

Cancer Disclosure and its Effect on Facebook Users

Nathan Duffy
nathan.duffy@
colorado.edu

Marissa Kelley
marissa.kelley@
colorado.edu

Jacob Paul
jacob.paul@
colorado.edu

William Tardif
william.tardif@
colorado.edu

Kexin Zhai
kexin.zhai@
colorado.edu

ABSTRACT

In this study, we drew from existing work on social media algorithms and conducted an interview-based study to understand the disconnect between the algorithmic presentation of content on Facebook and the content itself. Our results show that Facebook presents news feed content without regard to what posts actually contain, typically juxtaposing cancer diagnoses with much more casual content. Consequently, participants did not use Facebook to respond to a friend or family member being diagnosed with cancer but rather used other more personal forms of communication such as text messaging or phone calls.

Reactions to cancer diagnoses also were not short lived. Most participants reported the event of the diagnosis tended to stick with them after seeing the cancer diagnosis post. Seeing posts that disclosed a cancer diagnosis also prompted reflection in participants, but the amount and type of reflection varied by age. Our older participants tended to use the event of seeing a person's cancer diagnosis as a time to reflect on their own health and the importance of interpersonal connections. We believe that these people's experiences are important as a way to help future patients and survivors.

Author Keywords

Cancer; cancer patients; diagnosis; support; Facebook; social media; algorithms; disclosure

ACM Classification Keywords

Network Algorithms

1 INTRODUCTION

Facebook is one of the most commonly used social media sites in the 21st century. The age range on the site goes from 13+, creating an incredibly diverse and global ecosystem. The appeal of Facebook is its easy-to-use user interface as well as its social networking services. Because of this, millions of people log in every day to get the latest scoop on their friends, family and the world. From the newest Tasty food video to the latest and greatest BuzzFeed dog photo, Facebook is the network to connect us all.

Facebook's vision statement states that "people use Facebook to stay connected with friends and family, to discover what's going on in the world, and to share and express what matters to them." Meanwhile, its mission statement is "to give people the power to build community and bring the world closer together." We all decide what we put out there. We share the tiniest little pieces of our lives, and they're mostly pieces that we are proud of. So, what happens when somebody chooses to post on a heavier topic? How does one share and express what matters to them when it's something they're struggling with or a topic that's controversial or looked down upon in their society? And even once it's posted, how does one show empathy towards another user? What is the etiquette of posting and reacting to bad news like on a platform such as Facebook? While statements have merit, it demonstrates that this platform works under the assumption that most people are *not* struggling with something.

Our group chose to look at how technology fails to understand the ambiguity of the data we post online. For example, a user posting "they just got into a car accident" can be as mild as a fender bender to something more urgent, like a fatal crash. Algorithms are not always able to determine what degree of urgency some statements are written in, and we were interested in how that impacted people's emotions.

In this paper, we draw from existing work on social media algorithms to present an appeal for an algorithm that supports both short and long-term cancer diagnoses experiences. As the number of Facebook users increases, the social media site has begun to see more and more cases of people divulging bad news to their friends and family in a swift and easy way with minimal effort.

2 RELATED WORK

2.1 Content sharing on social media

Social media provides a platform for users to express their feelings and for sharing their day-to-day life moments. Users seek the use of social network websites in many different ways. Myrick et al [6] explored the intersections of social support, emotional expression, and message sharing within an online grass-roots community. Their study on Twitter showed that many of the tweets contained social support via information sharing. Cancer

patients discussed their experiences with cancer including their emotions to the cancer related social support messages which were found to help users reach wider audiences. Online communities and social platforms allowed people with ailment to share their emotions freely and have those emotions reciprocated which ultimately helped to build stronger bonds between users. This research describes a reason as to why patients posted their cancer diagnoses in the first place.

Moorhead et al [5] conducted a study to identify the use of social media for health communication. Their findings resulted in establishing six keys overarching benefits of social media which included increased interactions with others, more available shared and tailored information, increasing accessibility and widening access to health information, peer/social/emotional support, public health surveillance, and potential to influence health policy.

Without any limitation of content sharing on social media, patients chose social platforms as a place to cope with cancer on their own. People redefined themselves and applied social media to fit their own needs. Social network sites offer members of the cancer community the chance to connect with each other 24/7 from nearly any place in the world.

2.2 Cancer disclosure

The prior research focuses on experiences with the cancer disclosure on the patient side. While Schaepe [9], using narrative analysis, investigated the first impression of when a cancer diagnosis is disclosed to the patients, their prior research didn't show how the surrounding people reacted to patients' cancer diagnosis. Hilton et al [2] compares young adult's experiences of disclosing their cancer diagnosis to family and friends, and whether there are similarities or differences between men and women. Ngwenya et al [7] explores the process of information disclosure and privacy as patients share their news of cancer with significant others. Their findings show that patients as individuals are strongly interlinked with significant others, which impacts their experience of disclosing private information. This in turn shapes their psychological processes and outcomes influencing their illness experience. In our study, we instead focus on the reaction to a cancer diagnosis on the patient's support system including friends and family.

2.3 Social support

Support from others either on or off social media can help patients in both physical and mental ways. Milbury et al [4] examined how the caregiving burden is distributed to both the spouse and cancer patient, which in turn is a psychological adjustment for both. They noticed that a spouse's exhaustion could predict a patient's distress when the fatigued spouse was unable to adequately provide for the patient's physical and emotional needs.

This resulted in the importance of patients ensuring they were receiving support outside of the family as well. Nolbris & Nilsson[8] conducted a study to examine the experiences of people providing support for those with family members diagnosed with cancer. Supporters met with people when they were in their crisis. From the interviews, they observed that supporters normally provided support to people for as long as it was needed and facilitated opportunities for those people to connect with others who experienced similar experiences, while also creating an encouraging and positive environment.

Skeels et al [10] noted that cancer patients were keen on utilizing social media networks when they failed to seek out information, material assistance, and emotional support from their family and friends. Social networks are most effective when kept up to data on the cancer patient's status. Bender et al [1] concluded that Facebook groups have become a popular tool for raising awareness, fundraising, and seeking support related to breast cancer patients. Kim et al. [3] discovered the various roles of people involved in medical crowdfunding. While supporters often backed the patient monetarily, some of these supporters also assisted patients in their day-to-day life. Their finding shows that people who donated their time and services were closer to the patients than those who only donated money. They similarly found that patients with illnesses tended to not create and post their own crowdfunding page. These pages were normally done by the people who had close relationships with the patient and were knowledgeable in describing the situation and ailment well. The crowdfunding pages were usually shared several times within a social circle. Yi et al. [11] indicated that satisfaction and trust rates majorly influenced donations. Their study revealed that trusted sites positively benefited someone who created the crowdfunding page. When circles of friends shared GoFundMe pages, those in need of financial support tended to have a greater amount of donations. Given the important social support in dealing with expenses, physical pain, and emotional strain that comes along with a cancer diagnosis, it is invaluable that patients seek help from social media and real-life assistance.

3 METHODS

This study used numerous methods in order to collect the data. A total of four interviews were conducted, recorded and transcribed. The first participant was recruited via a Facebook text asking anyone with experience of finding out about someone's cancer diagnoses to reach out to the group via a separate research-specific email. After recruiting the one user via text, we altered the text to a graphic post in order to catch more people's attention. This did not gain us any more participants, so we reached out to a colleague, Melanie Sidwell, who offered us her network of peers and coworkers, where we were able to

recruit three more interviewees. Only one interviewee was under the age of 30, while the other three were above the age of 30. Of the four, three interviewees identified as females with one identifying as male. There were no specific independent variables identified as the study had no purpose in targeting a specific demographic.

The main method of data collection were standardized and informal, open-ended interviews. The group found these to be the most useful and efficient as it would allow us to gain specific insight to individual stories rather than a survey which would only provide a holistic overview. Interviews are a far more personal research method, allowing the team to take into account the other variables and factors associated with each encounter as well as ask any necessary follow up questions. The interview questions were made throughout the group prior to the interviews. Before sending out the questions, each researcher took the interview themselves to ensure that all questions needing to be asked were in the document. These interviews were formatted loosely in order to allow the researchers to insert their own questions to make the flow of the interview as smooth as possible. With many qualitative research studies, interviews are beneficial in that they allow the researchers to gain understanding of the stakeholders/users involved in the process.

Three of the four interviews were conducted over the phone with two student researchers present. One student conducted the interview while the other took notes and ensured that all crucial questions were asked. The purpose of the note taker was to provide the student interviewer with the ability to follow a written or typed out version of the conversation and jump in with extra questions, clarifications or follow-ups when necessary. The other interview was conducted in person with two researchers and the user. All interviews averaged approximately 30-45 minutes each and were recorded via generic phone recorders or through the app, tapeacall. Each interview was then transcribed using otranscribe.com. All student researchers reserved private rooms in order to ensure clarity of the interviews and for transcribing purposes. After each interview, the interviewee ended the call or left the study room. Following, the interviewers spent roughly 5 minutes typing a post-mortem write-up of the interview, as well as a peer interview/evaluation. As the majority of the interviews were conducted over the phone, participant observation was only used in the first interview. Much of the observation was based on their emotional reactions to the questions while the participant sat for the interview. Because each participant volunteered their time and willingness to tell their individual stories, we anticipated that there wouldn't be a lot of uncomfortable reactions, however each participant had the option to not answer a question or leave if the interview became too overwhelming.

After the content was transcribed, it was open coded by all of the student researchers. Following, each transcription was re-read and analyzed to reveal numerous themes and claims. The first round of affinity diagramming created eight codes including reaction, emotion, "tech", how did they [the user] see it on FB, other experiences on social media, "I wish...", tech Facebook reactions, and interpersonal relationships. The second round of affinity diagramming occurred a few days later allowing the researchers to approach the transcripts with a fresh pair of eyes. This round resulted in eleven claims that were more focused and dialed in. It was found that many of our original codes were too broad and could be broken down into more detailed codes, while some remained. The codes were as followed: "I wish...", immediate emotions, later emotions, immediate reactions, later reactions, types of cancer, drama, Facebook post description, diagnosed person, reflective, reasoning towards action, direct relationship to person with cancer, diagnosed person's post on Facebook/social media, and past experiences. The memos following the baby claims, were written with the intention of sharing new information. Taken into consideration were the researcher's own positionality statements. All student researchers were currently aged 19 or 20 years old, attending school in Boulder, Colorado. There were two females and three males in the group, with three members being Caucasian and two being Asian. One member was an international student, one was out of state while the others previously resided in Colorado.

4 FINDINGS

4.1 Immediate Reactions to a Cancer Diagnosis

Our data suggests that people desire one-on-one communication after seeing cancer diagnosis content rather than expressing their thoughts in public space. For instance, P02 relayed the information of cancer diagnosis with their friends through a text message and in person. They wanted to inform others about the cancer content they saw. For them, Facebook is not a place to share others illness information to their own social page and they tend to talk about it privately. P03 told us that: *"To this day, it's not my nature to comment on such a personal thing in such a public way. I know it was very public, the way the person did it but, at that point, I felt like I definitely wanted to reach out personally. You know, voice to voice."*

When reacting with personal content like cancer diagnosis posts, people preferred to talk in-person rather than leave a comment in a public way. When users leave a comment under the post, the comment would also be shown on their Facebook friends page. P02 explained, *"I think just making an announcement. I think people that they were really closed knew already. People who live nearby and family but they wanted to make an announcement to like*

the rest of their friends and then they also posted it as a fundraiser to help them cover expenses.” One of the reasons cancer patients posted their cancer diagnosis was to inform their friends to know about the serious illness. People who saw the post thought this kind of post was a personal thing and they tend to talk about it in a private way.

People who read of a cancer diagnosis on Facebook rely on their close friends and circles of friends to express their feelings. P01 called the cancer patient’s daughter after she saw the post. P01 said *“I didn’t know if it was real or not so I called her and she said it was.”* P01 checked the reality of the post against the patient’s daughter and asked her about the detail of the post. P03 told us that: *“It wasn’t until the next day. I talked to some colleagues first to see if anyone knew more than I had learned on Facebook. And then I did call the person the very next day.”*

As people typically talk to closer friends first before talking to the diagnosed person, they are able to receive more information than the diagnosis post might initially provide. Participants avoided asking the diagnosed person for more details online. Sometimes other people who saw the post asked similar questions, and many users thus felt it necessary to not overload the cancer patient with like questions. P02 has mutual friends she works with who also were friends of cancer patient. People tend to express their feelings with mutual friends of cancer patient. P03 had a similar experience. She said *“You know when I first read it, soon thereafter I contacted several colleagues, and we all kind of compared notes. And the reaction was all kind of universally what I just described.”* Different people who saw the same cancer diagnosis sometimes acquired different reactions. As they met up to discuss the post, they help each other cope with the unexpected content.

Participants reported different feelings and reactions to the social media post containing the diagnosis news depending on who originally posted the news. News broken by the cancer patient themselves generally had a different impact on participants than the news being broken by a friend or family member of the cancer patient. In most cases it seemed that if the news of the cancer diagnosis was posted by the individual cancer patient, the post was more impressionable on the participant.

When asked about the content of a cancer diagnosis post written by the cancer patient, P03 seemed to remember the post vividly as it had a lasting impact on them: *“It was so beautifully done, it was not odd or weird. Everyone that I’ve ever heard talk about it has said, “wow that is one of the most memorable things I have ever seen on Facebook.”*

Meanwhile, P01 remembered the content of the post fairly clearly w in this case, the original poster of the diagnosis was also the cancer patient. *“I’m trying to think. She just mentioned ‘my kids and my husband are like there for me’ and that’s pretty much it.”*

However, when participant P02 was asked about the content of the cancer diagnosis post, there was much less clarity. This is presumably because it was a friend of the cancer patient that posted the diagnosis: *“And so she posted. I think just making an announcement. I think people that they were really closed knew already. People who live nearby and family but they wanted to make an announcement to like the rest of their friends and then they also posted it as a fundraiser to help them cover expenses.”*

Our data suggests that users who have already experienced [cancer] news previously tended to pay more attention. This process for them has turned into a cycle in which a user will encounter the news, take action upon it via donating, calling/messaging or both, and keep an eye on it until further news is provided. P04 told us: *“And I think that’s... it was also in the circle of people, um so they had known that this other person had died from cancer so I think that kind of hit you know, it kinda hit people also because they dealt with this before and everybody stepped up and helped out...So I think that affected people’s responses also to this because we had already dealt with this before.”*

Upon spotting a similar cancer post, most users are quick to take it in and read deeper into the post and comments in order to gain a sense of familiarity before reaching out to the diagnosed person themselves. In this case, it seems this common process, has been normalized for users who have encountered this type of news before via social media. For those who have never encountered cancer related news before, the reaction becomes a tad more emotional. P02 told us: *“That was the first time social media had had an impact almost a tearful... to bring me to tears. And it was all good.”*

These posts can hit home for many people triggering a more specific emotion of shock. Facebook has set itself up as a site for obtaining news- but with that means that both good and bad news are mixed together. When users encounter this mix of emotions, it leads to more shock and surprise.

In our interviews, we saw that participants had longer-lasting reactions to this sort of content compared to other traumatic experiences such as death or alcohol consumption. Our participants tended to wait and contact either friends of their own or mutual friends prior to contacting the cancer patient who posted about the

diagnosis. This was something we found to be particularly interesting in the sense that people in a way needed to talk to others and see what they thought before they actually contacted the person themselves. Or in some cases, they'd wait to gather their thoughts together and compose themselves, before contacting the poster directly. When asked about timing decisions, the participant contacted the cancer patient after seeing the cancer diagnosis, P01 said: *"I called her the next day, so I could like sit and like actually comprehend it um and try to figure it out... ya, I called her the next day around like noon, so I gave like, almost 24 hours."*

P01 reports that they ended up waiting a day until contacting their friend with cancer which was decided due to personally needing to take time to comprehend the post. When asking if there were any other reasons why they chose to wait, they were unsure but believed it was because they didn't want to immediately contact the person due to many other people probably doing that at the same time as well. They also weren't too sure what to say and needed time to process what they had just read. P04 also wanted to contact the cancer patient's family, but for different reasons: *"I would say maybe shocked and then you know clicking on it and reading what was going on with him and everything else and then being very inquisitive about what is this cancer? What are they looking at? So then googling that, finding out what it is and different things like that and wondering if my other friends knew or what the story was."*

P04 said that their initial reaction was shock and curiosity. Only after researching and educating himself about the specific cancer, as well as contacting friends to see what they thought of the post, was it decided to contact the actual poster. This is different from P01, where instead of taking time to compose themselves, they took the time to discuss the news with friends and educate themselves about the specific type of cancer.

P02 explains that their choice to send their (text) messages privately stays in line with their decision to post privately as well. P03 is only a mutual friend to the diagnosed person, however they still chose to respond privately in respect to the person: *"You know you want to say I'm sorry. You want to be supportive. So, no I intentionally didn't like it. To this day, it's not my nature to comment on such a personal thing in such a public way. I know it was very public the person did it but, at that point, I felt like I definitely wanted to reach out personally. You know, voice to voice."*

P03 chose to comment privately, due to their nature, but also because by reaching out privately, they felt they were personally showing their individual support. By reaching out voice-to-voice, it felt like a better way to understand

the process and actions that the diagnosed person was choosing to make when publicly describing their current state. While there are many who choose to respond privately, others still commented publicly. P03 describes what they saw in the comments section of the post that they viewed: *"50 pieces of feedback (comments), if not more. I scrolled through to see who it was. Many of our good friends commented. I say good, it was a business, a little different than a close day to day friend. I did scroll to see all the people I knew, particularly the people I knew who were commenting. And there were lots."*

In terms of Facebook etiquette, it seems rational to respond regardless if it's private or public. People respond privately as a sign of respect for the diagnosed person, however the amount of users who post publicly also goes to show that some people want to express their condolences in a public manner- possibly for selfish reasons, but also to show that it's not uncomfortable. These are processes that occur frequently and should not be looked down upon as something to not share with friends and family once you're ready.

Facebook is typically perceived as a platform where users are trying to present the best form of themselves, and when content such as a cancer diagnosis shows up on a user's timeline, the reaction that they may have to the content isn't necessarily supported by Facebook's design. Firstly, seeing a post that contains news of a cancer diagnosis is usually presented in sharp contrast to more casual content that naturally populates Facebook users' news feeds. When asked to elaborate on what they were doing when they saw the news of the cancer diagnosis on their News Feed, P03 reported scrolling past the post only to come back to it because the word "cancer" caught their eye: *"I think I was just on my sofa, looking through Facebook and everything... and I scrolled past it but then I had to go back 'cause I thought I read something that said Cancer... so I had to go back and... ya... that wasn't a fun day"*

P03 was casually scrolling through Facebook but had to double back because the post with the cancer diagnosis caught their eye and ended up changing their mood for the rest of the day.

Facebook also doesn't offer users any attractive options for reacting to the post or communicating with the cancer patient after interpreting the post. Facebook rolled out reaction emoticons so users would have more choice over how they demonstrate their reaction to content other than just "liking". Still, most of our participants reported desiring or following through with more personal means of communicating with the patient, such as text messaging or calling. When inquiring P04 about whether or not they used the Facebook reaction emoticons, they

reported that they did not: *“That stuff...I don't think I did. I don't think I did with the original, no.”*

Going deeper, we asked what the participant did in reaction to the post if they didn't use the Facebook-provided reactions: *“...she posted on Facebook talking about her Cancer... I didn't know if it was real or not so I called her and she said it was. But when I read the post, a little piece of me kinda dies inside.”*

In this case, the participant desired a more personal interaction with the cancer patient and decided to call them. The fact that all of our participants used means similar to this to communicate with the cancer patient indicates that Facebook does not currently possess an accessible, effective way of communicating with others in circumstances like these.

None of our participants reported being prepared to see the post containing the cancer diagnosis when they were browsing their social media page. P01 told us that: *“I think I was just on my sofa, looking through Facebook and everything... and I scrolled past it but then I had to go back cus I thought I read something that said Cancer... so I had to go back and... ya... that wasn't a fun day.”*

People start to find out what happened after they viewed shocking content. P01 said *“I didn't cry right away when I found out, I kind of just like stood there in silence and kind of like just figured out how to process it.”* P04 confessed to us: *“I think you know initially seeing it and then being shocked -- I would say maybe shocked and then you know clicking on it and reading what was going on with him and everything else and then being very inquisitive about what is this cancer?”*

4.2 Relationships

Like many traumatic events, learning of someone's cancer diagnosis tended to bring the cancer patient and the participant closer and reignite past friendships or bring back together old friend groups. Participants often used words similar to “community” to describe the people that were supporting the cancer patient after being notified of the diagnosis as well as people from the cancer patient's hometown, their friend group or family friends. When we asked a participant about what the reaction was like in the comments of the cancer diagnosis post, they described the motivations that others had for commenting and supporting the cancer patient.

“Just an outpouring of a community and compassion and support for sure. It was a very positive reaction.”

“Umm... there was a lot of shock and support. And we just maybe a year prior to that, had lost another friend like in our group of friends, sort of a small town so

everyone pretty much knows each other. But we had lost a friend to a similar cancer and it kind of was a shock to everyone. But I think as a community still kind of reeling from that, and then they heard about this other guy and so there was a very large outpouring of support. It was all positive.”

P02 refers to “community” as friends back in the small town from where both the cancer patient and P02 were from. They elaborate further stating that previous experiences the friend group had with cancer acted as a motivation to support the cancer patient. While the people in these communities may not reside in the same place as each other, it seems that a cancer diagnosis can bring these communities together, despite physical distance. In asking P04 about who seemed to be involved with the Facebook post they saw, they responded about how it brought two different friend groups together from two different states: *“But I mean it touched both places so it touched Nebraska and California so I assume most of friends knew about it. I would say most of his friends knew about it.”*

P04 discusses how the cancer patient's friends from both Nebraska and California knew about their cancer diagnosis. P04 also alludes to the fact that although they and the cancer patient did not live in the same place, they still made an effort to catch up with the cancer patient when they were both back in their hometown: *“What it usually... it usually... um, it's usually when we go back to Nebraska for like the holidays and stuff. It happens to be that he's in town also. Um, sometimes we will bump into each other um when we're out or doing different things like that. But uh, since he's moved out to California, I've had much less contact.”*

When asking P03 how their relationship with the cancer patient had changed after reading of the cancer diagnosis on Facebook, they discussed how they become much closer to the cancer patient: *“Yeah, knew her for longer sort of say. That was like a year and a half so we talked like more on Facebook, visited her again, so kind of like going from like that outside friend to more of like a closer central friend. Kind of, through that process made it a little easier.”*

P03 divulges in how they went from more of an “outside friend” to a “closer central friend” after initially seeing the cancer patient's diagnosis on Facebook and then subsequently contacting them. In this case, it seems like the participant started a new friendship as a result of the cancer diagnosis.

Being the bearer of bad news is always difficult, but (can be and typically is) an important part of many processes. Our data suggests that having a close relationship or social proximity to the diagnosed person can affect their

acceptance with discovering the cancer via social media. Our P03 stated: *"I mean considering we weren't like the closest most personal day-to-day friends, I wouldn't have picked... oh it was a beautiful way to find out. It was just fine."*

P02 also felt similar: *"It is a...I don't know if I was particularly concerned to find out about the social media because we're not people that are umm...they are not friends that were very close to me. So I would never expect that they will call me with that information. So I was not...I wasn't hurt by that or anything."*

Both of these participants describe their relationships to those people as nothing more than friends, which shows that certain "levels" of friendships contain different expectations of what they should be informed of and how. It also goes to show that what things they might not be told if the diagnosed person doesn't feel this other person is close. However, sometimes, that unknown knowledge can be a hindrance in a friendship/relationship: *"It would've been nice to actually, if her mom could've told me in person, if, since we were close."*

When bad news is relayed via social media rather than personal texts or calls, it's always possible that there are two different "levels" of relationship status. In the example above, it's shown that the user felt closer to this person and therefore expected a more personal form of sharing the news. Because they found out via social media like many others, the user describes their frustration in not finding out earlier. When those who deem themselves close to that person also find out on Facebook, it can be hurtful to see where they stand relationship wise to the diagnosed person: *"It was a very long post about this new challenge. Very heart wrenching, but kind of cathartic, you could see that it solved some things. The person even wrote, 'It's easier to say it here in one foul swoop than to say it over and over again to 30 different people.'"*

Facebook is a great way to share and spread news quickly, to people physically near and far or ones who are socially not as close anymore. Because of this, from the diagnosed person's perspective, Facebook is a great platform to share updates with the process. It also allows for people to collect their own thoughts before acting on the news, which may also be a reason for posting this news on Facebook rather than individual phone calls. P03 found the site to be a perfectly adequate way for the cancer patient to inform their friends: *"I did understand the point of sort of telling people this incredibly tough thing you're going through. And to tell everybody in one fell swoop, and then you move on. I don't really know if that's what I would do. But I was glad that he came out so beautifully, and the person is a beautiful writer. It didn't strike me as weird that he was doing this on Facebook because of how it was framed. The person handled it very,*

very beautifully. You know sometimes you see posts like that and you think, "ah that's kind of weird." This one was very compelling and beautifully done."

In today's world, using Facebook is not uncomfortable or weird. While it's shocking, as most bad news is, many users aren't uncomfortable with seeing this event occurring.

The geographic relationship of the participant and the cancer patient affected how accepting people were with finding out via social media. All of our interviewees would have preferred to find out in person about the diagnosis, but a few of them didn't mind finding out over Facebook based on where they were geographically. With some being halfway across the country in relation to the poster, they understood why they wouldn't be able to be told in person about the diagnosis, but instead, they wanted to emphasize that they weren't pleased with the fact that they found out on Facebook. For some, they even said that it ruined their day. P01 discusses how they wished the cancer patient had reached out personally, especially since they had been together just weeks earlier: *"um, I mean, I wish I could've talked to her in person, 'cause I was, during that couple weeks before, we were talking about me going down to see her again, um, but, I would've been nice to actually, if her mom could've told me in person, if, since we were close."*

P01 discusses how they wished they'd found out about the diagnosis when they were ultimately planning on meeting up. The participant stated that they had a close relation to the poster and also felt that they were close enough to the family that they would want to either call or tell them in person. Although they were sad that action never happened, they understood why they just decided to post on Facebook and not tell a bunch of people individually. P03 discusses how they felt that Facebook was an acceptable way to find out about the cancer diagnosis: *"It was so beautifully written and so detailed, and it was almost a nice way of learning about this sad news and what the person had in mind for what was to come."*

Contrary to the feeling of P01, P03 was happy, in a sense, that they was to find out over Facebook because they felt the post was beautifully written and allowed them to see what was going on inside the poster's mind. This was something we didn't see from any of our other interviewees and, in a way, surprised us.

Overall, every one of our participants agreed that they wished that they would have found out in person or by a call. But, they also all understood why the cancer patient posted their diagnosis to Facebook. Facebook allowed the

poster to reach a vast audience instantly and allowed the viewers to contact them directly if they were to so please.

4.3 Medium and Long-Term Reactions

We were fortunate enough to have the ability to interview people who were of different age ranges, which allowed us to gain a unique insight on how different age ranges affect the reaction one provides. When we asked our youngest participant about their reaction to the post that they saw, they said: *"I didn't know if it was real or not so I called her and she said it was. But when I read the post, a little piece of me kinda dies inside."*

Before talking with anyone else about it, (as far as we know) P01 decided to contact the poster themselves to see if it was true and if they were ok. This is something that vastly contrasts how P03, one of our older participants, reacted: *"You know when I first read it, soon thereafter I contacted several colleagues, and we all kind of compared notes. And the reaction was all kind of universally what I just described."*

In this quote, P03 talks about how they reacted when they initially read the post. Instead of contacting the poster directly, they decided to contact other people who knew the poster and talked with them about how they should approach and address the situation. From what we learned later on, what the interviewee discussed with their colleges allowed them to feel better about the situation but also figure out the best way to approach the situation as well.

Comparing the responses of P01 and P03, one can understand the different approaches the participants took, but at the same time, keep the main idea of providing support the same. During the interviews, they both emphasized how they wanted to make sure that the person with the diagnosis felt not only supported, but also allow them to know that they are someone they can talk to. They also both ensured to contact the person who posted the diagnosis personally, instead of just posting a comment or liking the post. They felt that it wouldn't seem very appropriate to just comment on the post and wanted to make sure the poster knew they cared and wanted to help.

One significant reaction to seeing a cancer diagnosis on Facebook was reflection. Surprisingly, this reflection was not of the diagnosed person, but of our interview participants themselves. After reading of a cancer diagnosis, participants almost routinely self-reflected on their own lives. Cancer can be a long emotionally draining rollercoaster, which seemed to be one argument into why our participants chose to self-reflect: *"But, I think at the time, to be honest, I probably thought wow, I*

wonder if I would do it this way, put it out on Facebook. But I did understand the point of sort of telling people this incredibly tough thing you're going through. And to tell everybody in one foul swoop, and then you move on. I don't really know if that's what I would do."

It was compelling to see participants immediately turn towards themselves when asked about what they witnessed on the social media platform. Could this just be a testament to our own human nature, or something that could potentially be revealing of the self-disclosure process? The participant undertook how they would go about telling their friends and family if they had developed cancer. They later confided how efficient posting on Facebook was, but that it may not be the right way to do it: *"Umm...I think that it's just that experience and other experiences are different...with friends coming down with those kinds of illnesses. Just make me more aware of the possibility of losing my friends and family. At the mainstream stage of my life, that's different. So, it makes me think about umm...keeping my connections with people and appreciating the people in my life."*

The majority of our participants were middle aged which is also around the time when cancer has the greatest chance of developing. Witnessing their friends come down with this horrible illness forced them to really appreciate their current situation. But it also allowed them to cherish their current healthy relationships.

Having previous encounters with cancer diagnosis self-disclosures on Facebook tended to modify a user's reaction than if they had no experience at all. A few of our participants had learned of multiple self-disclosures on Facebook which led to a more candid conversation with them throughout the interview process.

"I was shocked. Umm...I think I started texting friends. (laughs)."

This quote is different because P02 originally said they were shocked, and texted friends to see if they knew yet, but then surprisingly after this statement, laughed. This candid response was confusing to us at first, but was later justified by the fact that P02 had seen content like this previously. The participant may even just be using humor as a way to cope with this disturbing news of their friend coming down with cancer.

"This is a thing that's happening more and more often in my social circle...And it's not entirely shocking I guess. Because like I said that happened other friends who had cancer the year before and...umm...it just becoming more common I guess at my age. So...umm...I just make sure I reach out to my friends a lot and let them know I support them. But I umm...I get up early, take much action other ways."

This participant is at the age where their close friends have a higher risk of being diagnosed with cancer, while P01 has unfortunately seen it happen more often than they want to admit. The participant explains how they have been trying to find ways to adjust to hearing of friends being diagnosed with cancer. Determining how our different participants coped with their situations was revealing of the self-disclosure process. It's important to understand what users are feeling when they see this sensitive content, and how Facebook could potentially help with revealing it.

Facebook is an online platform that excels in a fast-paced environment that users contribute to. Cancer is something that is usually a long and exhausting process, and if a user is trying to keep their friends updated with their condition, it can be difficult. Something that was contributing to this difficulty were GoFundMe links. In two of the four cases, our participants noted the post linked their Facebook status to a GoFundMe account to raise support for their treatments: *"Jeez, I probably did it -- well I donated and everything and then there were occasional updates, too that would send out updates and everything but within the first several days I wanted to see how it was doing and everything so I would probably go back daily to check for probably the first -- first week. It was kinda neat in seeing how it took off and everything else. So, I probably checked it every day for the first week."*

Here, P04 is explaining how they had to keep going to the original post to see how much the cancer patient had raised, and if they were anywhere close to reaching their goal. The link had to be posted multiple times so that he could eventually reach his entire friend group. Facebook could benefit from the implementation of something like Twitter's pinned tweet. Allowing the GoFundMe post to be at the top of the profile's timeline regardless of chronological order.

Updates on a cancer patient's treatment typically came in the form of follow up posts on social media: *"Umm...yeah, they did... they mostly reposted like photos when he went in for treatment. Umm...and then he has like on his Instagram account. He would post photos umm...I don't know just kind of umm...he would push a piece of paper off the table and then he...and he will hashtag it with #F*** cancer. (laughs) So they would...they would post like that. And umm...then when he had his diagnosis, just this spring that he was re-mentioned that he made a big post about that, too."*

Facebook didn't afford the functionality for the type of digital media posting that this participant wanted to do, so they looked to Instagram. Instagram allowed the cancer patient to easily post pictures with updates on chemotherapy treatments, and it also gave them the

opportunity to be a part of the online community with the hashtag #fuckcancer. This kind of support and community presence was not available on Facebook for P02, but it was on Instagram.

5 DISCUSSION

Since Facebook is regarded as a place where mostly casual, positive content is posted, news of a cancer diagnosis comes as a strong contrast to what a user might be used to seeing in their News Feed. This creates the initial shock that comes with learning of a cancer diagnosis and makes this event more memorable than coming across other content on Facebook. The design of the platform seems to be lacking any acknowledgement for the content of each post. Perhaps a more content-aware platform would be able to remedy this issue.

With recent advances in natural language processing, it is hard to make excuses to not make the algorithms that display this content aware of what the content actually is. It's possible to flag posts based on their content to benefit the user. In doing this, Facebook could warn users of possibly upsetting content, much the way explicit content is handled now. Theoretically, a feature like this would hide the content until the user chose to "open" and read said posts. This would offer the user another chance to confirm that they want to view the content of the posts if they deem it appropriate at the time, otherwise the content would stay hidden. Displaying a confirmation like this would allow the user to assess their current situation, such as if they're out in public, who might be looking over their shoulder, and if they are emotionally prepared to see the upsetting content. Presumably, such a design would also include a way for the user to save the post for later so that they can come back to it during a time that they are better prepared to view the content.

Some of our participants discussed how seeing a post with the cancer diagnosis distracted them from what they were doing or planning on doing during that particular day. Facebook would most likely prefer to keep users on their platform rather than discouraging usage by displaying upsetting content right next to more casual content.

Another component that makes up the process of seeing upsetting content, such as a cancer diagnosis, on Facebook is the reaction of the user. Recently, Facebook implemented reaction emoticons to expand the amount of reactions that users may demonstrate towards a post beyond merely just "liking". While it seems that this feature would work well in the case of a cancer diagnosis disclosure, the results of our study do not support this. Even with the expanded variety of reactions, Facebook does not support the complex reactions that users may have to seeing a cancer diagnosis in a post. We found that participants wanted to talk to the cancer patient one-on-

one using avenues such as text messaging, calling and direct messaging. While Facebook does allow for commenting below a post, none of our participants reported using this feature to talk to the cancer patient. All of them either desired a private one-on-one conversation with the cancer patient via calls or messages, typically outside of Facebook.

Just as participants typically desired to follow up with the cancer patient soon after seeing the cancer diagnosis post, some also reported that they checked up on the cancer patient afterwards whether virtually or in real life. Some would do this by calling or texting the cancer patient while others revisited the Facebook profiles of the cancer patient to see if they had posted anything about their cancer since the diagnosis. Facebook has implemented suggestion algorithms in the past to encourage users to reach out to friends that they don't often reach out to but this particular feature didn't receive very favorable feedback after implementation. However, we see a suggestion system as a valuable feature where users are reminded to check up on a cancer patient after the user reacts, via comments, saving the post, or reacting to a cancer diagnosis post on Facebook.

Along these lines, Facebook may want to consider implementing an algorithm that shows and ranks content based on both the geographical distance and social distance between two people. This can be valuable in times when users disclose things such as a cancer diagnosis. Our findings show that both types of distance affect a person's feelings about being notified via Facebook. For example, P03 thought that finding out about a coworker's cancer diagnosis was appropriate and wasn't expecting a phone call or text message. However, other participants whose friends were closer to them desired a more direct notification of the cancer diagnosis, such as through a call or text message. This variance in social distance could be measured by Facebook in order to show content like a cancer diagnosis to a user at an appropriate time. Facebook may also be able to alter the design around this type of content in a way that makes it seem more direct and personal.

Along with social distance, geographical and physical distance plays a role into a user's reaction to seeing a cancer diagnosis on Facebook. This is also something that Facebook News Feed algorithms could be more aware of and empathetic towards. Participants who saw cancer diagnoses of people that they worked with or lived close to often felt that they should reach out to the cancer patient directly. If the cancer patient was further away, the desire for one-on-one communication with the cancer patient still existed, but was not nearly as strong. In situations where the participant and the cancer patient lived close together or worked together, the timeline between seeing the cancer diagnosis and talking to the

cancer patient was condensed due to the chance of seeing the cancer patient in day-to-day life.

FUTURE WORK

After reviewing all the information/data we have acquired and making all the analysis above, there are still a few things we were not able to delve into that opens up the opportunity for future research in this area. We would've liked to have conducted more interviews to get a larger a richer set of perspectives. From all the interviews we conducted, our team focused our attention on people's reactions to seeing the post containing the cancer diagnosis and how they felt about it. This research was conducted primarily from the perspective of the Facebook user that saw a Facebook post containing a cancer diagnosis. From the interviews we conducted, there was some information provided by the interviewees about why they believed the poster decided to share their diagnosis on Facebook, but nothing from the actual poster themselves. Apart from that, we were able to accomplish many of our goals with this paper. However, we acknowledge that our findings could be further explored and studied if we had more participants and time.

The algorithms that present content to users are largely unaware of the content actually contained in posts. This causes interactions including cancer diagnosis posts right under more casual content. There are many opportunities for research into how content algorithms can be better aware of the content that they are displaying for users and the implications of these decisions. Consequently, research on the actual design of a product like Facebook's News Feed can also contribute to a user's reaction to seeing content such as a cancer diagnosis. We feel that if Facebook's design was altered to accommodate less positive content, interactions between people who have negative news to break would feel more human-like. This could be achieved through a feature that may save negative posts for later so that the user can read those posts when they are in the right place and frame of mind to do so.

CONCLUSION

This study has demonstrated the central role of social media, especially Facebook, in disclosing cancer diagnoses. Our research provided insight into Facebook's algorithm used when procuring text in an orderly manner. In responding to cancer posts, users were typically found to respond privately offline to the diagnosed user for privacy purposes. While Facebook is used as a platform to share news on a large scale at an instant, it doesn't support any long-term events, especially ones that contain sensitive news. Having researched the ways in which technology fails to understand the ambiguity of the data we post online, it's been revealed that Facebook does not

filter much of its text. Among the unfiltered text is the unfiltered geographic knowledge of its users. We offer the challenge of implementing a more content-aware algorithm that would display specific content at times appropriately chosen by the user. To accommodate the similar responses from users geographically near and far, this algorithm could also show and rank content based on both the geographic and social distance between two users.

The site's new additional reactions to the 'like' button has proved useful in some cases – but again, not towards a case quite as serious or long-term as cancer. Our research explores how many users choose to respond via personal and individual texts and calls off of the platform, proving further that Facebook does not always support the complex reactions that users may express when reading of a cancer diagnosis on their timeline. To this, we present the solution of reviving the “suggested friend” algorithm- which originally presented users with the chance to

reconnect with an old comrade- but rather than suggest a friend, we propose an algorithm that reminds users to check up on a current cancer patient and offer a sample message to send. The algorithm would target the users who have reacted to the cancer diagnosis post through comments, reaction buttons or hitting save.

The trusted GoFundMe pages have now been in constant use for those who are going through a financial burden. Currently, Facebook only allows these types of sites to be linked, but never pinned at the top of a timeline or account. We recommend Facebook take note of its neighboring social media platforms features, such as Twitter's pinned tweet or Instagram's new story highlights. Pinning a GoFundMe post to the top of a page would allow the user to keep track of the site, as well as any donors or followers of the cause, allowing for a better support system to the long-term processes.

REFERENCES

- [1] Bender, J. L., Jimenez-Marroquin, M., & Jadad, A. R. (2011). Seeking Support on Facebook: A Content Analysis of Breast Cancer Groups. *Journal of Medical Internet Research*, 13(1). doi:10.2196/jmir.1560 <http://www.jmir.org/2011/1/e16/>
- [2] Hilton, S., Emslie, C., Hunt, K., Chapple, A., & Ziebland, S. (2009). Disclosing a Cancer Diagnosis to Friends and Family: A Gendered Analysis of Young Men's and Women's Experiences. *Qualitative Health Research*, 19(6), 744–754. <https://doi.org/10.1177/1049732309334737>
- [3] Kim, J. G., Vaccaro, K., Karahalios, K., & Hong, H. (2017). “Not by Money Alone”: Social Support Opportunities in Medical Crowdfunding Campaigns (pp. 1997–2009). ACM Press. <https://doi.org/10.1145/2998181.2998245>
- [4] Milbury, K., Badr, H., Fossella, F., Pisters, K. M., & Carmack, C. L. (2013). Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. *Supportive Care in Cancer*, 21(9), 2371–2379. doi:10.1007/s00520-013-1795-6
- [5] Moorhead, S. A., Hazlett, D. E., Harrison, L., Carroll, J. K., Irwin, A., & Hoving, C. (2013). A New Dimension of Health Care: Systematic Review of the Uses, Benefits, and Limitations of Social Media for Health Communication. *Journal of Medical Internet Research*, 15(4), e85. <https://doi.org/10.2196/jmir.1933>
- [6] Myrick, J. G., Holton, A. E., Himelboim, I., & Love, B. (2016). #Stupidcancer: Exploring a Typology of Social Support and the Role of Emotional Expression in a Social Media Community. *Health Communication*, 31(5), 596–605. Doi: 10.10410236.2014.981664
- [7] Ngwenya, N., Farquhar, M., & Ewing, G. (2016). Sharing bad news of a lung cancer diagnosis: understanding through communication privacy management theory: The communication process of sharing bad news in lung cancer. *Psycho-Oncology*, 25(8), 913–918. <https://doi.org/10.1002/pon.4024>
- [8] Nolbris, M. J., & Nilsson, S. (2016). Sibling Supporters' Experiences of Giving Support to Siblings Who Have a Brother or a Sister With Cancer. *Journal of Pediatric Oncology Nursing*, 34(2), 83–89. doi:10.1177/1043454216648920
- [9] Schaepe, K. S. (2011). Bad news and first impressions: Patient and family caregiver accounts of learning the cancer diagnosis. *Social Science & Medicine*, 73(6), 912–921. <https://doi.org/10.1016/j.socscimed.2011.06.038>
- [10] Skeels, M. M., Unruh, K. T., Powell, C., & Pratt, W. (2010). Catalyzing social support for breast cancer patients (p. 173). ACM Press. <https://doi.org/10.1145/1753326.1753353>
- [11] Yi, F., Lanying, D., & Qian, L. (2017). How Social Media Strategies of Non-profit Organizations Affect Consumer Donation Intention and Word-of-Mouth. *Social Behavior & Personality: An International Journal*, 45(11), 1775–1786. Doi: 10.2224/sbp.4412