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Factors Influencing Engagement in an Online Support Group for Family Caregivers of Individuals with Advanced Cancer

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Abstract

Objective: To explore factors that influenced engagement in an online support group (OSG) for family caregivers of hospice patients with cancer

Design: Secondary qualitative data analysis

Sample: 58 family caregivers of hospice patients with advanced cancer

Methods: Template analysis of individual family caregiver interviews

Findings: Emotional isolation and caregiving downtime positively influenced engagement, while reluctance to share personal information, a short timeframe of participation in the OSG, and caregiving commitments were negatively influential. While the group facilitation and secure privacy settings of the OSG were viewed positively, reactions to the OSG platform and group tone were mixed. Information on pain and the dying process was found to be particularly engaging.

Practice Implications: Providers offering OSGs for family caregivers should maximize factors that promote meaningful member engagement, responding to changes in activity and tone over time.

Keywords

cancer; caregivers; engagement; hospice; Internet; support groups

Background

Researchers have extensively documented the psychosocial toll of providing informal care to cancer patients, identifying numerous consequences of family caregiver distress across the disease trajectory.[1] In the advanced illness phase, family caregivers often face significant burden associated with managing symptoms[2] and assisting with activities of daily living.[3]

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Conflict of Interest
The authors declare no conflict of interest with regard to the conduct or publication of this research.

They may become less likely to engage in self-care and other health-promoting behaviors such as physical activity, stress management, and healthy eating.[4] Feelings of depression and anxiety are also common,[5,6] particularly among caregivers who perceive their social support systems to be weak[7–9] or who have unmet information needs.[10]

Support groups, a staple offering in many cancer care settings,[11] provide a format for mutual support and information exchange and, thus, can address insufficient social support and knowledge deficits.[12] Barriers to participation in face-to-face groups (e.g., scheduling conflicts, transportation needs) coupled with technological advances have led to a proliferation of online support groups (OSGs) for people affected by cancer and other health conditions.[13] Dating back to at least the 1990's, OSGs have changed considerably over the years.[14] Earlier groups operated via technologies such as email or web-based discussion boards, while modern-day groups are commonly hosted on social media sites, which have added numerous tools to support administration of private online groups.[15] Like face-to-face support groups,[16] OSGs differ from naturally occurring online exchanges in that they are intentionally planned groups with a specific purpose, structure, and rules or guiding principles. Thus, while informal online exchanges with other family caregivers may be experienced as supportive, they would not constitute participation in an OSG. Although few studies have investigated outcomes of OSGs for family caregivers, the limited evidence suggests that OSG involvement can enhance caregivers' social support, self-efficacy, physical health, and emotional wellbeing.[17,18]

OSG Engagement

Member engagement is vital to the success of OSGs.[19] Defined as both the extent of usage and a subjective experience involving attention, interest, and affect,[20] engagement facilitates social support exchange and is an important mechanism of action for behavior change and alleviation of distress.[21] In their conceptual framework, Perski and colleagues[20] identified *context, content*, and *delivery* as three (of many) interrelated factors that drive engagement in web-based interventions. Important factors related to the *context* of an OSG intervention for family caregivers include characteristics of individual members and the realities of providing care to someone with a serious illness. Group *content* consists of educational information, member discussions, and notifications of group activity. *Delivery* refers to the mode of delivery, group facilitation, and overall tone. While this framework was originally developed to describe behavior change interventions, research has shown that these factors also influence engagement in internet-based interventions for cancer-related distress, as users appear motivated to engage with personally relevant, trustworthy content that is delivered in a positive tone via an easy-to-use platform.[22]

Research Questions

Research suggests that many family caregivers of individuals with advanced cancer would benefit from OSGs, yet the evidence on how to best promote engagement in such groups is underdeveloped.[23] Our research team sought to address this knowledge gap by answering the following research questions: (1) Which contextual factors influenced engagement in an OSG for family caregivers of individuals with advanced cancer? (2) Which group content influenced engagement in an OSG for family caregivers of individuals with advanced cancer? and (3) Which delivery features influenced engagement in an OSG for family caregivers of individuals with advanced cancer?

Methods

We conducted a secondary analysis of qualitative data originally generated during an ongoing cluster crossover randomized pragmatic trial sponsored by the National Cancer Institute (R01CA203999). The full trial protocol was approved by the University of Missouri Institutional Review Board and is registered at clinicaltrials.gov (NCT02929108). Study participants in the original trial were adult family caregivers of adult cancer patients who were receiving care from one of six hospice sites in the Midwestern United States. As is required by Medicare Hospice Conditions of Participation,[24] all patients whose caregivers participated in the study had a prognosis of six months or less, and all had stopped (or never initiated) disease-directed treatment, opting instead for an exclusively palliative approach to care.

After participants in the original trial provided verbal consent, they were enrolled in an OSG created specifically for study. The social networking site Facebook was utilized as the platform for the OSG, since it had previously been established that caregivers found it useful and easy to use.[25,26] The group's privacy settings were set to "secret," ensuring that it was not discoverable via online searches.[26] Access to the group was limited to family caregivers actively enrolled in the study.

Once participants were added to the OSG, the facilitator welcomed them by name. While conduct guidelines were enforced, there were no requirements for participation beyond joining the OSG. Discussions within the group followed the content posted by the group facilitator with additional topics of interest raised by group members. Participants were removed from the group following a brief transition period after the death of their hospice patient.

The OSG was facilitated by a hospice professional with a Masters of Social Work (MSW) degree. In addition to facilitating organically emerging interactions, the facilitator posted structured educational content a minimum of twice per week, encouraging discussion and exchange of personal experiences and support around the week's featured topic (see Table 1). Five of the six featured topics were selected based on preliminary research highlighting hospice caregivers' challenges related to managing pain,[27,28] witnessing patient decline as death nears,[29] participating in shared decision making,[30] accessing social support,[31] and engaging in self-care.[32] A sixth topic (i.e., hospice care) was added at the urging of the research's team's clinical partners, whose practice experiences suggested that family caregivers often held misperceptions about hospice and the hospice interdisciplinary team.

Each Monday, the group facilitator posted an educational video on the week's featured topic. The videos were created specifically for the OSG by subject experts (i.e., individuals with published research on the respective topic). On Fridays, the facilitator posted a link to an educational article disseminated by an established professional organization (e.g., American Cancer Society, National Hospice and Palliative Care Organization) on the same weekly topic. Given that the average length of service for hospice patients with cancer is approximately six weeks,[33] content was posted on a six-week rotation (i.e., the same content was repeated every six weeks).

In addition to educational content, the facilitator posted a mid-week “check-in,” inviting members to provide personal updates. Members themselves were able to create posts (i.e., statements or questions introducing a new topic) or interact with others by commenting on existing posts or using Facebook’s reaction buttons (e.g., “like,” “love,” “sad,”) in response to others’ posts or comments. Examples of member-created content included posts with unsolicited patient updates (e.g., “Hi, group. I wanted to let you know that my dad died on Tuesday. My sister and I were both holding his hand when he took his last breath.”) and posts concerning caregiving challenges (e.g., “Something I am having trouble figuring out [is whether his] trouble with words, confusion, and speech [are] from morphine or [metastases] to his brain.”).

Data Source

We obtained qualitative data from individual interviews of the group facilitator and a sub-sample (n = 58 or 64%) of the 90 total caregivers who consented to join the group during Year 1 of the OSG. Participant characteristics for both the sub-sample of interviewees and all OSG participants are provided in Table 2. The single facilitator interview (duration = 63 minutes) was conducted via telephone by a study investigator, digitally audio-recorded, and transcribed verbatim. Sample interview questions included, “*If someone asked you for advice on increasing engagement in an OSG for family caregivers, how would you reply?”* and “*Which topics seemed to resonate most and least with group members?”* Group member interviews were conducted upon caregivers’ exit from the study, which most often occurred due to patient death. These interviews (average duration = 23 minutes) were conducted by telephone by a member of the research team, digitally audio-recorded, and transcribed. While they specifically addressed engagement in some instances, these interviews also contained information on members’ likes and dislikes more broadly. Sample interview questions included, *“While you were receiving hospice services, you joined a Facebook group for hospice caregivers. What was it like to be part of that group?”* and *“What information provided as part of the Facebook group did you find most helpful? Which information was least helpful?”* Because satisfaction with group elements has been shown to positively influence engagement in online interventions,[20] we included all interview content pertaining to participation in the OSG in our analysis. Approximately 34% (n = 31) of the 90 total OSG members did not participate in an interview. Reasons for non-participation were inability to be contacted after six attempts (n = 15), continued study participation/non-exit (n = 11), or another reason (e.g., refusal due to bereavement stressors; n = 5). In addition, recording failed during one interview, resulting in 58 interviews eligible for analysis.

Data Analysis

Two members of the research team (KTW, LAJ) conducted a template analysis[34,35] of the transcribed interviews. We began by using NVivo qualitative data analysis software (QSR International) to label pertinent data segments with one or more *a priori* codes loosely based on Perski et al.’s[20] definitions of the following constructs: *context*, *content*, and *delivery*.

Because these constructs are interrelated rather than mutually exclusive, we relied heavily on Perski et al.'s definitions in determining how to code specific data segments. For example, an argument could be made for coding notifications of group activity (e.g., automated emails notifying members of a new post) as *content* or *delivery*. However, Perski et al.[20] clearly conceptualize notifications and other types of reminders as *content*, so we coded our data accordingly. Next, we coded each data segment based on whether it described a factor that positively or negatively influenced engagement in the OSG, operating under the theoretically-supported assumption[20] that features that were perceived favorably would have positively influenced member engagement. Then, we grouped conceptually similar data into broader themes that described key influential factors, noting whether group members perceived the influence to be positive, negative, or mixed.

Results

Context

When examining the OSG's context, we explored how members' personal characteristics and the realities of caring for someone with cancer near the end of life affected members' group engagement. In doing so, we identified two contextual factors that positively influenced OSG engagement: emotional isolation and caregiving downtime. Caregivers frequently described feeling emotionally isolated and poorly understood by others. This positively influenced their engagement in the OSG, where they perceived benefit in interacting with others with whom they could relate. Participant #82 explained, "[In the group], you don't feel like you're completely alone." While some members reported that caregiving demands impeded their participation in the OSG, Participant #6 welcomed the opportunity to participate while "stuck at home." Participant #57 stated, "There is a lot of downtime when you are a caregiver [and] you aren't actively doing something but sitting beside the person, so you have time to look at [the OSG]."

Contextual factors that negatively influenced OSG engagement included a perceived lack of need for support, personal reluctance to share private information, short duration in the OSG, and caregiving commitments. In some cases, caregivers mentioned infrequently engaging in the group because they had sufficient support elsewhere. Participant #75 stated, "I never looked to [the group] for support … because I had so much [from] my family." Others identified as relatively private and, therefore, expressed discomfort with the expectation that they would share personal information in the group. Participant #84 explained, "I'm not somebody that feels comfortable writing that kind of stuff to basically strangers." Another barrier to engagement was the short duration of time many of the caregivers were in the group (approximately one-third were in the group less than a week). At times, a pattern emerged in which caregivers joined the group only to exit days later when their care recipient died. Participant #22 stated that it seemed as if the OSG organizers were "bringing people in [and] introducing them to the group, and then a few days later, that person has lost their loved one and is in grief …. It was really depressing." Finally, some noted that caring for a seriously ill family member decreased their ability and desire to engage in the OSG. Participant #21 explained, "Every day was in such an upheaval … and I wanted to spend as much time possible [as] I could with [my husband] while he died."

Content

In many respects, our analysis revealed a lack of consensus with regard to perceptions of the group content, with the same factors viewed differently by different individuals. An exception was the educational topics featured each week (see Table 1), an issue around which there was considerable agreement. Overwhelmingly, the two most popular topics were death and dying (framed as "the final journey") and pain. Participant #33 reported that she appreciated learning "how to be prepared for that transition process, what it's going to look like…. and what the next steps are going to be." Participant #45 commented on the value of the video about pain, which explained "how to tell the … signs of pain," specifying that she benefitted from information about using the patient's facial expressions to assess pain. Feedback on the caregiver self-care and social support content was generally positive, although these topics were cited as beneficial less often than death and dying and pain. The two least popular topics were hospice care and shared decision making.

Feedback on member discussions was mixed. Some cited interactions with other caregivers as a primary motivator for their engagement, expressing strong satisfaction with the content of these interactions. Participant #26 discussed how she had infrequently visited Facebook before joining the OSG but was much more engaged since joining the OSG: "[Now] …. I'm on there at least once or twice a day, checking the posts to see how everybody's doing." Participant #83 discussed the supportive nature of the OSG content, stating, "Right now, the only thing that is supporting me emotionally would be that Facebook group." Others mentioned struggling to connect with other caregivers, noting that the content of their interactions with other members did not positively influence their engagement. Participant #21 stated, "I didn't really feel like I knew these people just from little posts now and then," and Participant #14 explained, "When I'd get on there and I'd say something, [the group facilitator] was about the only one I'd get a response from."

Facebook notifications of group activity were unanimously regarded as positive influences on engagement and were generally positively perceived by group members. Depending upon their individualized settings, participants received alerts notifying them of new OSG posts or of comments that had been added to discussions in which they were actively participating, which encouraged engagement. The group facilitator cited "tagging" group members (i.e., creating a link to the member's profile in a post or comment, resulting in their automatic notification) as one of the most effective ways to encourage engagement, equating it with calling on a specific group member in a traditional face-to-face group. Participant #15 explained, "[The group facilitator] would say someone's name. She would call you out, 'How are you doing today ….?' Of course, that's an effective way so to get an answer. When she did that, I would respond."

Delivery

Our final research question asked which delivery qualities influenced engagement in the OSG. In answering this research question, we specifically examined the ways in which the mode of delivery, facilitation style, and tone of the group influenced engagement.

The mode of delivery (i.e., a secret Facebook group) influenced group member engagement both positively and negatively. Among caregivers who were active on Facebook prior to joining the OSG, the mode of delivery was viewed as convenient. Participant #57, who explained that she spends “part of each day” on Facebook, stated that she would have been less engaged in the OSG had it been offered on another platform. Several members expressed appreciation for the OSG’s secret privacy setting, both because “other people can’t get into [the OSG] and make stupid comments” (Participant #70) and because it precluded members’ other Facebook connections from viewing the OSG content. The fact that the OSG used a web environment with agile design (i.e., the browser settings adjusted to the platform used by the participant, such as a desktop browser or a mobile phone) was also cited as positively influencing engagement, as it allowed members mobile access to education and support. Participant #78 explained, “Normally I have my cell phone with me, and when Dad was sleeping or whatever, maybe I could read [an] article on my phone [even if] I didn’t have … handouts or something with me.” For other caregivers, the mode of delivery negatively influenced engagement. This was particularly true for those who self-identified as “not a computer guy” (Participant #80) or “not a Facebook person” (Participant #62). For these individuals, the mode of delivery was not a good fit for their habits or preferences. The group facilitator also commented on individuals who were not “social media savvy,” noting that it was sometimes difficult for them to connect with others online.

The OSG facilitator’s interaction style and communication strategies tended to be perceived positively. Group members specifically commented on the facilitator’s provision of individualized attention, noting “she was so sweet about following up and checking up on you” (Participant #33). The facilitator’s use of welcome posts (i.e., posts that tagged new members and invited others to welcome them) was also cited as positive, as such posts helped members “start to come out of their shell” (Participant #88) and engage with the group. Participant #30 noted the facilitator’s overall responsiveness and supportiveness: “She has been super with all of this.”

Participants’ perceptions of the tone of the OSG varied. Some expressed dissatisfaction, describing it using phrases like “pretty depressing” (Participant #42). Participant #3, who expressed a preference for inspiring content, stated, “I like to put a smile on peoples’ faces. I’m a people person. Then I read some of their stories, and I kind of felt like, ‘I can’t do this.’” In contrast, others experienced the group tone as predominantly positive. Participant #26 said, “Everybody always had something nice to say to me, and I always tried to say uplifting and nice things to everyone …. I just put my heart out there, and I feel like they did too.” Participant #83 also expressed appreciation for the group’s tone, stating, “[The positive posts are] amazing because, to be honest, in my life right now I don’t have a whole lot of positivity.”

Discussion

The purpose of this study was to explore factors that influenced engagement in an OSG for family caregivers of people with advanced cancer. In many respects, the OSG context (emotional isolation and caregiving downtime), content (“death and dying” and “pain” topics, notification of group activity) and delivery (secret Facebook group format, positive tone) motivated engagement. While many interventions exist to address caregiving demands,[36] there are limited data describing strategies to promote caregivers' meaningful engagement with these interventions. Our study addresses this gap in the literature, particularly with regard to web-based interventions, which are clearly on the rise.[13]

Many of our findings are consistent with prior research. The contextual link we identified between emotional isolation and OSG engagement has been previously identified in the literature.[37,38] Others have investigated the OSG content preferred by caregivers, finding that pain and end-of-life care are topics of strong interest,[39] as we found in this study. With regard to delivery, a review of numerous online interventions for cancer caregivers led Tang and colleagues[40] to conclude that web-based formats provide a unique advantage of easy accessibility with no corresponding barriers related to geography or time,[40] similar to the findings we present here.

Design Implications

Our findings have a number of implications for OSG design. Designers of OSG tools should address the context of use and the needs and expectations of the target audience in system design. Family caregivers are often overwhelmed; thus, the introduction of a new tool that requires extensive training or does not provide flexibility in its use would not be appropriate. Preece[41] discussed sociability and usability as principles that link knowledge about human behavior with appropriate design of online communities, suggesting that a well-designed virtual community is one in which members are able to communicate with each other, find information, and navigate the community software with ease.[41,42] The agile design of a social media tool like Facebook, which allows users to access it regardless of hardware used, was appreciated by participants in our study and confirms the need for usability considerations when selecting and implementing OSG systems.

Clinical Implications

For many caregivers, the exchange of emotional support is a strong motivator of OSG engagement. OSGs can provide caregivers with the opportunity to feel understood, realize they are not alone, and feel inspired to address challenges introduced by caring for someone nearing the end of life. At the same time, repeated exposure to others' accounts of stressful, sad, and frustrating experiences can be demoralizing and diminish rather than bolster caregivers' wellbeing and sense of self-efficacy. Healthcare teams offering OSGs for family caregivers should ensure that group facilitators regularly monitor group activity, striving to balance the sharing and validation of difficult life experiences with content that is inspirational and uplifting.

OSGs also provide a unique opportunity for caregiver education, allowing healthcare teams to share expertly vetted information in numerous formats (e.g., demonstration video, informational article) potentially at a relatively low cost to a large number of people at the same time. However, not all educational topics are equally well received. These findings suggest that family caregivers of hospice patients with advanced cancer are highly interested in information about the dying process. While hospice teams typically strive to prepare caregivers for their family member's death, the median length of service for hospice patients with cancer is less than three weeks,[33] limiting opportunities for education and rapport building, which is often helpful prior to broaching potentially distressful subjects.[43] It is also important to note that caregivers' lack of reported engagement around specific topics (e.g., shared decision making, hospice care) may not reflect an actual lack of interest in the subject matter. It is possible that this information has been made accessible to them through other means or that presenting the same information in a different way might be more engaging. For example, research has shown that the presence of a storyline often positively influences engagement.[20] Thus, content that is perceived as uninteresting when presented in a traditional didactic format may be more engaging when communicated as part of a larger story.

Furthermore, while the popularity of specific sites varies over time, approximately 69% of the American public regularly uses social media; of those who use Facebook, nearly two-thirds (74%) do so daily.[44] By capitalizing on these existing behavior patterns and offering OSGs via popular social media platforms, healthcare teams may be able to serve more caregivers than they otherwise would, although such an approach also introduces the need to address privacy and information security concerns.[45]

Finally, the heterogeneity of feedback provided by family caregivers must be considered in the planning and implementation of future OSGs. As with any intervention, OSGs may be a better fit for certain caregivers than others. For example, individuals with informational needs who have adequate emotional support from family and friends may be better served by educational resources or interventions that focus more exclusively on strengthening caregiving knowledge and skills. Caregivers who have little interest in computers are unlikely to find benefit in OSGs, but they may appreciate spiritual support offered by the hospice chaplain. Those who want to maximize the time they are able to spend with their family member might prefer legacy activities (e.g., life review[46]) that involve both the caregiver and the patient. OSGs show significant promise, but they represent only one of many ways to support family caregivers of individuals with cancer near the end of life.

Study Limitations

Several study limitations warrant attention. First, engagement is not synonymous with benefit. The fact that family caregivers were motivated to attend to specific information or participate in specific types of discussions does not provide insight into the effect of that engagement on their wellbeing. Second, the sample of caregivers involved in this study was fairly homogenous, precluding a meaningful examination of differences based on demographic variables. Third, while all caregivers in this study were in the OSG at some point during its first year, they were not all in the group at the same time. Thus, it is possible that some differences in opinion can be attributed to unique experiences rather than different reactions to the same content, as is typically the case in open support groups (i.e., groups with shifting membership composition).[47] Fourth, effective support group facilitation requires an approach that is responsive to ever-changing group composition and dynamics.[47] Thus, the OSG facilitator was not provided with scripted responses or strict rules governing group facilitation, other than being instructed that caregivers with specific medical questions should be referred to their hospice interdisciplinary team. While clinically justified, this approach nonetheless introduces a number of potentially confounding variables and limits the replicability of the study. Fifth, because this was a secondary analysis of data collected as part of a clinical trial, we were unable to include in our analysis other constructs that were identified by Perski et al.[20] as important to engagement. For example, family caregivers with different psychological characteristics likely had different experiences in the OSG, but we were unable to include this information in our analysis as it was not collected in the original trial. The reader is referred to the original Perski et al. article[20] for a more comprehensive discussion of the entire framework, much of which was not considered in our analysis. Sixth, our findings are informed by self-report and, thus, may not accurately reflect study participants' actual behaviors or opinions. Researchers interested in OSG engagement should carefully monitor advances in social media analytics, as it may be possible to capture more objective user data for "secret" or "private" groups in the future. Finally, we acknowledge that our analysis considered participants' experiences in only one OSG. Future studies including participants assigned to a comparator group (e.g., an OSG offered on a different platform) would allow for more conclusive findings regarding factors that influence OSG engagement.

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Table 1

Summary of Scheduled Facilitator Posts

Week	**Topic**	**Monday Post**	**Wednesday Post**	**Friday Post**
Week 1	Pain	Video: Assessing physical pain	Mid-week check-in	Article: Emotional and spiritual pain
Week 2	Death and Dying	Video: The dying experience	Mid-week check-in	Article: What to expect when a person with cancer is nearing death
Week 3	Caregiver Self-Care	Video: Taking care of yourself while caregiving	Mid-week check-in	Article: Managing caregiver stress
Week 4	Social Support	Video: Getting help from others	Mid-week check-in	Article: Caregiver resources
Week 5	Hospice Care	Video: Myths about hospice	Mid-week check-in	Article: The hospice interdisciplinary team
Week 6	Shared Decision Making	Video: Making decisions with your healthcare team	Mid-week check-in	Article: Making your values known

Table 2

Participant Characteristics

	OSG Members (*n* = 90)	Interviewees (*n* = 58)
Gender, *n* (%)		
Male	16 (18%)	11 (19%)
Female	74 (82%)	47 (81%)
Age, mean (*SD*)	55.44 (12.18)	56.54 (12.18)
Race/Ethnicity, *n* (%)		
Black/African American	9 (10%)	7 (12%)
White/Caucasian	79 (88%)	49 (84%)
Other	2 (2%)	2 (4%)
Relationship to Patient, *n* (%)		
Spouse or partner	21 (23%)	13 (22%)
Parent	12 (13%)	7 (12%)
Adult Child	39 (43%)	29 (50%)
Sibling	6 (7%)	1 (2%)
In-law	2 (2%)	1 (2%)
Ex-spouse or ex-partner	1 (1%)	1 (2%)
Non-relative	3 (3%)	2 (3%)
Other	6 (7%)	4 (7%)
Distance lived from patient, *n* (%)		
In the same residence	41 (46%)	24 (41%)
Up to 1 hour away	37 (41%)	27 (47%)
More than 1 hour away	8 (9%)	5 (9%)
Prefer not to answer	4 (4%)	2 (3%)
Highest level of education, *n* (%)		
Less than high school	3 (3%)	2 (3%)
High School/GED	16 (18%)	9 (16%)
Some college/trade school	34 (38%)	23 (40%)
Bachelors/undergraduate degree	20 (22%)	11 (19%)
Graduate/professional degree	16 (18%)	12 (21%)
Other	1 (1%)	1 (2%)
Household Income, *n* (%)		
Under $20,000 per year	15 (17%)	10 (17%)
$20,000-$39,999	15 (17%)	9 (16%)
$40,000-$69,999	18 (20%)	13 (22%)
Over $70,000	33 (37%)	21 (36%)
Prefer not to answer	9 (10%)	5 (9%)