

Communal Coping with Chronic Illness: A Health Campaign for Couples Coping with Ehlers-
Danlos Syndrome

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There is a well-established connection between the psychological and physiological management of health, as scholars have widely regarded health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (WHO, 1948, p. 1). The benefits of social support and effective coping skills for those affected by chronic illnesses have been well-documented (Helgeson et al., 2018). Considering the potential for theoretical claims about social support and coping methods to be a prescriptive means of improving the lives of those affected by chronic illness, it bears consideration for the existing theories to be applied to specific chronic illnesses. Furthermore, under-researched illnesses associated with disruptive and detrimental symptomology warrant academic attention.

With this in mind, the present proposal aims to examine the impact of social support and coping skills on the well-being of patients diagnosed with Ehlers-Danlos Syndromes (EDS) and their partners. EDS is a series of rare and incurable chronic illnesses affecting 1 in 2,500 to 1 in 5,000 individuals. Due to the highly individualized nature of each of the thirteen subtypes of EDS, each subtype has its own unique clinical criteria for diagnosis. Moreover, the manifestation of symptoms varies from patient to patient, making the diagnosis process arduous and the management of adverse symptoms challenging (*What are the Ehlers-Danlos Syndromes?*).

The suggested campaign fills the gap between the theoretical assumptions and practical applications of existing health communication literature regarding coping and social support and applies these principles to the wellness management of those affected by EDS. Further, the implementation of this campaign as a workshop during the annual conference for doctors, patients, and loved ones of those affected by EDS presents a direct channel to the population in need of practical methods of integrating this existing research into their daily lives.

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The outcome of this campaign, and the suggested workshop, is ultimately the improved well-being of both patients and their partners. Additionally, the present proposal opens a channel of future research for both health and interpersonal communication scholars to apply more general theoretical findings to specific populations in ways that potentially offer more direct benefit.

Review of Literature

Social Support

From a communicative perspective, social support is characterized by the interactions that occur between the providers and recipients of support (Vangelisti, 2009). Oftentimes, social support from a communicative standpoint is measured by enacted support such, specifically, “researchers who study supportive communication usually evaluate the verbal and nonverbal behaviors that individuals engage in when they are trying to provide someone with help (enacted support)” (Vangelisiti, 2009, p. 40). There can be both positive and negative outcomes associated with social support (Vangelisiti, 2009). However, person-centered messages are more likely to be supportive than non-person-centered messages (Vangelisiti, 2009). Furthermore, support that is not overtly visible and often goes unnoticed and can be characterized as invisible support can be very effective (Vangelisiti, 2009). Utilizing these findings, our campaign aims to educate couples affected by EDS about the potential outcomes of each type of social support, while providing actionable suggestions for how couples can more effectively integrate social support in their relationships.

Empirical research supports the notion that social support is beneficial to one’s physical and mental well-being (Vangelisti, 2009). Since people who have chronic illnesses, such as EDS, have chronic physical and mental stress, social support acts as a buffer to this stress and can help improve their well-being (Cohen & Wills, 1985). Without this social support, the physical health

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and mental well-being of the chronically ill person can suffer (Cohen & Wills, 1985). In addition, the chronic illness can have an effect on the mental well-being of the partner. Since couples who have one partner with a chronic illness can have great levels of interdependence, it is important to recognize that levels of stress can also be high for the partners of the chronically ill. Therefore, social support in couples where one has chronic illness is necessary for the health of not just the patient, but also the partner (Gellert et al., 2018).

Communal Coping

However, social support alone is not as effective or beneficial when compared to the process of communal coping (Lyons et al., 1998). Existing research indicates that integrating available “social resources may foster stress resistance,” and communal coping involves the utilization of these resources in more effective ways than merely providing social support (Lyons et al., p. 581, 1998) When people engage in communal coping, they combine the available resources and energy of the group into a collective process of coping with adversity. In this way, stressful events are less daunting for any individual experiencing them. While social support and communal coping may seem to overlap in the way they operate during the coping process, there is a key difference between the two. Communal coping involves appraising the adverse circumstance with a communal orientation, meaning it is our problem, not just your problem. This discursive change takes the onus of coping from one individual, in this case the person actually diagnosed with EDS, and instead evenly distributes the metaphorical weight of processing the hardship. Reappraising a stressful event in this way also reinforces that coping is driven by a variety of motivators, not just the emotional well being of the individual experiencing the event. Utilizing communal coping can also present a couple affected by EDS a method of relieving relational tension (Lyons et al., 1998).

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The concept of communal coping is also particularly salient to the present proposal, as it involves the combination of both appraisal of a stressor and action to effectively manage it. The direct applicability of this theory lends itself to be involved in prescriptive research of coping with a chronic illness. In the formative research described further in the methods section to follow, the researchers can examine existing appraisals and actions of coping utilized by couples affected by EDS, before offering a suggested variety of appraisals and actions to other patients and partners. Essentially, the actionable nature of communal coping allows the concept to transcend the theoretical and become a teachable skill.

Communal Coping in Specific Contexts

While communal coping has been examined throughout several contexts, there is less emphasis placed on communal coping in individually centered circumstances, where there may be an auxiliary impact on others, but the majority of direct adversity is on a single person (Lyons et al., 1998). Among countless other contexts, chronic illness and disability fall into this category. The process of communal coping may look different in each unique context it is applied to, and thus a broad conceptualization of it may not be beneficial when it comes to direct application of the constructs within the theory. Afifi et al. (2006) highlight the limitations of existing communal coping literature to consider multiple perspectives outside the individual experiencing stress. The perspective of all those affected, and thus all those coping with the adversity, should be considered in the context of the stressor. Furthermore, the existing body of literature regarding communal coping largely applied to contexts in which the coping process is conducted individually at its core, with communal coping as a facilitator of this coping. Instead, Afifi et al. (2006) posits that research targeting contexts in which stress is managed both individually and collectively bears more academic consideration. One area of study they propose

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is communal coping within the family, and though their specific study is within the context of post divorce families, the same arguments apply to the present proposal. Couples and families affected by EDS involve individual and collective coping, especially considering the ability of EDS to often result in debilitating symptom flare ups in which the patient is more physically reliant on their partner (*What are the Ehlers-Danlos Syndromes?*).

Furthermore, there is significant possibility for communal coping efforts to actually undermine the efficacy of coping efforts if they are integrated incorrectly, for example in the event of oversharing information of one individual increasing the internalized stress of the other members of the family (Afifi et al., 2006). For this reason, it is crucial for continued research to examine communal coping behaviors used across a breadth of contexts so that these effective methods of coping can be explained and utilized by other individuals and groups experiencing stressors that function in similar ways within their own lives.

Communal Coping in the Context of EDS

As the concept of communal coping has evolved in health communication literature, researchers have catered an update to the theory to couples where one partner has a chronic illness (Helgeson et al., 2018). This allowed for the conceptualization of a model that included the previous theory's conceptualization of communal coping where partners view the illness as their shared problem (Lyons et al., 1998). In the updated theory of communal coping with chronic illness, Helgeson and colleagues (2018) conceptualized the communal coping process as also including collaboration between the two partners, where both work together to manage the illness. According to the updated theory (Helgeson et al., 2018) a shared appraisal of the illness can lead to supportive interactions between the two partners, where partners engage in acts of social support. These supportive interactions can help partners later collaborate and work

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together. Simply stating the hardship of EDS is an ineffective means of managing the illness, both for patients and their partners. However, following this updated process of communal coping, EDS patients and their partners can reframe the diagnosis, symptoms, and experiences associated with EDS as our problem, and not my/my partner's problem. The design of this updated theory argues that communal coping in relationships where a partner has a chronic illness first prioritizes the health and well-being of the chronically ill partner, then later prioritizing the relationship (Helgeson et al., 2018). Through a shared illness appraisal, collaboration, and social support, the partners can communicatively manage both their partner's health and their relationship.

In order to apply this theory to a specific chronic illness, it is necessary to take into account what patients' chronic illnesses would benefit from the information and be receptive to change. Since EDS is a chronic illness that is not well-understood, and each individual can have varying symptoms, relationships where one partner has EDS would benefit from learning about Helgeson and colleagues' view of communally coping with chronic illness (2018). Integrating the patients' and partners' opinions on what coping methods were the most effective grounds any prescriptive measures provided in the reality of the actual experiences of those affected by EDS. Combining these with the types of support Helgeson and colleagues (2018) proposed as effective provides patients and partners the ability to tackle the coping process together. This in turn lessens the load on the patients and partners individually, more effectively easing the stress managing a chronic illness can have on their relationship.

Resilience as an Outcome of Social Support and Communal Coping

Resilience can be defined in many different ways. However, the fundamental basis is that resiliency is a beneficial buffering factor when dealing with life stressors (Richardson, 2002). As

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Richardson (2002) states, “the resiliency process is a life-enriching model that suggests that stressors and change provide growth and increased resilient qualities or protective factors” (p. 319). Communal coping supports the development of resilience, specifically due to the largely held belief that resilience is not experienced in isolation, but rather is a communicative phenomenon that is “fundamentally grounded in messages, d/ Discourse, and narrative (Buzzanell, 2010, p. 2).” According to Buzzanell (2010), “human resilience is constituted in and through communicative processes that enhance people’s abilities to create new normalcies. Individuals and collectivities literally talk and enact five processes into existence: (a) crafting normalcy, (b) affirming identity anchors, (c) maintaining and using communication networks, (d) putting alternative logics to work, and (e) legitimizing negative feelings while foregrounding productive action. (Buzzanell, 2010, p. 9).” Communal coping facilitates the communicative processes involved in resilience. The five communicative processes of resilience identified by Buzzanell (2010) allows for the process of resilience to be taught to individuals through the “I SEE YOU” campaign. Communal coping between couples with an individual affected by EDS would better foster resilient reintegration and responses to the constant disruptions that come with living with a chronic illness.

In addition, Richardson’s (2002) resiliency model is applicable to the current campaign as it suggests that one’s response to adversity significantly impacts the outcome of the disruption. The resiliency model demonstrates that as an individual’s biopsychospiritual homeostasis is disrupted the individual must reintegrate either with resilient reintegration, reintegration back to homeostasis, reintegration with loss, or dysfunctional reintegration (Richardson, 2002, p. 311). A disruption may have many different forms, however, for the purpose of this study the disruption may be characterized by the stressors associated with a chronic illness. Through communal

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copied, a couple may learn to better cope with the stressors and disruptions that come with a chronic illness. Developing resilient qualities allows stressors to be less disruptive (Richardson, 2002, p. 311). Furthermore, “chronic stressors befall people when they do not develop resilient qualities or have not grown through the disruptions in their life (Richardson, 2002, p. 311). The development of resilient qualities allows individuals to better cope with future disruptions, such that the future disruptions will be less disruptive (Richardson, 2002). Overall, fostering communal coping among couples suffering from at least one partner affected by EDS is a practical way to develop resilient qualities for the couple.

Method

After obtaining IRB approval, the researchers will conduct formative research in the form of in-depth semi-structured interviews. The researchers will interview 4-5 couples in a pair where one partner is diagnosed with Ehlers-Danlos Syndrome and where both partners will attend the Ehlers-Danlos Society conference. The couples will be interviewed by one of the researchers who also has EDS and is in a long-term relationship in order to establish an immediate connection and understanding between participants and researcher. Participants will be recruited through the Ehlers-Danlos Society website and Facebook page. The purpose of these interviews is for the researchers to gain insight into the lives of these couples, including how they may struggle to cope with their partner’s EDS. This will allow researchers to form the campaign materials surrounding issues that these couples face in giving one another social support.

The interview will start by asking questions about how the couples experience EDS, in particular, in order to gain more insight to the physical and communicative struggles that accompany this specific illness, along with allowing the participants to understand that the

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researchers want to understand their experiences. Additional interview questions will be informed by the theory of communal coping with chronic illness (Helgeson et al., 2018). Since this theory originated from social support research, the interview will begin by asking questions about social support in their relationship, such as “How do you support each other in your relationship?” and “What are some ways you communicate support in your relationship?” Lastly, the theory will ask about how a couple copes with their partner’s EDS. An example of a question would include, “How do you cope with EDS as a couple?” After completing the interviews, the researcher will transcribe the data and find themes using a thematic analysis (Tracy, 2019) in order to establish areas where the researchers can help the couples better cope with their partner’s illness. These questions will also help the researchers to probe for what degree the couples may utilize principles of the theory of communal coping with chronic illness in their relationship, such as describing the relationship as “our problem.”

Social Marketing

After conducting formative research, the researchers will advertise the workshop portion of their campaign, called “I SEE YOU”, on how to communally cope with EDS. The workshop will discuss ways to communally cope with issues partners commonly face with EDS. The session will be marketed by advertisements in the conference booklet handed out at the beginning of the conference and also on the Ehlers-Danlos Society website prior to the session. This placement will allow for conference goers to see marketing regarding the training session and plan to attend. In addition, the two simultaneous patient and partner breakout sessions that take place immediately before the “I SEE YOU” time slot will inform the participants of the benefits of attending the campaign. Each of these breakout sessions are already implemented in the conference, and they are conducted by separating patients with EDS from their romantic

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partners and allowing them each to attend a conference session with other patients or other partners and discuss issues they face with coping with EDS. Since these sessions already discuss coping with EDS on the individual level, our training session will be helpful to market as a way for couples to cope communally with EDS.

“I See You” Workshop

After the patient and partner breakout sessions, the patients and partners can reconnect at the “I SEE YOU” workshop. The researchers will facilitate the workshop for both partners and patients at the same time. During the workshop, the researchers will explain the theory of communal coping with chronic illness to the patients and partners, along with how it can be used to help the couples cope with the specific issues represented in the themes through the formative research. The overall goal of the workshop is to clearly explain communal coping to those in attendance, highlighting its specific importance and benefit to patients and partners affected by EDS, including how communal coping and social support can improve the health of the partner and the relationship itself.

During the workshop, there will be both a lecture and a discussion portion. The lecture will be led by the researchers in order to explain the concept and benefits of communal coping. The discussion will allow partners to interact with each other about EDS and practice communally coping with each other. The use of minimal lecture alongside interactive discussion aims to encourage active participation with the concepts surrounding communal coping. In doing so, the researchers will attempt to equip both partners and patients with the necessary tools to facilitate communal coping in their relationship in the future.

Evaluation

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In order to evaluate the impact of the campaign, researchers will send out emails to participants in the workshop immediately after it ends, which will include an open-ended survey that will take participants approximately 10-15 minutes. Researchers will incentivize participation in the email by allowing participants to sign up for a random draw for a \$25 Amazon gift card. The open-ended survey will ask questions about the participants' intent to implement communal coping strategies, such as, "How do you plan to utilize the information you learned about communally coping with EDS in the future?" or "How might you and your partner act like EDS is your shared problem in the future?" The survey will also ask about what the participants thought about the campaign, such as asking, "How helpful or useful was the information you learned in the workshop?" After conducting the email interviews and collecting data, the interviews will be transcribed. The data will be analyzed using a thematic analysis in order to see how the participants (could be one or both members of the couple) plan on implementing what they learned in the campaign about communal coping.

References

- Afifi, T. D., Hutchinson, S., & Krouse, S. (2006). Toward a theoretical model of communal coping in postdivorce families and other naturally occurring groups. *Communication Theory, 16*(3), 378-409. <https://doi.org/10.1111/j.1468-2885.2006.00275.x>
- Buzzanell, P. M. (2010). Resilience: Talking, resisting, and imagining new normalcies into being. *Journal of Communication, 60*(1), 1-14. <https://doi.org/10.1111/j.1460-2466.2009.01469.x>
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*, 310–357. <https://doi.org/10.1037/0033-2909.98.2.310>
- Ehlers-Danlos syndrome*. Mayo clinic. Retrieved March 1, 2020, from <https://www.mayoclinic.org/diseases-conditions/ehlers-danlos-syndrome/symptoms-causes/syc-20362125>
- Gellert, P., Hausler, A., Suhr, R., Gholami, M., Rapp, M., Kuhlmeier, A., & Nordheim, J. (2018). Testing the stress-buffering hypothesis of social support in couples coping with early-stage dementia. *Plos One, 13* (1), e0189849. <https://doi.org/10.1371/journal.pone.0189849>
- Helgeson, V. S., Jakubiak, B., Van Vleet, M., & Zajdel, M. (2018). Communal coping and adjustment to chronic illness: Theory update and evidence. *Personality and Social Psychology Review, 22*(2), 170-195. <https://doi.org/10.1177/1088868317735767>
- Lyons, R. F., Mickelson, K. D., Sullivan, M. J., & Coyne, J. C. (1998). Coping as a communal process. *Journal of Social and Personal Relationships, 15*, 579–605. <https://doi.org/10.155/004940>

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The Ehlers-Danlos Society. *What are the ehlers-danlos syndromes?* Retrieved from

<https://www.ehlers-danlos.com/what-is-eds/>

The Ehlers-Danlos Society. *2020 global learning conference-arizona*. Retrieved from

www.ehlers-danlos.com/2020-arizona/

Thompson, T. L., Parrott, R., & Nussbaum, J. F. (2011). *The Routledge Handbook of Health Communication* (2nd Ed.). New York: Routledge.

WHO. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference; New York. 19–22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

https://www.who.int/governance/eb/who_constitution_en.pdf