



SPECIAL ISSUE

AMOR NARRATIO: A FESTSCHRIFT FOR
CATHERINE KOHLER RIESSMAN

A Small Story Concerning a Big Mistake: Returning Voice to a Breast Cancer Narrative¹

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.

¹ 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.² 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 presentation³ 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.⁴ Later, I saw how such claims resonated with the work of Adriana Cavarero (2006), who has written of the long history in scholarship and

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

³ “Story Theatre” or “Chamber Theatre” have been champions of this approach. For example, see https://en.wikipedia.org/wiki/Chamber_theatre

⁴ 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.⁵ 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.⁶ 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.⁷

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

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

⁶ 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.

⁷ For insight into this see especially the work of Gayle A. Sulik (2012), Evelyne 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”⁸ 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).⁹ It

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

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

highlights the variation between talk amongst ourselves and talk with doctors.¹⁰ 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...?*

¹⁰ 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).¹¹ 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 stories¹²
from journals, magazines, and online forums.
And we established
(by and large)
that the plot of the popular story¹³
proceeds thus:

1. Shock diagnosis

¹¹ 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.

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

¹³ 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.