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Capturing the Experience: Reflections of Women with Breast Cancer Engaged in an Expressive Writing Intervention

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Abstract

Background—Expressive writing has been shown to improve quality of life, fatigue, and post-traumatic stress among breast cancer patients across cultures. Understanding how and why the method may be beneficial to patients can increase awareness of the psychosocial impact of breast cancer and enhance interventional work within this population. Qualitative research on experiential aspects of interventions may inform the theoretical understanding, and generate hypotheses for future studies.

Aim—To explore and describe the experience and feasibility of expressive writing among women with breast cancer following mastectomy and immediate or delayed reconstructive surgery.

Methods—Seven participants enrolled to undertake 4 episodes of expressive writing at home, with semi-structured interviews conducted afterwards and analyzed using experiential thematic analysis.

Results—Three themes emerged through analysis: writing as process, writing as therapeutic, and writing as a means to help others.

Implications for practice—This study augments existing evidence to support the appropriateness of expressive writing as an intervention after a breast cancer diagnosis. Further studies should evaluate its feasibility at different time points in survivorship.

Conclusions—Findings illuminate experiential variations in expressive writing and how storytelling encourages a release of cognitive and emotional strains, surrendering these to reside in the text. The method was said to process feelings and capture experiences tied to a new and overwhelming illness situation, as *impressions* became *expressions* through writing. Expressive writing, therefore, is a valuable tool for health care providers to introduce into the plan of care for patients with breast cancer, and potentially other cancer patient groups.

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The American Cancer Society estimates that 231 850 new cases of invasive breast cancer and 60 290 new cases of in situ disease will be diagnosed in 2015 in the United States.¹ The World Health Organization notes that breast cancer is the most common cancer diagnosis in women worldwide, accounting for more than a half-million deaths per year. Survival rates range from 40% in low-income countries to more than 80% in North America, Sweden and Japan.² Mastectomy, particularly contralateral prophylactic mastectomy, is an increasing treatment choice, especially among young American women with breast cancer diagnoses.³ For a woman, the meaning of her embodied breasts can be complex and personal, whilst breasts also carry significance in social relations and cultural contexts.⁴ With so many women living with breast cancer and undergoing broad surgical interventions, developing tailored interventions to support patients through and beyond their treatment trajectories is pivotal to providing psychosocial support and improving wellbeing.

Expressive writing has been shown to affect bio-psychosocial health factors across clinical and non-clinical populations,⁵ with varying efficacy for breast cancer patients of different treatment stages and disease progression.⁶⁻¹² Despite the breadth of studies on the impact of expressive writing for this patient group, little has been published on its experiential aspects through qualitative empirical inquiry, which seeks to investigate lived phenomena as constructions of personal meaning in context. Insight into individuals' experiences of psychosocial interventions is critical to ensure thoughtfully developed implementations. This is essential, in light of appropriately enhanced attention to patient experience, preferences, and values, meriting integrated evidence-based practice.¹³ Hence, the purpose of this study was to explore and describe the experience and feasibility of expressive writing for women with breast cancer, following mastectomy/reconstructive surgery. We present findings from interviews conducted as part of a larger longitudinal study, described below.

"I am not the same" is an interdisciplinary research project seeking detailed knowledge about women's experiences of breast cancer, loss of breast and reconstruction, in psychosocial and cultural contexts. Affiliations with an international cancer research network enabled researchers to design and execute a trans-national study, enrolling participants in the US and Norway. The aim of the project is three-fold: a) to explore the experience of women engaged in a writing intervention following mastectomy; b) to investigate women's experiences with breast cancer following mastectomy and then 1-year after surgery; and c) to conduct comparative data analyses. Data presented here were provided by women treated at a cancer center in the United States, who were engaged in the research in 2012 and 2013.

Background

Expressive writing is a therapeutic method developed by James W. Pennebaker¹⁴ and designed to aid with working through traumatic life experiences. Several studies have shown that the method can be advantageous for patient groups and healthy populations with a variety of cultural backgrounds.^{9, 15-19} Expressive writing has been shown to reduce the frequency of physicians' visits, and have beneficial effects on somatic factors, such as wound healing,²⁰ blood pressure,¹⁵ lung and immune functions, as well as reducing symptoms, like pain.^{16, 19-21} Expressive writing has been demonstrated to contribute to

improved physical quality of life in cancer patients.²² Studies involving expressive writing among women with breast cancer have tended to rely on self-report instruments with results ranging from no significant effects on health outcomes to short- and longer-term health outcomes across largely randomized and/or controlled studies.^{6, 8, 9} Stanton et al. found that writing led to a significant decrease in medical visits for cancer-related illness at the 3-month follow-up with participants reporting beneficial effects on their quality of life, fatigue, post-traumatic stress, and negative thought patterns.²³ Two more recent trials (2013) have confirmed these findings, showing that the intervention test groups experienced significantly improved quality of life outcomes,¹¹ and fewer symptoms of depression and higher levels of positive mood at the 3-month follow-up.⁸

Methods

Design

Data presented in this article were collected as part of a longitudinal study with a descriptive and comparative design.^{24,25} In this parent project, a total of 7 American and 14 Norwegian women diagnosed with breast cancer participated in exploratory semi-structured interviews²⁶ at baseline following primary or reconstructive surgery and at 1-year following the initial interview. Data were collected through participant texts and semi-structured interviews at the 2 study time points, allowing for triangulation. Interview questions regarding the expressive writing intervention were primarily explored at the first study time point and are presented here. The project's eclectic design is informed by a psychosocial research paradigm,²⁵ whereby human subjectivity and experience are understood to involve dynamic relations between the inner world (the psychic) and the outer world (the social, societal and cultural). Psychosocial research is methodologically diverse, but converges on an appreciation for psychoanalytic concepts, and on the recognition of knowledge production as a situated, reflective and reflexive collaboration between researchers and participants.

Sample and Setting

The US study component (n=7) was conducted in the Plastic Surgery Department of a National Cancer Institute–designated comprehensive cancer center in the southwestern United States. Within this setting, approximately 1000 reconstructive surgeries following cancer-related mastectomy are performed annually. The enrollment criteria included women diagnosed with breast cancer and mastectomized, aged 18 and older, who read and wrote English, and were of diverse age and ethnicity. Purposeful sampling was used to enroll patients in the clinic over a 2-week period, following various stages of primary or reconstructive surgery. The last author, in collaboration with a research nurse from the study site, consented and enrolled the participants. The sample size was limited by logistical constraints for the Norwegian research team who were visiting fellows at the US institution.

Data Collection

Approval was obtained from the study setting's Institutional Review Board. The study was explained to potential participants orally and in writing, and written informed consent was obtained. Participants were asked to undertake expressive writing at home, either by hand or

electronically, according to an instruction tailored to breast cancer experiences (Appendix A). Interviews at this first study point took place 3-8 weeks after mastectomy/reconstruction, and 1-2 weeks after participants completed their writing. They were done in person at the treatment facility or by phone when participants were unable to attend because of their post-surgical recovery or geographical distance to the clinic. A loosely structured interview guide was used to explore the women's experiences with the intervention (see Appendix B). To ensure suitability for research purposes, this guide was piloted in Norway and the findings were published.²⁷ The first and last authors, who had designed the study and are both Norwegian, conducted all the interviews. Interviews occurred over 1 to 2 hours, with in-person encounters lasting longer. Interviews were audio-recorded and transcribed verbatim.

Data Analysis

Experiential thematic data analysis was used to explore the data in order to decipher and represent manifest content.²⁸ Analysis began with researchers immersing themselves in the transcribed interviews, in an initial 'naïve' reading, where one strives to put preconceptions to the back of the mind and create a fresh impression of the initial interview context and the particular participant. A structural reading condensed the text and identified meaningful units by drawing out relevant sections of the interview data related to the research question, which were then used to generate descriptive codes. The Norwegian and American research teams triangulated the analysis process by working independently when developing codes and themes, returning to the transcripts to ensure correspondence as part of the hermeneutic reading, oscillating between the parts and the whole.²⁶ This process ensured integrity in the coding and themes, based on the mutual peer-evaluation of each team's distinct analysis.

In the intervention participants are encouraged to write their innermost thoughts and feeling about serious illness, which are likely to elicit some repressive and defensive responses. A psychoanalytic cast or overtone has therefore been adopted in order to turn analytic attention towards latent psychic content, allowing us take the study beyond the descriptive.²⁴ The engagement of two research teams, one of which had designed the study and conducted the interviews, and the second of which shared the cultural and institutional context of the participants, contributed to a careful assessment of counter-transference. The Norwegian researchers were able to inform the richness of the data with their experiences of engaging with the participants, recalling the impact of circulating affects (e.g. laughter, anger, sadness, empathy) in live conversations. Explorations of these emotional responses in the interviews allowed both research teams to stay in touch with the lived qualities of the transcribed narratives. Reflective notes were made through interviews and analyses to map interactions among researchers, participants, texts and interpretations, thereby further consolidating the trustworthiness of the research process.²⁵

Findings

Of 10 patients approached to enroll, 7 agreed to participate. Three opted out for a) no specific reason; b) difficulties with taking part in the study; and c) acute illness in the family. Six out of 7 participants chose to write electronically. One participant wished to write by hand in a journal, which was collected, transcribed and returned to her. All 7 wrote in their

own homes, at a time of their own choosing, shortly after enrolling in the study. The length of the texts varied from 4 to 9 typed pages (average: 6 pages). Three participants were interviewed in person and 4 were interviewed by phone. Demographics are presented in Table 1. The analysis process condensed findings into 3 main thematic areas: 1) *writing as process: “telling my story”*; 2) *writing as a means to help others*; and 3) *writing as therapeutic*.

Writing as Process: “Telling My Story”

The first theme, *writing as process*, contained content related to the time spent in writing, how participants organized it, and what their responses were to the writing. Within this theme, a subtheme emerged: awareness of readership. This was expressed in participants’ attention to the intervention, as outlined by the investigators, and was reflected in comments including concerns about “what kind of information [the investigators are] after,” “the purpose of the study,” and whether they themselves were “going along the right track” or “going in the right direction.” This focus on writing in a correct manner suggested that, at least initially, participants were concerned about adhering to someone else’s expectations. This was reflected in one participant’s response that the “most difficult part was the start.” Others remarked on how they began by structuring or organizing their writing process: “I sort of thought, ‘Okay, this is how I want to begin’...and just sort of from the beginning when I had first learned [I had breast cancer] to...where I am today”; and “Before I did anything I actually thought about it [for] a couple of days...and so before I wrote I actually thought...about how I was gonna organize the entries...I came up with an approach about how I wanted to do it.” Some of the women said that they went about it as if telling a story: “I did it chronologically and so...I just sort of started telling my story about how I was diagnosed, what the process was, the things that happened to me, how I felt about some of the things.” Another stated, “I wrote kind of a story of just exactly how things happened, and as they happened and how I felt about them.” One participant wrote her story in book form: “I have a chapter in the book called ‘Diagnosis’, and I have one chapter called ‘Surgery’, and I have one that’s called ‘My Support Group’, and on and on. And so those are the things I [wrote] about...once I got started, it was easy...to share a story of how it happened and you know, how I related to it, and just how I felt about it.”

Several participants wrote for longer than suggested in the instruction, with one stating, “I actually sort of got lost in it. I ended up writing more, and I...enjoyed doing that.” Another said, “Normally I don’t write, but because I was at home...I wrote for longer.” Some participants stated specific amounts of time spent in writing: “I usually exceeded...the twenty minutes – I usually went thirty minutes or more,” or “I probably spent at least an hour and a half to two hours writing.”

The emotional response to the writing varied, ranging from unease to feeling comfortable, or even “encouraged and sort of excited.” One participant admitted, “I was nervous...I actually put it off a few days.” Alternately, another participant remarked, “I didn’t find [the writing] daunting. It wasn’t anything that was...a hurdle.” Several of the women seemed engaged and enthused with the writing process, with one participant explaining, “You would find yourself actually wanting to do it...longer than [suggested] because...you know, it was just a

good reflection...time.” Another participant juxtaposed the ease of writing with the difficulty of the content about which she was writing: “The thoughts came easy, easily... sometimes the content was not so easy...but it’s definitely thoughts that...I’ve been thinking.” Interestingly some participants felt committed to keep up the writing, stating how taking part in the study “inspired me to keep going...maybe capturing and making a diary of my everyday experiences cause every day is different.” Reiterating the idea that the process was like telling their story, one participant said she may keep writing “cause I’m not finished yet - I still have another chapter to go.”

Writing as a Means to Help Others

The idea of “telling my story” was also instrumental in informing the second theme of *writing as a means to help others*, which represented the participants’ desire to help others through either their participation in the study or through the writing itself. “Others” referred to women with breast cancer as well a wider audience. This was profoundly articulated by one woman who stated that her husband “felt like it [her writing] was going to be a testimony of sorts, and he said to her, ‘Mama, I just think that people need to hear your story.’” One woman said, “I think I’m probably going to let my family read it, maybe put... what I’ve written into a little book or diary, and have them read it.” Another stated that “some of those things [are] my learnings that I, you know, want to share with friends.” The most prominent expression within this theme was the participants’ desires to help other women with breast cancer. This was mentioned by nearly every participant in comments such as, “I just really wanted to support any kind of studies that will help the...patients.” Participants endorsed expressive writing: “I definitely would recommend that [other women] write about it...cause it was very helpful for me to see it and write about it”; and “I think [writing] would be helpful...for others. Especially if they’re really, really struggling...I think [writing]...can at least help you see your thoughts on paper...and maybe help you deal with them.” There was a shared recognition amongst several participants that their personal writings could be of value to others: “if anyone else is diagnosed of course and need me to talk to them about the breast cancer, maybe it’s something I can share with them. If I can pass that along to someone else, if I can be helpful to them, then I think that would be great.” Others stated, “So I sort of like the idea that this will be somewhat documented and my thoughts...maybe it will help somebody else out”; and “If it were released to be read, I would certainly hope it would help people...you know, ladies who had breast [cancer] to get through these times.” This last participant added, “I really tried to make it encouraging...I hoped that...at least some of my words...would touch the heart of everyone that read it.”

Writing as Therapeutic

All participants identified writing as having, in some capacity, therapeutic properties. This theme emerged in content related to adjusting to and processing the cancer experience and making discoveries about that experience or about oneself. Participants reflected that this aspect of the expressive writing could be emotional and, at times, painful, but that it was also often affirming to reflect upon what they had been through, the choices they had made, and how much they had overcome. Within this theme, two subthemes were identified: 3a) *the emotional nature of writing*, and 3b) emerging realizations about the experience and self.

The emotional nature of the writing—Participants reflected on writing as an emotional outlet. These responses ranged from stating how the writing “reveal[ed] the ordeal of the cancer experience” to “find[ing] the humor in some of this stuff.” One participant stated, “It’s interesting while I was [writing], you know I, it wasn’t a hard cry, it was just tears... coming down my face so I thought that was...sort of interesting—it surprised me quite frankly.” Others said, “It was very helpful to put it on paper cause you start writing and you think, ‘Wow, I didn’t even realize that’s what I was feeling’ until you start writing it. And there were many times I got emotional and, you know, tears start falling as you realize okay, not until I really thought about it...put it on paper...this is honestly what I’m feeling”; and “I had to address...the emotions I was feeling...you know, writing it down, and it coming up again...stirring up the feelings.”

Several expressed the sense that writing provided an outlet for issues they might not be comfortable expressing to others. One stated, “I put more intimate things in writing than I would tell my family and friends — I could express it on paper but not necessarily to people.” Another said, “It helped me express things I probably wouldn’t tell my family. I’m able to talk to them now.” This participant also reflected that, “It’s easier [reaching out for support] after doing the writing. You realize you should not... *no one* should go through this alone. So after the writing, I was like, ‘OK, I need to talk to someone.’ And this was a total stranger [a woman who had breast cancer], and I called her and just spoke to her on the phone. That’s something I would have never done.” The benefits of writing were reflected in statements such as “writing helped me feel positive and hopeful,” “writing released stress,” “it was “therapeutic to write it,” and “without the writing, I’m not really sure I would [have] come as far mentally and emotionally.” One participant stated, “I felt better about my breast cancer after doing the writing...being able to write made me realize that the whole process was a blessing, and it’s gonna be okay.”

One participant described herself as someone whose “head just goes...twirls...gears just all the time a mile a minute.” She felt that writing represented a meditative and soothing experience: “One of the things that writing does, I think, is that it gives your thoughts a place to be permanently...it’s a way of allowing them to leave you to reside somewhere else...to sort of give it over to something else. It’s not that it’s lost, it’s not that it’s gone, it’s just... you don’t have to contain it all in your head anymore.” She compared writing to prayer: “It’s like they give their problems over to somewhere else in prayer to a higher power...I think writing helps to do the same kind of thing, and it can be religious or not religious.” Another elaborated on this: “I don’t know if it was letting go. It was sort of like, ‘Okay, well that’s really sort of past, so...’ You know...it sort of became...a bittersweet versus bitter [experience], if that makes sense to you.” She used the writing to reflect upon the cancer experience and said: “Down the road, I can look back and go, ‘Yeah, that was a great point in time, and it was a valley that I learned from, and...you know, all is good now.’”

Emerging realizations about the experience and the self—Many participants repeated that realizations about themselves or their cancer experience emerged in the context of the writing. One participant said the writing made her really recollect the humiliations, pain and discomfort resulting from her illness, “All the crap that you have to go through [as a breast cancer patient].” This was reflected by another woman, who stated, “One of the

things I hadn't realized in the process was...I mean I knew I had so much stuff, but I hadn't ever sat down and written it out...and it took me by surprise about how much I had to write. Just like, 'Oh my God I really, I really did all that?'...and I'm not done yet." One participant, who had gone from being told initially she would need a lumpectomy, to eventually requiring a bilateral mastectomy with chemo and radiation, said writing had made her aware of "Just the ...whole ordeal of breast cancer...way frightening and way scary...when it started...I was so caught up in the snowballing of my story." Another participant stated, "I think the writing is a very, very...it's a very good idea, because it, it opens up your mind to what you're going through and it, it makes you realize, makes you understand what is happening to you. You're able to put it on paper that you hadn't expressed before, that was things and actions that I did, I didn't even remember until I started writing." Writing provided affirmation, with one woman stating how it "sort of validate[d] some of my decision process and the fact that, you know, researching, getting second opinions, you know, contacting others...that was all good." Another participant echoed this, saying "[Writing] reaffirmed my decisions...the reasons I had for doing this...the bilateral mastectomy, I wouldn't have changed anything...so it validated me."

As a result of the writing, other realizations emerged about the significance of losing a breast. This was mentioned by one participant who stated, "As I wrote, I realized, you know, for all the decisions I made... 'You know what, it's more about the breast than what I'm giving it credit for'." Another woman mirrored this: "It of course becomes emotional, and you realize that the breast is no longer there and here I am left without a breast. I have a scar that will always remind me of, you know, what I have gone through, having lost a breast... when you're writing about it, you're actually facing the reality that it happened...realizing that you'll wake up and you'll never see that part of your body again." This participant also presented the juxtaposing view that "I realized that you're talking about saving your life, as opposed to something that is...a part of your body, something that you could...if you had to weigh the choices of saving your life then maybe just losing a breast is something that with surgery could probably be restored."

One participant reflected on how the method, *after* completing the writing, triggered new contemplations about her mother's and sister's cancer ordeals, which involved a degree of conscientious introspection: "I didn't understand what [my mother] was going through...she was...like me, I mean a fairly private person...I missed a lot of it...I could have been better for my mother and my sister". This realization led to some discomfort and regrets for the participant in thinking about all the support she had received during her breast cancer treatment but that she herself had been unable to provide for her sister and mother because she was pregnant and lived in a different city at the time. One participant also noted how things were put into perspective: "Writing makes you really think about what you used to think of as important...all of a sudden, it's not that important...I'm not worried about what's going on [at work] at all." Expressive writing allowed for self-affirmative insights: "writing made me realize I am who I am," "writing made me realize I am going to be a survivor," and "I felt better about myself after doing the writing." One woman asserted how: "Writing was a big part of just making me realize...this is empowering me and that I will go somewhere and do something with this experience."

A Divergent Case

In the context of the interviews, a divergent case emerged. This participant had a culturally distinctive background from the other 6. Now living in the US, she grew up in North-East Asia, a biographical backdrop which may have influenced her experience with the method and her responses in the interview. Her reflections provide valuable insights into the psycho-emotional challenges that expressive writing can pose to participants who are newly diagnosed and treated for breast cancer. What set the data provided by this participant apart was the tone with which she described the writing process and family relations. She did not wish to talk openly with her parents about the disease. She stated that the writing “was not easy. It was kinda painful and then I just—I ignore things because I don’t wanna think about it...but then when you write, when I write I just have to actually go back, visit [those] thoughts...think through, and then I can just get done with it.” This was further emphasized as she shared, “I’m good at kinda like ignoring...some of my worries and things...but when I get really down and then write things down...I kinda find myself carried to the, like negative side...and worry more.” Concerning the writing process, she stated that, at first, she had started with the, “‘Oh, I’m lucky...I cannot complain’ kind of idea and it ended up like, ‘Oh, oh my God, I have cancer’.” She recognized that there were aspects of her illness that were difficult to confront, stating that “it’s something there that I know that it’s there, but I just don’t want to face it, or I don’t want to think about it...but I kinda ended up doing it...when I write.” She said, “There’s some uncomfortable thing—not only about that, what’s gonna happen next and then what, but...what has happened ... when they did this test, that test and then, I didn’t realize it until I really [wrote] it down that it really shocked me.” From an emotional perspective, this participant stated that the writing “is scary...because it kinda brings out all those emotions and things that I probably don’t really want...to face.” Unlike other participants who expressed the desire to share their writing with friends or family, this participant stated, “I didn’t tell anyone about the writing.” She added that “[I] try not to tell my mom...a lot about it [because] my mom worries a lot.” When asked whether she regretted the writing she stated, “I see the good side, but at the same time it’s so difficult.” She did note, however, that the process “really kinda narrows down my vague...worries”, and “after writing I kinda know what I specifically worry about...I actually found that...from here...I can...almost write some action items from those.”

Discussion

Results have revealed experiential aspects of expressive writing as a therapeutic intervention and an evaluation of the logistical framework. The findings have also illuminated the relational and communicative aspects evoked by the writing. Participants offered vivid descriptions of writing with someone in mind or wishing for their texts to find an audience whether before, during or after creating their texts. This reader awareness prompts the question of how psychological transference mechanisms²⁵ might play expressive writing, whether this is directed towards imaginary or real audiences. Counter-transference should also be recognized as it emerges through the hopes harbored by researchers who, in their turn, want to do something good for patients. All interventions are likely to be predicated on some such concerns. Our study illustrates how writing, as a communication of both conscious intent and unconscious wishes, made visible participants’ positive psychological

transference to researchers through their wish and desire to provide data that can support the research aim, in other words: to deliver what the researchers were looking for. E.g., several participants asked for confirmation as to whether they had been “going along the right track”, related to approaching writing as homework, as if there were a right and a wrong way to solve the assignment. In studies on expressive writing, reader awareness may be affected by what the participant knows about what will transpire with text (e.g. collected, analyzed, interpreted, published). It is difficult to assess this method’s efficacy outside the framework of explicit or imaginary readership and tacit transferences. We therefore acknowledge these dynamics as a striking presence in our data and interpret this as a meaningful finding per se.

In terms of practical implementation, the participants’ evaluation of the writing process confirmed that the tailored instruction offered an appropriate balance of suggestions and openings to pursue their own thoughts and feelings about life after their breast cancer diagnoses. Individuals may be differently affected by the same diagnosis, and the degree of resilience versus traumatization and emotional strain can vary considerably from one person to another. Serious disease can reactivate or enhance other stresses, traumas or losses in the patient’s life history.²⁹ An estimated 20% of breast cancer patients experience severe long-term psychological distress, which can be compounded by such previous ordeals.^{30, 31} The therapeutic effect of expressive writing may be intensified by reactivation of difficult historical experiences.¹⁹ Therefore, it is important to encourage participants from clinical populations to draw from their entire experiential life archive when writing. This was accommodated for in our study by providing a flexible instruction (see Appendix A) and we also avoided restricting the narrative prompts to ‘write about your illness.’^{15, 19}

Interviews revealed that unsupervised home writing involved time overruns and compositional ordering of texts, contrary to the instruction that was provided, which encouraged participants to focus away from self-censorship or style and to concentrate on really exhausting thoughts and feelings freely within a set timeframe. The use of structuring may reflect a phenomenon illustrated by one participant’s statement that she approached the writing like homework and that some of the women perhaps wished to be good students, going the extra mile. Expressive writing trials have largely been conducted in lab-settings, where participants’ activities can be standardized.¹⁹ A 2006 meta-analysis of expressive writing showed a greater health effect if the experiment takes place in a private room,¹⁶ supporting explorations of different experimental settings. In our study the intervention was tailored to make participants feel as if they had autonomy over when and how they wrote; therefore, they were encouraged to write at home. Participants explained how it was difficult to stop because they became absorbed in the writing, and many indicated that the creative writing process was pleasurable, describing an experience of “transportation into narrative”, in itself thought to be a positive phenomenon.³² Deviation from time frame during home-writing can probably be rebalanced with more meticulously worded instructions, or by cuing participants’ writing by phone.⁸ It was beyond our scope to determine whether participants’ ad hoc adaptations affected therapeutic outcome. However, the literature indicates that time expenditure is not a moderating variable. Expressive writing has been found effective in various configurations (1-5 times, 10-45-minute durations, within 1-4 weeks).¹⁹ Our participants’ descriptions of writing beyond the directed time period may therefore be interpreted to have served rather than impeded the therapeutic process.

Six participants did their writing shortly after having undergone primary surgery and before potential adjuvant treatments, a period associated with significant emotional stress.³³ These women's accounts confirm that writing was felt to be a meaningful activity, even though it took place at a challenging stage in their treatment trajectory, suggesting that the timing of the intervention was appropriate. Walker et al. emphasize the importance of timing in relation to individual treatment schedules, as their findings reported diminutive effect of expressive writing for breast cancer patients who were at the end of adjuvant radiotherapy.³⁴ However, women with breast cancer continue to face psychosocial challenges well beyond the first year after diagnosis.³⁵ Survivors often live with uncertainty about their future, which is exacerbated by the threat of late recurrence. One study participant had been diagnosed 18 months before taking part in the study and was on sick leave recovering from extensive secondary reconstructive surgery. She described finding release through writing, despite the time lag from diagnosis to enrollment, suggesting that the timing of the intervention was appropriate to her needs. During this phase of recovery, some women describe a sense of isolation or "survivor loneliness" as they move out of an acute phase of their illness and take on the symbolic reconstruction of their damaged selves, re-establish relationships with others, and rewrite their identities.³⁶ Findings reflected by this particular participant led to speculations as to whether breast cancer patients could benefit from undertaking expressive writing at 2 intervals: at baseline post-operatively and again one year after primary surgery. The question was whether they could find time to write 1 year after. Time alone to write was deemed to be a luxury by these women, 6 of whom identified themselves strongly as working women, and all 7 of whom described themselves as caring for parents, children, grandchildren, siblings, husbands, or friends.

Significantly, several participants spontaneously described the writing task as telling and sharing their stories. Stories represent a familiar narrative structure and implicitly carry the promise of a comforting resolution to conflict. Stories provide knowledge to be passed around and shared, as opposed to a private journal. Our participants expressed a desire for others to receive their stories, suggesting that they had not previously been told in full or that people around them had not been able to comprehend the personal magnitude of their illness. Arthur Frank notes how serious illness can become "a call for stories" when one loses the map that previously provided orientation in life.^{37(p53)} Telling the story, whether orally or in writing, may serve a reparation and reorientation function. At the time of the interviews, our participants were still very much in process and did not yet know how their stories would end. By the time they had finished their writing, there was still "another chapter to go", as one participant poignantly declared. For some of them, the text became a testimonial or documentation tracing and evidencing their illness experiences, supporting Frank's thesis on the reparative function of writing. For the oldest participant, who wrote by longhand in a journal, her testimonial gained value as a material artifact ("my book"), a memento that can be read and felt by others. This writer dually insists that her cancer ordeal must become part of the family learnings, *and* that she will not be forgotten. Crucially, such a testimonial carries an ethical call: it interpellates readers as empathic witnesses to the author's woes and victories, allowing us to retain lived illness experience in a manner characteristic of the many publicized breast cancer narratives, or what have aptly been named "mammographies."³⁸

Perhaps the choice of genre, the stories or testimonials that were directed towards an audience, enabled these women to see themselves through the autobiographical text as if they were looking in from the outside.¹⁴ One participant stated that the writing made her address her own emotions, suggesting an inner exchange where she was thinking for herself, writing to herself, and feeling for herself with tears dripping in the process, receiving the (previously displaced) suffering self as it emerged in narration on the computer screen. To her and other participants, a lot of difficult things had happened within a short space of time. Writing provided an opportunity for them to explore abandoned feelings attached to an uncontrollable acceleration of unplanned events. For some, there was a reverse process from affect to cognition, where writing appears to have afforded a representational bridge between an emotionally disheveled self caught in the snowballing of cancer treatment to a more contained self that can be thought, thereby allowing for “a transference to the self as object” to take place through the narration of the chain of events.^{39 (p61)} Taking this step out of the suffering (feeling) self and into the writing (thinking) self meant that participants were able to affirm decisions made earlier in their treatment trajectories. Perhaps this is the power of expressive writing – through transportation into narrative and telling the story, participants were able to give meaning to their experiences of being hit by an incomprehensible illness over which they have no control.^{29, 37} Telling the story stages a metaphorical and concrete interplay between creativity as a good production against the bad destruction of breast cancer illness reality.⁴⁰

Our findings indicate that participants experienced writing as a means to capture and articulate the many painful and overwhelming aspects of life after breast cancer. They describe an absorbing process of coming to know or feel themselves better or differently through illness and writing in tandem. This description mirrors a previous study, in which both illness and writing were reported to facilitate transformative or existential learning for cancer patients.²³ “Realization”, “reality” and “real” were recurrent terms deployed when participants described their writing experience. Illness experiences became *more real than before* and several participants had not previously *fully realized* what their feelings were. Writing allowed some to explore this previously suspended or unrealized register of feelings, including mourning of the loss of the breast/s, and of dealing with the scar, which was a constant reminder of the loss and therefore a double stigma marking a wound *and* an absence. For example, one participant described the cost of losing a breast, which only became fully realized through writing (“it of course becomes emotional...I am left without a breast”) and then proceeded to bring up a calculation (“if you had to weigh the choices”): life can be saved and the breast “probably” restored surgically. Through this understandably defensive shift, her emotional reactions to corporeal loss and threat of death could be contained by a more meaningful reason, and counterbalanced or compensated for, by adopting the rationalizing logic of a more emotionally detached medical discourse.²⁵

Despite going through difficult motions and adaptations, participants indicated that they hoped their ordeals might be turned into something significant. *Writing as a means to help others* reflects an altruistic motivation to take part in the study for the benefit of future patients, echoed in the wish to share personal stories with others, so that their private trials can be of some greater good for those who come after. Participants suggested that, through writing, they were performing for an imagined readership of breast cancer women,

suggesting a wish to contribute to peer-support, or a ‘cancer apprenticeship,’ in which the newly diagnosed woman (novice patient) can seek out and benefit from the narrative wisdom of survivors (veteran patients). One participant saw herself at the receiving end of such an apprenticeship: writing prepared her for reaching out to a total stranger, but one who she felt could truly understand what she was going through: another woman with breast cancer.

During the interviews, participants talked about relationships, whether it was with parents, spouses, children, friends, fellow cancer patients, or health care staff. Writing, though a solitary task, allowed participants to return to social situations, whether good or bad, or where their strength and vulnerability had led to relational dissonance. Cancer patients may opt to appear strong and resilient to protect loved ones from their own distress. In the gendered context of breast cancer, the patient often is a key caregiver in her social circle, and may feel particularly strongly that she must conceal her worries in order to stabilize others through a time of crisis.²⁷ Several participants reported that they found themselves writing about things they had not spoken to others about or that the writing had provided an opportunity to share their experiences or texts with their loved ones, or that it was easier to talk to loved ones about their experiences after writing. Previous research has confirmed that expressive writing can positively affect participants’ relationships.⁴¹

The participant identified in the divergent case, who actively avoided thinking about difficult feelings and thoughts, described how the writing forced her to confront material she would otherwise have shut out. Unlike others, she did not wish to share the text with her family, which may reflect adherence to social norms (e.g. honor, shame) or relational boundaries invoked by cultural conformity in her native country. She described herself as being initially diagnosed as precancerous stage 0 (i.e. ductal carcinoma in situ) and therefore did not identify herself as a typical breast cancer patient.⁴² She felt lucky: It was really hard to let go of the breast, but at least she did not require adjuvant treatment. Whereas many participants felt that the writing helped them to look back and find meaning in what they had been through, the experience for this participant was the opposite: writing emphasized the partly repressed trauma of diagnosis and mastectomy. Research has shown that denial, repression and associated defensive or avoidant behavior can be a predictive indicator for increased distress levels after surgical breast cancer treatment, suggesting that the intervention could be particularly beneficial for this sub-group of patients.^{43, 44} Expressive writing encourages articulation of deeply personal experiences, and may initiate emotional and cognitive processes even for those who are normally reluctant to talk to others.¹⁹ For our divergent participant, writing altered the direction of her thinking, by either introducing topics she had not believed were relevant to her situation or by awakening latent concerns that she had previously defended against. Taking part in a study designed for patients with invasive breast cancer may have induced more disturbing thoughts and feelings. During writing, she became concerned about the less fortunate fates of other breast cancer women she came to hear about, dead or dying. Remarkably, the pathology report following her mastectomy did reveal a more invasive cancer. Despite the discomfort she felt with some of the emotions and thoughts activated by writing, she did not regret taking part in the study.

Suffering can take on different guises and has rightly been identified as a “field of force” in the lives of breast cancer patients highlighting how, in their distress, dependency upon loved

ones, friends and health care professionals is brought to the fore.⁴⁵ Suffering can be difficult to talk about both for patients and care staff and may be evidenced in relation to the body, existential meaning, and experiences with health care. Findings in our study show how writing may encourage an outlet for such a deep feelings, which, because of self-censorship, defensive behavior, or social taboos on illness and emotional expression, expire in communication with others. These painful omissions may be thoughts and feelings experienced as shameful, whether they concern issues around vanity and changed appearance, sexuality and intimacy, feelings of distress, humiliation and powerlessness, or fear of dying.²⁹ Patients may conceal their suffering when significant others find it hard to tolerate,⁴⁵ and instead focus their energy on appearing positive and cheerful because these are socially accepted and culturally celebrated ways to act, even in a medical crisis.⁴⁶ However, previous research has shown that women with breast cancer who can express their feelings or actively accept their situation may have more favorable short-term health outcomes.²³ A 1989 psychosocial intervention study on metastatic breast cancer patients revealed that the test group (group therapy and self-hypnosis, n=50) lived an average of 18 months longer than did the control group (n=36)—a result that is comparable or superior to life-extending oncological treatments in pharmaceutical trials.⁴⁷ Such findings indicate how mental and physical health may be mutually dependent and reinforcing, and why dedicated attention to psychosocial wellbeing in relation to survival is long overdue.⁴⁸ Therefore, it may be vitally important for health care personnel to strive towards caring for and supporting the patient as a whole being during treatment and rehabilitation for breast cancer.^{48, 49}

Several potential limitations were identified in this study. First, inconsistencies in how interviews were conducted may have altered data quality. Phone interviews were a logistical necessity but in-person interviews were noted to be lengthier and richer in observational data. Face-to-face interviews offer a greater degree of intimacy and bonding, crucial in the context of exploring personal experiences. Through the analysis however, researchers came to see the transcribed phone interviews as producing not lesser but more condensed narratives. A second limitation was the unpredictable and inescapable impact of psychodynamics in the interviews. In the analysis of counter-transferences, the Norwegian researchers became aware of how their guilt, related to appropriating time and effort during a stressful period of the participants' lives, was balanced with a sense of worthiness in having provided them with an intervention that was received predominantly as a good offering. Findings from the divergent case suggest there was sufficient provision in the interviews for exploring critical responses to the intervention. Finally, the sample was socio-economically homogenous and therefore not fully representative of the diversity in this patient population. Despite these limitations, findings have credibility as the interviews produced comprehensive data, presented here in relation to expressive writing, with broader topics to be covered in forthcoming publications.

Implications for Practice and Conclusion

This study contributes a thoughtful analysis of *what it is like to take part* in expressive writing and therefore has important implications for clinical practice and future research. Findings augment a substantial body of international research supporting expressive writing

as a low-cost self-help tool for cancer patients in general,^{20,23} and for breast cancer patients in particular,^{8-14,42} provided that one takes into account moderating factors described in the discussion. Our findings show that expressive writing is a strong evidence-based intervention, not only from the perspective of measurable outcomes but also from the patients' own perspectives: the method was feasibly implemented as home-writing for breast cancer patients within weeks and up to 18 months after primary and reconstructive surgery, at times during which participants were on medical leave. Participants recommended the method for other women with breast cancer, especially in the initial period after diagnosis when patients are negotiating considerable psychic tensions. Distress in adaptation to loss (bereavement, serious illness, loss of mobility, amputation) is known to be heterogenic.⁵⁰ Younger breast cancer patients report greater psychosocial needs³⁵ and may therefore be more motivated to take part in writing. Future interventions to help patients come to terms with cancer-related loss and distress should therefore aim to identify accurate subgroups. Future research should explore how the intervention may be integrated into various phases of the treatment trajectory and survivorship, and assess whether it can be tailored around individual characteristics such as age, life situation, avoidant behavior, adaptation to loss, recovery, and support needs. Expressive writing texts offers care providers opportunities for imaginative identification with patients and may be a valuable point of reflection in clinical consultations.⁵¹ Future research may look into expressive writing to support cancer care professionals who may face considerable psychosocial stresses of their own in their working lives.

Our study illuminates experiential variations in expressive writing and how telling the story may feel painful while in process but produces a release of cognitive, emotional, and relational strains, surrendering these to "reside somewhere else," namely in the narrative. Participants reported that it was easy to write at home and described how absorbed they became in the creation of their texts. Findings elucidate the power of storytelling as a means to frame a painful life event and transform it into something graspable for both the writer and potential readers. The method was said to process feelings and capture experiences tied to a new and overwhelming illness situation, as *impressions* became *expressions* through writing. Expressive writing, therefore, is a valuable tool for interprofessional health care providers, including nurses, to introduce into the plan of care for patients with breast cancer, and potentially for other cancer patient groups.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table**Participant Demographic Characteristics**

Variables	No. =7
Sex	
Female	7
Race	
Caucasian	5
African American	1
Asian	1
Age	
41-50	3
51-60	3
61-70	1
Stage at Diagnosis	
I	2
IIA	1
IB	1
IIB	2
IIIC	1
Marital Status	
Married	6
Single	1
Highest Education Completed	
High School	2
Baccalaureate	2
Masters	1
Doctorate	2
Income Level (annual household)	
50 000-74 999	1
75 000-100 000	2
>100 000	4
Employment Status	
Full-time	6
Retired	1