, and relationship diversity and propose some ways that narrative and experience-based analyses may begin to close these gaps. In conclusion, we outline a series of concrete directions for furthering study of chronic illness management within intimate relationships.

1 | INTRODUCTION

Chronic health conditions are widespread around the globe, with over 117 million people affected in the United States alone (Centers for Disease Control and Prevention, 2015). People with at least one diagnosed chronic condition account for about 47 percent of all U.S. adults (Centers for Disease Control and Prevention, 2015). This implies that nearly half of all U.S. adults are likely to regularly be doing at least some illness management. The term “illness management” refers to a process of adapting to and coping with the consequences of chronic illness in one or more domains of health (Charmaz, 2000). Successful illness management often instills a perception of situated normalcy in which people’s expectations for daily life match their actual experiences of same (Charmaz, 2000). Likewise, successful illness management often foments a sense of confidence in people’s ability to handle future instrumental and emotional challenges stemming from their chronic conditions. Within the context of intimate relationships, this process may involve elements of collaboration, individualism, and even competition. However, few published studies have explored the specific dynamics of illness management between intimate partners.

In this article, we approach this gap in existing literature as an opportunity for developing innovative and intersectional analyses (see Choo & Ferree, 2010) of chronic conditions. To this end, we synthesize prior research on people with chronic conditions forming and negotiating intimate relationships while also managing their health. We define intimate relationships as partnerships between at least two people that include a romantic or sexual component.

Within this manuscript we focus most closely on people who are in long-term romantic partnerships, including marriages. These relationships may or may not include sexual intimacy, either in an absolute sense or at different points in time. Pursuant to this caveat, we note that there are also other valid definitions of “intimacy” and that intimacy can exist in other types of relationships that never include romance or sex. In this article, however, we focus on research on long-term relationships with a romantic or sexual component though we note here that research exploring other types of intimate arrangements would be a useful advance in this literature as well.

In examining prior scholarship directly engaging the experiences of people in intimate partnerships who live with chronic conditions, we engage our unique standpoint as scholars with multiple chronic conditions who collaborate both within and beyond research, sharing not only a variety of inquiry and writing projects but also a long-term intimate partnership. We both manage multiple physical and mental health conditions and engage one another consciously in these efforts. The first author has an autoimmune disease of the mucous membranes and the second author has a connective tissue disease exacerbated by traumatic injuries. Both authors live with chronic pain and functional limitations. Both authors also have posttraumatic stress disorder with a history of dissociation (first author) or depersonalization (second author).

We illuminate key gaps in previous inquiry that recommend new approaches to understanding how chronic illness shapes the experiences of partners who both understand illness management on a firsthand level. Although their specific diagnoses may differ, we see common threads in available research to suggest that intimate partners with very different conditions may still share certain core experiences. Scholarship on embodied health of Brown et al. (2004) illustrates these dynamics in general context. Further, other scholars (e.g., August and Sorkin (2010); Manne and Zautra (1990)) have illustrated these dynamics specifically for marital partners, albeit not within an explicitly collaboration-focused framework.

We also pay close attention to the potential for shared experience of health disparities within partnerships where illness represents one of many forms of social marginalization (Grollman, 2012). Within this framework, sharing of illness experiences engages intersectional discussion of experiences with discrimination and oppression. The creation and active cultivation of “safe spaces” (Grollman, 2012) for coping with multiple forms of marginalization—both those directly stemming from chronic illness and those that flow from other origins—may prove key to understanding how intersectionally oppressed partners with chronic conditions can pursue and achieve individual and shared health goals through conscious collaboration. Our understanding of such opportunities for collaboration and shared success is likewise informed by our unique experiences as gender nonbinary scholars in a sexuality-diverse intimate partnership who negotiate complex constellations of physical morbidity, functional limitation, and mental illness.

Currently, the limited body of research addressing illness management in relationships between two or more people with chronic conditions generally reflects more dominant social norms than it challenges. Specifically, we note a dearth of research on intimate partners with chronic conditions who identify as lesbian, gay, bisexual, and asexual; transgender or genderqueer; polyamorous or otherwise nonmonogamous; and any racial, ethnic, or cultural group not classified as European or European-American (see also Ivankovich, Leighliter, & Douglas, 2013). In reflecting on experiences that inform the unique standpoint of our own scholarship, we readily see how engagement of these intersectional perspectives may enhance understanding of how partners can achieve fruitful coping through mutual support in collaborative context. For example, both authors of this manuscript are sexual-abuse survivors who have experienced rape in contexts explicitly connected to gender nonconformity. We have engaged our resultant empathy for one another's experiences in creating safe spaces not only for explicit discussion of abuse history but also for broader support in showing vulnerability and accepting help with a variety of tasks in times of especially compromised physical health.

By drawing attention to the limitations of existing illness management studies, we do not seek to criticize the perspectives or motivations of prior researchers. Rather, we seek to champion their work and make specific recommendations for its application in future social science inquiry, both within and outside of academia. We thus conclude by highlighting opportunities for other scholars to build on this excellent foundation of knowledge. In affirmation of academic environments and social norms that more fully reflect the varied and intersectional perspectives of different

people and communities, we call for detailed inquiry on the nuances of intimate partners caring for one another across varied social locations and medical histories.

2 | ILLNESS MANAGEMENT WITHIN INTIMATE RELATIONSHIPS

Literature on illness management, a tradition extending back to the foundational years of sociology as a discipline, is generally well-developed. This body of research includes detailed explorations of how people with chronic conditions negotiate treatment and symptoms, construct and refine identities, adapt to functional challenges in daily life, and experience social activities and relationships.

Scholars from a variety of disciplines have explored how people negotiate social interactions and trajectories when one participant in a given relationship lives with a chronic condition. Much of this research has focused on intimate partnerships in which one person has a persistent illness. Yet, despite advancements made in the late 1990s and early 2000s toward understanding of illness management within intimate partnerships as a general construct (Kuyper & Wester, 1998), research remains limited on relationships in which more than one partner has a chronic condition. In this article, we examine existing illness management studies to reveal pathways for understanding collaborative illness management in varied social contexts. By collaborative illness management, we mean the ways partners may consciously work together to manage separate and shared illness experience in a context where both simultaneously occupy caregiver and patient roles at different times over the life course and in relation to one another.

Our interest in exploring illness management among intimate partners who share the experience of living with chronic illness stems not only from our history of working with literature on the experience of chronicity (Nowakowski & Sumerau, 2015) but also from personal experience of such a relationship. We are both interdisciplinary social scientists who study health and illness as a means of helping to illuminate and ease inequalities that impact people who live with chronic conditions. We are also life partners who engage in both collaborative and independent processes of illness management on a daily basis and increasingly leverage these processes consciously and seek to improve upon them through engagement of experientially acquired data and evidence from the literature.

Our explorations of research on illness management within intimate relationships thus reflect not only our professional experiences working with this literature but also our firsthand ability to evaluate and question core concepts from the standpoint of lived experience (Nowakowski, Graves, & Sumerau, 2016; Nowakowski, Sumerau, & Mathers, 2016a, b). We thus draw from our individual and collective standpoints to examine existing interdisciplinary research on illness management within intimate relationships and outline priorities for extending this research in innovative and intersectional directions. Although this manuscript focuses closely on people in long-term intimate partnerships, the benefits of expanding and diversifying research on collaborative illness management may yield valuable and actionable information for people in a variety of different types of relationships who live with chronic conditions (see also Nowakowski et al., 2016a).

3 | PARTNERS MANAGING ILLNESS TOGETHER

Early research on chronic illness management within intimate partnerships tended to focus on relationships between people with diagnosed conditions and people without them. Typically, these studies focused on married couples, one of whom takes on a caregiver role after the other is diagnosed with a chronic disease. Later portions of the life course have traditionally been a focus for this research, which began with explorations of caregiver burden (Pearlin, Mullan, Semple, & Skaff, 1990) and associated role captivity (Aneshensel, Pearlin, & Schuler, 1993). Later works focused on intersectional dynamics of later-life caregiving, such as gender disparities in burden (Kramer & Kipnis, 1995), performance and narration of gender identities (Calasanti & King, 2007), and racial differences in providing care (Fredman, Daly, & Lazur, 1995). Climbing rates of chronic disease in younger adults also led scholars to look at earlier stages of development.

Kuyper and Wester's (1998) detailed exploration of the experiences of intimate partners broadened research on partner experiences to an age-diverse group of adults in general practice settings. Their interviews with Dutch patients and their partners showed how supporting a person managing chronic illness can affect the daily life of an intimate partner. These impacts may come in the form of challenges, rewards, or nuanced combinations of the two. In the years following publication of their study, numerous others engaged the concept of partners living "in the shadow" of another person's illness (Edwards & Ruettinger, 2002; Eriksson & Svedlund, 2006; Maughan, 2003; Maughan, Heyman, & Matthews, 2002; Paulson, Norberg, & Söderberg, 2003).

Examining these studies reveals support for noted patterns related to marital status and age. Alongside these patterns, however, we also find that most people associated with these studies of illness management within intimate relationships occupied a number of privileged social locations. Most study participants, for example, were mostly or entirely identified as White. Participants also all had at least a high school education, but in most cases, they had 2- or 4-year college degrees. All participants spoke the language in which the research was conducted proficiently, and all were born in the country where the corresponding study was conducted. Information about participant income, wealth, and overall class background, however, was often limited. Even so, we did note that many of the participants in such studies had at least a lengthy history of consistent paid employment, and in the case of caregivers, frequently held paid positions at the time of data collection.

By contrast, we found no studies explicitly focused on illness experiences within intimate relationships for a diverse array of marginalized social groups. These include but are not limited to people in same-sex, mixed orientation, or multi-person partnerships; people who identify as trans or gender nonbinary; people of intersex anatomy or body chemistry; people identifying as asexual or celibate; people who have immigrated to or regularly migrate within their country of residence; people with disabilities extrinsic to other chronic conditions; people of low-income and medically underserved status; or people who have experienced physical or cognitive trauma. We also found only one study explicitly emphasizing experiences of racial and ethnic minority groups caring for partners (Fredman et al., 1995). We see attention to the experiences of these groups as important opportunities to expand and refine a literature that overall remains relatively homogeneous with respect to its study populations. However, we note that the lack of explicit attention to marginalized groups does not mean that no members of these groups participated in the studies here reviewed (see also Nowakowski et al., 2016b).

Within partnerships composed of people with mostly dominant social statuses or otherwise, we found little research explicitly exploring collaborative management of chronic conditions in cases where more than one person lives with illness. Specifically, this literature tends to focus on what one healthy partner does to help support a sick partner rather than the ways two or more partners with chronic conditions work to support one another over time while each occupying both caretaker and patient locations within the relationship (Nowakowski et al., 2016). We did find several studies exploring individual and even shared experiences of illness among partners living with chronic conditions, as noted in subsequent paragraphs. Yet, even these studies generally did not delve into the processes used by partners to help each other cope or into the conscious contemplation and refining of same. Much more common were studies of relationships where only one person had a chronic condition or noted having one during the course of the research. In these studies, attention to processes and the conscious contemplation thereof was more common.

Indeed, these studies have tremendous value on their own and as foundations for scholarship on collaborative illness management. The studies we reviewed frequently highlighted the importance of focusing on the experiences and insights of all partners. White and Grenyer (1999), for example, used a biopsychosocial perspective to explore the lives of people receiving kidney dialysis and their partners, focusing both on the illness experiences of those in the patient role and on the instrumental and emotional work done by those in the caregiver role. Studies like this one helped to lay groundwork for research explicitly focused on the experiences of partners with chronic conditions caring for one another—people who occupy the roles of patient and caregiver simultaneously.

Some of the studies we reviewed also offer nested information on the experiences of couples who both live with chronic conditions. For example, Manne and Zautra's (1990) study of women with arthritis and their husbands

includes several couples in which the male spouse also had arthritis at the time. Findings suggest that for couples who share a common diagnosis, the process of illness management could become a bonding experience. Some of the couples in which only one partner had arthritis echoed these sentiments but noted that feelings of closeness came primarily from shared extrinsic moments and actions, rather than shared intrinsic experiences with arthritis. Understanding of how relationship partners may engage in conscious processes of illness management together as a collaborative process thus remains mostly absent at present.

We see these gaps as especially worthy of exploration because they offer potential for gaining unique insight into the dynamics of social support (Thoits, 2011) as a valuable resource for illness management (Gallant, 2003). Revenson (1994), for example, examines the role of social support for married couples coping with chronic illness, concluding that social support is both helpful for people with persistent conditions in doing effective self-management and potentially more difficult for a spouse to provide as their partner's symptoms worsen. Yet, this study once again focuses only on legally married couples, which given its publication in the mid 1990s meant different-sex couples in most parts of the world, including the United States. Likewise, Revenson (1994) focuses on relationships with only one chronically ill partner, explicitly applying a "healthy spouse/sick spouse" dichotomy to explain how social support can flow and evolve in marriages affected by persistent illness.

This binary paradigm certainly has utility in explaining broader social responses to illness and the tendency of people without chronic conditions to assume falsely that people who experience illness cannot also experience wellness (Nowakowski et al., 2016a). Yet, by extension, it also offers insight into one of the key deficiencies in the relatively homogeneous—albeit methodologically strong and informationally rich—literature on illness management within intimate relationships. Specifically, it echoes the framing of illness as deviance (see Cockerham, 2007) that must itself be performed in specific ways. While not specific to chronically ill people in relationships with others who have persistent health challenges, literature on self-presentation among people with chronic conditions suggests that sanctions can result from not performing illness according to normative expectations (Conrad & Schneider, 2010). Violating established norms of the sick role (Varul, 2010) can lead others to withhold social support (Bury, 2000) and engage in microaggressions (Charmaz, 2000). Thomas (2007) notes that these sanctions are often especially strong for otherwise marginalized populations.

We thus question whether intimate partners who share the experience of chronic illness with one another are themselves marginalized in research (intentionally or otherwise) because they defy the conventional "caregiver and patient" norm of intimate relationships involving persistent challenges to health. Indeed, we encourage consideration and exploration of the idea that collaborative illness management disrupts contemporary understandings of illness management in many ways by blending the roles of caregiver and patient within the context of shared illness experiences. If so, attention to collaborative illness management may bring both advantages and disadvantages for people with chronic conditions who participate in relationships with one another. To this end, we encourage exploration of both intrinsic experiences of relationship partners in conducting collaborative illness management and extrinsic reactions of others in their lives to collaborative illness management activities.

Research on embodied health suggests that the kinship of shared experience can constructively impact quality of life among people with chronic conditions who form any type of social connection (Brown et al., 2011). Receiving social support from a partner who shares one's own experiences may thus buffer against loss of health for people with chronic conditions. Prior research on older relationship partners living with chronic illness seems to support this notion, albeit cautiously and implicitly. On the other hand, if partners are simultaneously ostracized for engaging in this process of mutual support rather than adhering to roles of "caregiver" and "patient," they may experience increased risk for declines in health over time.

Because it is unclear whether the same social expectations exist for younger adults in committed relationships who manage chronic conditions, this intersection of scholarship threads on illness, identity, and roles remains ripe for further inquiry. Likewise, younger adults may engage unique mechanisms for doing this emotional and instrumental work. This is increasingly evidenced by scholarship on how young people cope with chronic illness. Josefsson's (2005) exploration of people with chronic conditions supporting one another via online communities and Merolli,

Gray, and Martin-Sanchez's (2013) inquiry into the use of social media for mutual support with illness management offer excellent examples of this emerging content area. Indeed, Ziebland and Wyke (2012) suggest that the engagement of online coping resources so common among younger adults may offer a powerful tool for effective illness management in both individual and collaborative contexts but does not touch on the experiences of intimate partners who use social media for this purpose within their relationships.

A specific area for intensive inquiry in engaging partners with chronic conditions is the role of gender in collaborative illness management. Prior literature on illness management suggests that gender norms serve as salient contributors to the overall process of coping with chronic illness. Indeed, these norms may become particularly impactful within long-term relationships (August & Sorkin, 2010). Moreover, the fact that younger generations in some societies may have different attitudes than their older counterparts about gender norms, in the context of both broad social attitudes and specific expectations within intimate relationships, may also mean that patterns reflected in extant literature on how partners cope with chronic illness do not hold. Williams (2000) describes a diverse mixture of gendered attitudes and behaviors contributing to illness management in teenagers with common chronic conditions such as diabetes and asthma. Exploration of these dynamics with young adults in intimate partnerships offers valuable opportunities to enhance illness management at the population level by illuminating specific attitudes and behaviors that may prove especially useful for partners helping each other cope.

4 | MOVING COLLABORATIVE ILLNESS MANAGEMENT OUT OF THE SHADOWS

The few studies that explicitly address partners managing chronic conditions together offer rich and promising insights into how people in intimate relationships negotiate both illness management itself and many intersectional dynamics of this process. For example, Calasanti and King's (2007) work highlights how male caregivers who themselves have chronic conditions may simultaneously engage in collaborative illness management and affirm their masculinity by framing the core activities of negotiating life with chronicity as leadership acts. Likewise, Manne and Zautra's (1990) nested research on married couples with arthritis illustrates how illness management can contribute to the emotional health of couples as individuals and as teams. The fact that both of these studies were done with older adults strengthens the call for scholarship that engages explicit attention to age in a more diverse population of participants, as well as to marginalized social locations that may intersect with and shape their experiences.

By opening doors to various types of intersectional analysis in scholarship on illness management, these foundational works invite inquiry into how many additional forms of social advantage and disadvantage may shape the experiences of relationship partners in their individual and collective health journeys (see also Harrison, Grant, & Herman, 2012). These pioneering works provide a basis for further research in two key ways. First, they explicitly call for inquiry on several topics not yet explored in published scholarship on the sociology of health and illness. Second, they implicitly illuminate ways in which dominant social norms persist in, and may even be reinforced by, foundational scholarship on illness management within partnerships. Marginalized groups and younger adult populations may thus remain in the shadow despite gradual progress towards a generalized literature on collaborative illness management.

In reviewing literature on partners with chronic conditions, we observe ample suggestions for future research on the dynamics of relationships between people in specific social and clinical locations. These may be particular types of diseases (Edwards & Ruettiger, 2002; Manne & Zautra, 1990; Maughan, 2003), health care trajectories (Maughan et al., 2002; White & Grenyer, 1999), clinical settings (Edwards & Ruettiger, 2002), age ranges (Calasanti & King, 2007), sex and identities (Paulson et al., 2003), gender norms (Kramer & Kipnis, 1995) and identities (Calasanti & King, 2007), races (Fredman et al., 1995), or other characteristics frequently assessed by in-depth studies of health in social life. We echo these recommendations both conceptually with respect to broad horizons for the sociology of health and illness and within our prior work (see Cragun, Cragun, Nathan, Sumerau, & Nowakowski, 2016; Cragun & Sumerau, 2015; Nowakowski & Sumerau, 2015).

We also note that nuanced and sophisticated scholarship on illness management can invite further research by either explicitly reinforcing dominant social norms or—as we see more frequently in the literature reviewed—simply not actively challenging these expectations. We frequently observed norms of Whiteness, middle- and upper-class status, heterosexuality, male dominance, binary and cisgender identities, spoken language proficiency, able-bodiedness and mindedness outside of the specific chronic condition studied, and regular access to health care. We also noted that the only studies approaching a collaborative illness management perspective that we did find dealt exclusively with the experiences of older adults, potentially reinforcing the idea that younger adults' relationships do not involve this kind of teamwork (see Braithwaite, Delevi, & Fincham, 2010). Indeed, although it only explicitly engages an individualistic rather than collaborative perspective on illness management in its exploration of potential health benefits from relationships between college students, work by Braithwaite et al. (2010) implicitly suggests that younger adults may be doing this work as well.

We also note that a portion of the literature covered in this article suggests, if not explicitly recommends, methodological approaches that facilitate challenging dominant norms. Specifically, some of the studies we reviewed used both relatively broad inclusion criteria and narrative methods of inquiry. Kuyper and Wester's (1998) study and broad-spectrum inquiries that have followed from it (Eriksson & Svedlund, 2006) capture a broad range of social and clinical locations, showcasing some of the diversity likely to be found within larger groups of people with chronic conditions. Moreover, these studies highlight and champion the potential of narrative approaches (Andrews, 2004) to offer detailed and nuanced portraits of illness management within intimate relationships. We also note that closely related literatures on state and home care (see Fienieg, Nierkens, Tonkens, Plochg, & Stronks, 2012; Tonkens, Bröer, van Sambeek, & van Hassel, 2013; Ulmanen & Szebehely, 2015) offer ample guidance for intersectional scholarship on the collaborative illness management experiences of intimate partners with chronic conditions.

We believe that additional studies prioritizing the engagement of marginalized individuals and partnerships can promote social justice and health equity, not only in a conceptual sense but also in an instrumental one. The general “emancipatory research model” championed by disability scholars and activists (see Galvin, 2005) offers tremendous promise for research on illness management specifically. For people with chronic conditions, whether or not their conditions introduce any kind of physical or cognitive disability, the perception of social disability is a frequent myth against which those living with chronicity push back. At the same time, this masking of agency may cast a shadow over the abilities and unique insights of people with chronic conditions who find constructive ways to leverage their shared experiences. Emancipation thus involves both conceptual and instrumental considerations.

5 | EXPANDING RESEARCH ON COLLABORATIVE ILLNESS MANAGEMENT

As noted at the outset of this article, an important mechanism of reviewing existing illness management literature related to intimate partners emerges from the ability of this literature to point toward future studies. In this section, we outline some conceptual, instrumental, and broader theoretical implications revealed by taking collaborative illness management processes seriously in scholarship. In so doing, we seek to facilitate more in-depth, intersectional, and nuanced scholarship concerning the multitude of ways social locations and experiences shape the processes whereby intimate partners—as well as other significant others—collaboratively make sense of shared experiences of illness management and intimacy in contemporary society.

On the conceptual front, comparing and contrasting illness and caregiving narratives noted above can challenge dominant norms of illness, identity, and behavior—as well as the social locations that people can simultaneously occupy and navigate with respect to each. Moreover, affirming the stories and insights of partners who share experiences, thoughts, and feelings in the process of illness management can serve as a breaching exercise with applications for academic teaching (Rafalovich, 2006) and public practice (Marres, 2012). Focusing on narratives that challenge established norms can also increase awareness of socially constructed boundaries. By result, such stories can illuminate pathways to greater fluidity in thinking about what people with chronic conditions can be, think, feel, and do within and beyond intimate relationships (see also Nowakowski et al., 2016a).

On the instrumental front, collecting “forbidden narratives” (Liberti, 2004) from individuals and partners can yield rich data about how illness management operates and evolves for partners who share these experiences while negotiating marginalization in one or more forms. Health equity for people living with chronic conditions hinges not only on knowledge of what benefits their health but also resources to implement this knowledge consistently. Illness management can be understood as a case example of the broader phenomenon of fundamental social causation of health outcomes (see Link & Phelan, 2010). Effective illness management requires diverse resources that may be more numerous or scarce depending on social position. Given that intimate relationships themselves can constitute such a resource for health promotion and illness prevention (Braithwaite et al., 2010), explicitly studying the ways in which partners with chronic conditions work collaboratively towards desired health outcomes offers ample potential for improving population health and preventing suffering.

On a broader level, our review of this literature suggests many ways an explicitly intersectional approach to illness management—collaborative and individualistic based—may provide numerous insights into the complexity of such processes. Considering that differential social locations related to, for example, gender (Nowakowski & Sumerau, 2015), race (Grollman, 2012), and sexualities (Cragun & Sumerau, 2015) have been shown to influence both illness management and intimate experience outcomes within relationships of varied types and forms, it is striking that existing literature rarely explores the intersections of these identities and locations in the experience of chronic illness or in illness management within relationships (Nowakowski et al., 2016a). Like many other areas of contemporary health (Link & Phelan, 2010) and relationship (Cragun & Sumerau, 2015) research, review of earlier literature suggests that there may be much to learn from exploring the ways people individually and collaboratively manage chronic conditions together over time while occupying similar and different intersecting social locations, identities, and resource accessibility (see also Cragun et al., 2016; Sumerau & Cragun, 2016).

In outlining these possibilities, however, we acknowledge that we have the benefit of both hindsight and breadth. Especially in foundational works on a given sociomedical phenomenon, both space and scope constitute pressing concerns for scholars attempting to publish research. For example, in a contemporary piece about romantic bonding between older couples living with arthritis, it might be relatively easy to incorporate ample information about the experiences of same-sex couples. By the same token, it might be comparatively difficult to incorporate the same richness of information about the experiences of couples wherein one or both partners are transgender (see Harrison et al., 2012 for discussion of such challenges). These challenges may owe partly to transgender people fearing repercussions for disclosing their identities. People from younger generations and older ones may also narrate gendered experiences with different vocabularies and with different degrees of openness. We thus stress that our own call for attention to intersections and inequalities heretofore not addressed by research on intimate partners managing chronic conditions is not one of criticism but rather one of enthusiasm for the potential awaiting future research.

6 | RECOMMENDATIONS FOR FUTURE RESEARCH

With this in mind, we thus outline an agenda for future research on partners managing illness together. We do so by synthesizing the sound recommendations of our colleagues and mentors, by integrating the implications noted above from our review of existing literature, and by building on these suggestions to address outstanding gaps in emerging literature on collaborative illness management. Specifically, we suggest four key priorities for focused research on partners managing chronic illness together. These recommendations extend and enrich previous work on illness management within relationships in which people without chronic conditions care for those with persistent health challenges.

Indeed, we first recommend a general effort to expand and diversify research on people managing chronic conditions together within intimate relationships. Within this general domain of scholarship, we second recommend in-depth study of the dynamics of collaborative illness management within and across marginalized social groups. We third recommend thorough exploration of how collaborative illness management processes may simultaneously

contribute to and buffer against the differential and shared marginalization of individuals with chronic conditions who occupy varied social locations in relation to race, class, gender, sexualities, age, functional ability, and other disparate social locations. Finally, we recommend utilizing the above steps to begin creating detailed assessments of intersectionality between forms of stigmatization related to illness management and other social processes.

In making these overarching recommendations and in calling attention to specific forms of marginalization that hold promise for targeted study, we again remind our readers of our own standpoints in assessing the state of the field and priorities for future research therein. In reviewing literature on partners managing illness together, we often asked questions inspired by our own experiences if they seemed to challenge or enrich the key arguments of manuscripts we read. Our lived experiences as younger adult, mixed-sexuality, and gender nonbinary partners managing chronic conditions individually and collaboratively bring a diverse array of intersectional elements. However, we likewise note that our own life histories cannot remotely hope to represent the full scope of influences that are important to consider in understanding how partners may engage in collective illness management.

Indeed, the uniqueness of our own experiences of illness management and its interplay with other social processes has as much to offer for charting a specific research agenda on collaborative illness management as does the generalizability of these experiences. Both the literature we have reviewed here and the life experiences we have used to interpret and situate these important works point to a consistent shared priority for further inquiry. Specifically, explicit attention to processes of conscious collaboration in illness management among intimate partners would do much to enhance both social and clinical understanding of what it takes to live well with chronic conditions.

In support of this aim, we encourage the use of multiple research methods and data sources to operationalize these perspectives in ways that capture the tremendous diversity of social locations and lived experiences among the millions of people worldwide living with chronic health conditions. We strongly encourage engagement of methods ranging from the very qualitative to the very quantitative, and every possible dynamic arrangement of mixed methods approaches in between. Our own experiences and analysis of extant literature suggest two core strategies as next steps for this effort.

First, conducting both individual and shared life history interviews with people in intimate relationships with diverse characteristics offers a unique opportunity for formative assessment of how partners with chronic conditions can collaborate effectively for health promotion. This approach builds directly on the extensive contributions made by Kuyper and Wester's (1998) landmark piece that articulated how easily caregiving work can make relationship partners feel as though they are living in the shadow when no formal framework for mutual support exists. Subsequent studies have suggested, albeit not explicitly explored, how shared experiences of illness can start to establish that sense of sharing and contribute to a sense of collective agency.

Second and directly pursuant, conducting in-depth surveys with individuals and groups of partners offers a unique opportunity for summative assessment of which approaches to collaborative illness management might prove most effective within relationships sharing specific social and contextual characteristics. This approach builds directly on some of the newer quantitative datasets focusing on intersectional determinants of health across the life course. Examples include the National Social Life, Health, and Aging Project and Midlife in the United States. Both datasets use paired survey techniques to engage the perspectives of individuals and their partners simultaneously and thus offer ample guidance for the specific architecture of survey studies on collaborative illness management.

With this manuscript, we hope to offer a foundational framework for research on collaborative illness management within intimate relationships, along with elements of specific inspiration for future study. To this end, we reflected constantly on both the unique insight offered by our own lived experiences and the ways in which our histories may narrow our perspectives. Rich and nuanced understanding of how intimate partners with chronic conditions engage, support, and challenge one another in the ongoing process of illness management requires active and sustained dialogue by researchers with a diverse array of perspectives. We thus conclude by inviting and indeed encouraging other scholars—both those with very similar personal histories and those with vastly different ones—to critique our suggestions in kind and to illuminate opportunities for further inquiry that we ourselves have missed.

REFERENCES

- Andrews, M. (Ed) (2004). *The uses of narrative: Explorations in sociology, psychology, and cultural studies*. New Brunswick, NJ: Transaction Publishers.
- Aneshensel, C. S., Pearlin, L. I., & Schuler, R. H. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behavior*, 34(1), 54–70.
- August, K. J., & Sorkin, D. H. (2010). Marital status and gender differences in managing a chronic illness: The function of health-related social control. *Social Science & Medicine*, 71(10), 1831–1838.
- Braithwaite, S. R., Delevi, R., & Fincham, F. D. (2010). Romantic relationships and the physical and mental health of college students. *Personal Relationships*, 17(1), 1–12.
- Brown, P., Morello-Frosch, R., Zavestoski, S., McCormick, S., Mayer, B., Gasior, R., ... Simpson, R. (2011). *Embodied health movements*. Los Angeles, CA: University of California Press.
- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Gasior Altman, R. (2004). Embodied health movements: New approaches to social movements in health. *Sociology of Health & Illness*, 26(1), 50–80.
- Bury, M. (2000). On chronic illness and disability. *Handbook of Medical Sociology*, 5, 173–183.
- Calasanti, T., & King, N. (2007). Taking 'women's work like a man': Husbands' experiences of care work. *The Gerontologist*, 47(4), 516–527.
- Centers for Disease Control and Prevention. (2015). Chronic disease overview. Retrieved from <http://www.cdc.gov/chronicdisease/overview/index.htm>. Last updated May 18, 2015. Accessed on July 14, 2015.
- Charmaz, K. (2000). Experiencing chronic illness. In G. Albrecht, R. Fitzpatrick, & S. C. Scrimshaw (Eds.), *Handbook of social studies and health and medicine* (pp. 277–292). Thousand Oaks, CA: Sage.
- Choo, H. Y., & Ferree, M. M. (2010). Practicing intersectionality in sociological research: A critical analysis of inclusions, interactions, and institutions in the study of inequalities. *Sociological Theory*, 28(2), 129–149.
- Cockerham, W. (2007). *Social causes of health and disease*. New York: Polity.
- Conrad, P., & Schneider, J. W. (2010). *Deviance and medicalization: From badness to sickness*. Philadelphia, PA: Temple University Press.
- Cragun, D., Cragun, R. T., Nathan, B., Sumerau, J. E., & Nowakowski, A. C. H. (2016). Do religiosity and spirituality really matter for social, mental and physical health? A tale of two samples. *Sociological Spectrum*, 36(6), 359–377.
- Cragun, R. T., & Sumerau, J. E. (2015). Losing manhood like a man: A collaborative autoethnographic examination of masculinities and the experience of a vasectomy. *Men and Masculinities*. <https://doi.org/10.1177/1097184X15612516>
- Edwards, N. E., & Ruettinger, K. M. (2002). The influence of caregiver burden on patients' management of Parkinson's disease: Implications for rehabilitation nursing. *Rehabilitation Nursing*, 27(5), 182–186.
- Eriksson, M., & Svedlund, M. (2006). 'The intruder': Spouses' narratives about life with a chronically ill partner. *Journal of Clinical Nursing*, 15(3), 324–333.
- Fienieg, B., Nierkens, V., Tonkens, E., Ploch, T., & Stronks, K. (2012). Why play an active role? A qualitative examination of lay citizens' main motives for participation in health promotion. *Health Promotion International*, 27(3), 416–426.
- Fredman, L., Daly, M. P., & Lazur, A. M. (1995). Burden among White and Black caregivers to elderly adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 50(2), S110–S118.
- Gallant, M. P. (2003). The influence of social support on chronic illness self-management: A review and directions for research. *Health Education & Behavior*, 30(2), 170–195.
- Galvin, R. D. (2005). Researching the disabled identity: Contextualizing the identity transformations which accompany the onset of impairment. *Sociology of Health & Illness*, 27(3), 393–413.
- Grollman, E. A. (2012). Multiple forms of perceived discrimination and health among adolescents and young adults. *Journal of Health and Social Behavior*, 53, 199–214.
- Harrison, J., Grant, J., & Herman, J. L. (2012). A gender not listed here: Genderqueers, gender rebels and otherwise in the National Transgender Discrimination Survey. *LGBTQ Policy Journal at Harvard Kennedy Center*, 2, 13–24.
- Ivankovich, M. B., Leighliter, J. S., & Douglas, J. M. Jr. (2013). Measurement of sexual health in the U.S.: An inventory of nationally representative surveys and surveillance systems. *Public Health Reports*, 128, 62–72.
- Josefsson, U. (2005). Coping with illness online: The case of patients' online communities. *The Information Society*, 21(2), 133–141.
- Kramer, B. J., & Kipnis, S. (1995). Eldercare and work-role conflict: Toward an understanding of gender differences in caregiver burden. *The Gerontologist*, 35(3), 340–348.

- Kuyper, M. B., & Wester, F. (1998). In the shadow: The impact of chronic illness on the patient's partner. *Qualitative Health Research, 8*(2), 237–253.
- Liberti, R. M. (2004). "Forbidden narratives": Exploring the use of student narratives of self in a graduate sport sociology course. *Quest, 56*(2), 190–207.
- Link, B. G., & Phelan, J. (2010). Social Conditions as Fundamental Causes of Health Inequalities. In C. Bird, P. Conrad, A. Fremont, & S. Timmermans (Eds.), *Handbook of medical sociology* (6th ed.) (pp. 3–17). Nashville, TN: Vanderbilt University Press.
- Manne, S. L., & Zautra, A. J. (1990). Couples coping with chronic illness: Women with rheumatoid arthritis and their healthy husbands. *Journal of Behavioral Medicine, 13*(4), 327–342.
- Marres, N. (2012). The Experiment in Living. In C. Lury, & N. Wakeford (Eds.), *Inventive methods: The happening of the social* (pp. 76–95). New York: Routledge.
- Maughan, K. (2003). Specific keynote: In the shadow of illness—supporting women with ovarian cancer. *Gynecologic Oncology, 88*(1), S129–S133.
- Maughan, K., Heyman, B., & Matthews, M. (2002). In the shadow of risk: How men cope with a partner's gynaecological cancer. *International Journal of Nursing Studies, 39*(1), 27–34.
- Merolli, M., Gray, K., & Martin-Sanchez, F. (2013). Health outcomes and related effects of using social media in chronic disease management: A literature review and analysis of affordances. *Journal of Biomedical Informatics, 46*(6), 957–969.
- Nowakowski, A. C. H., & Sumerau, J. E. (2015). Swell foundations: Gender, fundamental social causes and chronic inflammation. *Sociological Spectrum, 35*, 161–178.
- Nowakowski, A. C. H., Sumerau, J. E., & Mathers, L. A. B. (2016a). Building a bright future for diabetes care and management by writing where it hurts. *PLAID: People Living with and Inspired by Diabetes, 2*(1), 64–67.
- Nowakowski, A. C. H., Sumerau, J. E., & Mathers, L. A. B. (2016b). None of the above: Strategies for inclusive teaching with "representative" data. *Teaching Sociology, 44*(2), 96–105.
- Nowakowski, A. C. H., Graves, K. Y., & Sumerau, J. E. (2016). Mediation analysis of relationships between chronic inflammation and quality of life in older adults. *Health and Quality of Life Outcomes, 14*, 46.
- Paulson, M., Norberg, A., & Söderberg, S. (2003). Living in the shadow of fibromyalgic pain: The meaning of female partners' experiences. *Journal of Clinical Nursing, 12*(2), 235–243.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583–594.
- Rafalovich, A. (2006). Making sociology relevant: The assignment and application of breaching experiments. *Teaching Sociology, 34*(2), 156–163.
- Revenson, T. A. (1994). Social support and marital coping with chronic illness. *Annals of Behavioral Medicine, 13*(1), 123–142.
- Sumerau, J. E., & Cragun, D. (2016). Frames of reference: Applying sociology in interdisciplinary medical settings. *Journal of Applied Social Science, 10*(2), 113–118.
- Thoits, P. A. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of Health and Social Behavior, 52*(2), 145–161.
- Thomas, C. (2007). *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology*. New York: Palgrave Macmillan.
- Tonkens, E., Bröer, C., van Sambeek, N., & van Hassel, D. (2013). Pretenders and performers: Professional responses to the commodification of health care. *Social Theory & Health, 11*(4), 368–387.
- Ulmanen, P., & Szebehely, M. (2015). From the state to the family or to the market? Consequences of reduced residential eldercare in Sweden. *International Journal of Social Welfare, 24*(1), 81–92.
- Varul, M. Z. (2010). Talcott Parsons, the sick role and chronic illness. *Body & Society, 16*(2), 72–94.
- White, Y., & Grenyer, B. F. S. (1999). The biopsychosocial impact of end-stage renal disease: The experience of dialysis patients and their partners. *Journal of Advanced Nursing, 30*(6), 1312–1320.
- Williams, C. (2000). Doing health, doing gender: Teenagers, diabetes and asthma. *Social Science & Medicine, 50*(3), 387–396.
- Ziebland, S. U. E., & Wyke, S. (2012). Health and illness in a connected world: How might sharing experiences on the internet affect people's health? *Milbank Quarterly, 90*(2), 219–249.

AUTHOR BIOGRAPHIES

Xan Nowakowski is a research faculty at the Florida State University College of Medicine and adjunct faculty in Sociology. Their teaching and research focuses on experience and management of chronic conditions, social causes of and

responses to health inequalities, and evaluation of programs and services that promote health equity. Lifelong chronic illness and a passion for social justice motivate them in advocating for others with health challenges through a variety of professional service activities.

J.E. Sumerau is an assistant professor and director of applied sociology at the University of Tampa. Zir teaching and research focuses on intersections of sexualities, gender, religion, and health in the historical and interpersonal experiences of sexual, gender, and religious minorities. Zir public and academic work may be found at www.jsumerau.com.

How to cite this article: Nowakowski ACH, Sumerau JE. Out of the shadow: Partners managing illness together. *Sociology Compass*. 2017;11:e12466. <https://doi.org/10.1111/soc4.12466>