

# A Small Story Concerning a Big Mistake: Returning Voice to a Breast Cancer Narrative

Elaine Martin

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Résumé de l'article

This article arose from an error. In 2000, I began recording the story of myself and nine other university women with later stage breast cancer. Following the fifth death, I took on the task to make what I could of the archive. An introduction to Cathy Riessman and narrative research began to direct and support this work. Of major significance was the performative aspects of our storytelling, especially our vocality. Text and reason, not voice and utterance, is privileged in the academy, but still I committed to honouring vocality in telling our story. My initial attempts failed, but this paper begins the redress.

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**SPECIAL ISSUE**

*AMOR NARRATIO: A FESTSCHRIFT FOR*  
CATHERINE KOHLER RIESSMAN

**A Small Story Concerning a Big Mistake:  
Returning Voice to a Breast Cancer Narrative<sup>1</sup>**

Elaine Martin

*Narrative Network Australia*

This article arose from an error. In 2000, I began recording the story of myself and nine other university women with later stage breast cancer. Following the fifth death, I took on the task to make what I could of the archive. An introduction to Cathy Riessman and narrative research began to direct and support this work. Of major significance was the performative aspects of our storytelling, especially our vocality. Text and reason, not voice and utterance, is privileged in the academy, but still I committed to honouring vocality in telling our story. My initial attempts failed, but this paper begins the redress.

**Keywords:**

Breast cancer, performative storytelling, narrative structure, politics of voice

We began as a company of 10 academic women with later-stage breast cancer. We met to come to terms with how and who we were now, for we had limited hope of long-term survival and found little comfort in the upbeat testimonials of survivorship that surrounded us. Some five years later, following five deaths and the group breaking apart, there was another significant beginning. I took on the task of making what I could of our archive of recorded conversations, notes, reports, and journals. Of those of us remaining, I was the only one with sufficient desire and health to commit to the task.

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<sup>1</sup> I wish to thank Tammy McCartney, Helen Mathwin, and Leo Martin for their recording of the script; and Susie Elliott and David Webb for their assistance with proofreading. I am most appreciative of the supportive and helpful comments by reviewers of this paper.

Then came a third beginning—a friendship and working relationship with Catherine Kohler Riessman. Cathy’s short course on narrative inquiry seemed heaven-sent, the perfect tool to interrogate this emotional and political archive. I began the task optimistic enough, but over the years have made limited progress. Health and confidence have ebbed more than flowed. There are now only two of us living, and beyond this, other scholars have since published significant critical work on the dominant breast cancer culture.<sup>2</sup> This Festschrift, however, offers opportunity to review my writing and consider what remains unique about this work. Of special consideration here is that this journal’s online status offers opportunity for audio, and for me, for us, the quality of voice was significant.

### Background

One of the first books Cathy recommended was *A Complex Sorrow: Reflections on Cancer and an Abbreviated Life*, by Marianne Paget (1993). This sad but beautiful book helped me work up my first attempt at a narrative inquiry paper. I was especially inspired by Paget’s staged reading (Ch. 2 & 3). I saw how staging and scripting a presentation<sup>3</sup> could help communicate the intensity of conversations in ways that more traditional academic writing never could. Merleau-Ponty (1964) argues that storytelling conjures and communicates past experience within the context of present conditions and audience. It is an embodied act, a seeing, listening, feeling encounter that urges an audience to hear, see, and feel in turn. Performance is open to experience, while text, especially academic text mostly works to disembody it (Paget, 1993).

One of our earliest claims was that our shared vocality had the quality of a healing incantation, precious beyond the meaning of our words. We spoke of how voice travelled on our breath, through our lungs, beneath the breasts, beneath the scars. There was something elemental here.<sup>4</sup> Later, I saw how such claims resonated with the work of Adriana Cavarero (2006), who has written of the long history in scholarship and

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<sup>2</sup> See especially Gayle Sulik (2012), but also, Samantha King, (2008), Devra Davis, (2007) and most recently Emilia Nielsen (2019).

<sup>3</sup> “Story Theatre” or “Chamber Theatre” have been champions of this approach. For example, see [https://en.wikipedia.org/wiki/Chamber\\_theatre](https://en.wikipedia.org/wiki/Chamber_theatre)

<sup>4</sup> I later learned of Luce Irigaray’s (2004) work on breath and became aware of the lack of attention to this in Western philosophical thought.

the academy of the privileging of text over speech. Cavarero argues we have both voice and reason, but the significance of voice has been overwhelmed by reason. She argues for a politics of voice, where voice is understood as a discrete power—not solely the vehicle of reason, but its own potent force.<sup>5</sup> Such a proposal made sense when working with an archive such as ours. I clung to the notion that whatever I was to ultimately take and make of it, I must awaken an audience to the power, promise, and complexity of voice within our breast cancer company. This precious voice that held us together sometimes baffled the rational; at other times, it coupled with reason and performed lucid, expressive invocations of our experience that I have since come to see as a poetic literacy.<sup>6</sup> Sometimes again, it was largely the vehicle of reason.

Across our five years together, the company morphed and following an intense time when there were three deaths, in close succession, our focus moved away from introspection and towards issues concerning breast cancer support that surrounded us. We dug out troubling reports that questioned the integrity of aspects of breast cancer land and we built on these and we became political.<sup>7</sup>

When generating a first draft of this political time, I too focused on these disturbing reports. I assembled evidence and made logical arguments and worked largely to accumulate a critique of cancer culture. I ignored the shaken and angry utterances of we women who did the researching and unearthing. I allowed myself to be captive to reason and other attributes of our vocality were all but lost. It was not until I re-read an initial completed draft of the work, with a piece for Cathy's Festschrift in mind, that I realized, with shock, how in this section voice had become subjugated. I also realized that through this Festschrift (as an online publication), I could begin the work of reinstating the status of voice.

The section below includes examples of what I have come to see as the major roles of voice in the larger work. The first of these is from our second month together and connects into my excitement at exploring vocality and scripted text. Here, voice is performative and works collaboratively with reason. The second is from the time we called "our dark night." Here, our talk is often disconnected, seeming to lack

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<sup>5</sup> This resonates with aspects of Julia Kristeva's (1986) work on the maternal *chora*.

<sup>6</sup> Ruth Salvaggio's (1999) *The Sounds of Feminist Theory* explores a turn towards the oral and evocative qualities of language by feminist critical writers. I am most appreciative a reviewer of this paper who recommended this book.

<sup>7</sup> For insight into this see especially the work of Gayle A. Sulik (2012), Evelyn Accad (2001), and Devra Davis (2007).

rationality. This was at the heart of what we called our “healing incantation.” The final scripted section, from the beginning of our political time, recalls the events that sent us back into the strongly reasoned research and writing, and which also distracted me, as author of our story, away from the vocality that had “held and healed”<sup>8</sup> us.

### Performing Text

Perhaps the first thing Cathy taught me concerning narrative inquiry was that the task of inquirer is to interrogate and to situate talk and story. Usually in narrative inquiry, comment is set apart from the narrative under scrutiny. When creating a scripted conversation in this work, however, a narrator becomes inquirer and commentator and speaks alongside the story-telling. In this way the commentary unfolds within the conversation, questioning what occurs and providing context.

All the written scripts are informed by the work of James Gee (see Riessman 2008; Gee 1991; Gee 1985). They are developed directly from repeated readings of extended sections of audio recordings and they attend closely to how talk is structured and how it falls into distinct units of meaning. Each unit of meaning, or stanza, is separated on the page with a blank line. Within each stanza, vocal inflections, such as change of tone or tempo or emphasis, are signalled by a new line. On the page it resembles the appearance of poetry. Our speech, especially in the early times, was tentative, hesitant, so lines are short. Notation for laughter, sobs, sighs or longer pauses are shown in brackets. Longer pauses are highlighted in bold, on a new line. The voice of the narrator, commenting on the conversation, adopts a voice that is sympathetic to the pattern of hesitancy or fluency, lightness or force, in the voices of speakers. The narrator gives context, poses questions, makes connections across the conversations. The ordering of talk on the page, in this way, makes it accessible to the reader and possible for a performer to replicate the intonation and emotion embodied in the recorded voice.

An excerpt from the first script is printed below. This early work is closely modelled on the chapter ‘The work of talk’ in Paget (1993).<sup>9</sup> It

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<sup>8</sup> Drawing on the work of Helen Cixous (2005), we suggested our vocality was like scar tissue that healed and held us.

<sup>9</sup> Performed on 14 & 15 May 1988 at Northwestern University, U.S.A.

highlights the variation between talk amongst ourselves and talk with doctors.<sup>10</sup> It also exposes our developing sense of distress and isolation.

**Narrator**

We met three times, in the first month of our time together  
we ten university women who had  
a second or third breast cancer diagnosis  
and had experienced mastectomy  
and chemotherapy  
and  
a loss of sense of self.



We-met-three-times.m4a

We shared journals and notes  
as well as conversation.  
For exchanges  
with doctors  
were rarely sustaining.

And the voices of we women are heavy with uncertainty  
and with fear  
and sorrow.

**Alice**

*And it's really only now.  
Now, after all these months*

**Narrator**

It had been 16 months for Alice.

**Alice**

*that it's sinking in.  
What it really means  
this...?*

**Brenda**

*But really, you're just catching up  
with what's happened.  
And coming to terms with...?*

---

<sup>10</sup> Doctors' comments are all taken verbatim from notes or recordings we had each taken during our individual consultations.

***Pause***

*all of it.  
And wondering if it's going ok  
like this scar  
that doesn't heal.  
If that's ok?  
And if the pain  
if the pain  
is normal.  
Because it wasn't so bad  
at first.*

**Narrator**

But the voices of the doctors  
they attend to the measures  
standards and norms.  
They are confident voices  
and sometimes  
dismissive, condescending.

***Doctors***

*Yes, the measurable signs?  
All ok  
the blood tests  
bodily functions  
the scans  
all satisfactory.*

*Some parts will take longer.*

*The pain?  
Mm well  
a lot of flesh there  
wasn't there?  
So there will be pain.*

*And the scars?*

*Mm.  
Yes all healing.*

*What's that?*  
*Tight*  
*well it will be tight. [sarcastically]*  
*Yes, apply the cream.*  
*Do the physio*  
*do the exercises.*

*Yes, yes*  
*even if it hurts.*

*What?*  
*Feeling low,*  
*Yes, well [slight laugh]*  
*The mental and emotional*  
*that'll follow.*

*I tell all my ladies*  
*You'll steady yourself once you're*  
*back into it*  
*back into life.*

*What?*  
*No, I can't say how long.*  
*I can't predict cancer [impatiently]*  
*I can only explain*  
*the general patterns*  
*and expectations*

*You might as well*  
*try a fortune teller*  
*for more.*  
*ha ha*

**Narrator**

But we women  
 we do not speak of measurable outcomes.  
 We attend to the day to day  
 and what it feels like.  
 And it doesn't feel right.  
 We don't feel right



in ourselves.  
 Yes, there is discomfort  
 and pain  
 but more than this  
 we feel dismissed.  
 We are not seen.

***Brenda***

*What emerges over time  
 is this unease  
 this disquiet  
 not just physically.*

***Alice***

*Yes,  
 I know that  
 At a wedding recently  
 we were all together,  
 me, my husband and daughter  
 and someone said to my husband  
 "How wonderful to have such a beautiful daughter  
 It's like having your beautiful young wife  
 Back."  
 And the idea that I'm not there  
 because I'm no longer ....  
 .....  
 It sends you off balance.*

The early months held much talk of this ilk and it seemed we would never tire of sharing such stories, for here in each others' company we were heard and acknowledged. But after three months or so our conversation did change and did so markedly. There developed significant sections of talk that seemed disconnected, confused, dream-like. At first, I was unaware of Cavarero's work and worried how to present we women, serious scholars, as the speakers of such incoherence. The work of Gee (see Riessman, 2008, p. 93) became a guide and inspiration. Gee's work with schizophrenia and dementia patients found that talk, which at first might seem incoherent, can be separated into discrete units of meaning, as it is spoken, and then restring, making connections across the differing temporal sections of speech. As Gee

explains, we all introduce asides and different topics, and skip back and forth between them, but this is often taken to extremes amongst those in a challenged mental or emotional state. I worked with this, re-stringing individual units of meaning, and was excited to find sections that had at first seemed incoherent now made sense—though, attending to Cavarero, I do now question the compulsion to seek coherence above all else. A major difficulty when sharing this disconnected talk is to present conversations in ways that highlight both potential confusion and connectivity. The words of the narrator are critical here, for they comment on how units of talk are either left hanging, or sometimes might connect into previous or subsequent units.



Within-three-months.m4a

### **Narrator**

Within three months  
our conversations changed  
significantly.

We later called this  
our healing incantation  
our dark night  
and this strange way of speaking  
stayed with us  
and held us  
for several weeks.

We were all  
struggling,  
and sometimes parts of this speaking  
made little sense,  
There appears little of the to and fro  
of conventional conversation.  
Sometimes it seems we are in a dream  
or speaking of a dream.  
And time as linear  
is often questioned.  
And the value of life.  
And the wanting, as well as the fear  
of death.

### **Pause**

all under scrutiny

**Fiona**

*Time takes on new dimensions.  
A minute can seem like an hour  
and more.  
And yet a month?*

*It's like the elastic that  
Keeps time taut  
It's perished.*

**Gerty**

*There is so much to fear  
And life can seem so precious  
and yet sometimes so overrated. [slowly]*

**Pause**

*I have mostly wanted to live  
but at times I have wanted to not live*

**Pause**

*I'm not sure if **not** living  
is the same as dying.*

**Narrator**

And now Jess picks up on Fiona's theme of time but the comments don't connect.

**Jess**

*And how many minutes in an anguished nightmare  
In a nightmarish life?  
And how many hours watching chemicals drip into the vein  
and poison?  
And wondering if the wondrous singing of the blackbird  
can block  
the ticking of the clock?*

**Narrator**

And our children  
they are often in our talk.  
Leaving school-aged children  
motherless  
that's hard.  
And thinking of it.  
The hardest thing

And Gerty speaks of this.  
and time and death are both  
present.

***Gerty***

*Once,  
once I thought  
they thought  
I'd always be there*

***Pause***

*Once upon a time*

***Pause***

*They loved the stories  
the children*

***Pause***

*soon likely  
I'll be  
a story...*

**Narrator**

But now  
Out of the blue  
Gerty asks

**Gerty**

*I'm going on the march on Sunday.  
Anyone else?*

**Narrator**

The question is ignored  
and Jess  
speaks of fate

**Jess**

*They say we  
have options  
But we know  
no option.  
The way the dice lands  
not a choice.*

**Narrator**

And Fiona  
maybe responds  
to Gerty's earlier question  
about the march

**Pause**

but maybe not

**Fiona**

*I will walk*

**Pause**

*in the park*

**Pause**

*I sometimes see my mother there  
by the lake...*

**Pause**

*Am I imagining it?  
I suppose.*

***Pause***

*She's dead*

***Pause***

*I believe*

**Narrator**

Fiona concludes  
And perhaps it is a coda?  
But it  
is a long  
long way  
from disconnect  
and madness.

***Fiona***

*There are so many hours  
In so-called resting  
But the only thing rested  
Is my sense of reality  
And they say  
"how are you?"*

***Pause***

*Well it's not like  
the life  
before*

***Pause***

*so there's no possibility  
of responding.*

***Pause***

*I have no idea  
how I am*

***Pause***

*nor who I am*

It was following this “dark night” that we women declared that the sound of our voices, our shared vocality, had become the heart of our connection, our healing incantation. We were not aware of any of the connection and cohesion suggested above, but we did accept this strange talk had purpose. We spoke of “*moving beyond reason*” to “*take up the deep truth, the beat, the murmurs, the intonations, of one another’s breath ... the life source.*” It was reconsidering talk of this ilk that was later to connect me to the scholarship of Cavarero.

Our dark night ended with three deaths, and when we re-gathered, we were changed. We looked beyond ourselves into breast cancer culture and became political. We called our adversary Pink Kitsch after the work of Barbara Ehrenreich (2001).<sup>11</sup> We began by picking apart the dominant breast cancer story. We were skilled at such analytic work and slid effortlessly into a textual web of facts and texts; this, in turn, shifted emphasis away from voice. But now with the benefit of hindsight and this Festschrift, vocality is reinstated.



We-mapped.m4a

**Narrator**

We mapped the plot line  
of 27 breast cancer stories<sup>12</sup>  
from journals, magazines, and online forums.  
And we established  
(by and large)  
that the plot of the popular story<sup>13</sup>  
proceeds thus:

1. Shock diagnosis

<sup>11</sup> A few years into our time together we read the work of Ehrenreich (2001), who, like us, railed against the ‘heavy traffic in positivity in breast cancer support and stories’. We borrowed her naming of Pink Kitsch.

<sup>12</sup> Some work on plot lines in breast cancer stories undertaken by Couser (1997, p.39), cited in Langellier & Peterson (2004).

<sup>13</sup> With a nod to Kubler-Ross (1973).

2. Challenging treatment
3. Significant physical and
4. Some emotional upheaval  
and finally
5. Transformation—the emergence of a brave, positive, triumphant  
shero, even in the face of death.

We were angry  
our conversation became percussive

***Irene***

*So you go through hell  
and you lurch back  
into something resembling life  
and you're treated  
as something not quite woman.  
You're given teddy bears  
and pink ribbons  
and condescension  
and at the end you're expected to be  
saintly  
good, gracious, brave, appreciative  
something between  
a child, an airhead, and an angel.  
We've lost the potent apparatus of womanhood.  
And  
In exchange  
we're given this story*

***Pause***

*And a teddy bear to embrace.*

**Narrator**

We agreed to  
put our questions  
out there  
in an online support forum.  
Anna made the submission

***Anna***

*I've had three remissions*



*and three recurrences  
Lost both breasts.  
I've got stage 3  
I'm frail  
and frightened  
but when I read the stories  
out there  
we frail, frightened people  
we're not there.  
Where are you  
those of you like me?*

**Narrator**

Within two hours of posting  
responses flew in

***Respondent 1***

*If you focus on the negative  
you stay negative.  
Negativity enables cancer.  
If you want to beat it  
stay positive.*

***Respondent 2***

*Of course you'll have bad times  
but if you focus on the misery  
harp on about how bad it is  
you'll make yourself miserable  
and knock your chances of survival  
most women know this  
and hang on in there.  
Please don't post again.  
We need positive stories to keep us going.*

***Respondent 3***

*You negative fool.*

**Narrator**

Over 12 days there were 52 responses.  
All but two emphasized the importance of positivity.

Forty were critical of Anne.  
 Five were offensive.  
 Three mentioned the so-called benefits of breast cancer:  
 Loss of weight  
 breast reconstruction  
 free wigs.

### **Pause**

Only four showed any sympathy  
 And nodded towards sometimes feeling  
 patronized  
 misunderstood.

### ***Anna***

*This response  
 It's shocked me,  
 appalled me.*

*The positivity trope,  
 It's so pervasive  
 not just as a necessary condition for survival  
 it's become a moral responsibility.*

*How do we work with this?*

### **Conclusion**

Exploring the culture and politics around breast cancer necessarily engages with the age-old struggle over the bodies of women, and in retrospect, this was too big a venture for us to take on, but work on it we did for a further two years and two deaths, and we did make progress. But this larger story is for another time, another place, and this present small story must now end. In many ways it is a small story, but it is significant, first, because it connects back into the core of our breast cancer coterie and the vocality we claimed as our bedrock. Second, because I now see how strongly our bid to reclaim embodied voice connects with Cavarero's plea to awaken a consideration of voice in the academy and balance "semantike with phone" (Cavarero 2006). It is especially significant in emotional work such as ours and yet, as I have experienced, it is so easy

to slip into a focus on reason and text and neglect the complex qualities and communicative capacity of voice. Finally, it is significant, for this work attends to the call Cathy made in the final sentence of her 2008 book, 'Narrative research is gaining strength in the human sciences and the field needs voices in different registers to become a chorus' (Riessman 2008, p. 200).

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**Elaine Martin**, PhD, was formerly Director of Graduate Research and Head of the Office for Postgraduate Research and Development at Victoria University, Melbourne. For 12 years previous to this, she headed three centres engaged in developing research capacity and teaching and learning at the Royal Melbourne Institute of Technology. In 2006, she became foundational Co-Director of Narrative Network Australia. For most of her career, she researched teaching and learning in higher education and has won ten Australian Research Council grants in this field. She has over 60 refereed publications, four edited and one sole-authored book.