Parental Grief Expression in Online Cancer Support Groups

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Abstract

Few studies exist on the benefits of online grief support for bereaved parents. We sought to learn from parents who lost a child to brain or spinal cord tumor who participated in an online grief-support group. Eighteen bereaved parents and two professional facilitators participated in 20 monthly online groups, with chat-room discussions analyzed for themes. Parents completed a 10-item survey evaluating reasons for participation and the group’s effectiveness regarding coping following loss. Examples of chat-room topics included: the grief process/adjustment, negative social interactions, milestones/holidays, and sibling grief. Seventy-eight percent of eligible parents completed the survey. They endorsed online groups as effective for connecting with other bereaved parents and offering grief support, among other positive outcomes. Parents used online groups for a variety of reasons, including convenience, anonymity, and lack of local support. Parents’ responses suggest that online support groups can be a convenient/effective grief-coping strategy for parents bereaved by cancer.

Key words: cancer, oncology, bereavement, grief, parent, online
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Although ubiquitous, grievers’ responses to loss vary greatly. Research shows that elevated grief symptomatology is associated with numerous factors, including one’s relationship to the deceased (Burke & Neimeyer, 2012), and the type of loss endured (Burke & Neimeyer, 2014). Parents, in particular, appear to suffer greatly following the loss of a child (Burke & Neimeyer, 2012), with childhood cancer deaths imposing unique challenges and difficulties on parents (Davies, 2004).

Traditional grief therapy is often effective in reducing grief symptoms, especially for those in significant distress (Currier, Neimeyer, & Berman, 2008). Contemporary society also relies on the Internet to provide a variety of bereavement services, including grief support groups. Users of these services often report positive results, and yet, scant research exists on the value and efficacy of such services (Stroebe, van der Houwen, & Schut, 2008).

We examined an Internet-based support group that used a chat-room format to address the unique needs and concerns of parents bereaved of a child to cancer. Using data derived from monthly chat sessions coupled with a short survey, we canvassed responses from bereaved parents about their perception of the utility of the group, its impact, if any, on their sense of connectedness with other cancer-bereaved parents, if group participation was a means of coping with the loss of a child and, if so, its level of effectiveness.

Background

Grief

Bereavement research reports on grief trajectories show that some grievers rebound emotionally within a few months (Bonanno & Kaltman, 2001), others endure symptoms for 1-2 years (Bonanno & Mancini, 2006), and others experience an elongated and severe reaction to loss called
complicated grief (CG; Prigerson et al., 1995; Shear et al., 2011; also termed prolonged grief disorder, PGD; Prigerson et al., 2009)—a protracted, debilitating, and sometimes life threatening reaction to loss experienced by 10-15% of the bereaved population. Complicated grief is characterized by prolonged grieving, profound separation distress, psychologically intrusive thoughts of the deceased, a sense of emptiness and meaninglessness, trouble accepting the loss, and difficulty in making a life without the loved one (Holland, Neimeyer, Boelen, & Prigerson, 2009). Eventually most survivors accommodate the loss into their lives (Neimeyer & Currier, 2009), with only the most distressed needing formal grief therapy (Currier et al., 2008).

Bereaved Parents

Between 1990 and 2004, 34,500 children died of cancer and nearly 60,000 parents grieved their deaths (Centers for Disease Control & Prevention, 2007). The loss of a child is a difficult loss to endure (Burke & Neimeyer, 2012), and is exacerbated with the passing of time (Bonanno et al., 2002). Parents are especially at risk of CG following loss (Burke & Neimeyer, 2012), and experience unique meaning-making challenges (Lichtenthal, Currier, Neimeyer, & Keesee, 2010), ranging from difficulties making sense of the pre-death cancer battle to the parent understanding his/her role and life purpose in the ensuing years (Davies, 2004). Beyond CG, serious loss-related risks for bereft parents include premature death (Li, Laursen, Precht, Olsen, & Mortensen, 2003). Still, parents underutilize traditional grief therapy (Institute of Medicine, 2003), and might turn to the Internet for symptom amelioration instead (van der Houwen, Stroebe, Schut, Stroebe, & van den Bout, 2010).

Online Grief Support

Grievers helping grievers through bereavement formally began with Silverman’s widow-to-widow work (Silverman, 1972). While face-to-face bereavement groups remain part of society, the
advent of the Web brought new assistance for mourners. Grievers looking online for symptom relief or in search of others who feel their pain have a range of options including loss-specific psychoeducation, peer-to-peer support groups, interventions, and research participation opportunities.

Bereavement websites provide information and connection with other grievers through Internet forums, email groups, chat rooms, and online memorial websites. Online grief support can be grouped into two clusters: synchronous groups, such as chat rooms where “attendees” exchange messages contemporaneously; and, asynchronous groups where individuals can log on anytime 24/7 to read/exchange messages, not necessarily simultaneously (e.g., listservs; van der Houwen, Stroebe et al., 2010).

This study focuses on Internet chat rooms—an online, interactive, synchronous discussion forum that typically consists of individuals with a specific commonality (e.g., loss). Chat rooms may or may not have a facilitator who may or may not be a professional. They may stand alone or be an extension of another face-to-face group. Once logged on, chat room participants submit typed messages to be viewed by the group and, likewise, can read contributions from other participants. Chat room members can initiate a message or respond to others’ comments or questions at any time, as desired, or not at all.

Three categories of online support characterize web-based, peer-support discussion groups: emotional support, informational support, and communality support (Aho, Paavilainen, & Kaunonen, 2011). Emotional support involves sharing oppressive feelings (e.g., guilt, bitterness, ambiguity), supporting wellbeing, and expressing sympathy. Informational support includes encouraging each other to seek out resources and assistance, and discussing positive and negative support received from others. Studies show, unlike non-members, online bereavement group members tend to be younger, female, divorced/separated, a parent, depressed, live alone, live in both urban and rural communities,
have low income, education, and social support, and greater emotional loneliness, grief, and suicidality (Feigelman, Gorman, Beal, & Jordan, 2008; van der Houwen, Stroebe et al., 2010).

Do bereaved individuals actually benefit from online mutual bereavement support groups? Are they helpful, harmful, or could they be both? Both pros and cons have been documented in the literature. Positive aspects of online grief support groups include the ability to: share anonymously, post messages or glean information anytime/Anywhere, access bereavement-related information (Strobe et al., 2008); and increase social and technological connectedness (Vanderwerker & Prigerson, 2004). The public nature of online groups provides opportunity to discuss sensitive topics (e.g., infant death) in an open manner. Additionally, its 24/7 availability makes online support attractive to many grievers (Feigelman et al., 2008); however, connecting with other grievers on a near-constant basis might accentuate rumination in some grievers (van der Houwen, Stroebe et al., 2010).

Potential negative aspects of online mutual bereavement support groups (in some cases also representative of in-person groups) include: increased distress from repeated sharing/listening to stories of loss (Laakso & Paunonen-Illmonen, 2002), over-reflection on loss may preclude bereavement adjustment (Hollander, 2001), lack of non-verbal communication cues can cause misunderstandings (Wagner, 2013), the non-face-to-face nature of internet groups may encourage social isolation (Dyregrov, Nordanger, & Dyregrov, 2003), difficulty professional facilitators have in distinguishing participants’ distress and providing crisis intervention when needed (Wagner, 2013), and potential manipulation/maltreatment of emotionally fragile mourners by online con artists (Waldron, Lavitt, & Kelley, 2000). Moreover, online grief support is contraindicated for individuals who have substance abuse issues or serious mental illness (e.g., major depressive disorder) primarily because of difficulties in amount and timeliness of professional support (Wagner, 2013). Overall, many bereaved individuals report better loss adjustment after using grief-based websites (Aho et al., 2011; Vicary & Fraley, 2010),
even though “scientific investigation of the precise impact of [bereavement support] on the Internet has lagged far behind the creation and use of these Web sites” (Stroebe et al., 2008, p. 560).

**Internet-based Bereavement Research and Intervention**

Internet-based research ranges from asking participants to complete questionnaires to conducting randomized controlled trials where participants participate multiple times over a period of time and data is analyzed quantitatively and/or qualitatively (e.g., Burke & Neimeyer, 2014; Burke, Neimeyer, Young, Piazza Bonin, & Davis, 2014). Potential advantages of online bereavement research includes the geographic scope of the Web that potentially reaches individuals who otherwise might not participate in research (e.g., socially isolated/shy individuals who are less likely to engage face-to-face), increased quantity and quality of the data because some individuals feel freer when providing information anonymously, ability to lead potential participants through a tailor-made survey system (e.g., Qualtrics, 2013) that includes an eligibility-determination screener (e.g., Burke, Neimeyer, Holland, Dennard, Oliver, & Shear, 2014) or a battery of pre- and post-intervention measures (Wagner, Knaevelsrud, & Maercker, 2006) or therapeutic treatments, such as email-based writing interventions (e.g., van der Houwen, Schut, Stroebe, & Stroebe, 2010). Moreover, the time saved with the elimination of traditional data entry is both substantive and cost effective.

Potential disadvantages of web-based bereavement research is that certain bereaved individuals are excluded due to lack of Internet access, such as individuals who are elderly, poor, non-Caucasian, unemployed, or have low SES (e.g., Robinson & Robinson, 2000). Thus, although far-reaching, online research is not available to all eligible participants and, as a result, the findings are less generalizable. And although anonymity entices some people to participate online, this data
collection method lacks the checks and balances found in face-to-face assessments because it is open to people using alternate identities or who want to participate multiple times.

In terms of online interventions for grief or depressive symptom reduction, computerized interventions devoid of personalized therapist feedback to the bereaved participant are less effective than interventions with therapist support (Andersson, Carlbring, Berger, Almlov, & Cuijpers, 2009), even with asynchronous groups and minimal levels of therapist contact (i.e., 10 minutes per client per session). Overall, professional facilitation of online bereavement groups appears to increase both participation and therapeutic effects.

**Children’s Brain Tumor Foundation**

Children’s Brain Tumor Foundation (CBTF) is a national, non-profit organization founded in 1988 by a group of parents, physicians, and friends. CBTF’s mission is to improve the treatment, quality of life, and long-term outlook for children with brain and spinal cord tumors (e.g., brain stem glioma, glioblastoma, medulloblastoma) through research, support, education, and advocacy. CBTF’s Loss, Grief, and Bereavement Program was established to support bereaved family members by offering a variety of services, including online support groups through Jenna’s Corner, CBTF’s online community.

CBTF established a goal to create supportive services accessible to families who had lost a child to a brain or spinal cord tumor, regardless of their geographical location. Results from a needs assessment distributed to bereaved parents affiliated with CBTF identified need and confirmed interest in live, online support groups and message boards. Jenna’s Rainbow Foundation, an organization that funds special activities/projects for critically ill children and their families, funded this project, and in 2010 Jenna’s Corner was activated.

**Study Aims**
Our goal was to learn about bereaved parents’ grief expression in online support groups and to determine whether our online grief-support group for parents bereaved by cancer was useful in terms of reducing isolation and in helping grieving parents to cope in the aftermath of the loss of their child.

**Method**

Eighteen bereaved parents from various U.S. states participated one or more times in online support groups facilitated monthly over the course of 20 months (June 2010-February 2012). Groups ranged from 1-7 participants, with three parents on average in each session. Parents were between 2 months and 11 years postloss and were grieving children who had died of brain or spinal cord tumors.

**Procedure**

We advertised online support groups through CBTF’s website, mailings, mass emails, outreach to other hospitals/organizations, and direct parent contact. Parents identified weekday evenings as preferable and monthly groups were held mid-week at 8PM EST, to accommodate families in different time zones. Online community members provided email addresses, to which we sent meeting dates/times and reminders one month, one week, and one day in advance of the group.

Jenna’s Corner membership requires a password, but to provide additional safety we reviewed, accepted, and monitored all participants. As trained bereavement co-facilitators, we provided clinical assistance as needed and attempted to decrease anticipated challenges of online support groups. Anticipated challenges included: the fast pace of message postings, which increased the difficulty of reading, monitoring, and responding to posts in the chat room, especially when multiple participants contributed to the conversation simultaneously; acknowledging and briefing members as they entered the chat room mid-conversation; and providing a balance of facilitation and information. Facilitators allotted 1.5-2 hours for support groups, with typical groups lasting an average of 81 minutes each.

Topics were participant driven such that the parents guided the conversations and initiated topics. We
monitored each post to ensure that all comments were read, acknowledged, and addressed, to avoid members feeling neglected within the group. We supported members by providing reflective responses, eliciting exploration of grief-related issues, and furnishing bereavement-specific information/education when appropriate or requested.

Measures

As well as providing the grief-based chat forum, we sought to learn about bereaved parents’ grief expression in online support groups. When the evaluation period was completed, we accessed and reviewed archived chat room discussions to record group participation statistics, trends, and content to determine the topics most commonly initiated by parents. Accordingly, we evaluated 19 online support group sessions.

To evaluate the effectiveness of online support groups for parents bereaved by cancer, we emailed 18 interested participants a link to a 10-item, multiple-choice questionnaire (i.e., accessed via Survey Monkey; see Table 1) with additional space for comments. We evaluated overall effectiveness of our live, online support group intervention for bereaved parents by determining if groups: helped parents, reduced the isolation that often accompanies grief, and served as a coping resource for bereaved parents. Evaluation questions explored participants’ decision to join the chat group, the group’s usefulness and effectiveness, if participation in the group affected their ability to cope with grief, the relation between group participation and their sense of social isolation, and positive and negative aspects of group participation.

Results

Fourteen out of 18 eligible parents completed the survey, resulting in a 78% response rate. Archived chat discussions revealed the most frequently initiated topics in online support groups: parental grief (e.g., the grief process, emotions, relationship changes); negative social interactions;
special events (e.g., milestones, holidays); grief of surviving sibling; and coping (e.g., use of faith/spirituality, maintaining a bond with the deceased child). Bereavement duration also influenced topics. Newly bereaved parents focused on pain, sadness, and anger, while long-bereaved parents discussed helpful support services and changes in grief over time.

Our results suggest that online support groups are an effective, supportive intervention. In fact, 93% (13/14) of parents reported that the group helped, with one participant clarifying, “it helped for a moment.” Eighty-six percent of parents (12/14) said it helped to meet other parents who shared a similar experience. Sixty-four percent (9/14) endorsed: I felt supported by other bereaved parents, and 64% selected: I had the opportunity to talk about my loss in a safe environment. Other responses included: felt comforted by the chat, felt supported by professionals, learned about my grief, grief resources, and support services.

Reportedly, 93% of parents (13/14) felt less isolated following the online chat, although one person endorsed less isolation during the group but not following. Parents’ most common explanation for feeling less isolated afterward was: connection with other bereaved parents and having feelings and experiences understood by others (71%, 10/14, respectively). Other explanations included: support from facilitators, supporting others, and sharing experiences.

Parents liked online groups because: the groups are supportive (79%; 11/14), and convenient 71% (10/14). Other reasons included: easier to access information via the Internet, to express feelings in writing versus verbally, and to express emotion online versus face-to-face, limited local support services, and anonymity.

When asked, “Why did you participate in a live, online chat,” 86% (12/14) stated that they wanted to meet other bereaved parents because they wanted to feel supported, and to discuss grief experiences. Other reasons included: receive support from professionals, and ask a specific grief
question. Finally, parents reported they would participate more often if more topic-based discussions were available, groups were offered on different days or times, and chats were available multiple times per month. Notably, 79% (11/14) of participants felt that online groups were useful in helping them cope with their grief.

Conclusions

Based on established need, CBTF created an online grief support chat room specifically designed to address the needs of parents grieving their children’s cancer deaths. Meeting these needs also allowed us to explore parents’ experiences through archived chat room discussions, which we descriptively reported here.

Given that Internet usage by bereaved individuals appears to be a common avenue for information acquisition and coping, we canvassed participants about their perceptions of the utility of our online grief-support chat group, specifically related to its ability to increase positive social interactions with other grievers (as opposed to the tendency for some bereaved individuals to isolate themselves), and more generally, to determine if the group was a resource to parents in terms of coping with the death of their child. Three-quarter of the parents who participated in our online chat groups responded to our survey questions, with results demonstrating the appeal of online support groups for bereaved parents.

Through our participant-driven discussion topic format, we discovered what parents would discuss if given the freedom to lead the conversation in any direction. Time since loss appeared to influence subject matter, with newly bereaved individuals focusing on their pain, anger and sadness; and, bereaved parents who were farther from the date of death concentrating on how their grief had changed and the services that helped them maneuver through bereavement. Not surprisingly, parents’ grief emotions (i.e., anguish, sorrow) was the most discussed topic. Something about the need to tell
How parents’ grief affected them at certain times of the year (e.g., holidays) or the feelings that rose up in them as they contemplated upcoming dates of significance (e.g., anniversary of child’s death) were both frequently mentioned and affected participation. For some parents, signing in to chat sessions was directly related to an upcoming significant milestone and his/her need to process the event within the context of the group.

Research shows that negative social interactions can exacerbate the grief response (Burke, Neimeyer, & McDevitt-Murphy, 2010). Not surprisingly, bereaved parents used the online forum to exchange stories of unhelpful, hurtful, and even caustic social interactions following the death of their child: “Some of the things people say to me are unbelievably ignorant and insensitive.” Conversely, parents reported that within the confines of the CBTF’s chat room they felt understood and supported, knowing it was safe to “talk” in the company of others who had endured similar experiences. That sense of a “safe place” likely contributed to parents endorsing less isolation as a result of participating in our groups. However, it is worth noting that for some, who signed off only to return to a less-than-supportive world, loneliness returns upon exiting the chat room. Perhaps for this reason, parents requested that the group meet even more frequently. These factors combined, speak to the need for this type of online bereavement support service.

Consistent with research showing that griever want to talk about their deceased loved more frequently than society allows (Dyregrov, 2005), parents in our study shared the descriptive details of their child’s life and death, including diagnosis, prognosis, and the funeral/memorial service. In fact, often they introduced themselves as if they perceived their own identity as an extension of their child’s
death: “Hi, my name is Stephen, and my son Zachary was diagnosed with medulloblastoma at 10 months old. He battled it through six hospitalizations and died at age 2½ last August.”

Connecting with other bereaved parents surfaced as the single most significant explanation for participant satisfaction and perceived group effectiveness, which also helped parents feel less isolated. Parents also noted the importance of professional facilitation, which contributed to the feeling of a safe environment. Parents stated that their inclination to participate stemmed from a desire to gain insight into their own grief, to “meet” other parents who “get it,” and to ask specific questions of bereavement specialists. Once engaged in a chat session, it seems members immersed themselves in an exchange of edifying, rich, and meaningful content, and commented that writing about their grief was preferable to merely talking about it, consistent with grief therapies encouraging meaning making through journaling (Lichtenthal & Neimeyer, 2012). Overall, online support fit many parents’ lifestyles by providing a convenient and abundant source of cancer-specific bereavement information, allowing them to reveal their true identity or not, and to interact on a deeply personal level from a safe distance versus face-to-face.

As well as the positive benefits claimed by group members, as facilitators we experienced great satisfaction in observing parents as they made connections with other griever, provided mutual support to one another, experienced post-traumatic growth, and, at least for some, seemingly found hope, purpose, and happiness in spite of their loss. Despite the equivocalness of research results on the benefits of Internet grief support groups, bereaved parents in our sample reportedly found the experience to be supportive and effective.

**Group Challenges**

Facilitating live, online support groups includes challenges. Lack of Internet access meant that a subset of potential participants was inadvertently excluded. Confusion during registration and
difficulty logging in to the online community frustrated some parents who were eager to join in on the ongoing conversation.

Generally speaking, online chat sessions are member driven. Therefore, that a particular topic is being discussed between members at a given moment does not preclude the introduction of another topic that may supplant the previous one or run alongside it concurrently. Moreover, two or more members might begin communicating with each other—engaging in their own mini conversation that may or may not be applicable or of interest to others, all of which can serve to increase confusion and stress, especially for participants who are less well versed in online chat protocol. Struggles with typing or in using online websites, especially fast-paced ones like chat rooms that require participating members to keep up with a variety of overlapping conversations while trying to formulate and type his/her own comments/question, can be frustrating. We found that with larger groups, or when several parents contributed at once, the challenges increased proportionally. This scenario required participants to read quickly and sometimes follow multiple conversations at once, something not all participants could do all the time. Professional facilitation was necessary in these moments to assist parents in following the conversations and to ensure that all comments were “heard.”

Participation was also unpredictable. Parents did not know who or how many people would join each time; however, parents did not express frustration with this pattern. Given that writing/typing easily can be misunderstood because participants cannot see facial expressions or hear each other’s voices/tones, participants had to rely solely on written communication. Thus, occasionally, it was difficult to ascertain a participant’s feelings or to gauge inadvertent offenses.

Use of confusing online usernames was another identified challenge. Participants use their own names or anonymous usernames (for example, “sugarapple”) when signing in to the online community. Even when participants with anonymous names shared their real names it became difficult for
participants and facilitators to keep names straight. Inclement weather in different parts of the country causing power outages or problems with one’s Internet provider sometimes also affected the ability of participants/facilitators to log into the group.

**Study Limitations**

This represents one of few studies on the experiences of bereaved parents using online chat rooms, providing useful data to serve as a guide for future groups with similar formats. However, our survey sample was small; therefore, this limitation should be considered when interpreting our results. Additionally, not only were some survey questions inadvertently worded such that a response bias may have occurred where certain questions likely elicited a uni-directional response (e.g., “Why did you like the group?”), a greater number and wider variety of questions likely would have garnered an even richer understanding of the experiences of bereaved parents.

Future studies that gather detailed background information from participants (e.g., general Internet use, concurrent or past participation in online or face-to-face grief groups, use of professional grief services such as psychotherapy and/or medications to relieve grief symptoms, and level and quality of perceived social support) might glean even more about participants’ experiences. In the absence of this information, it is difficult to identify, for instance, the mourners for whom a particular type of grief-specific Web support is appropriate or effectual.

**Future Directions**

Data from this study will be used to inform future directions for intervention and research. For example, based on evaluation results, CBTF staff now offers well-received topic-based discussions, additional online groups, and groups facilitated by trained parent mentors (although, to date, participants report no preference for parents-only versus facilitator-led groups).
Here we have presented a descriptive study with a small, homogeneous sample, and as such generalizations cannot be made. Thus, we concur with previous studies examining the need and efficacy of Web-based mutual bereavement support groups in calling for more extensive research with large samples to obtain data useful in guiding the field in terms of knowing how to offer good quality, meaningful, online grief support to families bereaved by child cancer deaths.
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Table 1

Survey Questions

1. Approximately how many times have you participated in a live, online chat discussion facilitated by Jessica Elder (from CBTF) and Laurie Burke?
   - 1 Time
   - 2 Times
   - 3 Times
   - 4 Times
   - 5 or more

2. Why did you participate in a live, online chat? (please check all that apply)
   - I wanted to meet other bereaved parents
   - I wanted to talk to or get support from professionals
   - I wanted to feel supported
   - I wanted to talk about my grieving experience
   - I wanted to learn more about grief
   - I had a specific concern or question about grief (e.g., a concern around a grieving sibling or a family issue)
   - Other:

3. I felt that the online chat(s) helped me in some way
   - True
   - False

4. The online chat(s) helped me because I: (please check all that apply):
   - Had the opportunity to talk about my loss in a safe environment
   - Felt comforted during the chat
   - Felt comforted during the chat and for some time after
   - Met other parents who shared a similar experience
   - Felt supported by professionals
   - Felt supported by other bereaved parents
   - Gained knowledge about my grieving experience
   - Received answers or information
   - Gained information about grief resources and support services
   - Other:

5. I felt less isolated after participating in a live, online chat because (please check all that apply):
   - I was connected to other bereaved parents for the first time
   - I was connected to other bereaved parents
   - I was able to talk to talk to the facilitators
   - My feelings and experiences were understood by others
   - I was able to explain my experiences to a group that listened
   - N/A I did not feel less isolated
   - Other:
6. I learned something about my grief while participating in the live, online chat(s)
   True
   False
   Other:

7. I think that participating in live, online chats could help me cope with my grief
   True
   False
   Other:

8. I like online groups because (please check all that apply):
   - They are convenient
   - They are supportive
   - There is not much support available where I live
   - I like being anonymous
   - I like accessing information and services via the Internet
   - I do not like in-person groups
   - It is easier to write about my experiences rather than talk about them
   - I do not like to be emotional in front of others
   - N/A I did not like the online group
   Other:

9. I would participate in live, online chats more often if: (please insert your response)

10. Is there anything else you'd like to share about your online group experience? Please feel free to share suggestions on how we can improve: (please insert your response)