



Social Support within Online Communities: Internet Reach and Content Analysis of a Cancer Anti-stigma Facebook Page in Mexico

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Abstract

Social networking sites (SNS) can serve as modern platforms to address disease-specific stigma, especially in Mexico where cancer stigma impedes healthcare access. This study examines the Facebook Page administered by the Livestrong Foundation in Mexico addressing cancer stigma, in order to elucidate key features of social media regarding the experience of cancer and cancer stigma in Mexico. The study is unique for its focus on a public online platform involving both support and outreach, as existing studies examine more exclusive forums for social support alone. We employ a mixed-methods approach involving qualitative analysis of posts and quantitative analysis of usage trends, focusing on January 1 to June 30, 2013 to encompass Livestrong Day. The 28 posts during this time period reached a total of 28,049 viewing users and 230 interacting users. As hypothesized, most support arose from strangers, consisting of primarily emotional and informational support, with most emotional support from women compared to men. The theme of empowerment appeared frequently within cancer narratives. Emotional support and narratives garnered the most user responses. Anti-stigma campaigns might further leverage users' primary interest in emotional support by featuring narratives of recovery and empowerment to reach a broader and more interactive audience.

Keywords: Mexico; Cancer; Social support; Stigma; Social media; Social networking

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Introduction

Cancer and stigma in Mexico

Due to disparities in healthcare, more than half of the global cancer burden is within low and middle income countries (LMIC) [1]. In particular, Mexico has significant cancer mortality accounting for 12% of all deaths in 2010 [2]. Studies suggest that in many LMIC such as Mexico, stigma of cancer is a principal barrier preventing effective intervention [3]. Within Mexico, common stereotypes of cancer include that the disease is equal to death, and people with cancer are less able to work. Fear of diagnosis and subsequent labeling may prevent an individual from seeking medical attention. Even after diagnosis, individuals may cope with stigma through denial, refusal to take medications, or social isolation, cutting off important emotional support systems.

Culturally-appropriate interventions to address stigma of cancer, decrease isolation, and increase social support networks are crucially needed to complement existing efforts targeting cancer prevention within Mexico [4].

Social support via social networking sites

Withdrawal from social engagement is a common coping mechanism against stigma, resulting in isolation as a major negative consequence [5,6]. Social support ameliorates these negative results, countering stigma's "othering" effects by marking individuals as full-status participants in society [5]. Social networking sites (SNS) can serve as novel platforms through which these mechanisms can take place towards addressing disease-specific stigma [7,8]. One study of online support groups for medical diseases found that decreased stigma was the most

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frequently mentioned benefit [9]. Another study showed a correlation between online interaction with Facebook friends and greater self-reported well-being and less physical illness. However, few studies analyze mechanisms through which social support is conferred online [10,11]. Existing research focuses on local and exclusive disease-specific online communities, conducted before the popularity of Facebook expanded social networking to a global scale. Facebook Pages is a unique SNS platform for its global visibility, ease of access to social support, and use for activism reaching an audience beyond the targeted group receiving social support. This equal emphasis on social support and activism makes Pages particularly useful for non-profits aiming to address disease-specific stigma, as well as a rich source for examining the nature of modern online social support.

Patterns of social support and user interactions

Existing research focusing on online disease-specific groups show that online social support is primarily in the form of emotional support and informational support [12-17]. In particular, emotional support and narratives draw more user engagement than informational support. Studies of online cancer groups show that emotional support and narratives around the process of diagnosis solicited more user engagement [18,19]. Gender may shape the prevalence of emotional versus informational support in online communities, with social expectations of gender performance affecting both men and women's preferences for online communication and narrative expression [20, 21]. Studies with online cancer support groups showed that more women use a communication style prioritizing emotional support compared to men [22,23]. Empowerment is a crucial component in reducing cancer stigma, as it protects against internalized stigma and the negative effects of labeling. Through telling one's own story, narratives allow reframing of suffering as opportunities for insight and action, which may lead to increased emotional resilience and empowerment [24]. Some studies on disease-specific online social support document increased self-reported empowerment among group users [25-27] however few studies examine themes of empowerment within cancer narratives. Analyzing themes of empowerment within users' cancer narratives may help us understand how users navigate, challenge, and cope with existing stigma against cancer.

Study aims

Existing studies focus on relatively small online groups dedicated to social support, which differ from larger multi-purpose platforms such as Pages combining social support with activism targeting a broader audience. This study expands upon previous research with a case study of a Facebook Page administered by a campaign in Mexico addressing stigma of cancer. We hypothesize that the Facebook Page replicates findings in smaller disease-specific online communities. We test hypotheses through a mixed methods approach, synthesizing quantitative analysis of user and post trends with qualitative analysis of user-generated content. We first hypothesize that most instances of support come from strangers previously unknown to the support recipient and who infrequently interact online, magnifying effects seen in more private online groups [12,28]. Second, we hypothesize

that emotional and informational support will appear most frequently as forms of social support, with women providing more emotional support compared to men. Third, we expect to see emotional support and narratives as more effective elicitors of user engagement, even within a Page platform that equally prioritizes support and activism. Fourth, we explore whether empowerment themes arise within user generated content and how it might relate to cancer stigma. While we are unable to provide formal statistical tests for these hypotheses, we make descriptive observations based on these analyses. This in-depth study highlights key features of social media, with implications for SNS-based health communication efforts to decrease cancer stigma in Mexico.

Method

Participants

Comparte tu Historia (a program of the Livestrong Foundation) is a Mexico-wide campaign aiming to decrease cancer stigma. This program created a Facebook page to encourage social support (featuring volunteers' cancer narratives and the dedication cards photo campaign) and to promote information and events (especially Livestrong Day, a major annual event). As of November 2014, the Facebook page has >1400 fans via Facebook "likes". Joining the page is free and open to anyone. Because Comparte tu Historia administrators create posts, we focused on the Comparte tu Historia Facebook community because of its Mexico-wide reach. Study data consisted of posts and messages (on the Facebook page), and page trends and demographics (from Facebook administrator data) from January 1, 2013 to June 30, 2013 to assess coverage of sufficient time and because this period encompassed Livestrong Day (May 16-17, 2013). This time period also highlights the page's dual purpose to provide informational support for activism and emotional support for a user-dominated support community, thus serving as a naturalistic test of the predominance of these types of support. This study was approved by Columbia Medical Center's Institutional Review Board.

Quantitative analysis of posts and users

For each post, three MA-level students recorded quantitative data regarding the type, date, and author and all modes of interaction with that post, consisting of: 1) likes, 2) comments, 3) shares, and 4) likes on comments (**Table 1**). Type, date, and author information for all posts and interactions were recorded to assess quantitative information related to demographics, post type, and trends in content. Using these metrics, posts were organized based on popularity. Unique Facebook users were identified, and patterns of use assessed based on demographic information including gender, cancer status (self-identified vs not self-identified), and relation to Comparte tu Historia (as cancer survivor volunteer, staff, or family member of a survivor). The "Like: Comment ratio"—the average number of "likes" recruited by each user's comment—was calculated for each unique user. A higher ratio indicated more successful average recruitment of "likes" (and therefore more user interaction solicited by one user's comments, or "higher popularity"). Some users were Page administrators, in particular the "Comparte tu Historia" account,

and were included in the analysis with public users, since staff and volunteers may contribute as individuals with unique experiences with cancer, in addition to posting campaign information.

Page administrator data

Comparte tu Historia page administrators can utilize Facebook statistics to monitor trends in page usage. Using these statistics, we exported both page and post level metrics, and utilized further information such as total number of non-interacting viewers by post, and user demographic information such as preferred language, age, and location according to users' profiles.

Qualitative analysis of posts and comments

Qualitative data consisted of Facebook posts and comments to the posts, which were translated from Spanish to English by a bi-lingual MA student (J.T.). Our qualitative analyses adapted a prominent social support framework [29], which posits that one's "primary support source" (intimate others) and "secondary support source" (experientially similar others) provide different types of social support via unique mechanisms. We utilized the directed content analysis described by Hsieh and Shannon [30]. This method allows extensions of existing conceptual frameworks to novel domains: i.e., an online cancer support community for which no unique social support framework currently exists. We identified initial coding classifications based on Thoits' mechanism of social support, which included emotional support, informational support, and instrumental support. When implemented with the qualitative data, social support categories were modified, elaborated, or replaced according to consensus within the research group to account for the unique context of our online dataset.

Analysis began with identifying initial coding categories and creating operational definitions based on the theory. This initial set of codes includes emotional support, informational support, and instrumental support. Posts and comments were coded independently by three MA-level students using these categories. The research team met extensively to discuss discrepancies

(16 meetings, including 8 to reach consensus with the principal investigator (LY), lasting 60 minutes each, over 3 months). All final codes were consensus codes between the three RAs. These classifications were refined by the narrative data and expanded to include additional codes, including support request (requests for empathy, participation, or information), and empowerment (motivation towards agency, social activism, and advocacy) (Table 2).

Synthesis of qualitative and quantitative analyses

Qualitative and quantitative analysis of posts were synthesized to assess patterns of social support conferral and relations to gender. To determine the most frequent types of support exchanges, post popularity according to quantitative analysis was matched with the post's 'most salient' social support codes according to qualitative analysis. 'Most salient' code was determined by frequency of the code (or RA consensus in cases of tied frequencies). In addition, users' gender was matched with the type of social support conferred via comments, according to qualitative coding.

Results

Participant characteristics

Table 3 shows demographic information for the people reached via the Facebook page (viewers) and people who interacted with the page (via likes, comments, shares, and/or likes on comments; henceforth referred to as "interactive users"). There were 230 unique users who interacted with the Facebook page; 67% were women, 27% were men, and 7% were of unspecified gender. There were a total of 28 posts. In addition to interactive users, additional users were reached via viewing posts alone (henceforth referred to as "viewers"). In total 28,049 unique people viewed the page. 84% of viewers were from Mexico, 8% from USA, and 8% from all other countries combined. Within Mexico, the city with the most people reached was Mexico City (52% of viewers in Mexico), followed by Guadalajara (11%), and Merida (7%). Of all viewers, 85% used Spanish, and 14% used English; 56% were

Table 1 Facebook interaction terms.

Term	Definition
Post	Publicly visible text, picture, or video created by the Page moderator (Comparte tu Historia). Users can interact with posts via Likes, Comments, Shares, or Likes on Comments.
Like	one-click affirmation of support for a post, which allows users to receive updates on the "liked" post in their personal news feed
Comment	publicly visible message, picture, or link that a user attaches directly to the post
Share	a method for users to disseminate the post through their own friends or page, with the option of adding a personal message
Like on Comment	one-click affirmation of support attached to a comment

Table 2 Codes for qualitative analysis.

Code name	Code description
Emotional support	demonstrations of caring, encouragement, and sympathy
Informational support	provision of facts, advice, or guidance
Instrumental support	behavioral assistance with practical tasks or tangible material assistance, such as gifts, blood donations, etc.
Support request	requests for empathy, participation, or information
Empowerment	motivation towards agency, social activism, and advocacy
Social Influence	Setting of norms among others with similar experiences
Stigma	Explicit mentions of cancer stigma

women, and 42% were men, a more equal gender distribution compared to the subset that actively interacted. Additionally, 38% of viewers were between 25-34 years of age, the most highly represented age group (Table 3).

Quantitative patterns of user interaction

64% of interactive users did so only once. Therefore most were infrequent contributors, with the number of contributors decreasing with increased frequency of interaction (Figure 1). The most frequent form of interaction was “likes,” followed by comments, and shares. As expected, the most frequent contributor was Comparte tu Historia as the page moderator. Even when removing consideration of Comparte tu Historia, the general trend of user interaction still reflects more infrequent contributors. Comparte tu Historia as a contributor had a “Like: Comment instance” ratio (the number of likes per comment, signaling ‘popularity’ of a comment via more recruited interaction) of 1.625. Comparte tu Historia commented 8 times, while all other commenters did so either once, twice, or three times, with a range of “Like: Comment instance” ratio of 0.333 to 2. 14% of interactive users commented at least once to a post.

Posts and qualitative analysis

Figure displays user interactions solicited by each post (28 total posts) (Figure 2). Posts solicited a total of 576 interactions, with the most popular post soliciting 68 interactions, and the least popular post soliciting 3 interactions. Including viewers, posts reached a total of 13,886 people, with the most popular post reaching 2100 people and least popular post reaching 20 people. Most support came from unaffiliated users with no relation to

Table 3 user demographics.

Demographic	n (%)
Age	
13-17	837 (3)
18-24	5291 (19)
25-34	10623 (38)
35-44	6840 (24)
45-54	2683 (10)
55+	1271 (4)
Unknown	560 (2)
Gender	
Female	15707 (56)
Male	11780 (42)
Unknown	560 (2)
Country	
Mexico	23561 (84)
USA	2160 (8)
Other	2328 (8)
Language	
Spanish	23842 (85)
English	3927 (14)
Other	280 (1)
Interacting Users	230 (< 1)
Female	153 (< 1)
Male	61 (< 1)
Unknown	16 (< 1)

Note: Interacting users refers to the subset of viewing users who actively engaged via likes, comments, shares, or likes on comments.

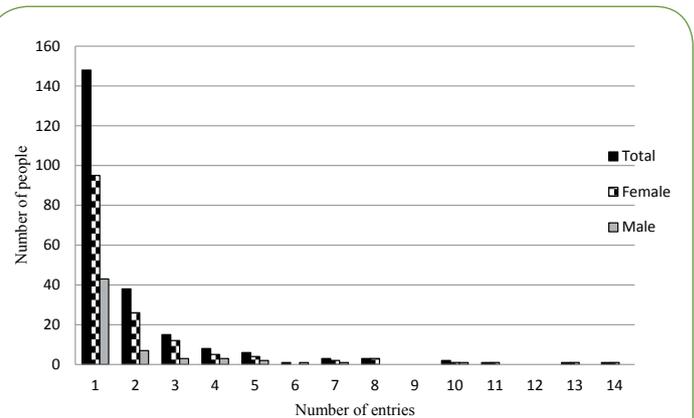


Figure 1 Total user interactions.

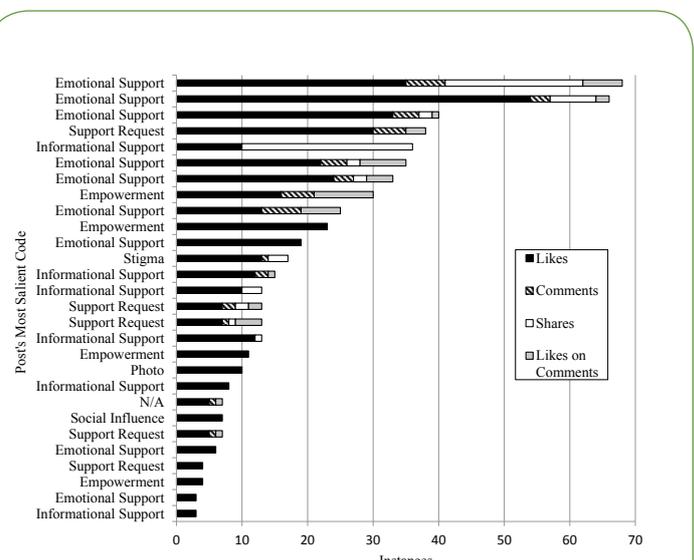


Figure 2 User interactions per post.

the support recipient and no self-identified cancer status. Figure 2 also displays the most salient code for each post. The most salient code was emotional support (8/28), while second was informational support (5/28) and support request (5/28) (Table 2). Emotional support posts were most popular; 7 of the 8 total emotional support posts were among the top 11 most popular. More female users provided emotional support compared to men. 20 women offered emotional support via comments, while only 3 men did so. Two of these men were volunteers through Comparte tu Historia, and one was a cancer survivor. The predominance of women extended to informational support, but to a lesser extent; 6 female users provided informational support via comments, compared to 3 male users. There were 13 total narrative posts, 6 from survivors sharing their story and the rest from volunteers or family of survivors. 6 were from women, 5 from men, and 2 from users of unknown gender. Narrative posts were popular. Of the 10 most popular posts, 6 were narratives, with 3 from survivors. In addition to the narrative posts, 2 more narratives came from unaffiliated users through commenting upon a post by sharing their own story. All survivors’ narratives

Table 4 Themes from qualitative analysis.

Theme	Example	Source
Emotional Support		
Empathic story-sharing	I understand how you feel. As of three years I passed through a similar process, they extrapolated my uterus and I also do not have the opportunity to be a mother. And like you said well, only those people who have experienced all this process understand what happens not only to our body, but in our soul and our heart...We are fighters and nothing holds us down. God bless you.	Cancer survivor
Family members and God	My secret is the love of all my family who has always been with me in the most crucial moments, and the hand of God which I don't let go of. God would allow others to have the same opportunity and the desire to live that I have.	Cancer survivor
Informational Support		
Event announcement	Remember to spread the word about this event: in the XXX [city] we are located within the XXX Hospital in the Cancer wing (on May 15, 16, 17, from 10:00am to 2:00pm),	Comparte tu Historia
Disseminating information	Friends we want to share with you all the page that reports information regarding the stigma associated with cancer and the actions and impact in the countries where we are working to diminish it, as is the case in Mexico... spread the word... www.livestrong.org/stigma	Comparte tu Historia
Encouraging information from survivors	Cancer does not mean death, if detected on time they are stories of success.	Cancer survivor
Empowerment		
Speaking out as activism against discrimination	it is important to bring awareness to society...That is why I am here as a volunteer...so that we can finish with discrimination in regards to the illness called cancer.	Cancer survivor
Speaking out as helping other survivors	If we share our stories (histories), we are giving more emotional support to people who, like you and I, need to feel that they are not alone and to share their life stories.	Cancer survivor
Inspiration from recovery	...not everyone has three relapses and three opportunities for re-birth. Now I ask myself which is the mission I have in life, my fear is not the cancer, but to guide my steps and give a true meaning to life.	Cancer survivor
"Fighting" cancer	Individually we will fight our own fight, but we are not alone. You can't have life without death but you can leave a mark. You can live (exist) and the way to live is to fight it [cancer], and above all, search for happiness.	Cancer survivor

featured either empowerment (3 of 6) or emotional support (3 of 6) as the most salient code.

Themes from qualitative analysis

Table 4 displays examples of emotional support, informational support, and empowerment with their associated themes. The most frequent form of support was emotional support, most often directed towards cancer survivors. Emotional support consisted of well wishes, expressions of sympathy, and tended to be less than a sentence in length. Cancer survivors also shared longer personal narratives, with many of these testimonials seeking to shed light on the reality of living with cancer and helping others feel less alone. Not all of these anecdotes were solicited by Comparte tu Historia; spontaneous sharing occurred via comments in direct response to another individual sharing their story. For example, one survivor responded to another's experiences with cancer treatment by sharing her own healing process. Survivors frequently cited their family members and God as sources of emotional support and motivation.

The second most frequent form of support through the Facebook page was informational support. The majority of informational support was provided by the moderator, Comparte tu Historia, through event announcements for socializing or campaign involvement, and information about cancer and stigma. Cancer

survivors also offered informational support via encouraging facts about cancer, often through cancer narratives (**Table 4**).

Empowerment was a prominent code, especially within the cancer narratives, appearing as the fourth most frequent code. Those who chose to share their story mentioned deriving strength from their condition, desire for activism, and concern for other survivors. Survivors who spoke about empowerment mentioned the need to speak out to educate others about cancer, as a way to address discrimination against cancer survivors. In addition to activism towards cancer stigma, participants mentioned allowing one's story to impact other survivors as another reason to speak out. Participants stressed that recovery from symptoms can be a great source of inspiration allowing one to see life in a different way, and that recovery is possible. The language of "fighting" cancer commonly appeared in user contributions featuring empowerment (**Table 4**).

Discussion

Summary of main results

The Comparte tu Historia Facebook page aimed to decrease stigma of cancer in Mexico, engaging 230 unique interactive users who contributed via likes, comments, shares, or likes on comments, and reaching 28,049 total viewers in a 6 month period. The majority of participants were adult females, who

spoke Spanish and resided in Mexico. More female participants actively interacted with the page compared to male participants but this distribution became more balanced when considering non-interacting viewers. Unlike prior research focusing on more closed online groups, this campaign's Facebook page prioritizes both social support (e.g. dedication card photos, featured cancer narratives), as well as education and awareness (e.g. Livestrong Day). As hypothesized, most interacting users did so one time via low-commitment actions such as a "like", with the vast majority of users viewing without interacting. In addition, most support arose from unaffiliated strangers. Social support was conveyed primarily through emotional support and informational support, with emotional support appearing most frequently and primarily from women users. This supports our hypothesis based on prior studies with more closed, private online groups. Consistent with current research emphasizing the importance of emotional support and story-sharing in online environments, our study showed that emotional support and narratives garnered the most user interactions. In addition, the theme of empowerment appeared frequently, especially within cancer narratives. This is a unique finding, as few studies have examined empowerment within user-generated online content.

Patterns of user interaction

Quantitative patterns of user interaction replicate existing literature on online communities, where most users infrequently interact. Our results support this finding, with 64% of interacting users doing so one time and the vast majority of users viewing without interacting. In addition, most social support came from strangers, emphasizing the page as a means for unaffiliated survivors and community members to come together as "weak tie" networks. These results are expected, given the public nature of the Facebook Page. The page moderator was the most frequent contributor and commenter, with a high "Like: Comment instance" ratio, highlighting the Page platform as the organization's interface with its online community. At the same time, many individual users had high "Like: Comment instance" ratios, with 14% of interacting users contributing comments to posts. This demonstrates the active presence of individual users creating a supportive community amidst the organization's informational support and education.

Social support and cancer narratives

Although prior research on disease-specific online support focus on more private groups intended for social support, our results suggest that effective social support is possible on public groups that also emphasize activism. The Facebook page used for analysis in our study is a unique platform, as studies show that cancer-specific online groups are mostly intended either for social support, or awareness and fundraising [18,31]. Although one might expect an organization-run public page to contain few instances of emotional support and narrative sharing, the relative anonymity, ease of access, and de-stigmatized norm may facilitate the exchange of emotional support [9]. In addition, activism and social support may complement each other. We speculate that activism may serve as a buffer, as the vulnerability of individual users sharing their story is decreased under an overall message of

empowerment and education. Therefore, the campaign's general mission diffuses the risk for any individual who chooses to share their personal story. Our results reveal that women represent the majority of users and provide most of the emotional support compared to men, disproportionate to their representation in the total reached population. The relative lack of male presence might be explained by previous research noting that the norm of online social support communication differs from that preferred by men, involving a level of emotional communication which may be unsettling for many male users [22]. The female-dominated emotional support and user population in our study raises questions about women's "cyber-agency." As Pitts [21] discussed within a study on breast cancer survivors' websites, women-dominated online platforms may be opportunities to invent selves and define one's embodiment of disease. In addition, our study's finding of frequent empowerment themes further highlights SNS as potential facilitator of women survivors' empowerment. However, SNS is not inherently empowering, and critical analysis of power relations, gendered norms, and individual cancer experience is needed to prevent reinforcement of hegemonic messages. Posts that solicited the most user interactions featured emotional support and narratives. This result is especially relevant to health communication, as existing studies show that SNS users with more frequent interaction report closer relationships and social capital [10,11]. Therefore, users' interaction and sense of support may be maximized through cultivating more emotional support and story-sharing. This echoes existing literature on disease-specific online communities, where users may be more interested in empathy rather than information which can be obtained from other sources such as doctors [32]. Narratives and the experience of cancer may be of primary concern, rather than informational support such as advice and facts about cancer. This result supports existing research in narrative medicine, which posits that "the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness" is crucial to healthcare practice and understanding patient perspectives [33].

Implications for cancer stigma reduction in Mexico

As SNS become increasingly utilized for maintaining social connections, creation of social support pages may serve as an effective medium to address disease-specific stigma. In particular, online social support can alleviate stigma's major consequence of social isolation, which may take different forms across cultures [34,35]. Social support from primarily unaffiliated strangers adds new ties, albeit transiently, to a user's social network. Receiving encouragement to speak out may counteract harmful coping mechanisms such as secrecy, which can delay diagnosis or treatment. We speculate that online communities may serve as non-stigmatizing cultural alternatives, through which users might compare, resist, and gain insight into cancer stigma in their local cultural worlds [36]. The online page may elucidate alternatives to cancer stereotypes and labeling, providing models for sharing via cancer narratives, and allowing direct opportunity for action and engagement via comments. Instances of emotional support frequently mentioned family members and God, suggesting that cancer stigma reduction efforts in Mexico may benefit from

increased attention to these support sources. Emotional support and narratives elicited more user engagement, suggesting that future online initiatives might reach a more interactive audience through featuring stories of recovery and emotional support [37]. Empowerment frequently appeared in cancer survivor narratives, which described finding new meaning in life with cancer, social activism, and a desire to support others. Campaigns might further leverage the existing common theme of empowerment within narratives to promote a culture of activism, prognostic optimism, and survivors' agency. In particular, a culture of empowerment might further improve from moderators who self-identify as cancer survivors and actively participate with their own story.

Study limitations and future directions

This study is limited by its analysis of a single Facebook Page on a single health topic, and hence cannot be generalized to all disease-specific Facebook Pages. In addition, our results do not distinguish between the various types of cancer; the experience of living with various types of cancer differs, as does the stigma associated with each condition. Given that SNS content and features continually evolve, our results are not directly replicable, although general trends should be replicable in similar Facebook Pages. The page administrators were included as users in the analysis, since we could not distinguish their personal posts from their posts representing the program. However, including

the administrators did not skew overall trends in user interaction and qualitative analysis of social support. Most participants were female and the most represented age group was 25-34, hence our results are not representative of general SNS users or cancer survivors in Mexico. The majority of female users may additionally impact our interpretations of the conferral of empathy and emotional support online.

This study's strengths include analysis of an online platform with national reach in Mexico and with international recognition via Livestrong Foundation, coinciding with Livestrong Day. We employed a context-specific, inductive qualitative coding method which is applicable to a social support via SNS. To our knowledge, our study is one of the first exploring online social support and cancer stigma in Mexico or any other LMIC. Further research in disease-specific online communities might continue exploring the role of dual awareness and support platforms, assessing the potentially complementary role of activism with survivor support. Additional work with user interaction patterns may explore how individual characteristics such as gender, age, and cancer status impact methods of user interaction. Future qualitative work with user-generated content might investigate culture-specific ways through which users may express cancer narratives, which may inform appropriate online support platforms and health-care practices in Mexico.

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