



# Searching for Community and Safety: Evaluating Common Information Shared in Online Ex-Vaxxer Communities

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**Abstract.** This study examines a collection of artifacts passed on from some closed Facebook groups of anti-vaxxers. The study conducted a thematic analysis to determine whether or not the group is a community of practice, evaluate and categorize the types of information shared in these groups, and determine the sources of over 1,100 links across two compiled documents to address a series of questions related to claims of ex-vaxxers when compared to anti-vaxxers and the types of data commonly referenced. Findings indicated that ex-vaxxers and anti-vaxxers have separate and distinct claims, abstracts are the most commonly shared scholarly document, and select information is most often taken out of context. This data set can be analyzed for valence and language use in future studies. The purpose of this study is to evaluate information shared in among anti- and ex-vaxxer parents. This study does not seek to validate a specific position or point of view, nor does the researcher want to explore or determine correctness of beliefs.

**Keywords:** Anti-vaxxer · Health information sharing ·  
Community of practice · Support group

## 1 Introduction

Many parents want the best for their children. This includes their health and safety as well as emotional well-being. What happens when you believe in the power of science and vaccines, but you watch your child have a violent reaction or become “vaccine damaged” as a result of a vaccine injection (Anonymous, personal communication, July 21, 2018)? This is an uncommon occurrence for many parents, but it does happen [6]. While it is not an experience that may make parents become anti-vaxxers (those who do not believe in immunization or the current vaccination schedule), it is an experience that makes some question what is in vaccines, the vaccine schedule in their country, and barriers to

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vaccination research. This community of parents is called ex-vaxxers, and the community is growing in number as they experience first-hand the reactions their children have to vaccines.

To date, no literature about a schism in the anti-vaxxer community in the United States exists, and scholarly research exploring anti-vaxxers and the information they share is a growing field. This study first seeks to identify the beliefs of the ex-vaxxer community and compare these with the beliefs of the anti-vaxxer community. Next, this study examines a small subset of compiled documents to determine the nature of information shared to conclude whether or not the information is scholarly research. Finally, this study identifies whether or not these closed Facebook groups are communities of practice.

Since many ex-vaxxers still believe in the concept of herd immunity, which is the need for a percentage of the population to be immunized against viruses and bacteria for the survival of the community ([13]), their desires and motivations appear to be different from anti-vaxxers. Next, this study explores whether or not the ex-vaxxer community is a community of practice with claims distinct from the anti-vaxxer community. Whereas anti-vaxxers spread conspiracy theories, disinformation, and misinformation about vaccines on social media ([40]), the demands of ex-vaxxers include the need to research safer adjuvants and other additives in vaccines that do not react with unique allergies [3]. Finally, a thematic analysis was performed on a data set passed on from a member of several ex-vaxxer Facebook anti-vax groups to determine if the data is peer reviewed or consists of unfounded claims.

The purpose of this study is to evaluate information shared in the anti-vaxxer community. This study does not seek to validate a specific position or point of view, nor does the researcher want to explore or determine correctness of beliefs.

## 2 Literature Review

It should be noted that a prevalence for conspiracy theories exist in the anti-vaxxer community. As Stein writes “Conspiratorial beliefs have become endemic among anti-vaccination groups” [40]. Stein lists several common conspiracies spread on social media today including the belief that airlines inoculate passengers through the ventilation system on planes. Opposition to vaccination is not new. This opposition dates back to the Victorian age and since the 18th century, fear and controversy accompanied the introduction of every new vaccine.

### 2.1 Language

Fear language is common in anti-vaxxer literature. When talking with new or young mothers, in “Recovering Trust,” Boser explains that anti-vax beliefs are rooted in fear. In her conversations with mothers and analysis of literature to convert anti-vaxxer to pro-vaxxers, Boser writes, “The implied danger is mainstream medicine. Medical professionals were said to be ‘authoritarian’... and medicine an ‘impersonal monolith’...Mothers recount fear and a fundamental need to protect

their children from the unnecessary poisons present in vaccines” [5]. A fear was also found when discussing the possible reporting of outbreaks on university campuses [35]. Also, fear and fear-based decision-making is the focus of Guillemond’s paper on addressing concerns about vaccines in writing [15].

Other papers that have examined the claims of the anti-vax community include Kata’s research about tropes and tactics of the movement as a whole [23], Murakami et al.’s visualization of argument analysis in vaccination debates [31], Nichols’ information credibility analysis [32], and the importance of patience when discussing vaccines with a member of the anti-vax community [10]. While these are interesting approaches to researching engagement with anti-vaxxers, none are cited by the community itself.

One study examining the language of anti-vaxxers in debate examines the use of science language in context in a Facebook post. This research about the comment thread accompanying an image posted by Mark Zuckerberg, Facebook CEO, is by Faasse, Chatman, and Martin (2016). Referenced often in anti-vax documents, this study superficially reinforces the narrative that anti-vaxxers are well-researched. The researchers, however, found that, “Although the anti-vaccination stance is not scientifically-based, comments showed evidence of greater analytical thinking, and more references to health and the body. In contrast, pro-vaccination comments demonstrated greater comparative anxiety, with a particular focus on family and social processes” [12]. It shows that anti-vaxxers can reference information but not necessarily that it is properly understood or interpreted. Additional research in health information sharing led to the development of the following question:

*Are the claims of the anti-vaxxer community different from the claims of those who identify as ex-vaxxers?*

It is worth examining social media and health information trends in order to situate the current landscape.

## 2.2 Health Information and Social Media

Sharing health concerns and health information on social media platforms is growing, and so is this area of research (e.g. [26]). Not only do people share their personal experiences with family, followers, and friends in social networking sites, they also reach out to try to create change in their communities, seek support and share information. Facebook groups are one such example. Ilhan [22] explores why users join fitness groups on Facebook from a uses and gratifications perspective. In addition, some niche platforms exist for solely for this purpose. Cancer care ([cancercares.org](http://cancercares.org)) for example, is one such site where the goal is to get support from a community for cancer survivors, those in treatment, and caregivers of those living with or recovering from cancer. Research on cancer support groups is growing, as can be seen in [4] and [20]. Another group that seeks online support and knowledge sharing is the anti-vax community.

Some of the data shared in this community includes the Vaccine Adverse Event Reporting System (VAERS) (see [6, 9, 47] for more information), the economy of vaccines [28], and compiled documents with links to information about

vaccines, vaccine injury, and vaccine research. Included in this list is also misinformation about vaccines. Research about health information sharing led to the development of the following question:

*What types of information are shared in ex-vaxxer communities?*

Information is shared in these groups to educate, so it is worth evaluating whether or not these groups can be considered communities of practice.

### 2.3 Communities of Practice

Communities of practice are peer to peer groups that focus on knowledge-sharing and problem solving and are driven by the participation of a willing membership [37]. Wenger-Trayner and Wenger-Trayner [43] define a community of practice as "...[a] group of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly" (2). Some ways in which a community of practice might emerge are to exchange data or knowledge or accomplish a task. These groups engage in continuous communication in order to create a sense of belonging where it is safe to discuss or try to change a given "area of shared inquiry" (1). Communities of practice also provide a social aspect for their membership. This may include creating and sharing biographies or profiles or directories, facilitating online meetings, or nesting subgroups in online forums.

In many ways, Facebook is a wonderful platform for communities of practice. The Group feature allows like-minded people to gather together around ideas, causes, concepts, or events. Park, Kee, and Valenzuela examined uses and gratifications in a 2009 study of college students in Facebook groups. They found that gratifications varied based on engagement and relationships, but participants who were willing to get involved in an online community were satisfied overall [33].

In addition to evaluating Facebook groups for gratification, several studies have examined the effectiveness of Facebook groups as communities of practice (e.g. [44]). Duncan and Barczyk examined using a Facebook group in conjunction with a class in a university setting. Social learning and a sense of belonging were enhanced, but the community of practice was not statistically significant when compared with other classes that only met face to face [11]. Pi, Chou, and Liao evaluated knowledge sharing, an important aspect of a community of practice, in Facebook groups [34]. Research about communities of practice led to the development of the following question:

*Can the anti- or ex-vaxxer community be considered a community of practice?*

In the 2013 study, the group dynamics of information sharing were evaluated. Findings indicated that "...reputation would affect knowledge sharing attitude of Groups members and sense of self-worth would directly and indirectly (through subjective norm) affect the attitude" [34]. While Duncan and Barczyk showed that sharing information was enriched because of the connection afforded by Facebook groups, Pi, Chou, and Liao found that information is only as respected

as the user sharing it. This may become problematic in groups where misinformation is frequently shared to maintain group norms (see [19] for information about knowledge management). Exploring these questions led to the development of this study, which employs a grounded approach to data collection and interpretation.

### 3 Methods

To evaluate the first research question, a grounded approach using open coding and thematic analysis of the data set passed on from an informant in several closed anti-vax Facebook groups was conducted. This analysis catalogued and counted the types of media passed on over a six-week period from July 19, 2018 to August 31, 2018. The informant volunteered to pass on information from these groups because it is understood that entry is difficult to obtain, and questions about group activity are closely monitored [1]. In addition, because the informant is an active participant in this community, certain information was selected to be passed on for its value in one or several of the communities. This data set, called the Original data set, consists of memes, scholarly articles, vaccine inserts, messages about interpretation or information and context to frame certain articles, videos, newspaper articles, and infographics.

This collection was sorted into a table to identify specific type and count information using thematic analysis. The information collected in this thematic analysis was the author name, type of content, year it was published, country of origin (where the research took place or the location of the first author), where the research was published, the title, whether the information was the full version or an abstract or abbreviated in some way, whether the information is open access or accessible without a paywall, if the source was peer reviewed, the subject or tags or keywords identified, and the conclusion of the argument. The data set was then examined further.

After the information was sorted, the scholarly articles were checked to determine whether or not the study was retracted or edited and whether or not the journal is peer reviewed. This information was then evaluated by descriptive statistics. Another subset of data, the compiled documents, were then evaluated for nominal variables. Content in tables were listed in the order in which they first appeared.

Several collections of data are shared in these groups. They are accessible as Google Docs, as a collection of links and quotes housed on an external resource server. Some are partially accessible with most hidden behind a paywall. These documents are shared among members of the Facebook groups and are generally deemed credible. These compiled documents were evaluated to determine the accuracy of source information. Links were coded by source type using a thematic analysis and open coding approach.

In addition, some links on one document, Vaccine File, had claims either preceding or following links. These claims were evaluated in the surrounding links to determine whether the information could be identified or if it was unfounded

based on its presence or absence in the linked source. This was determined by copying and pasting a quote in Vaccine File and searching for the quote using the Find or Search feature in the abstract, article, or web page.

One researcher read for stated claims and beliefs held by anti-vaxxers in publicly accessible memes and posts in two prominent Facebook groups shared in the Original data set and the compiled documents using a close reading approach. These claims were then distilled into broad categories of claims using thematic analysis. These claims were compared and contrasted with claims stated from an informant in the ex-vaxxer community about what they (the self-proclaimed ex-vaxxer community) believe. In addition to this interview, artifacts from several closed ex-vaxxer groups were evaluated employing thematic analysis and open coding techniques in a grounded theory approach. Some interesting results and findings will now be explored and hypotheses posited.

## 4 Results

### 4.1 Claims Found

Claims from ex-vaxxers were gathered from an interview with an informant speaking on behalf of the self-proclaimed ex-vaxxer community while anti-vaxxer claims were gathered from open coding and close reading from links and memes generated the Facebook groups Dr. Tenpenny, Stop Mandatory Vaccination, and Revolution for Choice. Some claims are listed in the compiled document Vaccine File. Most anti-vax claims revolve around vaccines causing autism and other spectrum disorders. While these claims continue to be disproved in current scientific research, (e.g. [21,30]) the claims of anti-vaxxers persist in their current iterations. The anti-vaxxer claims as found in memes created and disseminated by two Facebook groups are listed below:

1. Vaccines cause mental disorders.
2. Vaccines cause autism.
3. Childhood vaccinations contain mercury.
4. Mandating vaccines is government overreach.
5. The science behind vaccines is disputable.
6. Vaccines cause the diseases.
7. Doctors get paid by pharmaceutical companies to give vaccinations.
8. Society does not need vaccinations.
9. Measles is a harmless disease.
10. “Natural” immunity (i.e., immunity gained by infection with the disease) is better or lasts longer than immunity gained by a vaccine.

(see [27] for the Facebook groups from which the majority of anti-vax posts originate).

It appears as though ex-vaxxer claims can be distinguished from anti-vaxxer claims in content. These claims are primarily based on experience, but in cases where research backs up those claims, those articles have been referenced. The ex-vaxxer claims are:

1. Vaccines don't cause mental disorders, but parents have watched their children have seizures after receiving a vaccine [3,46].
2. Recent studies of brains of patients with various spectrum diseases and disorders revealed an accumulation of aluminum in the brain [29]. Since not all bodies can process aluminum, alternatives to aluminum should be incorporated into vaccines.
3. Vaccines contain many things that need further study [2,14].
4. The vaccine schedule should be amended so adverse reactions in children can be better monitored.
5. Because we acknowledge the reality of vaccine injury, less harmful adjuvants should be added to vaccines [3,16,17].
6. Vaccines cause adverse reactions [18,36,42]
7. We need to maintain herd immunity, but not at the cost of children [3].

It should be noted that a study published in February 2019 found that the majority of Facebook posts relating to anti-vaccination come from a relatively small number of people. Madrigal writes, “the top 50 Facebook pages ranked by the number of public posts they made about vaccines generated nearly half (46%) of the top 10,000 posts for or against vaccinations, as well as 38% of the total likes on those posts, from January 2016 to February of this year. The distribution is heavy on the top, particularly for the anti-vax position. Just seven anti-vax pages generated nearly 20% of the top 10,000 vaccination posts in this time period” [27]. Therefore, the use of the subset of memes and posts by these groups was sufficient to establish the claims listed. These memes can be seen in Vaccine File, a compiled document.

As seen in the above section, the claims made by ex-vaxxers can be argued for using current scientific research. One study is McLachlan et al. published a 2019 study on aluminum build up in neurodegenerative diseased brains post-mortem [29]. While this study did not find an overabundance of aluminum in brains with autism spectrum disorder, some neurodegenerative diseased brains did exhibit more aluminum. This study was conducted using a network of brain banks. Amaral et al. highlight the importance of a network of brain banks for post-mortem research on spectrum disorders, metal accumulation, and brain development [2]. Because of the contrasting claims and a reliance on current research, it can be hypothesized that

*Anti-vaxxers and ex-vaxxers are separate and distinct groups with different goals for national vaccination.*

## 4.2 Types of Information Shared

The initial data set shared from the Facebook groups in the original data set consisted of several types of media.

As seen in the table above, the number of articles shared from the informant totaled the same as the memes and comments. Each of these categories account for 16.7% of the shared content. While all of these types of data were interesting, and meaningful studies could be produced from this data set or newly

**Table 1.** Types of content shared in a six week period.

Type	Total	Peer reviewed	Open access
Article	9	4	8
Meme	9	0	2
Documentary	2	0	0
Book review	2	0	2
Book	1	2	0
Comment	9	0	3
Posts	1	0	0
Insert	1	0	1
Compiled doc	3	0	1
Blog	1	0	1
Court order	1	1	1
Facebook group	1	0	0
Anon analysis	3	0	0
op.ed post	1	0	0
Screenshots	2	0	0
Statistical report	1	0	1
Website	1	0	1
Donation request	1	0	0
Videos	5	0	4

constructed data sets based on these types of media, the next part of analysis in this study focused on the compiled documents.

The compiled documents only account for 5.5% of the shared information, but these files are stored online, publicly available, and are rich with links and claims for analysis. Some of the content in these documents were then analyzed.

**Vaccine File.** Vaccine File is a complicated document. When printed to PDF on 15 February 2019, it totaled 88 pages. This document was then copied and pasted to a spreadsheet where it totaled over 17,000 lines of text. It was cleaned to 483 links and 177 statements. The link types can be seen in the following table.

As can be seen in Table 2, 31.5% of the links were broken, 22.8% were redundant and appeared multiple times throughout the document, and 6.7% were Facebook posts. A total of 23.6% of links in this document led to scholarly databases. The majority of those were terminal abstracts with articles either only accessible behind a paywall or not accessible at all. Abstracts accounted for 15% of the total links but are 63.2% of the 114 scholarly links.

A unique aspect of this data set were the retracted articles and articles with commentary. It should be noted that 11 links to corrections and commentary



**Table 2.** Vaccine file links.

Source type	Total
Broken links (all)	152
Abstract	72
Article (OA)	23
Full text available	19
Compilations	8
News article	6
Second hand news article	2
WHO	3
CDC	6
Web page	7
Vaccine insert	2
Facebook post	32
Buy book	5
Vaccine documentary	4
Video	9
Untrusted site	6
Retracted article	2
Blog search	3
Redirected video	4
Database search	1
Facebook group	1
Institution of education statistics	1
Letter	1
Login required	1
Meme	1
Trailer for documentary	1
USFDA	1
Redundant (Total)	110
Total	483

were available on 4 abstracts. Only 2% of the articles were redacted, but commentary and amendments were available by link on approximately 7% of the abstracts. Again, this would be an interesting data set to explore in further research, especially since this document leads to eight additional unique compiled documents. This data set was reviewed for descriptive information about sets of links like, Doctors who explain clearly why vaccines aren't safe or effective. Those statements were removed from the document upon analysis. This file

contained 177 meaningful statements. These consisted of claims, arguments, and quotes from articles. An example of this type of text is:

“Tylenol (Acetaminophen) depletes glutathione levels in the body, which are essential for detoxification. Vaccines have alum adjuvants and other ingredients (See attached link to see specific vaccine ingredients and adverse reactions associated). If you give your child Tylenol before or after vaccines, they can’t process these toxins and they become even more susceptible to autism and other vaccine injury, as these peer reviewed scientific studies affirm [no citation].”

Another example in which a link is provided is, Wild animals don’t have food allergies unless vaccinated. People in countries without modern medicine available to them do not have food allergies. (That is used as the reasoning behind the hygiene theory of food allergies. See [www.medscape.com/viewarticle/842500](http://www.medscape.com/viewarticle/842500)). Unfortunately, this link is broken at the time of data analysis and writing. When a search for the statement is conducted using Bing and Google, no results are found. Again, these 177 claims analyzed did not include descriptive statements about the links, but such statements were in the document.

Of the claims made, like this one, approximately 75% are unfounded. This does not mean these claims are fabricated; rather, these claims cannot be found in the document either preceding or following the statement. This result could have been averted by properly citing documents. If this document was compiled like an annotated bibliography, finding sources and quotes again would be easier for future researchers. Five of the 177 claims relate to requesting a religious exemption. Finally, 11 claims have been omitted from this evaluation as they are, admittedly, conspiracy theories. One interesting subset of data was the redundant, or repeated, links.

Redundant posts made up 22.77% of the total links available, but 33.23% of active links in this data compilation. The redundant links were defined as a repetition of a link which connected to the same article, abstract, post, web page, or other source of information that was previously mentioned. A table of categories and total of each can be seen below (Table 3).

**Table 3.** Redundant and repeated source categories.

Redundant type	Total
Abstract	55
Article	24
Compiled documents	6
Facebook posts	4
Government news	5
Secondhand news	8
Webpage	8
Total	110

The other compiled document evaluated was the Vaccine Research Guide.

**Vaccine Research Guide.** Vaccine Research Guide is a file that houses links and descriptions of documents including vaccine schedules and inserts. The Vaccine Research Guide is the easiest document to navigate. It consists of clickable links that are easy to identify. As seen in the table below, only 4.6% of the links were unclickable, and 15% were broken. An overview of the types of material in that file can be seen in Table 4 below.

**Table 4.** Vaccine research guide links

Resources	Total
CDC	2
Book	2
For profit website	66
Database search results	5
Patent	3
Full peer reviewed article	4
Scientific information about compounds	18
NIH	1
Blog	1
Medline	2
Abstract	11
Uncontextualized data	2
Digital image	2
US news outlet	1
Video	1
Vatican analysis	1
Broken link	23
Unclickable	7
Total	152

Looking back to Table 1, it can be seen that the majority of information shared in this time frame was not scholarly, peer reviewed studies. While that is the case, it is all information that is needed for a good foundation in the reasons and beliefs of this community from the perspective of the informant.

Posts of solidarity seemed to be the most important type of information conveyed among users. This again reinforces the idea of a support group and to know that if your child or you experienced some adverse reaction to vaccines, a group of people also understand and share your pain.

**Table 5.** Comparison of data in originally shared artifacts and Vaccine File, and Vaccine Research.

Resources	V. Research	V. File	Original
Abstract	11	72	0
Anonymous analysis of information	0	0	3
Blog	1	0	1
Blog search	0	3	0
Book: about, buy, or review	2	5	3
Broken link	23	152	0
Centers for disease control	2	6	0
Compiled documents	0	8	3
Court order	0	0	1
Database search results	5	1	0
Digital image	2	0	0
Documentary	0	4	2
Donation request	0	0	1
Facebook group	0	1	1
Facebook post or comment	0	32	12
For profit website	66	7	1
Full text article, not peer reviewed	0	0	5
Full text available (open access)	0	19	0
Full text, peer reviewed article	4	23	4
Institution of education statistics	0	1	0
Letter	0	1	0
Login	0	1	0
Medline	2	0	0
Meme	0	1	9
National institute of health	1	0	0
Op ed post	0	0	1
Patent	3	0	0
Redirected video	0	4	0
Redundant (Total)	0	110	0
Retracted article	0	2	0
Scientific information about compounds	18	0	0
Second hand news article	0	2	0
Unclickable	7	0	0
Uncontextualized data	2	0	1
Untrusted site	0	6	0
USFDA	0	1	0
US news outlet	1	6	0
Vaccine insert	0	2	1
Vatican analysis	1	0	0
Video	1	9	5
Video trailer	0	1	0
World Health Organization	0	3	0
Total	152	483	54

A comparison of the types of data shared in the original data set shows that Facebook posts and comments were the most often shared (22.2%), followed by memes (16.7%) and then full texts of articles that were not peer reviewed and videos at 9.25% each. Compared to the types of data shared in the other compiled documents, visible in Table 5, personal interaction is most highly valued in the Facebook groups.

As Table 5 shows, the publicly housed data sets have broken and redundant links, but the originally shared artifacts did not have any broken links. Everything shared from the informant was accessible. Some things to consider are that, according to these data sets, scholarly articles appear 7.4% of the time in the Facebook group, 4.8% in Vaccine File, and 2.6% of the time in Vaccine Research. Converted to ratios, a reader is likely to find an open access, peer reviewed article 7 out of 100 times in the original data set, 6 out of 125 times in Vaccine File, and 13 out of 500 times in Vaccine Guide. From these results, it can be hypothesized that

*The amount of scholarly articles in compiled documents are not statistically significant when compared to broken links, for profit links, and other types of media shared in anti-vaxxer and ex-vaxxer groups.*

After evaluating the types of information most commonly shared in these groups, it is now possible to evaluate whether or not these groups are a community of practice.

### 4.3 Community of Practice

Even though the members of these Facebook groups may feel as though information sharing and learning are priorities, these groups cannot be classified as a community of practice. Based on their information sharing habits and what was shared from the informant, it may be likely for these groups to function like support or self-help groups. Bender, Jimenez-Marroquin, and Jadad researched support groups on Facebook. They identified support groups as the most commonly created type of group relating to breast cancer is support for survivorship or support for caregivers of survivors [4]. It seems likely that Facebook groups for anti-vaxxers and ex-vaxxers may fall into this category, but more research must be examined.

First, Katz and Bender define support groups as “Voluntary, small group structures for mutual aid and the accomplishment of a special purpose. They are usually formed by peers who have come together for mutual assistance in satisfying a common need, overcoming a common handicap or life-disrupting problem or bringing about social and/or personal change” [24]. Huber distills this to mean that support groups have been used to improve individuals psychological, behavioral, physical, and interpersonal well-being [20]. The primary focus of a support group is not learning or developing a skill or accomplishing a task, as it is in a community of practice.

Instead, Zambelli and DeRosa (1992) define support groups as a modality that emphasizes peer support and can serve as an additional system. They further indicate that support groups typically do not aim to ameliorate inter-apsychic or interpersonal difficulties, even though this may occur as a result of participation in the group [45]. This seems to be one form of relief in sharing posts about experiences or seeking positive feedback from other members of anti-vax and ex-vax communities.

While there are several types of support groups, it must be examined whether or not ex-vax and anti-vax groups are self help groups. Some common characteristics of self-help groups that are associated with some cognitive behavior modification programs include their:

- “voluntary nature- they are run by and for group members, have regular meetings, and are open to new members (17);
- generally being formed in response to a particular issue, e.g. no access to education for children with disabilities, limited income-generating opportunities;
- clear goals, which originate from the needs of group members and are known and shared by all members (15);
- informal structure and basic rules, regulations and guidelines to show members how to work effectively together;
- participatory nature involving getting help, sharing knowledge and experience, giving help, and learning to help oneself (18);
- shared responsibility among group members each member has a clear role and contributes his/her share of resources to the group;
- democratic decision-making;
- governance by members, using an external facilitator only if necessary in the formation of the group (15);
- evolution over time to address a broader range of issues;
- possibility of joining together to form a federation of groups across a wider area.” ([25], p. 3)

The agenda-setting, roles, rules, and democratic nature of self-help groups are not applicable to ex-vax and anti-vax groups. While members in these groups come together as a result of a particular event, the lack of governance, structure, and goals set self-help groups apart from the communities evaluated on Facebook.

One research question sought to examine whether or not anti-vax and ex-vax groups can be considered communities of practice. While the anti-vax and ex-vax communities are knowledgeable about some of the risks associated with vaccines and vaccine injury, communities of practice also have clearly defined goals and rules, regulations, and guidelines. Based on this information and the sharing practices exhibited by the original data set, it can be hypothesized that *Ex-vaxxer and anti-vaxxer communities in Facebook groups are support groups and not communities of practice.*

It is now possible to examine the shortcomings and future study possibilities for this area of study.

## 5 Discussion

Limitations for this study existed in several areas. First, this study only evaluated the data shared in communities by one member in a six week time span. Many factors of information retrieval may have impacted the data set. The member of the community may have excluded articles that did not favor a specific position or that may have come from unreliable sources. Additionally, the member might not have seen every piece of information shared in the community. It must be acknowledged that this study evaluates only a portion of information shared by ex-vaxxers.

Next, because data for this study was not collected directly from closed Facebook groups, random sampling could not be employed for further evaluation. The idea for this study was to evaluate scholarly articles to determine information accuracy, but there was no guarantee that all of the scholarly articles shared in the groups were passed on or that the data set constructed by the informant was comprised only of artifacts shared during the six week window. As a result, one future study on this topic is a participant observation, where researchers in the community observe and record events, artifacts, and conversations. Another area of future research is to evaluate compiled documents using content analysis with interrater reliability. Further, the subset of information shared within communities to what exists in the scope of scientific and scholarly journals only accessible behind paywalls can also be evaluated using thematic analysis and content analysis.

Linguistic and semantic studies on the originally shared content and compiled documents should be conducted. Some studies like [7, 8, 12, 31, 38, 39] have shown several approaches to evaluating language, rhetoric, and narratives in anti-vaxxer and vaccine debates. These approaches could be applied to any subset of the data collected from the original data set to evaluate language choices and the agendas set by these groups.

Another future study is to take each compiled document file and individually examine the statements, quotes, and claims for valence and use of emotional language. This type of study will provide insight to the agenda shared in each compiled file. In addition, teasing out the language and valence of each statement may help clarify true statements from created narratives. Like Faasse, Chatman, and Martin write, anti-vaxxers are better able to use scientific language in discussions about vaccines because they read excerpts from these studies [12]. While anti- and ex-vaxxers are not experts or even scientifically trained in these complex concepts, distilling the studies and concepts for mass dissemination will help communities as a whole better understand the issue and dispel some of the myths on both sides of the argument.

Another future study is examining the interpretations of information by members in the community. This study did not seek the opinions of community members, nor did the study solicit the interpretation of highlighted, non-annotated information that is publicly accessible. The study also did not ask members of the community to interpret any of the passages to ensure the continuity of meaning or continuity of conclusions reached in the published article.

To better understand the proliferation of scholarly articles in this community, examining the meaning, comprehension, and interpretation internalized from articles by community members is a crucial area of future research.

Perception studies about highlighted information in the Vaccine Guide should be conducted with members in the ex-vax and anti-vax community Facebook groups. This file includes a court case with only highlighted information on the first two pages of a 50+ page document highlighted [41]. A null hypothesis about information interpretation can be evaluated using a Mann-Whitney U-test and communication with other members of the closed Facebook groups. A follow up study on Vaccine Guide, the vaccine schedules, and Vaccine File should be the next phase in this line of research.

Finally, there was no way to evaluate the level of engagement in or between the groups in which this information was shared. Another avenue for future study is the evaluation of popular articles or most popular posts in groups as well as cross-group members and cross-group posting. The dynamics of community and information-sharing from a network perspective may possibly contribute to which articles get read, shared, or liked. This area should receive attention in the future.

## 6 Conclusion

What started off as a simple sharing of information turned into an evaluation of the presence of and access to information. The three compiled documents and the originally shared information became a complex data set of 1,105 links, claims, and highlighted information that were manually tested and coded by one researcher. This area of research should be continued in order to better understand the claims, experiences, and fears of those who have witnessed vaccine injury. In addition, research of the commonly shared documents in ex-vaxxer and anti-vaxxer communities can help to reach an understanding about where and how information gets misinterpreted. Finally, research in health information can further discourse about public health and safety. Future studies should be pursued by researchers interested in communication, health information, information sharing, and the interpretation of complex data.

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