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An Exploration of Health Misinformation in a Facebook-delivered Health Education Intervention

Kelsey Arroyo
kelsey.arroyo@uconn.edu

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Kelsey Marie Arroyo

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Presented by

Kelsey Marie Arroyo, B.S.

Major Advisor_____
Sherry Pagoto, PhD

Associate Advisor_____
Molly E. Waring, PhD

Associate Advisor_____
Anne Oeldorf-Hirsch, PhD

University of

Connecticut 2020

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Committee

Sherry Pagoto, Ph.D., Molly E. Waring, Ph.D., Anne Oeldorf-Hirsch, Ph.D.

UConn Center for mHealth and Social Media

Undergraduate and Graduate Research Assistants

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Table of Contents

I. Acknowledgements……. iv

II. Table of Contents…….. v

III. Abstract…… vi

IV. Introduction……..…… 1

a. Specific Aims ……..……...… 3

V. Methods……..... 4

a. Parent Study……...… 4

b. Content Analysis.……...… 5

i. Participant Engagement Types.……...6

ii. Misinformation……....7

c. Statistical Analysis……...……..… 7

VI. Results……..… 8

VII. Discussion……..….. 9

VIII. References…….... 14

IX. Tables and Figures…… 19

Abstract

Background: Health misinformation is commonly shared on social media but little research has examined how misinformation is communicated and what health messages are most likely to receive misinformed responses on social media.

Purpose: The purpose of this work is to explore the extent to which health misinformation was shared by participants in a private Facebook-delivered health education intervention moderated by a health counselor.

Methods: We used engagement data from a randomized controlled trial of a yearlong Facebook-delivered health education intervention. We conducted a content analysis of 6,016 participant comments (including original posts and replies) to examine the nature of comments (i.e., sharing an experience, opinion, intention, and/or fact), if the comment included misinformation, and the type (i.e., narrative vs didactic) and health topic (e.g., tanning, vaccines) of intervention posts that elicited misinformation.

Results: Six percent of participant comments included misinformation (n=388). Approximately a third (34.6%; n=159) of participants shared misinformation. Most participant comments that included misinformation were narrative style (n=302, 77.8%). A larger proportion of participants replies to didactic intervention posts included misinformation compared to narrative intervention posts (8.1% vs 4.1%; $p<0.0001$). Prevalence of misinformation in replies to intervention posts differed across post topic ($p<0.0001$) with vaccine posts eliciting the most replies with misinformation (30.5%).

Conclusions: While participants share misinformation in professionally-moderated Facebook groups, only a small proportion of comments include misinformation, with vaccines being a topic that accounts for the majority of misinformation. Narrative-based health messages may

deter people from sharing opinions or experiences in opposition to the narrative.

Key Words: health misinformation, social media, health communication, health messaging

Introduction

The Health Information National Trends Survey (HINTS) showed that 68.9% of U.S. adults turned to the internet in their most recent search for health information from 2008-2017 [1]. Social media specifically has become an increasingly popular modality for seeking and sharing health-related information online [2] because users have the ability to communicate and exchange information with others [3] [4]. Because social media users have the autonomy to respond to and share any information they choose, it is important to understand the credibility of the health information they share, how they share it, and the contexts in which it is shared [5]. Some research suggests that health misinformation is prevalent in certain peer led online communities (e.g., anti-vaccine groups) [6] but infrequent in others (e.g., diabetes support groups) [7]. Little is known about whether professionally-moderated online communities also elicit health misinformation from members. The purpose of this work is to explore the extent to which health misinformation was shared by participants in a closed online patient community moderated by a health professional and the type of health misinformation they shared.

Sharing health information on social media is only beneficial to the extent that the information being shared is accurate and credible [8]. The content people share is influenced by their beliefs, which can make them disproportionately attend to information that confirms those beliefs [9] whether that information is accurate or not. A recent review found that misinformation was most commonly shared on social media platforms when users were discussing communicable diseases (e.g., HPV, measles, flu and infections) followed by non-communicable diseases (e.g., cancer, cardiovascular disease) and then diet, nutrition, smoking, and water safety, which elicited a smaller amount of misinformation [10]. YouTube videos about vaccines also share misleading content about the health risks of vaccines [11] and contradict

credible information sources such as the Centers for Disease Control and Prevention [12]. Though research has examined the presence of health misinformation on social media and which health topics provoke the sharing of misinformation, knowledge is lacking about how misinformation is communicated and which health messages provoke the sharing of misinformation.

Health information has been classified by degree of veracity (i.e., accurate, inaccurate, or potentially misleading) [11][13][14][15] but we know little about *how* health information is communicated. Public health experts have highlighted the importance of distinguishing between misinformed narratives (e.g., "I refuse to give my daughter the HPV vaccine") and other misinformed didactic content (e.g., links to non-reputable sources) [16]. While health misinformation is often thought of as false or misleading claims that are communicated like facts (e.g., "The HPV vaccine causes chronic pain"), people can perpetuate misinformation when they share misinformed narratives such as experiences (e.g., "I use coconut oil to protect my skin from the sun"), opinions (e.g., "I personally think marijuana is more addictive than cocaine") , and/or intentions (e.g., "I will not have my child vaccinated when she turns 12") but research has yet to categorize and examine misinformation in this way. Examining how health misinformation is shared in online patient communities could improve our ability to identify all the ways it is expressed and inform counter-messaging efforts.

In addition to examining how misinformation is communicated, understanding the type of health messages that are most likely to receive misinformed responses will help inform health promotion messaging efforts. For example, transportation theory posits that narrative messages can influence attitudes, beliefs and behavior to the extent that the audience identifies with the person whose story is conveyed in the message [17]. A systematic review showed that narrative

messaging is commonly used in interventions for substance use prevention, vaccinations, tanning, injury prevention, and nutrition and physical activity [18]. Given the effectiveness of narrative messaging [19], they may be less likely to elicit opposing, misinformed responses. In the present study we will compare narrative and didactic health messages on the degree to which they elicited comments that contained health misinformation.

Data for the present study came from a randomized controlled trial of a yearlong Facebook-delivered health communication intervention that aimed to reduce mothers' permissiveness to allow their teenaged daughters to use tanning beds [20]. Along with indoor tanning messages, the community received messaging on health topics such as prescription drug abuse, mental health, nutrition and physical activity, vaccines, and mother-daughter communication. Intervention posts were delivered in either narrative or didactic formats. Narrative health messages featured a personal story about a mother or daughter dealing with the relevant health topic, whereas didactic posts contained informational content (e.g., facts, statistics) that was often accompanied by links to articles [20]. Participants were encouraged to post in the group and participate in discussion threads started by the intervention posts. The group was moderated by an experienced health counselor who was also a mother.

The purpose of the present study was to examine participants' comments (original posts and replies) to determine: 1) the proportion of participant comments that contained health misinformation, 2) the proportion of participants who shared misinformation, 3) the proportion of misinformation that was shared by participants in didactic (e.g., facts/statistics) versus narrative form (e.g., experiences, opinions, or intentions), 4) if narrative or didactic intervention posts were more likely to elicit participant comments with misinformation and 5) if the presence of misinformation shared in participant comments differed by intervention post topic. Findings

will lend important insights about how health misinformation is shared and which health topics and message characteristics might elicit more misinformed comments than others.

Methods

Parent Study

The current study is a secondary analysis of the participant engagement data from a randomized controlled trial testing the efficacy of a 12-month Facebook-delivered skin cancer risk reduction health education intervention compared to an attention control Facebook group on prescription drug abuse [20]. The intervention messages leveraged health communication strategies to reduce mothers' permissiveness to let their teenage daughter use indoor tanning. In the intervention condition, 10% of posts addressed indoor tanning and in the control condition, 10% addressed prescription drug abuse, the attention control topic. The remaining percentage of posts in both conditions addressed other health topics such as substance use, vaccines, nutrition, mental health, physical activity, and mother daughter communication or were designed purely to entertain and engage participants (e.g., raffles) to enhance group cohesion and retention. Posts tied in current events (e.g., holidays and relevant news stories) when possible to keep the feed timely and relevant. The intervention also included posts that were designed to encourage participant engagement via likes and comments using strategies such as fill-in-the-blanks, quizzes, and questions. We used participant data from both conditions. Intervention posts were either narrative (n=836, 35.9%) or didactic (n=1,493, 64.1%).

Participants in the parent study consisted of mother-teenage daughter dyads but only mothers participated in the Facebook group. Participants (N=881) were 43 years old (SD=6.6) on average and 82% were non-Hispanic white [21]. To be eligible for the trial, mothers needed to have a daughter between the ages of 14-17 years old. Mothers also had to be able to read English

and have a Facebook account or be willing to create one for the purpose of the study. Eligible participants also needed to provide consent to participate in the study and complete the baseline survey. Mothers and daughters were not required to have a history of indoor tanning to participate in the trial. Daughters also needed to provide consent to participate and have a mother enrolled in the study although they did not have access to the Facebook group. The informed consent notified potential participants that their data could possibly be used for further analyses but that their information would not be identifiable after the parent study. Mothers and daughters in the study completed a survey assessing health-related attitudes, knowledge, and behaviors at baseline, and 6-, 12-, and 18-month follow up. The University of Connecticut, East Tennessee State University and Colorado State University Institutional Review Boards approved this study and all participants provided informed consent.

After the intervention, research staff extracted de-identified engagement data (posts, replies, and likes) from Facebook's Applications Programming Interface (API) using Grytics. Research staff then manually labeled the data with participant ID numbers in order to identify participants.

Content Analysis

We conducted a directed content analysis [22] of participants' comments (i.e., original posts and replies; N=6,016) in response to intervention and control condition posts (N=2,329). We did not examine participant responses to intervention and control condition posts that were solely designed to elicit participant engagement as these posts did not pertain to any health topic (n=602; 20.5% of total intervention posts). Two raters independently coded participant comments to identify participant engagement types (i.e., personal experience, opinion, intention and/or facts) and whether the participant comment conveyed misinformation or not.

We used percent rater agreement and kappa to determine inter-rater reliability for participant engagement types and sharing of misinformation. The two coders discussed any participant posts that were discrepantly coded to reach consensus. Coders had 90.1% agreement (κ=0.83 [95% CI: 0.80-0.86]) when coding participant posts as personal experiences, 84.9% agreement (κ=0.69 [95% CI: 0.65-0.72]) when coding opinions, 92.7% agreement when coding intentions (κ=0.69 [95% CI: 0.64-0.75]), and 89.6% agreement when coding facts/information (κ=0.49 [95% CI: 0.43-0.56]). When coding participant posts as narratives with misinformation (e.g., personal experiences, opinions, intentions) or not, coders had 93.9% agreement (κ=0.61 [95% CI: 0.53-0.68]). Coders had 96.9% agreement when coding facts/statistics as misinformation or not (κ=0.31 [95% CI: 0.15-0.47]).

Participant Engagement Types. First, we coded participant comments as sharing an experience, opinion, intention and/or fact based on previous work [4]. Participant posts were coded as sharing an experience if the participant shared a situation she had been in (e.g., "I told my doctor I didn't want my daughter to get the HPV vaccine and she agreed with me") or something she has done before (e.g., "I wear SPF daily"). Sharing an opinion was defined as the participant sharing her personal point of view, judgement, outlook, or belief about a topic (e.g., "I don't think the HPV vaccine is effective"). We coded participant posts as sharing an intention if they stated how they would carry out an action in a hypothetical situation or stated something that they planned to do (e.g., "I would let my daughter and her friends drink alcohol at my house"). Participant posts were coded as sharing facts/information if the participant shared information, facts, and/or statistics about any topic (e.g., "The flu vaccine was only 33% effective last year"). As posts could include multiple statements (e.g., sharing an experience and

stating an intention), we coded whether each post included each engagement type as "yes" or "no".

Misinformation. We coded participant posts as either sharing misinformation or not. Health misinformation was defined as sharing an experience, opinion, intention, and/or fact that went against laws, guidelines, standards (e.g., "You can use tanning beds at any age in Connecticut") or is not supported by scientific evidence, meaning it simply has no scientific evidence to support it or goes contrary to scientific evidence (e.g., "I think vaccines cause autism"). Coders followed a health misinformation check protocol if they were unsure if participant posts shared misinformation or not. This 2-step process included 1) checking if the health information met health standards/guidelines and public health expertise by searching online for information about health topic recommendations made by state and national level health agencies (e.g., CDC, NIH, and NCI) and 2) searching for the support of the health information in peer-reviewed scientific research (e.g., PubMed).

Statistical Analysis

We used SAS 9.4 (SAS Institute, Cary, NC) for analysis of quantitative data. We reported the overall number of participant comments (original posts and replies). We calculated the proportion of participant comments that included misinformation. We calculated the percentage of participants who shared misinformation at any point during the intervention, and the number and percentage of comments that included misinformation for each participant. As these numbers were skewed, we described distributions with median and inter-quartile range (IQR). We reported the proportion of misinformation that was shared in the form of facts/statistics versus experiences, opinions, and intentions. We compared the proportion of participant replies to narrative versus didactic intervention posts that included misinformation using Pearson's chi-

squared tests. Lastly, we compared the proportion of participant replies to intervention posts that included misinformation in relation to intervention post topic using Pearson's chi-squared tests.

Results

Topics of intervention posts included mental health (n=470, 20.2%), mother-daughter communication (n=468, 20.1%), substance use (n=346, 14.9%), healthy lifestyle (n=327, 14.0%), indoor tanning (n=241, 10.3%; intervention condition only), prescription drug (n=233, 10.0%; control condition only), vaccines (n=86, 3.7%), safety (e.g., safe driving, relationship violence, gun safety) (n=71, 3.0%), general health (n=66, 2.8%) and media literacy/technology (n=21, 0.9%). We did not include intervention posts designed to solely elicit engagement (n=602).

In the 12-month intervention, participants posted 93 original posts and 7,979 replies. We excluded participant comments that were in response to engagement type posts (n=2,045) and participant comments (n=11) that were no longer accessible in the Facebook group at time of abstraction, resulting in an analytic sample of 6,016 participant comments.

Very few participant comments included misinformation (n=388; 6.4%). Of participant comments with misinformation, only one original participant post had misinformation while 387 replies included misinformation.

Participants who engaged in the Facebook group (N=459) shared a median of 4 comments (IQR: 2-13; range: 1-272) over the yearlong intervention. Approximately a third of participants shared misinformation at least once over the course of the yearlong intervention (n=159, 34.6%). Participants who shared comments with misinformation shared a median of 1

comment with misinformation (IQR: 1-4; range: 1-17). Participants shared misinformation in a median of 12.5% (IQR: 6.3%-25.0%; range: 0.7%-100%) of their comments.

A majority of participant comments that shared misinformation were expressed narrative style (n=302, 77.8%), 11.9% (n=46) were didactic style, and 10.3% (n=40) included both narrative and didactic content (Table 1).

A greater proportion of participant replies to didactic intervention posts (n=311, 8.1%) included misinformation compared to participant replies to narrative intervention posts (n=76, 4.1%; $p<0.0001$). The proportion of participant comments that included misinformation differed by intervention post topic ($p<0.0001$; Figure 1). Vaccine posts elicited the most misinformation from participants (n=58, 30.5%), followed by indoor tanning (n=54, 11.5%), substance use (n=113, 11.1%), healthy lifestyle (n=66, 7.7%), general health (n=10, 6.3%), prescription drug (n=32, 6.1%), safety (n=7, 5.0%), mental health (n=30, 3.1%), mother daughter communication (n=17, 1.3%), and media literacy/technology posts (n=0, 0.0%; Figure 1).

Discussion

Findings revealed that participants shared some but very little health misinformation in a professionally-moderated health education Facebook group for mothers of teenage daughters, with 6% of participant comments including some form of misinformation. While third of participants shared misinformation, the typical participant who shared misinformation during the intervention only shared 1 comment that included misinformation, representing 12.5% of their total comments. Misinformation was expressed via narratives in 77.8% of comments with misinformation which is concerning given literature showing that narrative messages can be effective at influencing attitudes and behavior [17]. Didactic intervention posts elicited a greater

proportion of participant comments that included misinformation than did narrative intervention posts, and the proportion of participant comments that included misinformation varied by intervention post topic, with vaccine-related intervention posts being the most likely to elicit misinformation. Studies of participant engagement in online communities can provide important insights about how health misinformation is shared online and the characteristics of health messages that elicit it.

The proportion of participant comments that included misinformation differed by intervention post topic. Our finding that vaccine posts elicited the most misinformation from participants is consistent with findings from previous studies showing that vaccine misinformation and anti-vaccination information is commonly spread in social media [10][11][23]. The spread of vaccine misinformation even in a private community moderated by a professional health counselor is evidence of the reach of the powerful anti-vaccination movement on social media [24]. Vaccine messaging by public health organizations is often in didactic form (e.g., statistics, research, and facts) although this may not be an effective strategy to change vaccine-hesitancy in parents [25]. Some examples of misinformed participant posts include, "I refuse to let my daughter get the HPV vaccine" or posting a link to a retracted journal article that supported the relationship between vaccines and infertility in young women [26]. Future research should examine how messenger and message characteristics elicit misinformation sharing about vaccines as anti-vaccination sentiments and vaccine misinformation is still shown to be a major public health issue.

Our finding that a smaller proportion of participant replies to narrative intervention posts included misinformation compared to replies to didactic intervention posts is consistent with previous studies showing that narrative messages are powerful in combatting misinformation

[27] [28]. Skeptics might be less inclined to respond to narrative posts with misinformation for fear of appearing insensitive or lacking in empathy in front of the group. For example, one narrative intervention post was a video of a tearful mother who had lost her daughter, an avid tanning bed user, to melanoma. A person who enjoys tanning beds or believes they are healthy might be disinclined to use this post as a moment to defend tanning beds compared to a post that simply presented statistics connecting tanning bed use to melanoma. Narratives might be useful for promoting mask wearing during the COVID-19 pandemic given the existence of misinformation on this topic [29]. Our findings amplify the importance of narrative techniques to deliver evidence-based health information on social media to improve health-related knowledge, attitudes, and behavior as well as to combat the misinformed beliefs people have about certain health topics.

A majority (78%) of participant comments with misinformation were shared in the form of narratives. This finding is consistent with research showing that social media is a space in which people use narratives to reject or replace scientific evidence [19] [28]. Sharing misinformed narratives in the form of experiences, opinions, or intentions (e.g., "My daughter and I use indoor tanning before going on vacation to give us a base tan and we don't burn") might be more common than sharing inaccurate facts as they might believe a narrative is still credible even if it contradicts scientific evidence. Participants may put forth narratives because they think their experiences might help others or they have also discovered they encounter less resistance when they communicate in this way compared to when they share what they believe to be facts. Narratives are often emotion-laden, which gives those messages the power to mislead others and provoke mistrust in the scientific community [10][19][28]. Further research could examine the sentiment of misinformed narratives in private online groups to understand the

impact they might have on the development of misinformation echo-chambers [28] and the health-related attitudes and beliefs of others.

We also found that 34.6% of all participants who shared comments during the intervention shared comments with misinformation and that most participants shared very few comments with misinformation. Moderators of online patient communities are encouraged to communicate with participants in social media delivered interventions [30]. The ways they engage with participants could differ depending on if the participant shares misinformation once in a while versus sharing it often. Research has shown that patients think moderators of online communities play a critical role in providing medical information [31] but it could be more acceptable for the moderator to correct a participant who shares misinformation once in a while versus correcting someone who shares it more often. For example, someone who occasionally shares misinformation may be more open to receiving evidence-based information from the moderator if they randomly come across misinformation and share it whereas someone who shares misinformation often could have misinformed health-related beliefs and attitudes making them less open to being corrected by a moderator. These findings can encourage public health researchers to be aware of who is sharing misinformation in their online studies and how often this takes place as this could inform counter-messaging efforts in online communities.

This study has limitations. Our study only included mothers of teenage daughters so our findings may not be representative of how misinformation would be shared in a group led by health counselors if this study were conducted with U.S. adults with broader demographic characteristics, however the sample was recruited from 34 states which increases geographic generalizability. A majority of participants were also non-Hispanic white which may not be

representative of all mothers of teenage daughters across the U.S. given the growing racial and ethnic diversity of parents in the United States [32].

Engagement data from a health communication intervention moderated by a professional counselor allowed us to examine the extent to which health misinformation was shared by participants, how they shared it, and the type and topic of intervention posts that elicited misinformation from participants. Our findings could inform public health professionals about which message characteristics (i.e., narrative/didactic) and health topics are more or less likely to elicit misinformation sharing in online groups even when health professionals are present and active in group interactions. Future research is still necessary to evaluate the effectiveness of using certain message and messenger characteristics on combatting the spread of misinformation even in spaces where health professionals are present.

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Tables and Figures

Table 1. Examples and frequency of participant posts and comments that included misinformation by how misinformation was shared in a Facebook-delivered health education intervention

Type of Misinformation	Example	n (%)
Narratives		302 (77.8%)
Personal Experience	"(I use) coconut oil…shhh…don't tell the sunscreen companies!!"	
Opinion	"I don't think tanning is bad for you if you do it once or twice"	
Intention	"If my daughter did want to drink I would allow it but definitely not all the time and not in excess."	
Facts/Information	"Tanning in beds does help prevent sunburn on vacation."	46 (11.9%)
Both	"I'm not letting my daughter get the flu vaccine it was only 33% effective last year"	40 (10.3%)

Figure 1. Percent of participant comments that included misinformation by intervention post topic in a Facebook-delivered health education intervention