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"It will go away": A descriptive qualitative study about unwelcome and bad advice in chronic conditions

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ABSTRACT

Background: More than half of Americans lived with at least one chronic condition in 2018 and more than one-quarter lived with multiple chronic conditions. Many individuals with chronic conditions report receiving unsolicited and, often, bad advice from non-medical professionals, including family, friends, and even complete strangers. Aim: The purpose of the present study was to investigate the bad and unwanted advice that individuals with chronic conditions receive from non-medical professionals. **Methods:** We used a descriptive qualitative approach to investigate our research questions and collected qualitative responses using a Qualtrics survey. Participants included 45 individuals over the age of 19, who identified having at least one chronic medical condition. Results: Using an inductive process through thematic analysis, we found four overarching themes: (1) bad advice, (2) responses to bad advice, (3) impact of bad advice on relationships, and (4) an unchanged response, as well as several subthemes. **Discussion**: Overall, findings suggested that while advice-givers tended to have good intentions, they were perceived as uneducated about chronic conditions. Participants expressed feelings that the advice was unhelpful and, in some cases, potentially harmful. **Conclusions:** The findings contribute new knowledge to the area of chronic conditions and bad advice received from non-medical professionals.

KEYWORDS

Bad advice, chronic health conditions, descriptive qualitative research, unsolicited advice.

BIOGRAPHIES

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Introduction

The Centers for Disease Control and Prevention (CDC) defines chronic health conditions as "conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both" (CDC, 2022). According to the CDC, more than half of Americans lived with at least one chronic condition in 2018 and more than one-quarter lived with multiple chronic conditions (Boersma et al., 2020). Many individuals with chronic conditions report receiving unsolicited and, often, bad advice from non-medical professionals, including family, friends, and even complete strangers (e.g. Carrell, 2016; Davidson, 2020; Maran, 2007). Poor medical advice from nonmedical professionals can be unsupportive and annoying at best and dangerous at worst (e.g. Cole et al., 2016). Additionally, unsolicited and bad advice is often unwanted and may have a negative impact on the relationship between the advicegiver and the advice-receiver (e.g. Bar-Or & Meyer, 2018; Landis et al., 2022). Yet, there is a dearth of research about the bad and unwanted advice that individuals with chronic conditions receive. The present study's purpose was to examine the bad health-related advice received by individuals with chronic conditions from nonmedical professionals.

Literature review

Chronic conditions and communication

Existing research into chronic health conditions and communication has been concentrated in a few areas. Much research has focused on patients' and their families' ability to cope with the condition itself (e.g. Hatchett et al., 1997; Mamba & Ntuli, 2014; Revenson, 1994); or on the effects of chronic conditions on the patients' lives (e.g. Beatty, 2012; Beatty & Joffe, 2006; Stage, 2022; Whittemore & Dixon, 2008). Other research has investigated the relationships between patients and healthcare providers (e.g. Glasgow et al., 2003; McCorkle et al., 2011; Thorne et al., 2004). However, existing research into the effects of chronic health conditions on communication has rarely addressed the impacts of advice.

Much of the research thus far that focuses on advice has concerned advice that was (a) solicited from (b) either other patients or healthcare professionals. For example, researchers have found that patients seeking out advice from medical professionals online prefer advice components to be presented in different orders depending on the provider's medical specialty (Wu et al., 2023). Other researchers have focused on the social support and connections available to patients in online communities or face-to-face support groups (e.g. Huh & Ackerman, 2012; Huh et al., 2014; Karlsson, et al., 2024; Rueger et al., 2020). These communities allow patients to seek out advice, information, and emotional support from other patients with the same or similar conditions. The fact that advice received in these communities is provided by other patients differentiates it and its effects from advice received from friends, family, or other non-professional sources in that the patients are perceived as having higher credibility and greater

'standing' to speak on the subject. Furthermore, since advice from healthcare professionals or organized communities is sought out by the advice-receiver, it is likely to be received more positively than unsolicited advice would be.

Where research has looked at communication and relationships with family and friends, it has found that chronic conditions can have negative impacts on those relationships (Tran et al., 2015). Patients have reported feeling blamed by others for their conditions (Mahon et al., 2014), feeling that their loved ones "overdo" things in trying to provide support, and feeling frustrated at the need to repeatedly explain their condition to loved ones (Tran et al., 2015). Additionally, patients report feeling a need to take control of their own lives, treatments, and health (Mahon et al., 2014). One investigation into social support provided to patients with chronic conditions found that better social support (measured with a composite scale including informational support) led to more social activity but had few other effects after controlling for patient demographics, illness, and stress (Curtis et al., 2004). A synthesis of qualitative studies on self-management of chronic conditions concluded that, for some patients, advice and input from loved ones had negative effects, feeling to the patient "like a form of social control" (Dwarswaard et al., 2015, p. 199). In general, instrumental and emotional support from relatives was appreciated, but informational support was preferred to come from providers or from other patients.

Bad health related advice

A chronic health condition has implications for many aspects of a patient's life, including their relationships with others. However, while researchers have investigated the effects of having chronic conditions on interpersonal relationships, there seems to be limited information regarding the effects of communication surrounding that condition on the relationship or on the patient. Also, there is a lack of information surrounding health-related advice, particularly health-related advice, that is (a) unsolicited, (b) offered by non-health providers and non-patients, and (c) considered poor quality. It should be expected that such advice would be understood differently by recipients and would affect recipients differently when compared to advice from high-credibility sources like healthcare providers or patients with the same condition. To improve our understanding of bad health-related advice, we seek to answer questions regarding the nature of that advice:

RQ1: What sort of unwanted and bad health-related advice do people with chronic health conditions receive?

the impact of that advice on the giver-recipient relationship:

RQ2: How does this bad and unwanted advice affect the relationship between the recipient and the advice-giver?

and the recipient's understanding of that advice:

RQ3: How do participants with chronic health conditions understand the unsolicited health advice they receive?

Methods

This study presents a descriptive qualitative analysis of responses to a short-answer online survey. We used descriptive qualitative methodology (Doyle et al., 2020) to answer research questions. In descriptive research, "The researcher does not manipulate any of the variables but rather only describes the sample and/or the variables" (Siedlecki, 2020, p. 8). Despite the documented usefulness of qualitative approaches in exploring health-related topics (Al-Busaidi, 2008; Britten, 2011; Ngenye & Kreps, 2020), there is a dearth of qualitative research within the area of health communication. A qualitative approach is ideal when limited previous research exists about a topic area (Creswell & Poth, 2018; Schonfeld & Dreyer, 2008). We selected a descriptive approach specifically because it is an ideal starting point to answer research questions (i.e. about participants' experiences of receiving bad advice from non-medical professionals) which have not been explored in previous research (Doyle et al., 2020; Sandelowski, 2010) as in the present study. Additionally, we selected a descriptive approach because findings are data driven and developed inductively, through an iterative process (Doyle et al., 2020; Lambert & Lambert, 2012; Saldaña, 2021). This inductive process allows for findings to be derived directly from the data and occurs by first identifying open codes and then sorting those codes into emergent themes (Saldaña, 2021).

Participants

Participants were 45 individuals who met eligibility criteria. The chronic conditions experienced by participants are summarized in Table 1. Participants varied in age (M = 48.1, SD = 14.0), included more women (n = 27) than men (n = 17), were mostly white (n = 38), and were primarily in a relationship or married (n = 30). Participants were well-educated, with 73.3% having earned at least a 2-year college degree. Participants' median household income was \$45,000 (SD = 94,633).

Table 1. Frequencies of chronic conditions

Condition*	Count
Depression	19
Diabetes	19
High Blood Pressure (Hypertension)	19
Arthritis (Rheumatoid and Osteoarthritis)	11
High Cholesterol (Hyperlipidemia)	8
Heart Failure/Disease	7
Autism Spectrum Disorders	4
Drug/Substance Use Disorder	4
Asthma	3
Cancer	3
Chronic Kidney Disease	3
Obstructive Pulmonary Disease	3
Schizophrenia / Other Psychotic Disorders	3
Other**	37

^{*} These categories are not mutually exclusive.

** Participants had the option of specifying any other chronic conditions not listed.

Participant recruitment and materials

Individuals were recruited using purposive sampling techniques, which is appropriate for a descriptive qualitative approach (Doyle et al., 2020; Palinkas et al., 2015). We invited participants to complete a short-answer Qualtrics survey using an email distribution list and social media. When these initial recruitment approaches failed to result in more than a few participants, we chose to recruit additional participants through Prolific. Prolific allows researchers to recruit participants online. Users are required to verify their identity and can be recruited based on demographics. The study was made available to adult participants living in the United States who indicated that they lived with at least one chronic condition. Participants' responses to essay questions were used to judge the quality of the response (e.g. screening for irrelevant or nonsensical answers) and none needed to be rejected from the dataset. Each participant was paid \$4.00 USD for completing the study. In total, 40 were recruited through Prolific and 5 through other methods.

Participants were asked to answer a short survey consisting of 5 essay questions and 19 quantitative questions. The essay question component of the survey was designed to elicit detailed descriptions of bad advice received by the participant (i.e. questions asking for "types of bad advice" and "the worst piece of advice" each participant received from non-medical sources regarding their condition) and the circumstances surrounding that advice (i.e. descriptions of the participants' response, any impact on their relationship with the advice-giver, and how the participant views the advice looking back on the advice now.). The quantitative questions asked about the participants' feelings regarding their condition(s), descriptions of their condition(s), and basic demographic questions. The quantitative questions allowed either for multiple answers (e.g. what specific condition(s) the participant has; gender; race), multiple-choice answers (e.g. frequency of feeling various emotions; feeling of belonging in communities related to the condition(s)), or short answers (e.g. age; household income).

Procedures

Following previous descriptive qualitative procedures, we achieved data saturation, which indicates that we collected an appropriate number of responses (Doyle et al., 2020; Fusch & Ness, 2015). According to Fusch and Ness (2015), data saturation is reached "when there is enough information to replicate the study, when the ability to obtain additional new information has been attained, and when further coding is no longer feasible" (p. 1408). Moreover, Rahimi and Khatooni (2024) defined the concept of code or thematic saturation, which refers to a point at which repetitive themes or codes are identified through analysis. In the present study, we reached code or thematic saturation after analyzing approximately 20 responses, meaning no new codes and therefore, no new themes emerged beyond this point. However, we analyzed all 45 participant responses to ensure validation of our findings and to provide representative quotes for most of them. Additionally, multiple researchers

(Authors 1 & 3) completed data analysis independently and all three researchers discussed the emergent themes, which act as forms of triangulation and help confirm data saturation (Fusch & Ness, 2015).

We used an iterative and inductive process to analyze the qualitative data through thematic coding (Saldaña, 2021; Vaismoradi et al., 2013), facilitated by MAXQDA data management software. Participants' responses from the Qualtrics survey were cleaned and organized into a Word Document. We then used an initial line-by-line review of the data in which we assigned open codes to segments of the text (Saldaña, 2021). Then, we grouped these codes into categories called emergent themes (Saldaña, 2021). For example, codes like meditating, seeing a healer, and using essential oils were grouped under the broader term of alternative medicine, which later became the emergent theme of complementary and alternative medicine (CAM) as a subtheme of bad advice. We met as a group twice to discuss our individual findings and finalize emergent themes presented in this study. While we made minor adjustments to the names of themes during each discussion, researchers agreed overall about the findings of this study and the specific themes and subthemes to be presented. The first and third authors completed the data analysis, and all three authors met to discuss emergent themes.

Ethical considerations and researcher reflexivity

Study approval was obtained from the University of Nebraska at Kearney's Institutional Review Board (IRB) and informed consent was provided to and completed by participants via Qualtrics before beginning the survey. Participant names were not collected and identifying information was removed from the data to protect participant privacy.

Results

In answering the research questions, thematic analysis revealed four overarching themes in the present study: (1) bad advice, (2) responses to bad advice, (3) impact of bad advice on relationships, and (4) an unchanged response. To highlight those themes and subthemes most salient to the present study, we have opted not to discuss all subthemes within the results section. However, we provide a complete overview of all themes and subthemes, with representative quotes in Table 2.

Table 2. Themes, subthemes, and representative quotes

Theme	Subtheme	Representative quote
Bad advice	Medical non- adherence/altering medical advice	"Stop taking prescribed medications because they are bad for me or dangerous."
	Balanced/healthy lifestyle	"Extreme diets or fasting, as miraculous solutions for chronic conditions, even though there's no scientific evidence to back these claims."
	Complementary and alternative medicine (CAM)	"I was told by a friend that I should try getting adjusted by a chiropractor. With rheumatoid arthritis, that can actually be quite dangerous!"

	"I might as well just pack it in and die" (blaming, shaming, and ignoring)	"That my illness is not a big deal. That the illness is not real. Dismissing the challenges outright."
Responses to bad	"I tried explaining" (spoke up)	"I told them that I couldn't do that because it could cause serious problems if my sugar were mismanaged."
advice Avoidance	"[1] politely thanked them for their input, and disregarded it. Continued with therapy thereafter."	
bad advice on	Negative impact	"This encounter with the individual giving me advice made our relationship tense and a lot less favorable."
	Neutral/no impact	"It didn't really impact [our relationship] because this person always gives me bad advice."
An unchanged response	"They had good intentions mostly but"	"I am sure she wanted to be helpful and not harmful. However, she apparently knows nothing about thyroid disease, and she has been swept away with the Keto eating fad. I will continue to ignore her."

Types of bad advice

Participants readily provided long lists of bad, and often unwanted, advice they have received about their chronic conditions. Advice-givers were often family members and close friends, though they were sometimes coworkers or in other cases even complete strangers. Contexts for sharing bad advice included informal gatherings, like having lunch with a friend, and more formal events, such as family holidays. While some participants shared the source of their bad advice and the context in which it was received, we did not specifically ask about the advice giver's relationship to the participants or context in which the advice was shared, which may be a limitation of this study. For most participants, the advice was unsolicited, meaning they were given advice about their health conditions without asking for it. In the present study, our analysis revealed four subthemes or types of bad advice, including (1) medical nonadherence/alterina medical advice, (2) balanced/healthy complementary and alternative medicine (CAM), and (4) "I might as well just pack it in and die" (blaming, shaming, and ignoring).

Medical non-adherence/altering medical advice

Many participants shared advice which encouraged them to alter or ignore medical guidance, particularly related to their prescription medications. For instance, one participant shared, "The worst piece of advice was from someone who advised me to stop taking insulin and instead eat less carbs. The individual didn't seem to understand that as a Type 1 diabetic, if I stop taking insulin, I'll die." Another participant shared, "I was told that my medication was poisoning me and that the meds were why I felt bad." While most participants reported that they did not consider taking this advice, we found it alarming that others may be tempted to take such advice because of its potential for damaging and long-lasting consequences. Additionally, a common thread throughout this study is the lack of understanding about chronic conditions

among advice-givers (e.g. not knowing the difference between types 1 and 2 diabetes).

In addition to advice to completely discontinue medication, other participants received advice to modify use of their medication, such as "half the dosage of your medication so it will last longer" and "if your blood sugar drops suddenly, chug a Coke or grab a Snickers to counteract the effect." Other participants received "suggestions to take medications that [the advice-giver had] tried, or that I should not listen to my doctor because they aren't helping me enough." Many participants received similar suggestions not to listen to medical providers because "doctors don't really care about you and don't get paid enough now to do a good job." We found it concerning that many advice-givers shared distrust of medical professionals, which contrasted with our participants who tended to put the opinions of their healthcare providers above others.

Complementary and alternative medicine (CAM)

As with advice related to leading a healthy and balanced lifestyle (presented in Table 2), advice about complementary and alternative medicine (CAM) may not necessarily be harmful on its own (e.g. advice to try yoga or take vitamins). Yet, participants perceived this type of advice as generally unhelpful and, in some cases, potentially dangerous. Additionally, some advice-givers were perceived as motivated by a desire to sell products, such as essential oils or supplements. Participants expressed feelings of frustration and irritation in such cases. A few participants described CAM practices that could be harmful for them because of their chronic conditions. One participant explained advice that "the best thing for me was massage. This was dangerous because I have [Ehlers-Danlos syndrome] and if I'm handled too roughly my joints could pop out of socket. I was told that the chemicals released during a massage would boost my immune system." Experiences like these highlight how seemingly harmless advice has the potential for damaging consequences when the advice-giver lacks knowledge about the chronic condition. Moreover, examples like these underline the importance of this study as other individuals with chronic conditions may accept such advice.

In many instances, participants described advice to consume specific supplements, such as "try coral calcium and glucosamine" and "take elderberry, double up in vitamin c" and "have IV Vitamin C infusions" and "what supplements I should take so I don't need to take prescription meds any more (seriously!!)" and "...[to take] supplements and shakes that that person is selling." As with other examples provided, advice to take supplements may not be harmful on its own, but it may be irrelevant and/or counterproductive. Additionally, use of supplements falsely suggests efforts at 'magical cures' for these complex and, often, long-lasting conditions. Other participants described misleading advice they received, which suggested that their chronic conditions could be cured by taking specific supplements. One participant shared, "I have hypothyroidism, specifically Hashimoto's disease, and someone online told me that if I would just take iodine supplements there would be no need to take my thyroid medicine anymore." Another participant explained advice which stated, "The best way to cure Type 1 Diabetes is to eat cinnamon or this one magical herb from a remote jungle." These 'cure all' or 'magic bullet' approaches are likely to leave those with chronic conditions feeling frustrated and disappointed. Additionally, the availability of such advice in online forums may perpetuate misinformation and lack of understanding about chronic conditions.

Other participants described a variety of CAM related advice, such as "just meditate" and use "natural oils" and "...drink some tea" and "see a 'Healer'" and "try reiki." The suggestions seemed almost endless and often revealed participants' frustration with irrelevant and unhelpful advice. Some participants described advice based on what worked well for the advice-giver, such as "acupuncture worked miracles for me" or "kombucha cured all my problems." However, in such cases, the advice-giver spoke from experiences that were different from and unrelated to the participant's chronic illness. Unfortunately, this again left participants feeling like they and their illness were unseen and misunderstood. In a few cases, participants described very specific advice which seemed to border on folk remedies. For example, one participant described, "The binding of my stomach while upside down for abdomen pain." Another participant described bad advice received "to blow the smoke of a cigarette into a spoon of milk then drink for acid reflux." And yet another participant described a suggestion to "wrap yourself in Vaseline coated saran wrap." Though such examples of bad advice were given with good intent, these excerpts further demonstrate the potential for harm when advice is given without expertise and understanding of the chronic condition.

"I might as well just pack it in and die" (blaming/shaming/ignoring)

In this final subtheme of bad advice described by our participants, we explore dynamics of advice related to blaming, shaming, and ignoring individuals with chronic conditions. We named this theme using an in vivo code, "I might as well just pack it in and die," a name we believe helps capture the reality of our participants' lived experiences. An overwhelming majority of participants described being dismissed. They were frequently told that their conditions were not real and/or that their conditions would go away if simply ignored. They shared sentiments given such as, "Just let it ride it's course, it will go away" and "It's all in your head, so common and SO WRONG [sic]..." and "To work through the pain. To try and ignore the pain." Such excerpts demonstrate a clear dismissal of chronic illness and of the individual living with it. We were alarmed in some cases to find that such feedback was given by partners or other close family members, which may reflect unhealthy and potentially dysfunctional relationships. We suggest that this reiterates the importance of the present study and may be a pathway for future research. Yet other participants described bad advice including, "That I should still work even though it makes my condition worse" and "It only gets better with time" and "Just push through it." These examples demonstrate a lack of understanding about chronic conditions and also reveal a general lack of empathy for individuals experiencing the consequences of chronic conditions.

Other participants shared accounts which suggested they were to blame for or able to fix their conditions. One participant shared commentary they received that, "People with chronic diseases are the reason that the 'rest of us' are paying extreme healthcare costs." The participant went on to explain that "It was meant to be shaming and infer [my chronic condition] could have been avoided in some way." We suggest that such responses not only lack empathy but are in some ways dismissive of the individual's personal circumstances and their right to respond emotionally to their condition. Other

participants shared similar bad advice received, including "That I need to try harder to go get better" and "...That just talking and being around people will make my anxiety go away" and "...In regards to my mental health struggles (i.e. depression and anxiety), I've had several people over the years tell me all I need to do is go outside and I'll be happy." As with many of the other examples discussed, these excerpts clearly demonstrate a lack of understanding about specific chronic conditions, such as anxiety and depression. The advice is not only potentially harmful (i.e. just "go outside" instead of seeking professional medical help) but again represents a lack of empathy for the individual.

Still other participants described advice which seemed intended to discourage and diminish hope. As one participant shared how someone suggested they seek out "hospice because I didn't want to listen to doctor advice, they thought I might as well just pack it in and die." Other participants shared similar accounts, "That my condition was hopeless" and "I was told to think positively because I am never going to get any better if I just sit around feeling sorry for myself" and "everything happens for a reason." Such examples border on abuse and are likely to have damaging psychological consequences. These excerpts further reflect a lack of empathy and dismissive rhetoric.

Responses to bad advice

Participants shared a wide range of responses to the bad advice they received. Overall, these responses fit into two subthemes: (1) "I tried explaining..." (spoke up) and (2) avoidance. While participants chose two divergent approaches for responding to bad advice, in both cases, participants expressed a sense of frustration and, often, feelings of not being heard or seen by advice-givers.

"I tried explaining..." (spoke up)

The first subtheme, "I tried explaining..." (spoke up), reflects an effort to advocate for oneself and to educate the advice-giver. Many participants shared accounts in which they gently attempted to explain why they could not accept the bad advice. One participant recalled, "I tried explaining my illness and how it affects me. I explained how it leaves me with no energy and when I workout, I can feel way worse. This person did not listen, and I no longer talk to this person." Admirably, these responses tended to demonstrate a sense of compassion for the advice-giver and a willingness to help educate and share knowledge. However, as this excerpt demonstrates, in some cases, advice-givers still chose not to listen, which negatively impacted the relationship. Another participant said, "I stated that much like heart disease, obesity is a chronic medical condition and its treatment should be multifaceted as the causes are complicated and no one answer fits all." This quote helps to articulate the complexity of many chronic illnesses and underscores, in comparing it to heart disease, the seriousness of conditions like obesity.

While some participants provided a more educational response, others focused on self-advocacy. For example, "I smiled and said that I would only take medical advice from my doctor." And, in another instance, a participant shared that they said "... Yeah, I know it's not great, but I'm trying my best and have been making progress in other areas..." In both examples, participants chose to justify their responses to the advice-

givers (e.g. I'm not taking your advice because...) again demonstrating a level of respect if not compassion for the advice-giver. One participant shared how their friends helped empower them to respond to bad advice, "Luckily my disabled friends were with me at the time, and they helped me because they could tell I was frustrated and felt humiliated. I attempted to say that I've tried all kinds of things but ignoring medical advice and refusing treatment that is proven to help with rheumatoid arthritis (RA) had very negative effects on me in the past." This experience helps to demonstrate the power of community and connection with others experiencing similar conditions. While this is not a focus of our study, we suggest that such support through online forums or support groups in addition to other means, may provide a productive outlet for sharing advocacy, empowerment, and more helpful advice.

Impact of bad advice on relationships

Participants discussed how their relationships with the advice-givers were impacted by this bad advice. The different impacts on relationships can be described in two subthemes: (1) negative impact and (2) neutral/no impact. While the bad advice was typically unsolicited, it came from a variety of non-medical sources, including close friends and family members as well as complete strangers.

Negative impact

Many participants shared that receiving bad advice had a negative impact on their relationship with the advice-giver. One participant shared how the advice-giver simply could not accept the participant's response and the ultimate outcome on their relationship, "They accepted it then, but they repeatedly suggested the same types of things, and we are no longer as close." Another participant simply wrote (in all caps) that this exchange "MADE [THE RELATIONSHIP] WEAKER." As with previous findings discussed in this section, the sense of frustration is palpable among our participants. While some participants were initially tolerant of receiving bad advice, many disclosed that the repeated attempts at bad advice and unwillingness to simply listen ended or damaged the relationship.

Many participants expressed feelings of being unheard and unseen, which led to the demise of their relationship. One participant shared their experience:

This encounter from her, and several others related to my condition, impacted this relationship in a negative way. For her to refuse to do the basics of learning about the condition and/or listening to me when I told her what it's like to live with it... like, what are you supposed to do at that point? It made me feel like she wasn't actually paying attention to who I am as a person at all.

As with some of the previous examples, this excerpt suggests the advice-giver's dismissiveness and perceived lack of empathy. Another participant expressed how bad advice damaged her trust with the individual, "It made me trust her considerably less and made me realize she does not understand my condition at all." Overall, we found that several participants experienced a loss of relationship which stemmed from advice-givers' unwillingness to educate themselves about specific chronic conditions or to listen to individuals with chronic conditions.

UNWELCOME AND BAD ADVICE IN CHRONIC CONDITIONS

Though most participants reported that their relationship was negatively impacted or unimpacted, we saw one anomaly in our data. In a single case, a participant noted that their relationship with the advice-giver was strengthened through the exchange:

This encounter had a mixed impact on my relationship with the individual offering the advice. While I appreciated their concern and intentions, I also felt the need to assert my honest conversation about healthcare decisions, ultimately strengthening our relationship.

We make note of this case because of its uniqueness and suggest that positive impacts (e.g. strengthened relationship, higher levels of trust) resulting from bad advice and, more specifically, from conflict that allowed for an honest exchange of ideas, may be an area for future research.

An unchanged response

When asked how participants would change their responses today, given the opportunity, most said they would not change the way they responded. For most participants, they found a way of coping with the bad advice that worked best for them, and they committed to it. As in previous sections, participants often shared sentiments that the advice-givers lacked knowledge about their chronic conditions and, in some cases, lacked empathy. One participant explained, "People are crazy to give such unfounded and unasked for medical advice that would actually harm the person they are supposedly trying to help. I would respond the same way now as I did back then." This quote helps capture the essence of this study in its entirety. While some advice-givers were complete strangers, many were close friends and family members who we presume are likely to have high levels of compassion and empathy for their loved ones. Yet, the bad and unwanted advice (often given repeatedly) demonstrated a lack of empathy and unwillingness to simply listen to their loved ones.

Other participants shared, "I would respond the same. The person was just ignorant and unsympathetic" and another participant who said:

I feel the person giving me advice lacked empathy and understanding of my illness and the suffering that I go through because of it. I feel that the individual's intention was to be mean and uncaring. If I had to respond to this advice now, my response would be the same as before.

While our findings demonstrated overwhelmingly that participants saw the good intention in the advice, some advice-givers were perceived as being purposefully hurtful as this case helps demonstrate. Yet another participant explained, "As I look back now it irritates me because it makes me realize that many people think all types of diabetes are the same. I don't think the advice-giver had bad intentions. I think the individual was simply uneducated. I wouldn't respond differently. In the moment, I think I handled it well." Whether ill-intentioned or not, majority of participants confidently stated that they would not change their response given the opportunity. This is an important finding as it suggests a high level of self-confidence among participants despite facing the challenges of receiving bad and unwanted advice.

"They had good intentions mostly but..."

While many participants expressed frustration with advice-givers' lack of empathy and ignorance about their chronic conditions, most shared how they believed the advice was given with good intent. Accounts included, "The person was trying to help me and doesn't really understand the problem. I'm used to it so I'd respond the same way." Excerpts like these suggest that good intention simply is not enough and does not excuse advice-givers from sharing bad and unwanted advice. Advice-givers should educate themselves and work to respond more empathetically, which starts with listening. Another participant shared:

I think I understand the family member's intention. I don't think it was malicious, but on the other hand I don't think scolding is an effective behavior modification technique for most people, and definitely not for myself. I'm almost guaranteed to react negatively to that.

This excerpt and others like it further demonstrate a lack of empathy as the advice-giver scolded the individual, suggesting that they see this person as infantile and incapable of making their own informed decisions. Yet another participant explained, "I think they had good intentions mostly but some people are just ignorant. I'd probably do the same thing today." Overall participants perceived the good intentions behind the bad advice. Yet, the bad advice worked to frustrate and disappoint. In some cases, it damaged relationships and hurt participants with a lack of empathy, leaving them to feel unheard and unseen. Additionally, it may have led to dangerous outcomes if participants had simply accepted the bad advice at face value.

Discussion

The findings of this study reveal the types of bad and unwanted advice that individuals with chronic conditions receive, common responses to bad advice, how this bad advice impacts relationships with advice-givers, and how individuals would (or would not) change their responses given the opportunity. Though the topic of bad advice received by individuals with chronic conditions has not been widely explored in previous literature, the present study's findings closely align with related health communication research. Work by Tran et al. (2015) and Dwarswaard et al. (2015), which found that chronic conditions may have a negative impact on patient relationships with family members and friends, parallels the present study's finding of a negative impact on relationships resulting from bad advice. Additionally, while not a thematic finding, many participants reported feelings of frustration with needing to repeatedly explain their chronic condition to loved ones which corresponds with the findings from Tran et al. (2015).

The findings of the present study also suggest that most of the bad advice received was unsolicited and unwanted, and came from sources including family members, friends, co-workers, and in some cases complete strangers. Research by Feng and Magen (2016) supports the idea that unsolicited advice can negatively impact the relationship between the advice-giver and receiver. Unsolicited advice is often viewed as inappropriate or unhelpful, and can even exacerbate the advice receivers' "stress, depression, and loneliness" (Feng & Magen, 2016, p. 2). In addition to negatively impacting the relationship, unsolicited advice can negatively impact the likelihood of the advice recipient seeking advice from the advice giver in the future (Feng & Magen, 2016).

Finally, the finding of "I might as well just pack it in and die" (blaming, shaming, and ignoring) as a form of bad advice supports previous work by Mahon et al. (2014)

related to patients feeling blamed for their chronic conditions and adds a new communicative dimension to Stage (2022)'s investigation into feelings of shame experienced by individuals with chronic health conditions. Work by Browne et al. (2013) also supports participants feelings of blame and shame for having a chronic condition. In their research, participants with Type 2 Diabetes shared experiences of interactions with people who said things like, "well you've dug your grave with your own teeth" (Browne et al., 2013, p. 4). Their research supports findings like the present study which highlights how participants may become hopeless and discouraged because of the unsolicited advice and negative perceptions surrounding their conditions.

One potential limitation of this study is the use of surveys to collect qualitative data since it may have restricted our ability to ascertain deeper insights and discern nuances based on participants' experiences. Additionally, recruitment using Prolific may have limited our ability to reach broader populations (e.g. individuals outside of online recruitment forums). We suggest that future research efforts include a variety of recruitment efforts as well as the use of interviewing and/or observational qualitative methods of data collection. Another limitation is the lack of information about who advice-givers tend to be and in what context or settings bad advice is given since we did not specifically ask for this information. Future research projects would benefit from including such questions in their study design. While the purpose of qualitative research is typically not to be widely generalizable, we acknowledge that the small sample size could be another limitation. Past research about chronic conditions has largely focused on patients' and their families' ability to cope with the condition itself (e.g. Hatchett et al., 1997; Mamba & Ntuli, 2014; Revenson, 1994) or on the effects of chronic conditions on the patients' lives (e.g. Beatty, 2012; Beatty & Joffe, 2006; Whittemore & Dixon, 2008). While other research has investigated the relationships between patients and healthcare providers (e.g. Glasgow et al., 2003; McCorkle et al., 2011; Thorne et al., 2004). The present study contributes new knowledge about relationships between advice-givers and advice-receivers (i.e. patients with chronic conditions) and unsolicited advice from non-medical professionals about chronic conditions.

Conclusions

The findings of the present study provide insights about the bad and unwanted advice that individuals with chronic conditions receive from non-medical professionals. While participants perceived that advice-givers had good intentions, the bad advice was viewed as unhelpful and lacking empathy. Additionally, in many instances, the bad advice had potential to be harmful, which underscores the importance of this topic and need for future investigation. Our findings also revealed how participants responded to bad advice and how their relationships with advice-givers were impacted by it. Of note is the potential for future investigation about productive conflict which could lead to an enhanced relationship between the advice-giver and advice-receiver. Finally, we learned that participants were confident in their responses to bad advice, which suggests they maintained a positive self-perception through this exchange.

The findings of this study provide implications for healthcare providers, who may wish to educate patients with chronic conditions about the potential for bad advice from

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non-medical professionals and where to find reliable and accurate resources about their conditions. Moreover, this study may help provide guidance for family members and friends who wish to offer support to someone with a chronic health condition. We suggest more empathic responses would involve listening to the individual, educating oneself about the chronic condition, and deferring advice to medical professionals. We hope the findings of this study offer some insight into the lived experiences of individuals with chronic conditions and that this will lead to more compassionate and empathetic responses.

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