Title: Protocol for a feasibility trial (EXPRESS-C-GVHD) for an expressive helping intervention within a support group for cutaneous graft-versus-host-disease

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Supplement 2

EXPRESS-C-GVHD STUDY: Expressive helping for chronic cutaneous GVHD

Adapted from Expressive Helping Trial Protocol for Patients Undergoing Stem Cell Transplantation(1)

Writing Session and Discussion Group Scripts

Pre-Session 1 Assessments

-Email patients an online survey where they can complete (2 weeks before survey)

-Baseline Demographics

-SF-36

-Lee Symptom Survey

-DLQI

-Due date is day before the intervention

Day Before Session 1: Email the discussion prompt for that week

Support Group (SG) Agenda Day 1

Hi everyone, thank you so much for being here. Introduce facilitators, share that it is going to be recorded. We are really honored to be able to interact with each of you through this 4 week support group and writing exercise. Before we start for this week we'd like to do an icebreaker. So to start off, why doesn't everyone share (items are below).

Ice Breaker

- My name is _____.
- I am a _____ survivor.
- My stem cell transplant was on _____.
- I was diagnosed with GVHD in _____
- My number one support system is _____.
- My favorite food is _____.

Expressive Helping (EH), Writing Day 1

Hi everyone, thank you so much for engaging in the icebreaker. We are going to transition into the writing part of this session. It will take about 20 minutes of uninterrupted time. You may choose to write on the computer such as a word document, or using pen and paper.

First, I'm going to tell you the goals of the writing sessions and give you some general instructions. Then I'll give you specific instructions for today's writing.

The goals of the writing sessions are based on a large body of research. We and other researchers have found that many people going through a very stressful experience benefit from writing, whether or not they've written before and regardless of whether they consider themselves to be good writers. In fact, writing has been shown to help people in many different types of stressful situations, including people coping with serious illnesses. And we think that writing can help people with GVHD.

We find that many people who have <u>had</u> a transplant like the idea of helping people who are <u>getting ready</u> to have a transplant. We also see that GVHD patients seek more opportunities to share their experiences and learn from others with GVHD.

We think that it helps them in three different ways. One is that it gives them an idea of things that <u>might</u> come up, like side effects they would not otherwise know about. The second is that they realize their feelings and concerns about GVHD are shared by others, and that their feelings and concerns are normal and understandable. The third benefit of knowing about other people's GVHD experience is that people learn practical tips and ways of coping that help them. All in all, knowing about other people's experiences can help them feel more <u>emotionally</u> prepared and they know that people <u>do</u> get through this.

With your permission we will be taking a look at the writing samples you share with us, and it will all be anonymous. We hope to use this to understand how to help patients and also create resources for people who were just diagnosed. Do you all have any questions?

In this study, you're going to complete four brief writing sessions. They're 20 minutes each. For each one, I'll give you a different writing task. In a moment I'll tell you the topic you'll be writing about today.

But first, let me tell you that the first three writing sessions, including today's session, are mainly to help you start thinking about different aspects of your GVHD diagnosis experience. The first three writing sessions will end with the fourth session which asks you to write a letter to someone else who has just been diagnosed with GVHD.

There's one suggestion I'd like to make about that last writing session, and you can think about this as you do the first three writing sessions. Don't be reluctant to share the hard parts of your experience. If you want, you can write about the good and bad parts of it. Most people say they want to hear both. For instance, you might write about the things you are most proud of, or the good days you had, but also feel free to write about your more difficult moments and the challenges you faced. You can talk about how you coped with them, if you'd like. Maybe it would be helpful to think about what you wish someone had told you right at the start of your diagnosis.

Just one more thing before I give you your writing instructions for today. The writing you'll be doing is the most important part of this study. The only rule I'm going to give you for the writing is that once you start writing, you need to keep writing until your 20 minutes are up. If you run out of things to say, you can just repeat something you've already written. I don't want you to worry about spelling, sentence structure, or grammar. Those things are unimportant for what we're doing. The most important thing is that you delve deeply into your experience and think about what might be most helpful for others. What questions do you have for me so far? [ANSWER THEM]

[SPEAK SLOWLY. BE SENSITIVE WHEN GIVING INSTRUCTIONS]

If you're ready to start, I'll give you specific instructions for today's writing. Today I'd like you to write about what it was like for you when you first developed symptoms of GVHD and before you were formally diagnosed with GVHD. What symptoms did you have? What emotions did you experience? How did it affect your day-to-day life and the people close to you? What concerns and hopes did you have? These are just examples. You can write about any aspect of the time before your diagnosis that you'd like. But it's important that you really let go and explore your very deepest thoughts and feelings about that time. This will give you the chance to examine your thoughts and feelings and to think about things you found hard to share with others.

So, now you're going to write continuously for 20 minutes about your initial symptoms before your GVHD diagnosis, and you're going to delve deeply into your thoughts and feelings as you write.

Okay. Do you have any questions? Then, if you're ready, please get started.

[AFTER 20 MINUTES…]

Hello. It's time to stop writing. Were you in the middle of a thought that you would like to complete? [IF YES: Go ahead and finish your sentence.]

For those of you typing, please save your file. At the end of the session today, you will receive a link where you would check off a box indicating that you participated in this activity. You can also copy your writing into a text box. For those of you using a pen and paper, you can take a picture and upload it to the link in your email after this session. You can also send your writing in the mail up to 3 days after this session.

Thank you all for your participation. We are now going to move into the second half of the group today, which includes group discussion. The topics we are discussing are the ones that were emailed to you yesterday. This week, we will discuss friends and colleagues. I will read the prompts out loud and open it up for discussion.

Discussion Prompts: Relationships Part One: Friends and Colleagues

- Reflect on your relationships with your friends and colleagues
  - Have these relationships gotten stronger or weaker since your transplant?
  - Why have they gotten stronger or weaker?
- How has your diagnosis and treatment affected your ability to make new friends or meet a significant other?
- Do you feel like the people in your life do not understand how debilitating GVHD is?
  - Would your parents, siblings, friends, significant other be willing to attend an educational seminar or read information about GVHD and how it affects you?
- Have you found new ways to spend time with family, friends, and significant others (ie; going to get coffee instead of going out to a bar, etc.)
  What about others - acquaintances, colleagues or total strangers?

At the 1 hour mark:
All right everyone, we don't want to take more time than we are scheduled for, so we are going to wrap up the first session. Thank you all so much for being here and sharing your experiences. As a reminder, you should have a link in your email now where you can check off a box to indicate that you completed the activity. You can also copy your writing into the text box or upload a picture if you used pen and paper. You can also send

your writing in the mail up to 3 days after this session. We will stay on the call for a few minutes to help any of you who are having trouble adding your writing to the link.

We will see you all at the next session!

Post-Session 1
Check in 3 days later to see if samples were uploaded and the form was filled out

Day Before Session 2: Email the discussion prompt for that week

Support Group (SG) Agenda Day 2

Hi everyone, thank you so much for being here. Introduce facilitators, share that it is going to be recorded. We are really honored to be able to interact with each of you in week 2 of this 4 week support group and writing exercise.

Ice Breaker

- My name is _____.
- I was diagnosed with GVHD in _____
- My favorite movie is _____
- Something fun I did this week is _____

Expressive Helping (EH), Writing Day 2

Hi everyone, thank you so much for engaging in the icebreaker. We are going to transition into the writing part of this session. It will take about 20 minutes of uninterrupted time. You may choose to write on the computer such as a word document, or using pen and paper.

Now, I'll give you specific instructions for today's writing. Today I'd like you to write about what it was like for you when you were diagnosed with GVHD. How did you react? What emotions went through your head? Were you told anything that surprised or frightened you? These are just examples. But it's important that you really let go and explore your very deepest thoughts and feelings about that time.

As a reminder, these 3 sessions are mainly to help you start thinking about different aspects of your experience and to help you get ready for writing a letter to help others with this diagnosis. You have today and one more writing day to gather your thoughts when you will write your letter, so this is a chance to delve even more deeply than you did last time.

You don't need to worry about spelling, sentence structure, or grammar. The only rule is that you need to write continuously for 20 minutes. If you run out of things to say, just repeat something you've already written. Okay. Do you have any questions? Then, if you're ready, please get started.

[AFTER 20 MINUTES…]

Hello. It's time to stop writing. Were you in the middle of a thought that you would like to complete? [IF YES: Go ahead and finish your sentence.]

For those of you typing, please save your file. At the end of the session today, you will receive a link where you would check off a box indicating that you participated in this activity. You can also copy your writing into a text box. For those of you using a pen and paper, you can take a picture and upload it to the link in your email after this session. You can also send your writing in the mail up to 3 days after this session.

Thank you all for your participation. We are now going to move into the second half of the group today,which includes group discussion. The topics we are discussing are the ones that were emailed to you yesterday. This week, we will discuss family. I will read the prompts out loud and open it up for discussion.

Discussion Prompts: Relationships Part Two: Family

- Reflect on your relationships with your parents, siblings, extended family and significant other
  - Have these relationships gotten stronger or weaker since your transplant?
  - Why have they gotten stronger or weaker?
- Do you feel like your parents, significant other, siblings, etc. do not understand how debilitating GVHD is?
  - Would your parents, siblings, significant other be willing to attend an educational seminar or read information about GVHD and how it affects you?

-Has GVHD affected the way you treat family / loved ones?

- Are there times when you feel guilty and/or righteous in the way you treat others on account of GVHD?

At the 1-hour mark:

All right everyone, we don't want to take more time than we are scheduled for, so we are going to wrap up the first session. Thank you all so much for being here and sharing your experiences. As a reminder, you should have a link in your email now where you can check off a box to indicate that you completed the activity. You can also copy your writing into the text box or upload a picture if you used pen and paper. You can also send your writing in the mail up to 3 days after this session. We will stay on the call for a few minutes to help any of you who are having trouble adding your writing to the link.

We will see you all at the next session!

Post-Session 2

Check in 3 days later to see if samples were uploaded and the form was filled out

Day Before Session 3: Email the discussion prompt for that week

Support Group (SG) Agenda Day 3

Hi everyone, thank you so much for being here. Introduce facilitators, share that it is going to be recorded. We are really honored to be able to interact with each of you in week 3 of this 4 week support group and writing exercise.

Ice Breaker

- My name is _____.
- I was diagnosed with GVHD in _____
- My favorite song is _____
- My favorite musical artist is _____

Expressive Helping (EH), Writing Day 3

Hi everyone, thank you so much for engaging in discussion. We are going to transition into the writing part of this session. It will take about 20 minutes of uninterrupted time. You may choose to write on the computer such as a word document or using pen and paper.

Now, I'll give you specific instructions for today's writing. Today I'd like you to write about what it was like for you in the time after you were diagnosed, until today. For instance, did you have any concerns? Did you have any difficulties you had to cope with? What was it like for you and your caregiver to start taking over tasks for your recovery? How was it emotionally? These are just examples. But it's important that you really let go and explore your very deepest thoughts and feelings about that time.

Remember that the first three writing sessions, including today you start thinking about different aspects of your experience and to help you get ready to write a letter to help others with this diagnosis. This is your last day to gather your thoughts for the fourth writing session when you will write your letter, so it's a chance to delve even more deeply than you did last time.

You don't need to worry about spelling, sentence structure, or grammar. The only rule is that you need to write continuously for 20 minutes. If you run out of things to say, just repeat something you've already written. Okay. Do you have any questions? Then, if you're ready, please get started.

[AFTER 20 MINUTES…]

Hello. It's time to stop writing. Were you in the middle of a thought that you would like to complete? [IF YES: Go ahead and finish your sentence.]

For those of you typing, please save your file. At the end of the session today, you will receive a link where you would check off a box indicating that you participated in this activity. You can also copy your writing into a text box. For those of you using a pen and paper, you can take a picture and upload it to the link in your email after this session. You can also send your writing in the mail up to 3 days after this session.

Thank you all for your participation. We are now going to move into the second half of the group today, which includes group discussion. The topics we are discussing are the ones that were emailed to you yesterday. This week, we will discuss employment and education. I will read the prompts out loud and open it up for discussion.

Discussion Prompts: Employment and Education

- What were you doing for work or education prior to your diagnosis?
- Are you still able to perform your work or educational program?
    - If so, have you made any modifications to make this more feasible for your new lifestyle? Are these modifications beneficial or can they be improved?
        - If not, what prevents you from engaging in this work or educational program? Do you want to return to this work or educational programs? Are there modifications that can be made to help you return to work or education?
- In what way does your energy level affect your "new normal?"
- How do you communicate to your colleagues or educators about your diagnosis?

- At the 1 hour mark:
- All right everyone, we don't want to take more time than we are scheduled for, so we are going to wrap up the first session. Thank you all so much for being here and sharing your experiences. As a reminder, you should have a link in your email now where you can check off a box to indicate that you completed the activity. You can also copy your writing into the text box or upload a picture if you used pen and paper. You can also send your writing in the mail up to 3 days after this session. We will stay on the call for a few minutes to help any of you who are having trouble adding your writing to the link.
- We will see you all at the next session!

- Post-Session 3
- Check in 3 days later to see if samples were uploaded and the form was filled out

Day Before Session 4: Email the discussion prompt for that week

Support Group (SG) Agenda Day 4

Hi everyone, thank you so much for being here. Introduce facilitators, share that it is going to be recorded. We are really honored to be able to interact with each of you in the final week of support group and writing exercise.

Week 4:

Ice Breaker

- My name is _____.
- I was diagnosed with GVHD in _____
- My favorite way to relax is _____.
- My dream vacation would be _____

Expressive Helping (EH), Writing Day 4

Hi everyone, thank you so much for engaging in the icebreaker. We are going to transition into the writing part of this session. It will take about 20 minutes of uninterrupted time. You may choose to write on the computer such as a word document or using pen and paper.

Now, I'll give you specific instructions for today's writing. During the first three writing days, you wrote about the time before, during, and after your GVHD diagnosis. That writing gave you a chance to think about your experiences and to consider what you might want to share with people with the same diagnosis.

Today is the last day of writing, and it's time to wrap things up. Today I want you to write as if you were writing a letter to someone recently diagnosed with GVHD. You can write about anything you like, perhaps using ideas that came out of the first three writing sessions. For instance, you can summarize your entire GVHD experience. Or you can write about some part of your experience that you think will be most helpful for others to know about. You can even include advice and encouragement if you'd like. Remember that it doesn't matter if their experience ends up being very different than yours. People with GVHD get a lot out of knowing the full range of what other people experienced. And don't be reluctant to share the hard parts. People can benefit from knowing they happened and how you got through them. Maybe it would be helpful to think about what you wished someone had told you right when you were diagnosed.

As you write today, I still don't want you to worry about spelling, sentence structure, or grammar. That's something we can deal with later. Just try to get on paper the things that you think will help people with the same diagnosis.

Okay. Do you have any questions? Then, if you're ready, I'll hang up so you can write, and I'll call you back in 20 minutes.

[AFTER 20 MINUTES…]

Hello. It's time to stop writing. Were you in the middle of a thought that you would like to complete? [IF YES: Go ahead and finish your sentence.]

For those of you typing, please save your file. At the end of the session today, you will receive a link where you would check off a box indicating that you participated in this activity. You can also copy your writing into a text box. For those of you using a pen and paper, you can take a picture and upload it to the link in your email after this session. You can also send your writing in the mail up to 3 days after this session.

Thank you all for your participation. We are now going to move into the second half of the group today, which includes group discussion. The topics we are discussing are the ones that were emailed to you yesterday. This week, we will discuss mental health. I will read the prompts out loud and open it up for discussion.

Discussion Prompts: Mental Health and Fatigue

- Do you feel like your overall mental health has been adequately addressed throughout your diagnosis, treatment, and follow-up?
  - If so, what resources did you find useful?
  - If not, why?
- Do you feel all stem cell transplant patients should be required to see a psychiatrist or psychologist throughout the entire course of diagnosis, treatment and follow-up?
- Do anniversaries such as diagnosis date, transplant date, etc. trigger anxiety or fear?
  - If so, why do you think this happens and how can you work to change that anxiety or fear to a feeling of accomplishment?
- Are you able to exercise? Is so, why? If not, why?
- Do you want to exercise?
- Would you be willing to participate in physical therapy?
- Do you think all stem cell transplant patients should receive physical therapy upon hospital admission for transplant?
- Are you self-conscious about changes in your physical appearance?

What are some ways you can promote self-appreciation and prevent self-depreciation?

At the one-hour mark

- All right everyone, we don't want to take more time than we are scheduled for, so we are going to wrap up the first session. Thank you all so much for being here and sharing your experiences.
- As a reminder, you should have a link in your email now where you can check off a box to indicate that you completed the activity. You can also copy your writing into the text

box or upload a picture if you used pen and paper. You can also send your writing in the mail up to 3 days after this session.

Next Steps:

Let me tell you about what's going to happen next.

The next step is for us to contact you for follow-up measures that let us know how you're doing over the next few months. These will be like the forms filled out before the sessions:

The first assessment will be emailed tomorrow and you will have 2 weeks to complete it. The second will be emailed at 1 month and you will have 2 weeks to complete. You will receive reminders.

[IF THEY WANT TO KNOW MORE ABOUT THE WRITING: Once you finish the study, I will be able to tell you all about the writing and what we think this study will show. To keep the study as "tight" as possible, I can't tell you all of the details now.]

Thank you all for your participation. We appreciate you joining the study. We will stay on the call for a few minutes to help any of you who are having trouble adding your writing to the link.

****IN SITUATIONS WHERE <u>DEBRIEFING IS NEEDED</u> -- FIRST AND FOREMOST, MAKE SURE PARTICIPANTS ARE OK AND GIVE THEM THE OPPORTUNITY TO TALK ABOUT ANY FEELINGS THEY MIGHT HAVE ABOUT THE WRITING. VALIDATE AND NORMALIZE THEIR FEELINGS.**

[HAVE SUPPORT GROUP NUMBERS AVAILABLE IF NEEDED: Cancer Care at <u>www.cancercare.org</u> or 1-800-813-HOPE (4673) (free of charge, support groups and individual counseling online, by phone, or onsite in NJ, CT, and NY. Can also offer referrals.)]

SOME QUESTIONS YOU MAY NEED TO USE TO DRAW OUT PARTICIPANTS WHO ARE DISTRESSED SO YOU CAN UNDERSTAND THEIR LEVEL OF DISTRESS ARE:

- CAN YOU TELL ME MORE ABOUT THAT?

- WHAT HAS YOUR MOOD BEEN?

- HAVE YOU BEEN CRYING A LOT?

- IS THIS AFFECTING YOUR DAILY FUNCTIONING?—ARE YOU FINDING THAT IT'S HARD TO DO THE THINGS THAT YOU NORMALLY DO?

- HAVE YOU BEEN GETTING ENOUGH SLEEP?

- HAVE YOU BEEN THINKING ABOUT YOUR TRANSPLANT A LOT MORE?

- IS THAT GOOD OR BAD?

- WHAT DO YOU THINK IS GOING TO HELP YOU COPE WITH THIS?

- DO YOU HAVE ANYONE YOU CAN TALK TO ABOUT THIS?

IF PERSON IS ONLY MILDLY DISTRESSED: FEELING SAD AFTER THE WRITING IS A NORMAL REACTION. IF YOU FIND YOU'RE NOT FEELING BETTER, I'D LIKE YOU TO GIVE ME A CALL.

IF IT IS CLEAR THAT THE PERSON IS QUITE DISTRESSED, OFFER THE FOLLOWING IF APPROPRIATE: I'M NOT A PROFESSIONAL COUNSELOR, BUT I CAN HAVE ONE CALL YOU IF YOU THINK THAT WOULD BE HELPFUL. WOULD YOU LIKE THAT?]

Post-Session 4 Assessment 1: Day after group ends: Send out surveys of Lee cGVHD, SF-36, DLQI. Due 2 weeks later, reminders every 3 days

Post-Session 4 Assessment 2: 4 weeks after group ends: Send out surveys of Lee cGVHD, SF-36, DLQI. Due 2 weeks later, reminders every 3 days

Reference

1. Whitmore L, Schulte T, Bovbjerg K, Hartstein M, Austin J, Luta G, et al. Efficacy of expressive helping in adult hematologic cancer patients undergoing stem cell transplant: protocol for the Writing for Insight, Strength, and Ease (WISE) study's two-arm randomized controlled trial. Trials. 2021;22(1):722.