



# Investigating relationships among cancer survivors' engagement in an online support community, social support perceptions, well-being, and moderating effects of existing (offline) social support

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## Abstract

**Purpose** Socially supportive relationships help cancer survivors cope with their diagnosis and may improve quality of life; however, many survivors report unmet support and information needs. Online communities of survivors may address these needs, but research on their benefits have been equivocal. This cross-sectional, self-report study investigated relationships among cancer survivors' level of engagement in an online survivor community (The American Cancer Society Cancer Survivors Network®; CSN), perceptions of emotional/informational support available from online communities (“online social support”), well-being, and moderating effects of “offline social support.”

**Methods** Participants were 1255 registered users of the CSN who completed surveys between 2013 and 2014. Three types of engagement with the CSN—*social/communal*, *interpersonal communication*, and *informational/search* engagement—were identified through principal components analysis. Regression analyses examined hypotheses.

**Results** More frequent *social/communal* and *interpersonal communication* engagement were associated with increased online social support ( $p < .0001$ ), and the relationship between *interpersonal communication* engagement and online social support was strongest for survivors reporting lower offline social support (interaction  $\beta = -.35$ ,  $p < .001$ ). Greater online social support was associated with increased well-being, but only among survivors reporting low offline social support (interaction  $\beta = -.35$ ,  $p < .0001$ ).

**Conclusions** Engagement in online survivor communities may increase support perceptions that promote well-being, but benefits may accrue more to survivors reporting low offline social support.

**Implications for Cancer survivors** Newly diagnosed cancer survivors, particularly those with unmet emotional/informational support needs, should be given the opportunity to communicate with other survivors through online survivor support networks.

**Keywords** Cancer survivor · Internet · Online health community · Social networking · Social support · Quality of life

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## Introduction

Experiencing a cancer diagnosis, subsequent treatment, and its ongoing long-term and late effects often leaves cancer survivors with heightened needs for social support and information throughout their lives [1–3]. To cope with these challenges, survivors often seek emotional and informational support from friends and family, healthcare providers, and individuals with similar experiences [2, 4]. Receiving (or perceiving) social support from these sources has been linked to a variety of favorable outcomes for cancer survivors such as reduced

mortality [5], higher health-related quality of life [6], and lower anxiety and depression [7–9]. Whether survivors' needs for these supportive resources and their potential benefits can be fulfilled by online survivor communities, however, has not been established.

### Online communities for cancer survivors

With the advent of the internet, there is now an abundance of online resources for gathering cancer-related information and connecting with other survivors and caregivers. Online health communities are unique in that they overcome geographical barriers to connecting with others who share similar experiences, allow users to maintain anonymity if desired, and are accessible at all hours. A recent review reported over 100 active cancer-specific online communities available to breast cancer survivors seeking online support [10].

The psychosocial benefits of *peer-to-peer* communications among survivors in online survivor networks have been investigated in both observational studies and randomized controlled trials (RCTs), but results have been mixed. [11]; one recent review published in 2017 found mostly non-significant relationships with survivors' well-being and other patient-reported outcomes such as mood, stress, depression, or adjustment to cancer [12]. RCTs have also reported negative, null, or mixed findings [11, 13, 14].

Possible explanations for inconsistent, null, or negative findings by both RCTs and observational studies include a lack of statistical power, lack of consideration of survivors' use of or comfort with the internet, focus on only breast cancer survivors [11, 12], and the potential moderating effect of participants' pre-existing levels of offline social support [15]. Moreover, many experimental investigations included professionally trained facilitators offering coping and other socially supportive assistance, making it difficult to discern the unique effects of peer-to-peer online communication. Further, it is unclear if findings from these proprietary systems generalize to existing, publicly available communities that are largely member directed [16].

Investigating whether survivors lacking social support from offline relationships would benefit most from online survivor communities would address the question of “for whom?” or “under what circumstances?” online support communities may be most beneficial. Observing that survivors with low offline social support benefit most from online social interactions with other survivors, compared to those with higher offline social support, would also be broadly consistent with Optimal Matching Theory. According to Optimal Matching Theory, the provision of support matched to specific needs is hypothesized to result in the greatest benefit [17]. Consistent with this, a study of breast cancer patients using an “interactive eHealth system” found that those who reported

unmet informational needs spent more time using the informational functions, and those reporting unmet emotional needs spent more time using social–interactional functions [18]. In a subsequent study of participants recruited from a “computer mediated support group” [19], breast cancer survivors reporting lower offline emotional support had larger online communication networks, and those reporting low family cohesion were more likely to communicate personally with others through the online network [19].

While the above findings suggest survivors with less offline support seek more online support, studies did not assess how supportive these communications were, nor did they link online social support to psychological outcomes such as wellbeing or quality of life. In addition, the above studies were conducted with female breast cancer survivors. Including male cancer survivors in studies would help increase the generalizability of studies about the benefits of online support communities.

### Overview of study

In the current cross-sectional study, we examined the psychosocial benefits for cancer survivors of participating in an organic, publicly available member-directed online community, and whether those with lower offline social support were more likely to benefit. Launched in 2000, The Cancer Survivors Network (CSN) is a free online community designed to facilitate exchange of peer support among cancer survivors and informal caregivers. The site allows participants to use a variety of informational and interpersonal communication features to connect with others through topic-specific discussion forums, chat rooms, user profiles, private messaging, personal blogs, an expressions gallery, and a member resource library. Over 170,000 have registered and it adds an average of approximately 14,000 new registrants each year [20]. Specific hypotheses as illustrated in our conceptual model (Fig. 1) were:

*Hypothesis 1:* More frequent usage of (i.e., engagement with) the CSN will be associated with perceiving more emotional/informational support available from online communities, particularly among survivors reporting low offline social support (i.e., offline social support will moderate positive associations between engagement in CSN and perceived online social support).

*Hypothesis 2:* Perceiving more online emotional/informational support from online communities will be associated with greater well-being, particularly among survivors reporting low offline social support (i.e., offline social support will moderate a positive association between online social support and well-being).

## Methods

### Study design and participants

Data were collected as part of a CSN survey administered between 2013 and 2014 to characterize the user population and evaluate user participation in CSN features. Further details on the purpose and scope of the evaluation have been described previously [20]. CSN members who logged in to their accounts between January 1, 2008 and October 30, 2013 ( $n = 83,497$ ) were sent an email invitation in November 2013 describing the purpose of the study and timeline for survey distribution. Two reminder emails were sent before the participation window was closed in February 2014. Of the emails sent to valid accounts ( $n = 72,220$ ), 7818 individuals opened the survey link and 4788 completed some or all survey questions. We excluded respondents who did not have a history of cancer ( $n = 493$ ), reported visiting the CSN only once or did not remember ever visiting CSN ( $n = 2151$ ), or were missing data on questions assessing how frequently they used various CSN features ( $n = 288$ ), demographic variables ( $n = 103$ ), medical variables ( $n = 330$ ), or other variables used in the current analyses ( $n = 168$ ). The final analytic sample included 1255 registered CSN members with a history of cancer. IRB approval was obtained prior to data collection and the survey was implemented using software meeting all standards for protecting participant confidentiality.

### Measures

#### Frequency of engagement in CSN

A 12-item scale asked participants to rate their frequency of using various CSN functions. Response options ranged from 1 to 5 (never, less than once a month, monthly, weekly, at least

once a day). Responses were subjected to principal components analysis with varimax rotation to identify dimensions of engagement frequency from the larger set of items. After eliminating an item that did not differentiate among components, results revealed three distinct components accounting for 60% of total variance explained. The first component accounted for 35.3% of variance, with five high loading items (.58–.68) that reflected frequency of deep involvement with the CSN community and its socially or communally interactive functions. Items included “creating/writing one’s own blog,” “using the chat function,” and “adding friends.” Items formed a reliable scale (Cronbach  $\alpha = .74$ ) labeled *social/communal* engagement.

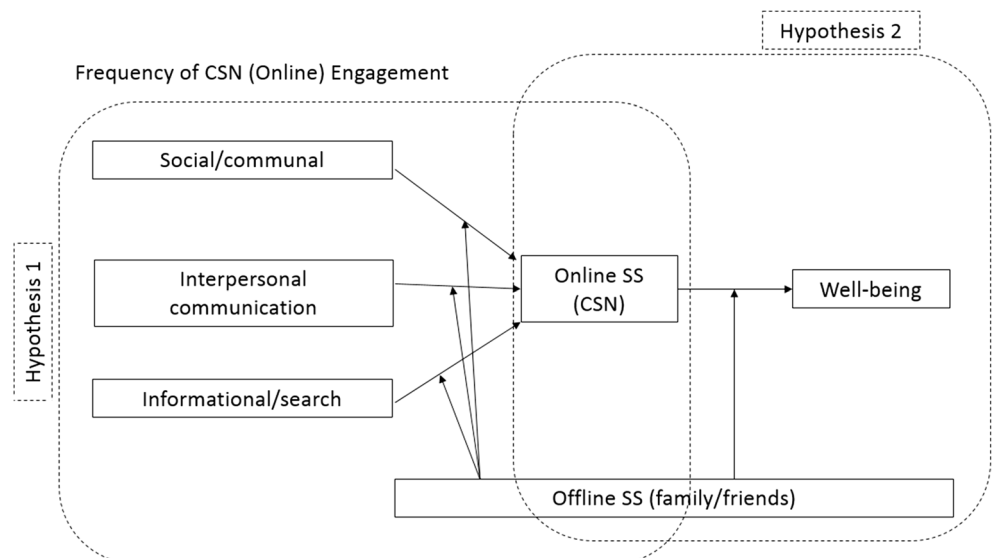
The second component accounted for an additional 14.3% of variance and reflected frequency of use of the CSN simply as a communication channel; its three items (loadings from .70 to .84) were “reading discussions boards,” “posting to them,” and “read/send private messages.” Items formed a reliable scale (Cronbach  $\alpha = .75$ ) labeled *interpersonal communication* engagement.

The third component accounted for 10.1% of total variance with three high loading items (.58–.81): “using the CSN search function,” “reading blogs,” and “read/contribute to the member resource library” (Cronbach  $\alpha = .61$ ). This scale was labeled *informational/search* engagement. Standardized component scores were used in analyses with higher scores indicating greater frequency of engagement.

#### Perceived availability of emotional/informational support

**Offline communities.** Six items from the eight-item *emotional/informational* support subscale of the Medical Outcomes Study (MOS) social support survey [21, 22] were used to assess respondents’ perceptions of emotional/informational support available from offline sources (we used fewer items

**Fig. 1** Conceptual model of proposed relationships among online social network use, social support, and well-being. SS = perceived availability of emotional/informational support



to minimize overall survey length and participant burden). Participants were asked “How easily could you get the following kinds of support from your family, friends and acquaintances, if you needed it?” Examples of items included “someone I can count on to listen to me,” and “someone to give me information that would help me understand a situation.” Responses ranged from “never” to “every time” and were coded from 1 to 5. Items were internally consistent (Cronbach  $\alpha = .95$ ) and mean scores were calculated, with higher scores indicative of greater perceived social support from offline communities.

**Online communities.** Using the same MOS survey items as above participants were asked “How easily could you get the following kinds of support on the CSN or other on-line community, if you needed it?” Higher scores (Cronbach  $\alpha = 0.97$ ) were indicative of greater perceived social support from on-line communities. For brevity and convenience, we use the terms online and offline “social support” to refer to these assessments of perceived availability of emotional/informational support.

### Well-being

The 7-item functional well-being subscale of the Functional Assessment of Cancer Therapy–General (FACT-G) [23] was used to assess overall quality of life among cancer patients. This subscale taps aspects of emotional and physical wellbeing (e.g., “I am able to enjoy life,” “I am content with the quality of my life right now,” “I am able to work”), and demonstrates greater sensitivity to stage of disease and to performance status compared to other FACT-G subscales, according to its developers. Response options ranged from “not at all” to “very much” and were coded from 0 to 4. Summed scores (ranging from 0 to 28) were used in analyses; higher scores indicated higher levels of functional well-being (Cronbach  $\alpha = .90$ ).

### Medical and sociodemographic variables

Sociodemographic variables assessed were self-reported age, race/ethnicity, gender, marital status, educational attainment, and employment status. Cancer survivor status was determined by a “yes” response to the question “have you ever had a diagnosis of cancer?” Because survivors may themselves be caring for someone with cancer, survivors were asked “Have you ever provided care for someone with cancer?” Survivors who chose “I am currently caring for someone with cancer” were defined as also being cancer caregivers.

From a list of 42 cancers, respondents were asked to indicate what type of cancer they were recently diagnosed with and the stage of their most recent cancer. Participants also

indicated their treatment status for their most recent diagnosis. Time since most recent cancer diagnosis was calculated as the difference between the year the survey was completed and year of their most recent cancer diagnosis.

Comorbidities were assessed by asking participants to indicate the medical conditions they had experienced in the past 12 months (e.g., heart attack, kidney disease, etc.). Comorbidities were summed with each participant coded as having no, one, or two or more comorbid conditions. Respondents also indicated the extent to which their physical health interfered with their normal social activities and interactions with others in the past month on a 5-point scale, with response options ranging from “not at all” to “extremely.”

### Analytic plan

Pearson correlations examined relationships among frequency of engagement in CSN and offline and online social support. A hierarchical linear regression analysis (hypothesis 1) investigated whether greater engagement in CSN was associated with greater perceived online social support. The interaction terms of offline social support  $\times$  each frequency of CSN engagement variable, entered in the second block, examined moderating effects of offline social support (Fig. 1). The final model excluded non-significant interaction terms.

A second hierarchical regression (hypothesis 2) investigated whether perceiving more online social support was associated with greater well-being (Fig. 1). The online social support  $\times$  offline social support interaction term, entered in the second block, examined moderating effects of offline social support. Medical and sociodemographic variables were controlled for in both regressions.

## Results

### Sample characteristics

Univariate analyses (Table 1) indicated that the mean age of survivors in our analytic sample was 55 years (SD = 9.72). A majority were non-Hispanic White (87.4%), female (73.3%), married or cohabiting (72.2%), and college educated (64.1%). Most participants were actively employed or self-employed (56.1%). The most commonly reported cancer types were breast (28.3%), colorectal (12.7%), and female reproductive cancers (13.5%). For 32% stage of cancer was either “in situ” or “local,” for 47.7% it was regional, and for 20% it was distant. Approximately 10% were receiving treatment at the time of completing the survey. The most commonly reported cancer treatment received was surgery (83.1%) followed by chemotherapy (63.5%) and radiation therapy (54%). Thirty-

**Table 1** Sample characteristics ( $N = 1255$ )

| Variable                          | $N$ (%) / mean (SD) |
|-----------------------------------|---------------------|
| <i>Sociodemographic variables</i> |                     |
| Age                               | 54.95 (9.72)        |
| Race/ethnicity                    |                     |
| Non-Hispanic White                | 1097 (87.4)         |
| Other                             | 158 (12.6)          |
| Gender                            |                     |
| Female                            | 920 (73.3)          |
| Male                              | 335 (26.7)          |
| Marital status                    |                     |
| Married or cohabiting             | 906 (72.2)          |
| Not married or cohabiting         | 349 (27.8)          |
| Education                         |                     |
| Less than a college degree        | 451 (35.9)          |
| College graduate or more          | 804 (64.1)          |
| Employment                        |                     |
| Employed at least part time       | 706 (56.3)          |
| Retired                           | 265 (21.1)          |
| Unemployed or disabled            | 284 (22.6)          |
| <i>Medical variables</i>          |                     |
| Cancer type                       |                     |
| Breast                            | 355 (28.3)          |
| Colorectal                        | 160 (12.7)          |
| Female reproductive               | 169 (13.5)          |
| Head and neck                     | 77 (6.1)            |
| Prostate                          | 60 (4.8)            |
| Other                             | 434 (34.6)          |
| Stage                             |                     |
| In situ/local                     | 403 (32.1)          |
| Regional                          | 599 (47.7)          |
| Distant                           | 253 (20.2)          |
| Primary treatment status          |                     |
| Not in treatment                  | 1133 (90.3)         |
| In treatment                      | 122 (9.7)           |
| Had surgery                       |                     |
| No                                | 212 (16.9)          |
| Yes                               | 1043 (83.1)         |
| Had chemo                         |                     |
| No                                | 458 (36.5)          |
| Yes                               | 797 (63.5)          |
| Had radiation                     |                     |
| No                                | 577 (46.0)          |
| Yes                               | 678 (54.0)          |
| Time since diagnosis              |                     |
| 0–2 years                         | 411 (32.7)          |
| 2–5 years                         | 572 (45.6)          |
| > 5 years                         | 272 (21.7)          |
| Comorbidities                     |                     |
| None                              | 369 (29.4)          |
| One                               | 370 (29.5)          |

**Table 1** (continued)

| Variable                         | $N$ (%) / mean (SD) |
|----------------------------------|---------------------|
| Two or more                      | 516 (41.1)          |
| Caregiver status                 |                     |
| No                               | 694 (55.3)          |
| Yes                              | 561 (44.7)          |
| Physical health interference     |                     |
| Not at all/a little              | 746 (59.4)          |
| Moderately/quite a bit/extremely | 509 (40.6)          |
| Offline social support           | 3.71 (1.01)         |
| Online social support            | 3.10 (1.23)         |
| Well-being                       | 19.09 (6.91)        |

three percent of survivors were within 2 years of diagnosis and 45.6% between 2 and 5 years since diagnosis. Twenty-nine percent reported no comorbid conditions, 29.5% one condition, and 41.1% two or more comorbidities. Forty-five percent of survivors also reported simultaneously being a caregiver to someone else with cancer.

Mean ratings of offline social support ( $M = 3.71$ ;  $SD = 1.00$ ) were higher than those for online social support ( $M = 3.09$ ;  $SD = 1.23$ ). Average well-being was similar to that reported in other cancer survivor samples ( $M = 19.10$ ;  $SD = 6.89$ ) [24]. Offline social support was not correlated with any of the three engagement variables (all  $p > .53$ ; see Table 2 for correlations among engagement, social support, and well-being).

### Hypothesis 1: Offline social support will moderate positive associations between engagement and perceived online social support

Results from the regression (Supplementary Table 3) indicated that after controlling for medical and sociodemographic variables, more frequent *social/communal* and *interpersonal communication* engagement in CSN were associated with greater online social support ( $\beta = .11$ ,  $p = .001$ , and  $\beta = .31$ ,  $p = .001$ , respectively). Higher offline social support was also associated with greater online social support ( $\beta = .47$ ,  $p = .001$ ). Interactions between offline social support and frequency of *social/communal* or *informational/search* engagement were non-significant (results not presented); however, the offline social support  $\times$  frequency of *interpersonal communication* engagement interaction was statistically significant ( $\beta = -.35$ ,  $p = .001$ ). This interaction indicated a moderating effect of *offline* social support (Fig. 2). Specifically, at the lowest levels of *offline* social support ( $x$ -axis), the positive association between *interpersonal communication* engagement and *online* social support ( $y$ -axis) was greatest.



**Table 2** Correlations among engagement in CSN, off- and on-line social support, and well-being ( $n = 1255$ )

|                                | Social/communal engagement | Interpersonal communication engagement | Informational/search engagement | Offline social support | Online social support | Well-being |
|--------------------------------|----------------------------|--|---------------------------------|------------------------|-----------------------|------------|
| Frequency of engagement in CSN |                            |  |                                 |                        |                       |            |
| Social/communal                | –                          |  |                                 |                        |                       |            |
| Interpersonal communication    | .000                       | –                                      |                                 |                        |                       |            |
| Informational/search           | .000                       | .000                                   | –                               |                        |                       |            |
| Offline social support         | –.018                      | .012                                   | –.006                           | –                      |                       |            |
| Online social support          | .113**                     | .329**                                 | .028                            | .166**                 | –                     |            |
| Well-being                     | –.063*                     | .071*                                  | –.084**                         | .406**                 | .132**                | –          |

\* $p < .05$ , \*\* $p < .01$

### Hypothesis 2: Offline social support will moderate a positive association between online social support and well-being

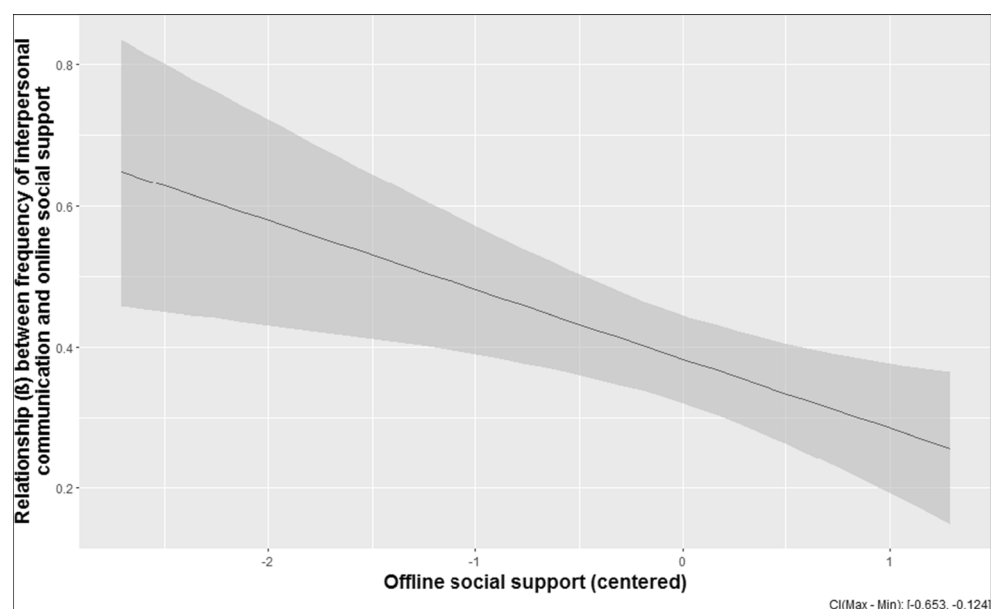
Regression results (Supplementary Table 4) indicated that after controlling for medical and sociodemographic variables, both offline ( $\beta = .47, p = .001$ ) and online ( $\beta = .31, p = .001$ ) social support were associated with higher ratings of well-being. In addition, the offline social support  $\times$  online social support interaction was significant ( $\beta = -.35, p = .001$ ), supporting a moderating effect of *offline* social support in the relationship between *online* social support and well-being. The interaction (Fig. 3) indicated that at low levels of *offline* social support ( $x$ -axis), the positive association between *online* social support and well-being ( $y$ -axis) was highest. In contrast, for survivors perceiving the highest levels of *offline* social support, the relationship between *online* social support and well-being weakened to non-significance. In a subsequent regression, we tested whether these results were also

independent of level of engagement in CSN; results from this follow-up analysis indicated frequency of engagement was not associated with well-being and that the magnitude and significance of main and interactive effects did not change when frequency of engagement was controlled for.

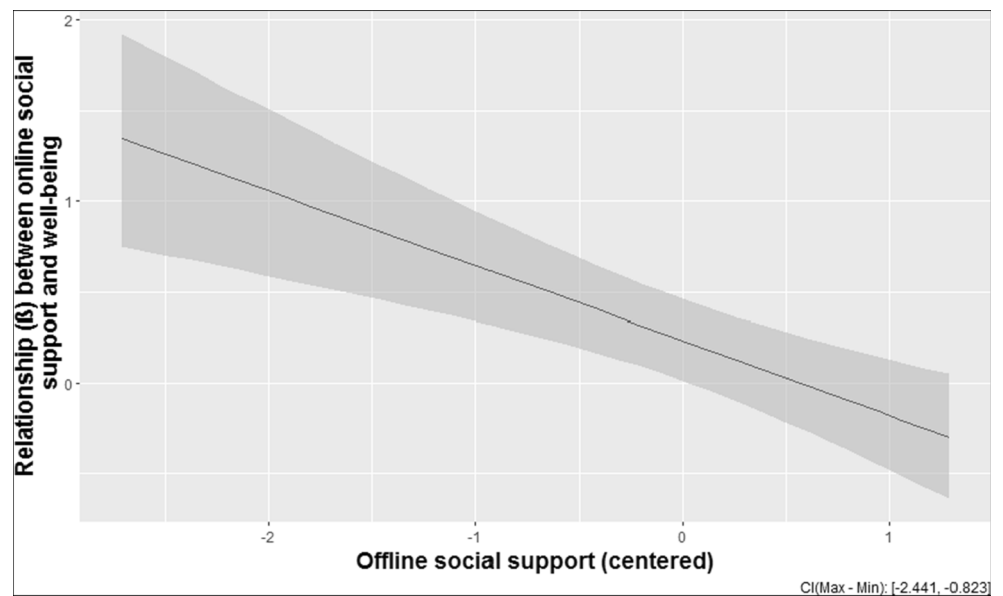
### Discussion

The current study examined the psychosocial benefits for cancer survivors of participating in an online, publicly available, member-directed social network, and whether benefits observed were more apparent for survivors whose emotional and informational needs were not met by their existing (offline) social relationships. Results indicated that greater frequency of both *social/communal* and *interpersonal communication* engagement were associated with perceiving greater social support from online communities. The relationship was strongest for *interpersonal communication*

**Fig. 2** Change in relationship between frequency of interpersonal engagement and online social support as a function of offline social support



**Fig. 3** Change in relationship between online social support and well-being as a function of offline social support



engagement, in fact three times greater, compared to *social/communal* engagement. Moreover, it was *interpersonal communication* engagement for which an interaction with offline social support was found. Specifically, the strength of the association between greater *interpersonal communication* engagement and increased social support from online communities was highest for survivors reporting the lowest levels of offline social support. Our findings also suggest that perceiving greater online social support may translate to increased feelings of well-being. This relationship, however, was also moderated by levels of offline social support, as it was strongest for survivors reporting the lowest levels of offline social support, but not significant for survivors perceiving the highest levels of offline social support.

In general, these results support the idea that member-driven online cancer survivor communities such as the CSN can be an important source of informational/emotional support for survivors; however, the frequency and nature of participant engagement in such networks appeared to be important. Engaging simply by using search functions and reading blogs (which we labeled “*informational/search* engagement”) was apparently not sufficient to reap the benefit of perceiving greater social support from online communities. Rather, perceiving greater social support from online communities may require more active engagement with other online members, whether simply by communicating personally with one or more members (as reflected in our *interpersonal communication* engagement variable), or to a lesser extent through more communal communications such as blogging, creating a profile, and interacting with the general community through chats and other functions (i.e., *social/communal* engagement). As indicated by our interaction effect for well-being, however, these social support benefits of greater *interpersonal communication* engagement appeared to be

strongest for survivors who were not receiving the support they might have expected from their existing social networks.

Surprisingly, we did not find any significant associations between levels of offline social support and frequency of any type of CSN engagement. One possible explanation is that some survivors, despite experiencing satisfactory or high levels of social support from their (offline) social networks, nevertheless engaged frequently with CSN, thereby diluting possible correlations between offline social support and frequency of engagement. These individuals’ reasons for engaging may have included altruistically wanting to help others navigate the difficult terrain of coping with a diagnosis by providing information and emotional comfort that they themselves may have experienced from others.

Our results may also help to explain equivocal findings in previous research examining the benefits of online support networks for survivors if prior studies varied in how much offline social support participants were experiencing. Other methodological differences between the current study and prior research may also explain differences in results. For example, the current study used a member-driven, peer-to-peer network as opposed to one created by researchers to study specific hypotheses. In addition, the current study also included survivors with several diagnoses, a quarter of whom were male, whereas most previous studies were conducted among breast cancer survivors.

## Limitations

Although our response rate was low, our sample size of 1255 is relatively large for studies conducted on cancer survivors’ use of online support networks. Moreover, the focus of our analyses was on examining relationships among level of

engagement in an online network, perceived online and offline support, and well-being, rather than attempting to characterize users of the CSN or the prevalence of engagement or support (which would make representativeness more of an issue). The variables in our analyses also demonstrated high variability and our sample size provided us with adequate power to examine our hypotheses.

Because our analyses were based on cross-sectional data, it is not possible to make conclusions about directions of causality. Our results controlled for gender, race, and other sociodemographic variables, suggesting that these were not a factor in results obtained; post hoc analyses pointing to greater perceived online social support among female compared with male survivors ( $M_s = 3.16$  vs.  $2.92$ ,  $p = .002$ ), and slightly higher well-being among male compared to female survivors ( $M_s = 19.72$  vs.  $18.86$ ,  $p = .05$ ), highlighted the importance of controlling for gender. Nonetheless, future research with larger numbers of males or survivors of other races/ethnicities could help determine whether for these groups the relationships we observed are stronger or not.

It is also possible that survivors who did not find the CSN to be helpful, or directly unhelpful, chose to not participate in the current study; however, as alluded to above, we obtained responses from survivors who reported from very low to high frequencies of engagement, and there was also significant variability in our measures of online and offline social support.

It is possible that the lower internal reliability of the *informational/search* engagement variable precluded detection of statistically significant relationships with online social support, especially if such effects are small; however, its lack of an association with online social support is also plausible because *informational/search* engagement refers only to searching for information on the network, rather than engaging in some meaningful capacity with other network members. As such, it can also be seen as providing some measure of discriminant validity for our measures of engagement.

## Conclusions

The current study of survivors experiencing a range of cancer diagnoses points out the importance of assessing offline social support in future research studies examining the psychosocial benefits of online social networks for survivors. The ease, convenience, and potential benefits of participating in an existing online cancer survivor community lead us to recommend that newly diagnosed survivors, particularly those with low levels of offline social support, be provided with information on joining online survivor networks.

**Compliance with ethical standards** This study was funded by The American Cancer Society.

**Conflict of interest** The authors declare that they have no conflict of interest.

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

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