Dissemination innovation: Using found poetry to return study results to patients and partners facing cancer

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ABSTRACT

Objective: Investigators should return study results to patients and families facing cancer to honor their research contributions. We created a found poem from transcripts of sexual and gender minority (SGM) couples facing cancer and returned it to study participants.

Methods: Participants were randomized to receive the found poem in text, text and audio, audio, or video format, completed dissemination preferences and emotion questionnaires, and open-ended questions about their experience receiving the poem.

Results: Participants preferred the format they received ($n = 15$, 75.0%), with text-only and combined text and audio formats evoking the greatest number of emotions ($n = 13$ each). The following categories and sub-categories were identified: dyadic experiences (support, strength, depth, durability); dissemination preferences (timing, method); emotion (positive, negative); utility of the found poem (affirming; fostering reflection; not useful or inaccurate, and sense of community). SGM participants utilized positive emotion, affirming, and a sense of community with greater frequency than non-SGM participants.

Conclusion: Innovative approaches to dissemination are acceptable; providing choices in how and when participants receive results may increase engagement; and SGM versus non-SGM groups may describe dyadic experiences differently.

Innovation: Returning study results via found poetry is an innovative way to honor research participants facing cancer.

1. Introduction

Research among critically or seriously ill individuals and their families aims to discover ways to address complications, pain and suffering, and improve the quality of life [1]. When agreeing to participate in research, those facing serious illness and the end of life may prioritize research (instead of engaging in other meaningful activities) and or surrender what little time might remain to the possibility that research will contribute to the greater good. Given the sacrifice these individuals make in the name of science, investigators should honor this gift by involving participants in the research process, including returning study results [1], a best practice in community-based participatory research [2].

Dissemination is "the intentional, active process of identifying target audiences and tailoring communication strategies to increase awareness and understanding of evidence and motivate its use in policy, practice, and individual choices" [3]. Seventy-five percent of past research

participants believe they should receive study results, with both past participants and researchers believing that sharing findings can improve community support and trust in research [4]. Disseminating findings to study participants also ensures that new knowledge reaches the individuals and communities who may benefit the most from this information [5], what is often called distributive justice, or the "fair distribution of the burdens and benefits" of research [6].

Despite recommendations to share findings with participants, it is not a common practice [7]. In a survey of 3381 health research participants from ResearchMatch, only one-third received results with half unable to request study results [8]. Researchers often report barriers to sharing findings with study participants such as a lack of knowledge regarding best practices [4]. The publication of study findings in traditional academic journals may be inaccessible to past study participants [9] and may contain unnecessary jargon that makes findings difficult to understand and apply to real-world settings. In addition, many journals require a subscription or charge fees for reading a single article—a

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financial barrier that makes accessing and benefitting from scientific research unfeasible and burdensome for the most underserved and socioeconomically disadvantaged groups. As the ability to use study findings in actively improving population health is especially important for the most at-risk groups, investigators must consistently disseminate findings back to participants and may increase participants' interest in receiving results by utilizing creative and non-traditional dissemination methods [5].

Found poetry, a specific narrative form, is created by taking words and phrases from other sources—such as interview or focus group transcripts—and changing the order, spacing, and or lines of the transcript text to create a poem reflecting research findings [10]. Using "found" words and phrases from participants' recorded and transcribed speech can center findings around participant accounts instead of researcher interpretations [9]. Found poetry can be a more accessible format to present research findings, elicit an emotive reaction, and encourage deeper insight into the subject matter [11] while "illuminating the wholeness and interconnections of thoughts," unlike traditional analytical writing [12].

Our purpose in returning results to past study participants was to share the information learned, give back to participants, and engage them in the research process. Furthermore, we sought to return study results in a way that might elicit emotional reactions and foster deeper insight. As such, found poetry was the narrative form that aligned the most with our specific context, results, and dissemination purposes.

While little is known regarding the best methods of creating and disseminating found poetry, researchers suggest that content should be tailored for different learning styles and needs, as study participants may have different preferences for receiving findings [13]. The Visual, Aural, Read/Write, and Kinesthetic (VARK) classification system of learning styles suggests that learners with each learning style learn best from specific formats [14,15]. We utilized VARK classifications to create different dissemination formats appealing to each learning style. This manuscript reports the methodological development of the found poem, various ways of communicating research results to participants, and participants' dissemination preferences, experiences, and emotions evoked by the found poem.

2. Methods

2.1. Original study

The original study examined the posttraumatic growth (PTG) and life course stress of sexual and gender minority (SGM) and non-SGM couples facing cancer (see Fig. 1). Complete study methods and findings have been published elsewhere [16,17]. PTG refers to the positive psychological change that can occur through the struggle with a highly stressful or traumatic event [18].

In the qualitative arm of the original study, half the sample was SGM ($n = 12$ couples or $n = 24$ individuals) and half was non-SGM (n = 12 couples or n = 24 individuals) for a total sample size of 24 couples ($N = 48$). The final sample contained 13 individuals with advanced, five with early-stage, and six with unknown cancer stages, as well as each person's partner caregiver. Participants were recruited online and through a National Cancer Institute-designated cancer center in the Intermountain West. All procedures were approved by the University of Utah Institutional Review Board (#00133699).

Dyadic semi-structured interviews were conducted and recorded with consent via video-conferencing software. Interviews were transcribed verbatim by professional transcription services, imported into NVivo 12 qualitative analysis software, and de-identified [19]. Qualitative interpretive descriptive approaches were used to analyze the data [20,21]. The main findings included the identification of six new dyadic domains of PTG experienced by SGM and non-SGM couples. Dyadic strength and durability—in which couples described how the cancer experience contributed to feeling stronger as a couple, and or affirming the durability of their relationship—was one of the most frequently discussed dyadic domains [17].
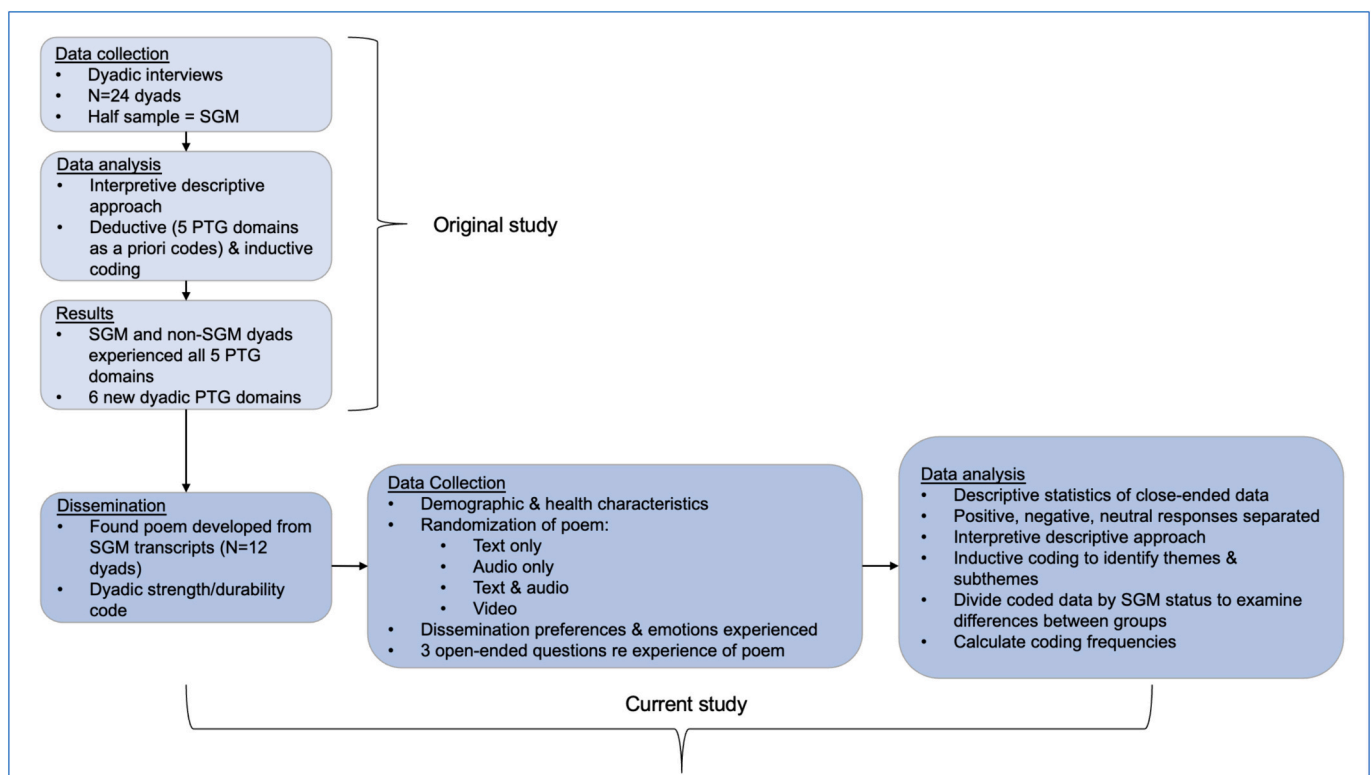

Fig. 1. Study flowchart.

2.2. Dissemination and creation of found poem

To fulfill our moral obligation to return results to past study participants in an accessible, understandable, and evocative way, we focused on dyadic strength and durability, which had been validated by the original study authors [17]. We chose to solely utilize SGM couples' interviews to prioritize returning study results to this historically marginalized group [9,11]. The dissemination plan originally involved returning to non-SGM couples' interviews at a later time. However, after developing the found poem we decided that 1) it did not exclude non-SGM participants, and 2) we wanted a larger sample size for assessing participant dissemination preferences. As such, while the found poem was developed from SGM couples' interviews, both SGM and non-SGM couples received the poem. For sample demographics of the SGM individuals interviewed see Bybee et al. (2023) [17].

The methods involved in creating the found poem were informed by qualitative researchers in the medical humanities [9,11,22-24]. The first author, a health science researcher with experience in the context of cancer, PTG, and conducting research with SGM communities, also has experience writing and publishing poetry. Every excerpt (quotation) within the code *dyadic strength or durability* was exported by the first author from each SGM couple's interview transcript and combined into a single word processing document. The first author, who interviewed all participants, read all transcripts and previously identified the new dyadic PTG domains, read all excerpts coded as dyadic strength and durability to regain familiarity with the content, and wrote memos of initial observations. Similar to Glesne (1997), re-reading all words/excerpts contained within one qualitative theme helped "understand the essence" of what participants were saying [12]. Initial observations included imagery of circles, wholeness, and couples' sense of impenetrability, which suggested an "essence" of togetherness and unity. We also noted text related to battle, fighting, and or violence against the world outside of the dyad. Observations were shared with the second author (JE), a gerontology researcher and higher education expert who utilizes transdisciplinary approaches to enhance the quality of life for older adults and their caregivers through arts-based interventions.

Aligned with Brown (2020), who suggested that found poetry should entail choosing words and phrases repeated throughout the text [23], the first author then re-read the word processing document while highlighting similar concepts, words, and imagery. The highlighted text was exported into a new word-processing document. Unnecessary words (such as uh, um, like) were removed to reveal the core words/phrases and reduce document length. The first author removed sections of text that did not coalesce with the growing collection of similar words while including the voices of every participating couple. When a couple had more than one phrase or stanza from which to choose, the first author selected the words that most clearly and strongly reflected the essence of unity and togetherness.

Once eight pages of excerpts were reduced to two pages through this process, the first author changed the order and spacing of some words and phrases while maintaining the original language from participants, continuing to cut unnecessary words. The first author then shared multiple iterations of the poem with the study team and faculty members from the health sciences and medical humanities. The order of stanzas was changed based on feedback from co-authors and external faculty members. The current poem version was shared in an oral presentation at a national conference, where a diverse group of health and social science researchers—many of whom conduct narrative work with SGM populations—reacted positively (see Fig. 2).

2.3. Current study

2.3.1. Data collection

Once the found poem had been drafted, revised, and approved by research team members and external reviewers, the first author emailed all participants (SGM and non-SGM) from the original study who previously agreed to be contacted with study findings with an invitation to participate in a new study on the dissemination preferences of study participants receiving found poetry. Potential participants clicked on a personalized REDCap link connecting them to study information and consent documents [25,26]. After providing electronic consent, participants were routed to a brief demographic and health questionnaire. They were then automatically randomized into one of the following four dissemination methods informed by VARK learning classifications [14]: 1) listening to an audio recording of the found poem (aural), 2) reading the found poem (visual, reading/writing), 3) listening to an audio recording of the found poem while reading it (visual, aural, reading/writing), or 4) watching a video in which an audio recording plays while the text of the poem is displayed (visual, aural, reading/writing, kinesthetic). The randomization allocation sequence was generated by author BW. Primary outcome measures were collected by online questionnaires (within REDCap) directly after participants received the found poem.

Distinct emotions were assessed with the following question that was informed by Plutchik (1991) [27] and Cowen & Keltner (2017) [28]: "What emotions (if any) did you experience while receiving the poem? (choose all that apply)." See Table 1 for the eight primary and related emotions [29].

We assessed dissemination preferences and experiences receiving the poem utilizing the following open-ended questions: 1) How did the content of the poem reflect or not reflect your experience coping with cancer as a couple? 2) How did the poem shed light on/describe/or change the way you see your relationship? 3) Is there anything else you would like the researchers to know about the experience of receiving the poem?

2.3.2. Data analysis

All statistical analyses were conducted using SPSS Version 28 software [30]. Descriptive statistics summarized demographic information as well as dissemination preferences and emotions experienced. Responses to the open-ended questions were exported by the first author into word processing software and read to gain familiarity with the content. Preliminary impressions were annotated by the first author. The first author then re-organized open-ended responses so that similar "chunks of text [we]re ordered or placed proximally" [31]. Developed from theories of relational maintenance and therefore aligned with the essence of unity and togetherness, the Relational Affective Topography System (RATS) informed our decision to separate affective expressions into positive, neutral, and negative groupings to conduct our initial analysis [32,33]. Excerpts that contained both positive and negative emotions were pasted in between the positive and negative groupings to enable adjacent visualization. Once responses were rearranged by the first author, they were shared with additional team members (JE) for verification.

Responses were analyzed using an interpretive descriptive approach, which discovers relationships, patterns, and associations within phenomena of interest [20,21,34,35]. The first author reviewed the cluster of "positive" responses to inductively identify and form initial codes that were then grouped into categories and expanded or collapsed as coding continued [36]. This process was undertaken for responses labeled as neutral and negative. The first author created a qualitative codebook containing code labels, definitions, and example quotations [37]. The unit of analysis was meaningful units of speech in response to open-ended questions; Thus, a participant's response could fit within multiple categories. The qualitative codebook was shared with research team members (JE) and revisions were made until consensus was reached. Using this codebook, the first author coded all open-ended responses, recorded memos to help identify and interrelate categories, and recorded analytic decisions as a type of audit trail [20]. To qualitatively compare SGM and non-SGM participant responses, we split the data into two groups, and calculated the frequency of categories and subcategories within each group.

<u>Trust the vow</u>
Sucks to see your partner hurt
Not be able to fix it
Not be able to
Make it better

Her mood
Affects me too
Hardest thing
I've ever done

See somebody you love
Going through
All this
She's my rock

True love
He supported me
Despite the hard patches--
Unbroken

Every day
There for me
Support he gave me
Deep gratitude

Together we're fantastic
See each other for exactly who we are
She knows me better
Then I know myself

Cancer made us stronger
Our bond
Our commitment
No matter what

Always come back
Meet in the middle
Strong
Get through anything together

Yin-yang stuff
Can't leave her
Wouldn't be here without her
Wouldn't have a reason to live

Closer
More aware
In tune
With each other

Deeper level
Connected
Never hurt me,
Leave me

Stronger
Solidified
Just be there for him
We cry

Get each other's moods
I can get through—
I have her
Support

We are a team
Face it together
How do you know when you're in love?
Drain their nasty surgical juice

Stuff that used to bother me
Pick up your towel--
Stupid shit
None of that matters

Hasn't been hard between
The two of us
More challenging
With the outside

Whenever there is a challenge
To us
From outside
We are shoulder to shoulder

Not going to penetrate us
Not going to get between us
We come together
Fight it together

Together,
Bring it on
We'll stand back to back and move in circles
Nobody get us

Is that all you got?
We can handle it
Two tough old broads
We can handle it.

No matter how bad
I look back
After cancer
We can do this

Trust
the vow
Til' one of you
Dies

Fig. 2. The found poem.

Table 1
Primary and related emotions assessed.

Primary emotion	Related emotions
Anger	Fury, outrage, wrath, irritability, hostility or resentment
sadness	grief, sorrow, gloom, melancholy, despair, loneliness, or depression
Fear	anxiety, apprehension, nervousness, dread, fright or panic
Joy	enjoyment, happiness, relief, bliss, delight, pride, thrill, or ecstasy
Interest	acceptance, friendliness, trust, kindness, affection, love, or devotion
Surprise	shock, astonishment, amazement, astound, or wonder
Disgust	contempt, disdain, score, aversion, distaste, or revulsion
Shame	guilt, embarrassment, chagrin, remorse, regret, or contrition

3. Results

3.1. Fixed-choice survey responses

3.1.1. Demographics

Twenty participants completed demographic and health questionnaires and were randomized ($N = 20$) to receive the found poem as follows: $n = 7$ (35.0%) read the word document, $n = 3$ (15.0%) listened to the audio recording, $n = 4$ (20.0%) listened to the audio recording while reading the word document, and $n = 5$ (25.0%) watched the video. Of 20 participants, two (10.0%) did not complete the emotion or dissemination preferences questionnaires.

Over half of the participants self-identified as women ($n = 11$, 55.0%) and half ($n = 10$) belonged to an SGM group. Participants were on average 57.4 years (SD = 14.8, $R = 27$–78) and had been in their relationship for an average of 26.3 (SD = 18.3, $R = 5$–53) years. Fourteen (70.0%) participants were patients and 6 (30.0%) were partner caregivers. Patients reported advanced cancer (stage III or IV) ($n = 6$, 30.0%), early-stage cancer (stage I or II) ($n = 5$, 25.0%), or did not know their cancer staging ($n = 3$, 15.0%) (see Table 2 for sample demographics).

3.1.2. Emotions experienced

Participants who read the text or listened to the audio recording while reading the text reported a total of 13 emotions, respectively. Solely listening to the audio recording of the found poem elicited three emotions, and the video elicited four emotions. Across all dissemination methods, interest was the emotion most commonly reported ($n = 11$), followed by sadness ($n = 8$), and joy ($n = 6$) (see Table 3).

3.1.3. Dissemination preferences

Participants reported strongly liking (n = 6, 33.3%), somewhat liking (n = 4, 22.2%), feeling neutral (n = 7, 38.9%), somewhat disliking (n = 2, 11.1%), and strongly disliking (n = 1, 5.5%) the dissemination method to which they were randomized. The majority of participants (n = 15, 75.0%) preferred the format of the poem they received. While none of the non-SGM participants preferred a different format, three SGM participants (30.0% of SGM participants) reported preferring text only (n = 2) or text and audio (n = 1) (see Table 4 for dissemination preferences displayed by SGM status).

3.2. Open-ended responses

Four categories and 12 subcategories were identified in participants' ($n = 9$ SGM and $n = 17$ non-SGM) responses to open-ended questions (see 2.3.1): dyadic experiences (support, strength, depth, durability); dissemination preferences (timing, method); emotions (positive, negative); utility of the found poem (affirming; not useful or inaccurate; fostering reflection; and sense of community). Table 5 provides a modified ecological sentence synthesis to enhance the accessibility and usability of findings [38,39].

Table 2
Sample demographic characteristics.

Variables		SGM (n = 10)	Non-SGM (n = 10)	Total (N = 20)
Age	M (SD), Range	46.4 (9.20), 27–54	68.5 (10.4), 43–78	57.4 (14.8), 27–78
Ethnicity	Hispanic/Latino	n = 1 (10.0%)	–	n = 1 (5.0%)
	Non-Hispanic/Latino	n = 9 (90.0%)	n = 10 (100%)	n = 19 (95.0%)
Race	American Indian/Alaska Native	n = 1 (10.0%)	–	n = 1 (5.0)%
	White	n = 9 (90.0%)	n = 10 (100%)	n = 19 (95.0%)
	Other	n = 1 (10.0%)	–	n = 1 (5.0%)
Gender	Woman	n = 7 (70.0%)	n = 4 (40.0%)	n = 11 (55.0%)
	Man	n = 2 (20.0%)	n = 6 (60.0%)	n = 8 (40.0%)
	Non-binary	n = 1 (10.0%)	–	n = 1 (5.0%)
Biological sex	Female	n = 9 (90.0%)	n = 4 (40.0%)	n = 13 (65.0%)
	Male	n = 1 (10.0%)	n = 6 (60.0%)	n = 7 (35.0%)
Sexual orientation	Lesbian or gay	n = 6 (60.0%)	–	n = 6 (30.0%)
	Straight	–	n = 10 (100.0%)	n = 10 (50.0%)
	Bisexual	n = 3 (30.0%)	–	n = 3 (15.0%)
	No orientation	n = 1 (10.0%)	–	n = 1 (5.0%)
Education	High school graduate/GED	–	–	–
	Some college/technical	–	n = 4 (40.0%)	n = 4 (20.0%)
	College graduate	n = 1 (10.0%)	n = 4 (40.0%)	n = 5 (25.0%)
	Post-graduate/professional degree	n = 8 (80.0%)	n = 2 (20.0%)	n = 10 (50.0%)
	Missing	n = 1 (10.0%)	–	n = 1 (5.0%)
Income	Less than $25,000	–	n = 1 (10.0%)	n = 1 (5.0%)
	$25,000–$34,999	–	n = 1 (10.0%)	n = 1 (5.0%)
	$34,999–$49,000	n = 2 (20.0%)	n = 2 (20.0%)	n = 4 (20.0%)
	$50,000–$74,999	n = 3 (30.0%)	n = 2 (20.0%)	n = 5 (25.0%)
	$75,000 or above	n = 5 (50.0%)	n = 4 (40.0%)	n = 9 (45.0%)
Relationship status	Single	–	n = 1 (10.0%)	n = 1 (5.0%)
	Married	n = 10 (100.0%)	n = 8 (80.0%)	n = 18 (90.0%)
	Civil union/partnership	–	n = 1 (10.0%)	n = 1 (5.0%)
Years together	M (SD), Range	12.7 (5.8), 5–21	41.3 (15.1),8–53	26.3 (18.3), 5–53
Mental health dx	Anxiety	n = 7 (70.0%)	n = 4 (40.0%)	n = 11 (55.0%)
	Depression	n = 6 (60.0%)	n = 5 (50.0%)	n = 11 (55.0%)
	Bipolar	–	–	–
	Schizophrenia	–	–	–
	Other dx	n = 1 (10.0%)	–	n = 1 (5.0%)
	No mental health dx	n = 3 (30.0%)	n = 4 (40.0%)	n = 7 (35.0%)
History of cancer		n = 8 (80.0%)	n = 7 (70.0%)	n = 15 (75.0%)

(continued on next page)

Table 2 (*continued*)

Variables		SGM (n = 10)	Non-SGM (n = 10)	Total (N = 20)
Current cancer		n = 1 (10.0%)	n = 3 (30.0%)	n = 4 (20.0%)
Role in parent study	Patient	n = 8 (80.0%)	n = 6 (60.0%)	n = 14 (70.0%)
	Partner caregiver	n = 2 (20.0%)	n = 4 (40.0%)	n = 6 (30.0%)
Cancer patient characteristics		n = 8	n = 6	n = 14
Cancer type	Breast	n = 3 (37.5%)	n = 1 (16.7%)	n = 4 (28.6%)
	Prostate	–	n = 2 (33.3%)	n = 2 (14.3%)
	Hematologic	n = 1 (12.5%)	–	n = 1 (7.1%)
	Gastrointestinal	n = 1 (12.5%)	–	n = 1 (7.1%)
	Skin	–	n = 1 (16.7%)	n = 1 (7.1%)
	Head/neck	n = 1 (12.5%)	–	n = 1 (7.1%)
	Other	n = 2 (25.0%)	n = 2 (33.3%)	n = 4 (28.6%)
Cancer stage	Stage I	n = 2 (25.0%)	–	n = 2 (14.3%)
	Stage II	n = 3 (37.5%)	–	n = 3 (21.4%)
	Stage III	n = 2 (25.0%)	n = 1 (16.7%)	n = 3 (21.4%)
	Stage IV	–	n = 3 (50.0%)	n = 3 (21.4%)
	Don't know	n = 1 (12.5%)	n = 2 (33.3%)	n = 3 (21.4%)
Cancer prognosis	More than 12 months	n = 6 (75.0%)	n = 1 (16.7%)	n = 7 (50.0%)
	Don't know	n = 2 (25.0%)	n = 5 (83.3%)	n = 7 (50.0%)

Table 3
Emotions reported per randomization group.

Emotions	Text only (n = 7)	Audio only (n = 3)	Text & audio (n = 8)	(n = 0)	Total (N = 18)
Anger	–	–	1	–	1
Sadness	3	–	4	–	7
Fear	2	–	1	–	3
Joy	2	1	3	–	6
Interest	5	2	2	–	9
Surprise	–	–	2	–	2
Disgust	–	–	–	–	0
Shame	1	–	–	–	1
Total # emotions felt using this format	13	3	13	0	

3.2.1. Dyadic experiences

3.2.1.1. Support. Support, the first subcategory within dyadic experiences, involved participants feeling grateful for the help, assistance, aid, encouragement, or reliability of their partners: " [It] made me realize that I'm not the only one who appreciates how much I rely on my spouse for support," (patient, non-SGM). Participants also felt grateful that others had similar support within their dyads: "It's nice to hear that others are in a supportive situation," (patient, SGM). Participants described partners' support as being present "ever since the diagnosis," (patient, non-SGM) with one participant reporting their partner had been "stepping up and helping navigate the ups and downs," (patient, non-SGM).

3.2.1.2. Strength. Strength, the second subcategory within dyadic experiences, reflected the fact that participants' relationships were solid

Table 4
Differences in frequency of SGM versus non-SGM participant categories and subcategories.

Category/subcategory	SGM (n = 10)	Non-SGM (n = 8)
Emotion		
-Positive	6	2
-Negative	3	2
Dyadic experiences		
-Support	2	2
-Strength	1	1
-Depth	1	1
-Durability	2	1
Dissemination preferences		
-Timing	1	1
-Method	1	–
Utility of the found poem		
-Affirming	6	3
-Not useful or inaccurate	7	5
-Fostering reflection	2	1
-Sense of Community	5	2

even before the cancer experience: "I am strong in my relationship, and it didn't change that," (patient, SGM). Participants also described how cancer fortified their relationships: "The poem didn't really change the way I see my relationship - but just reiterated the fact that I have a stronger relationship because of cancer/the experience of cancer," (partner, non-SGM). Participants described their dyadic relationships as gaining power or stability throughout the cancer journey and that they were stronger as a unit than as individuals: "We are stronger together," (patient, SGM).

3.2.1.3. Depth. Depth was described as a greater sense of connection, closeness, emotional vulnerability, or mutual understanding in the dyad: "I think it very much reflected the depth of love and closeness we felt after experiencing such an intense thing as cancer," (patient, SGM). The level of depth within dyadic relationships was also described by participants as being greater than it had ever been before the experience of cancer: "We are closer now than ever," (patient, non-SGM).

3.2.1.4. Durability. Durability, the final subcategory within dyadic experiences, involved participants discussing how the poem reflected the longevity of their relationships or the ability of their relationships to withstand anything: "It [the poem] was about commitment no matter what, which we have, so it did reflect our experience," (patient, SGM). Another participant said, "I have a strong, loving, ride-to-die wife!" (patient, SGM). Participants also described how cancer helped solidify the durability of their relationships and the fact that their partner would always be there for them: "We've had our ups and downs over the years. Ever since the diagnosis he's been there," (patient, non-SGM).

3.2.2. Dissemination preferences: Timing and method

Participants' responses highlighted the fact that timing is an important consideration when returning results to study participants: "All this other stuff from the poem was before the complications of treatment escalated," (partner, non-SGM). Reflecting on how they wished they had received the poem earlier in their cancer journey, one participant wrote, "I think it would have been valuable for me to hear [the poem] in those earliest and darkest days after my diagnoses," (patient, non-SGM). Similarly, a participant felt uneasy receiving the poem while currently facing cancer: "I had extremely mixed emotions reading it being a young person (mid 30s) and having a diagnosis of cancer that is unresolved," (patient, SGM). One participant also commented on the dissemination method to which they were randomized, saying, "I think it would have been nice to hear the poem as well but I did like seeing it. You can go back and reread that way," (patient, SGM).

Table 5
Modified Ecological Sentence Structure of Study Findings.

Participant	in this role	in persons of this gender	with this SGM status	faced with this stage of cancer	responded within these categories	regarding the
1	Patient	Female	SGM	Stage II	Utility – not useful or inaccurate	Poem content reflecting their dyadic coping/ Poem describing dyadic relationship
5	Partner caregiver	Female	Non-SGM	Stage IV	Utility – not useful or inaccurate	Poem content reflecting their dyadic coping/
					Emotion – negative	Experience receiving poem
					Utility – affirming	Poem content reflecting their dyadic coping /Poem describing dyadic relationship
					Utility – fostering reflection	Poem describing dyadic relationship
					Dissemination preferences – timing	Poem describing dyadic relationship
						Poem describing dyadic relationship/Experience receiving poem
6	Patient	Female	SGM	Stage III	Dyadic experiences – strength	Poem content reflecting their dyadic coping/ Poem describing dyadic relationship
					Utility – affirming	
					Utility – sense of community	Poem content reflecting their dyadic coping/ Poem describing dyadic relationship
					Emotion – positive	Experience receiving poem
						Experience receiving poem
9	Patient	Male	Non-SGM	Stage IV	Utility – affirming	Poem content reflecting their dyadic coping
					Utility – sense of community	Poem content reflecting their dyadic coping
					Dyadic experiences – support	Poem describing dyadic relationship/Poem describing dyadic relationship
					Dyadic experiences – depth	
					Dissemination preferences – timing	Poem describing dyadic relationship/Poem describing dyadic relationship
					Emotion – positive	Experience receiving poem
					Utility – fostering reflection	Poem describing dyadic relationship
						Poem describing dyadic relationship
15	Patient	Male	Non-SGM	unknown	Utility – not useful or inaccurate	Poem content reflecting their dyadic coping
						Poem describing dyadic relationship
						Experience receiving poem
16	Partner caregiver	Female	Non-SGM	Stage IV	Utility – fostering reflection	Poem content reflecting their dyadic coping
					Dyadic experiences – strength	Poem content reflecting their dyadic coping/Poem describing dyadic relationship
					Utility – sense of community	Poem content reflecting their dyadic coping/Poem describing dyadic relationship
					Utility – affirming	Poem content reflecting their dyadic coping/Poem describing dyadic relationship
17	Partner caregiver	Male	SGM	Stage II	Utility – not useful or inaccurate	Poem content reflecting their dyadic coping/Poem describing dyadic relationship/Experience receiving poem
					Emotion – negative	
						Experience receiving poem
18	Patient	Female	SGM	Stage II	Utility – affirming	Poem content reflecting their dyadic coping
					Dyadic experiences – support	Poem content reflecting their dyadic coping
					Utility – fostering reflection	Poem describing dyadic relationship
					Emotion – negative	Poem describing dyadic relationship
					Utility – sense of community	Experience receiving poem
					Emotion – positive	Experience receiving poem
20	Patient	Female	SGM	Stage III	Utility – affirming	Poem content reflecting their dyadic coping
					Dyadic experiences – durability	Poem content reflecting their dyadic coping
					Utility – sense of community	Poem describing dyadic relationship
22	Patient	Male	SGM	unknown	Dyadic experiences – depth	Poem content reflecting their dyadic coping
					Utility – affirming	Poem content reflecting their dyadic coping
23	Patient	Female	Non-SGM	Stage IV	Utility – affirming	Poem content reflecting their dyadic coping /Poem describing dyadic relationship
					Dyadic experiences – support	Poem content reflecting their dyadic coping/Poem describing dyadic relationship
					Dyadic experiences – durability	Poem content reflecting their dyadic coping with cancer
					Emotion – positive	Poem content reflecting their dyadic coping with cancer
27	Patient	Female	SGM	Stage I	Utility – affirming	Poem content reflecting their dyadic coping
					Emotion – positive	Poem content reflecting their dyadic coping
					Utility – not useful or inaccurate	Poem describing dyadic relationship
					Dissemination preferences – method	Experience receiving poem
28	Patient	Female	Non-SGM	Stage III	Utility – affirming	Poem content reflecting their dyadic coping
					Utility – fostering reflection	Poem describing dyadic relationship
29	Patient	Male	Non-SGM	unknown	Utility – not useful or inaccurate	Poem content reflecting their dyadic coping/Poem describing dyadic relationship
						Experience receiving poem
31	Patient	Female	SGM	Stage II	Utility – affirming	Poem content reflecting their dyadic coping
					Emotion – positive	Poem content reflecting their dyadic coping/Poem describing dyadic relationship
					Utility – fostering reflection	
					Utility – sense of community	Poem describing dyadic relationship
					Dissemination preferences – timing	Poem describing dyadic relationship
					Emotion – negative	

Table 5 (*continued*)

Participant	in this role	in persons of this gender	with this SGM status	faced with this stage of cancer	responded within these categories	regarding the
						Experience receiving poem
						Experience receiving poem
33	Patient	Female	SGM	Stage I	Utility – affirming	Poem content reflecting their dyadic coping/Poem describing dyadic relationship
					Dyadic experiences – durability	Poem content reflecting their dyadic coping
					Utility – sense of community	Experience receiving poem
					Dyadic experiences – support	Experience receiving poem
					Emotion – positive	Poem describing dyadic relationship/Experience receiving poem

3.2.3. Emotions: Positive and negative

Participants voiced positive emotions (including pride, love, gratefulness, and appreciation) in response to the poem and their relationships. Reporting on the found poem, one participant stated, "I loved the last paragraph," (patient, SGM). In regards to their partner, a participant said: "I am grateful and blessed to know I have her in my life," (patient, SGM). Another stated, "I'm very proud of my husband," (patient, non-SGM). Humor was also present: "I laughed at the line about "surgical juice" as my wife had to empty my drains with each surgery. We would laugh every time she emptied them about how sexy it was," (patient, SGM).

Some participants bridged positive and negative emotions in the same open-text response: "There is incredible grief and joy all at the same time," (patient, SGM). Another participant described holding both positive and negative emotions simultaneously: "Although it brought me sad memories and the feeling of being overwhelmed from the unknown, the reminder of [that] challenging time in my life it reminded me of the beautiful people that surround me. That even though I felt sad, scared, and lost I wasn't the only one going through this," (patient, SGM).

Negative emotions about the poem included "disinterest and/or boredom," (partner, SGM). Other negative emotions were specifically attributed to the cancer experience: "I feel trapped. I'm tired and want to be free of the responsibility and live for ME not always someone else." This same participant also alluded to negative emotions experienced by both members of the dyad: "I have NO idea why my husband whines about his quality of life and fights like hell to stay alive while complaining about "being over it". He's not [the] only one, that's for sure," (partner, non-SGM).

3.2.4. Utility of the found poem

3.2.4.1. Affirming.
For many participants, the found poem confirmed or upheld their experiences with their partner while facing cancer: "Much of it reflected my experience with my husband," (patient, non-SGM). Participants felt that the excerpts chosen for the poem were ones that were easy to identify with: "I think we can identify with all the quotes," (patient, non-SGM). For another participant, the found poem "showed the way we felt," (partner, non-SGM).

3.2.4.2. Fostering reflection.
Participant responses also demonstrated that the found poem fostered internal consideration, thinking, or contemplation about their relationship or the experience of facing cancer: "Perhaps it made me think back on our experience together of my cancer," (patient, non-SGM). The poem even prompted one participant to want a discussion with their partner: "Some people seem to worry less about little things. It makes me wonder if we need to discuss perceptions we have," (patient, SGM). Another participant stated that the poem was able to "help me recall when I felt some of those thoughts," (partner, non-SGM).

3.2.4.3. Not useful or inaccurate.
Some participants stated that the poem did not affect them in any way: "[The poem] meant nothing to me," (patient, non-SGM). Other participants reported that the poem

wasn't helpful: "This is not useful for me personally," (partner, SGM). A partner caregiver questioned why the poem was being shared with participants: "Not sure what you hoped to get by us hearing/reading the poem," (partner, non-SGM). Other experiences within this category include instances in which participants felt that the poem did not accurately depict their experiences. When asked how the poem did or did not reflect their experiences coping with cancer as a couple, one participant said, "It's just not true," (partner non-SGM).

3.2.4.4. Sense of community.
The final subcategory within the utility of the found poem illustrated how participants felt the poem encapsulated a sense of community or a feeling of not being alone. This category was specific to experiences feeling connected to people outside of their dyadic relationship: "Even though I felt sad, scared, and lost I wasn't the only one going through this," (patient, SGM). Participants reported that the poem, "Affirmed common humanity," (patient, SGM). Participants also expressed their appreciation for the poem, saying, "I appreciate this. I feel like I'm a part of it. It brought tears to my eyes in a good way," (patient, SGM).

3.2.5. Qualitative differences between SGM and non-SGM participant responses

The frequency of the following subcategories across SGM and non-SGM participant responses was identical or within one frequency count: negative emotion, fostering reflection, depth, support, strength, durability, and dissemination timing and method. The greatest difference in subcategory frequency between SGM and non-SGM participant responses was noted in positive emotions, with six instances among SGM participants compared to two instances among non-SGM participants. Affirming and sense of community differed by a frequency of three each (6 SGM vs. 3 non-SGM and 5 SGM versus 2 non-SGM, respectively). Not useful or inaccurate, was identified seven times among SGM participants and five times among non-SGM participants.

4. Discussion and conclusion

4.1. Discussion

Creating, disseminating, and assessing the experience of receiving found poetry provided insight into how patients and partners facing all stages of cancer prefer to receive study findings. While most participants liked the format of the poem they received ($n = 15$, 75.0%), the responses of those who preferred another format ($n = 3$, 15.0%) can illuminate how participants want to receive information. The fact that only SGM participants preferred to receive the poem in an alternate format may speak to their natural inclination to question the status quo [40]. Two of these participants stated that they would have preferred to receive text only which could allow participants to create their own interpretations and hear their own voice, whereas audio and video formats may not resonate with participants. These results align with findings that written aggregate study results were found to be understandable and important by mothers of child study participants [41]. However, these results contradict other studies which found that

participants felt written communication was either too complex or too simplistic [42]. Researchers may have greater engagement and interest if they offer participants a choice in how they receive study results. Offering this choice to SGM participants could also give more autonomy and control to this historically minoritized population. Future research into study participants' preferred methods of receiving study results (as well as larger sample sizes among diverse participant populations and contexts) would help clarify inconsistent findings across studies and populations [43].

Researchers could also consider the timing of dissemination. One participant's response demonstrates that attitudes and emotions can change over the treatment trajectory. For this participant, the poem reflected their past experiences but was no longer representative of their current situation. Another participant mentioned that receiving the poem closer to their diagnosis may have helped give them hope at a time when they felt hopeless. These responses demonstrate that the timing of dissemination is an important factor when returning results to study participants. In the context of serious illness, researchers should consider how results might be received at varying points in the illness trajectory.

Both fixed-choice and open-ended questions demonstrated that emotions can be evoked through the use of creative methods such as found poetry. Interest (which included the secondary emotions of acceptance, friendliness, trust, kindness, affection, love, or devotion) was the most commonly reported emotion experienced by participants receiving the found poem, which aligns with the fact that positive emotions were more frequent than negative emotions in the open-ended responses. Taken together, our findings demonstrate that returning results to participants in the form of a found poem can garner interest, engagement in research, and other positive emotions. These findings are consistent with a review article by Shalowitz and Miller (2008) which found that 75% of studies empirically assessing the impact of receiving study results found psychological benefits for participants including satisfaction and pleasure [43]. These findings also speak to the possibility that returning research results to participants may increase trust in researchers and science/academia [4].

The qualitative differences between SGM and non-SGM participants may suggest that the found poem—while absent of language or content specifically related to sexual orientation or gender identity—more closely mirrored SGM participants' experiences facing cancer as a couple, elicited a greater number of positive emotions, and a greater sense of community. These findings speak to the fact that the poem was developed from SGM couples' transcripts and may point to the resilience of SGM communities, a finding from the original study [17,44]. However, all categories and subcategories were more frequently identified in the responses of SGM participants, possibly because more SGM participants completed the open-ended questions than non-SGM participants ($n = 10$ vs. $n = 8$).

Future research could examine differences in dissemination preferences between SGM and non-SGM populations, as well as differences in emotions reported by participants receiving found poetry versus traditional scientific manuscripts. Furthermore, there is a need for randomized controlled trials that prospectively assign participants to different dissemination methods and ascertain participant understanding, engagement with the findings, emotions, and trust in researchers/science.

4.1.1. Limitations

This study was limited by a small sample size. The number of participants randomized to each group and in SGM versus non-SGM groups was not large enough to make definitive comparisons. In addition, the majority of participants in this study were white (95.0%), female (55.0%), and married (90.0%), and therefore findings may not be generalizable beyond similar groups. The found poem was developed from the transcripts of interviews with SGM couples only; However, the poem was disseminated to both SGM and non-SGM couples to obtain a larger sample size. Despite these limitations, this study provided an innovative method of disseminating results to past study participants. Knowledge from this study can help researchers develop dissemination methods that best meet the preferences of their study participants and can encourage future research participation.

4.2. Innovation

The research presented in this article is innovative in multiple specific ways. The use of found poetry as a means to reorganize and present interview data is uncommon. To our knowledge, there are also no best practices for disseminating found poetry to study participants, which is an important avenue of investigation for future studies. This article provides critical information that can help investigators return results in a manner that is more accessible and meaningful to past study participants. Finally, the found poem was created solely from the dyadic interview transcripts of SGM couples, a population that has been historically marginalized and underserved in research.

4.3. Conclusion

The use of creative methods for disseminating findings to study participants has the potential to engage participants and encourage reflection and emotional processing. Creative methods may: be more accessible for participants, center their voices, and affirm their experiences. They may also honor the contributions of participants who (in hospice, palliative care, or in the context of serious illness) are willing to give their time and share what are often complicated and emotionally charged experiences. In community-based research and research with seriously ill patients and their families, investigators should allow participants to choose if, how, and when they wish to receive research results. Ultimately, when researchers share findings with study participants, they are engaging the interest of these community members and building trust, paving the road for future scientific collaborations, and contributing to research that may improve pain, suffering, and quality of life for patients and their families.

CRediT authorship contribution statement

Sara G. Bybee: Writing – review & editing, Writing – original draft, Project administration, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Jacqueline Eaton:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization. **Bob Wong:** Writing – review & editing, Supervision, Software, Resources, Project administration, Methodology, Investigation, Data curation.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Sara Bybee reports financial support was provided by National Center for Advancing Translational Sciences. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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