

The use of research-based theatre in a project related to metastatic breast cancer

Ross Gray PhD^{*}, Chris Sinding MA[†], Vrenia Ivonoffski MA[‡], Margaret Fitch RN PhD^{*}, Ann Hampson MA^{*} and Marlene Greenberg MS^{*}

^{*}Toronto-Sunnybrook Regional Cancer Center, Toronto, Ontario, [†]Department of Public Health Sciences, University of Toronto, Toronto, Ontario

[‡]Act II Studio, Ryerson Polytechnic University, Toronto, Ontario

Abstract

Correspondence

Dr Ross Gray
Toronto-Sunnybrook Regional Cancer
Center
2075 Bayview Avenue
Toronto, Ontario M4N 3M5
Canada
E-mail: ross.gray@cancercare.on.ca

Accepted for publication

7 October 1999

Keywords: breast cancer, drama,
research dissemination, theatre

Research-based theatre represents an innovative approach to disseminating the results of qualitative studies. In this paper, we provide a rationale for the importance of research-based theatre and also review previous work that has been done in the area. We then describe our experience in transforming research data into a dramatic production, *Handle with Care?* This production was based on two studies – one with women with metastatic breast cancer, and the other with medical oncologists treating breast cancer patients. Results from ongoing assessment of the project are reported. We discuss some of the factors related to the success of *Handle with Care?* and reflect on what has been learned about the process of developing dramatic pieces related to serious illness.

Introduction

I was devastated the second time, worse than the first, because it is worse.

It's not any easier for a 74-year-old woman to die of breast cancer than it is for a 33-year-old. It's unjust to say that because you're 74 you should just grin and bear it.

I needed to hear and talk to women who were living with metastatic disease.

I didn't even tell my sister, I felt so ashamed.

As long as I get up, get dressed and put my make-up on, everybody thinks, 'Oh, mom's OK. Mom's gonna be fine'.

I found I was given almost too much to decide on my own.

Not being able to get behind the fear is the biggest enemy.¹

The quotes above were drawn directly from qualitative research related to metastatic breast

cancer, and were spoken in the opening scene of a dramatic production, *Handle with Care? Women Living with Metastatic Breast Cancer*. The production began to tour cities in Ontario, Canada in the fall of 1998. Slightly different versions were presented to audiences of health professionals, and the general public. The production was based upon research results of two studies – one conducted with women with metastatic breast cancer² and the other with medical oncologists treating breast cancer patients.³ In this paper we will provide a rationale for research-based theatre, describe the process we underwent to transform research data into drama, and report results from ongoing assessment of the project.

There are two main arguments that have been made in support of research-based theatre. The first has to do with the often-neglected responsibility of researchers to have their work make a difference in the everyday world.⁴⁻⁶ Linking

research data to drama is arguably much preferable to the fate of many manuscripts that lie unread on library shelves, or are commented upon perhaps occasionally by other academics.⁴ Theatre has the potential to present research material in a way that helps to clarify and transform social understandings; where insights occur because of audience engagement with dramatic material, the potential for positive individual change is heightened.⁵

The second argument made for research-based theatre, attractive especially to those with a predominantly realist (as opposed to constructivist or post-modern) perspective, is that it has advantages over purely textual reports in terms of validity (i.e. remaining true to qualitative research data and ultimately to lived reality). This is because it sustains connections to bodies, emotions and the full range of sensory experience that was present in the original data-gathering situation.^{7,8} Audiences, often comprised of members of groups under study, can further validate research-based drama through provision of post-performance feedback, potentially affecting the shape of future presentations.⁸

There is a long tradition of using drama in educational, therapeutic, and social change contexts, with some projects employing participatory strategies in script development and using the actual voices of members of the community under study.^{9–12} Whilst research has definitely been an aspect of this work, the emphasis has most often been on political, educational, and/or aesthetic considerations. Drama that emphasizes research is much more recent, with only a handful of authors publishing their attempts to foreground research in the construction of drama.^{5,8,13–17} This new work has varied along a number of dimensions, including how much dramatic structure appears, how many (if any) narratives run through a performance, how the audience is included or not, and how the performers approach the work (e.g. the use of scholarly versus lay syntax).⁶

The fullest use of drama in presenting qualitative research material has been provided in the groundbreaking 'ethnodrama' work of Jim

Mienczakowski and his colleagues. During the past decade, they have mounted major research-derived productions related to schizophrenia, substance abuse and sexual assault.^{18–20} Mienczakowski stresses the importance in this work of adherence to 'the principles of a formal and recognizable ethnographic research methodology, above and beyond the artistic demands of aesthetics, in its attempts to produce cultural critique'²⁰ (p. 8). He also provides cogent theoretical arguments that create a foundation of relevance for research-based theatre.¹³

Although important work has accumulated, there remains much to explore and define in this exciting new field of research-based theatre. Our production of *Handle with Care?* provided the opportunity to investigate challenging aspects of the linkage between research and drama.

Development of a research-based dramatic production

Handle with Care? was not a planned outcome when we first started to investigate issues related to metastatic breast cancer. We began with a series of focus groups, asking women with metastatic disease about their information needs. They had much to say about information, but they also talked much more broadly about the life issues they were facing. We wrote up the results of that study and published them in a peer-reviewed journal.² But the research team had become fascinated by the struggles that women described, and felt compelled to engage with the topic further. We decided to conduct a companion study, to investigate the perspectives of medical oncologists about the issues women had identified as important. In addition, *Living With Metastatic Breast Cancer: a Resource Guide*, was created and disseminated to help women more easily track down the information they wanted.²¹ Finally, we decided to experiment with translating the results of our two studies into a dramatic format, following the first author's (RG) interest in the potential for research-based theatre.

The research team created a partnership with ACT II Studio, a theatre group for older adults

at Ryerson Polytechnic University in Toronto. Their director (VI), agreed to provide artistic leadership. The process of working on the project began with a series of meetings, held every few weeks over a period of 6 months. The group comprised of researchers, women with breast cancer (two with metastatic disease and several who remained well after initial treatment), and actors who were part of the theatre school. Initially, there was considerable discussion about what it meant to have metastatic breast cancer. The research team provided background information. Women with breast cancer told their personal experiences. Actors responded to what they heard and raised their impressions, fears and concerns. Transcripts from the studies with breast cancer patients and oncologists were circulated amongst the group, and subsequently discussed. The membership of the group was fluid through these early months, with people coming and going. A few left permanently, distressed by the topic.

Once there was considerable familiarity with the topic and there had been some discussion of transcripts, improvisation exercises were introduced to explore in depth the major themes identified by the research team. Over a series of weeks, we experimented with all manner of physical response to issues like 'the importance of hope' and 'difficulties getting information'. Visual images were recorded and later referred to when it came time for writing the script.

After six months of intermittent meetings, the group then met for several weeks almost every day. Many more improvisation exercises were conducted, and there was also an effort to substantively return to the transcript data. Individuals read in the evenings and came prepared the next day with key quotes to exemplify the central themes from the research. The quotes selected as being most powerful were written across banners on the wall. These then became stimuli for further improvisations, allowing exploration of additional metaphors, symbols and sculptures. Eventually we had created a large repertoire of both visual images from the improvisation exercises and of quotes selected from transcripts for their representa-

tiveness, clarity and visceral impact. The artistic director (VI) then wrote a draft script, woven from the material the group had generated. When the actors began to work with the script in intensive rehearsals, changes were made. We then made a trial presentation to an audience of health professionals and breast cancer patients. More changes were made. Further tightening of the script followed the eventual performances for both health professional and community audiences. Explicit feedback and audience reaction has continued to shape the presentation throughout.

Dramatic presentation as research report

Did the dramatic presentation stay true to the research conducted with women with metastatic breast cancer and with medical oncologists? Before addressing this question, we need to first acknowledge the slippery quality of concepts like 'truth' and 'validity'. Like others influenced by post-modern and constructivist critiques, we acknowledge that 'all stories, including accounts of scientific knowledge, are relative and provisional. All are but temporary way points in the ongoing construction of meaning'²² (p. 160). Our original research thus provided a provisional perspective on issues related to metastatic breast cancer, and the dramatic production that followed did the same. Whilst recognizing the limits of qualitative research for establishing immutable truths, we nevertheless did our very best to represent the perspectives of women with metastatic breast cancer in a way that they would recognize. This required a strong reliance on the transcripts to guide the writing of the script. Continually, we returned to the words that women had spoken during the original focus group discussions. But we also looked for guidance from the two women in our project with metastatic disease. They were able to provide feedback when content or tone began to stray from the realities of their experiences. Although this same correcting influence was theoretically available through referral to transcripts, the immediacy and intimacy of women living with the disease was exceedingly

compelling for limiting excesses in the expression of artistic license, or departures into intriguing but unessential byways. Also important was the intermittent presence of the facilitator of the original focus groups (AH), as she was able to draw on her remembered sensory experiences to add richness and depth to our theatrical interpretations of transcript text.

Whilst we felt it was important to stay closely connected to the research base of the studies, we collectively agreed to numerous explorations beyond word-for-word excerpts from transcripts. Some of these departures were simply to allow for clearer expression of thoughts that study participants had articulated. Other explorations were more related to artistic considerations, and the desire to produce a compelling presentation that would entertain and engage an audience, not just inform them. For example, in one scene various well-meaning and not so well-meaning friends and acquaintances push a woman with metastatic breast cancer back and forth from one side of the stage to the other, all the while giving unsolicited advice. This image represents what we heard from women, but is not, of course, literally what happened to them. But we have had many comments about the image's usefulness for portraying the emotional situation of ill women. Seeing women pushed around provided a more direct pathway to the lived 'truth' of their experiences than a compilation of verbal statements ever could have.

Another type of exploration arose out of the experiences of the women with metastatic breast cancer participating in the project. Their engagement with the transcripts often led to the telling of personal stories that helped bring themes even more to life. For example, during a discussion of how family members sometimes resist acknowledging the seriousness of the disease, one of the women recounted an incident with her spouse. It became part of the script:

Not long after my diagnosis, a radiation oncologist told me her longest surviving patient with metastatic disease lived for 23 years. And there it was – long distance hope. I was thrilled. I told my husband during the drive home. 'Twenty-three

years' I said, 'Can you believe it?' 'Of course', he replied with that I-told-you-so-look of smugness. Well, I lost it! I wanted to pull the car over and whack him one. I was livid because he was dismissing my reality, my fear, my agony. Sure – one patient lived 23 years, and maybe I will too. The fact that one did opened up a world of possibilities. But it's a long shot and it's the not knowing, and being all too aware of the statistics that makes this disease hell. And I've learned to live with this hell and even become brilliant at it at times – and I didn't want him minimizing all that with his glib, 'Of course'.¹

This evocative 'rant' was more dramatically revealing than material from the transcripts. We felt it belonged, and paralleled the data gathered through the broader research process.

Audience feedback

Questionnaires were distributed at performances held for both health professionals and the general public. From seven Ontario cities, attendees at public performances returned 507 questionnaires (estimated as 60–70% of attendees). Many attending the public performances were themselves cancer patients (41%), were family members or friends of patients (48%) and/or were health professionals or volunteers working in a health care context (48%). Audience members checked as many of these categories as applied to them.

All (100%) of those attending presentations for the public agreed or strongly agreed that they enjoyed the drama, and that they benefited from seeing it. Similarly, 99% agreed or strongly agreed that there 'was a lot of truth in this drama'. The vast majority (99%) also agreed that the fact that the research was based on research made it more 'true to life'. Most (96%) expressed a desire to see other dramatic productions about living with cancer. Any respondent who did not agree or strongly agree with statements chose 'neutral' as their response. No respondents disagreed or strongly disagreed with any of the statements.

Open-ended comments on questionnaires most often expressed the interest and enjoyment of audience members, and/or their resonance with the material that was presented:

I was blown away. You said everything I ever said.
I wish my family could see this.

This is a much better way of getting research results across than a written report.

The production helped me to understand what my sister is going through.

An excellent performance! Must be seen by many, many more patients, family and caregivers.

Other types of comments included those where respondents made suggestions about future productions, or about aspects that might warrant further elaboration:

Suggest perhaps stressing difficulties with children, especially teenager reactions.

Might be beneficial to actually include some family members as actors.

I feel strongly that you should have this drama on tape, so that more patients, relatives and doctors can learn from it.

Feedback forms ($N = 249$) were gathered from health professional audiences in eight Ontario cities (estimated as 40–50% of attendees). More forms would have been returned if the discussion facilitator (RG) had not (annoyingly and repeatedly) forgotten to ask audience members to be sure and complete them. All (100%) members of health professional audiences who completed the feedback form agreed or strongly agreed that they enjoyed the presentation and that the format of the presentation was engaging. Very importantly, all attendees also agreed or strongly agreed that the use of research transcripts to create the presentation 'increased its validity substantially'. Most (95%) were in agreement that dramatic presentations like *Handle with Care?* have a place in hospital rounds. Most also felt that the issues presented were relevant to (95%), and useful for thinking about (93%), their clinical practice. For the above items, any respondents who did not agree or strongly agree with statements chose 'neutral' as their response. No respondents disagreed or strongly disagreed with any of the statements:

Everything was great! You forget that there's a real person that you are dealing with rather than just a 'breast' or a 'brain'.

Being currently in training to be an oncologist, this presentation increases my awareness about what the patients go through. It will help me to be a better doctor.

Engaging format; quick pace; variety; hats off!
What a novel way to present research findings!
How could you not be glued to every word?

Additional evaluation activities are currently underway, including in-depth interviews with selected audience members, and interviews over time with key persons (actors, researchers, breast cancer patients) involved with the development of the production.

Discussion

Our experience with *Handle with Care?* has led us to conclude that dramatic presentations of research results have tremendous power to trigger individual insights and positive change. In part, we wonder whether the overwhelmingly positive response to this project about metastatic breast cancer is due to the societal avoidance of issues related to serious illness, dying and death. Have we helped to fill a gap, or create a place for discussion where there has mostly been silence? Whilst our topic may have helped to ensure success, we are aware that similar positive responses to research-based theatre have been achieved by others in relation to different content.^{16,17} Clearly, more than just the relevance of the topic influenced the success of *Handle with Care?*

One aspect of media in modern times has been to simplify and sensationalize important life issues.²³ In the case of advanced illness and dying, Hollywood movies and television programs have made us witness to countless heroic struggles by ill people who refuse to give in to their dire predicament. Many of these screen heroes overcome formidable odds and beat death. If they don't beat death, they at least bring rich meaning to their dying days. The predominance of this type of narrative blocks out other potential narratives,⁵ reducing the places in which ill people and their families can recognize their own complex reactions and even

potentially reducing their options for coping. The inclusion of multiple voices and perspectives in productions like *Handle with Care?* allows for more points of recognition for audience members, thus helping to normalize their experiences, and also extending the meanings that can be created and derived from illness. This approach is in keeping with the insights provided by postmodernism, such that unitary, streamlined versions of truth are understood to always obscure and limit the full range of lived experience.^{5,6,24}

The feedback we received from both health professional and public audiences revealed that the research foundation for *Handle with Care?* was important for ensuring a sense of relevance. This finding is critical, and argues for the importance of programs within the health care context that consciously employ systematic research to mould dramatic productions. Whilst theatre can certainly be profound without a research base, audiences that are oriented towards empiricism (e.g. health professionals) appear to be more receptive and comfortable with 'data' that have been accumulated within traditions of inquiry that they respect.

It is worth reflecting further on the roles played by the two women with metastatic breast cancer involved with this project. Whilst it is correct to say that they helped to inform and educate the rest of the cast about the realities of metastatic disease, it would be a mistake to view this process as a purely cognitive one. Clearly it was not. Indeed, the women's major contribution to ensuring the integrity of the project may have been to create an empathic starting point for others to enter the transcript material. It was in listening to the stories about their lives, and in coming to care about them as people, that we entered more fully into the meanings of diagnosis for their lives and for the lives of the people around them. From this, we were able to engage in a more direct and emotional way with the research data, to understand it more fully, and to carry that understanding into our performances.

Learning as we go

Qualitative research often generates great mounds of typewritten transcripts, and our project with women with metastatic breast cancer has been no exception. Although it was important for the cast to read through full transcripts, in future work we would seek to also organize quotes according to codes or themes, thereby allowing readier access to pertinent material. This organizing might best be accomplished with the support of a computerized data analysis program.²⁵

The initial phase of our work on *Handle with Care?* was bumpy at times. The transfer of key pieces of information did not occur in a straightforward manner. For example, it took a long time for the group to understand the implications of 'metastatic' cancer, partly because of lack of clarity by the researchers and partly because of cast members' resistance to painful realities. Similarly, the process of developing a theatrical production might have been better described at the beginning, thereby allowing for more successful advance planning. In future work, we will attend more fully to up-front communication of basic information. This is not to suggest that we think it is possible, or even desirable, to remove uncertainty and confusion from the process of developing a dramatic piece. Indeed, the shared struggle to find our way in dangerous emotional terrain was important to our creative process.

All of the actors involved with *Handle with Care?* have expressed appreciation for their experiences with the project. Indeed, everyone has become highly committed to the continuation of the production beyond its original schedule. We have had an enormous amount of fun and the cast has grown very close to each other. But having said this, actors were not always prepared for how difficult it was at times to deal with our topic. It might be helpful therefore to spend more time at the beginning of a project talking about possible reactions to the material. This is not likely to alter the challenge associated with engaging emotionally with the

project, but it might help people better recognize and understand what they were going through.

Particularly for the women with breast cancer, reading the transcripts was distressing at times. Women who were well following initial treatment for cancer were forced to face their own risk of recurrence, and worries surfaced about their health. One woman with no history of breast cancer had recurrent dreams about being diagnosed. And everyone felt anticipatory sadness about the possibility of losing members of the cast to the disease. These experiences have reinforced for us the importance of providing openings to discuss issues that arise in the course of developing a dramatic piece.

We had rich data sets to draw from to help us shape the roles of patients and oncologists in *Handle with Care?* However, we did not conduct interviews with family members and friends, which constrained our understanding of their issues. Although most feedback about our characterization of family issues in the production has been positive, we are aware that our depictions were less textured and sympathetic than for women with breast cancer and health professionals. In future, we hope to take a more comprehensive approach to establishing a research foundation for dramatic productions.

Final comments

The linking of qualitative research to dramatic productions has enormous potential for making research more vital and useful in health care settings. Productions like *Handle with Care?* provide practicing health professionals with an opportunity to reconnect, in deep ways, with the issues facing ill people, and to also reflect on their own contributions to patients' suffering and/or healing. Research-based drama can also be an extraordinary vehicle for training health professionals. Drama shows concretely the dilemmas surrounding issues, such as how to communicate prognosis to a person with non-curable disease. Even more importantly, it takes audience members beyond a preoccupation with techniques and goals, to an empathic experience with the ill person. It is exactly such empathy

that is arguably the precondition for transformation of health care.

As this new field of research-based theatre continues to grow it will be important for more researchers to detail the process they go through, including their many (inevitable) mistakes and dilemmas as well as their resolutions. It will also be important to study the ongoing effects of dramatic productions, in order to better understand benefits and limitations. In the process, it will hopefully become possible to articulate the core elements that allow research-based theatre to make a positive difference outside of academia, in clinical and community settings.

Acknowledgments

We wish to thank Mary Sue Douglas and Jan Livingston for their many contributions to the development of *Handle with Care?* and to also acknowledge the work of all of the actors and writers at ACT II Studio who helped to make this project possible. Funding for the original research that informed *Handle with Care?* was provided by the Ontario Breast Cancer Information Exchange Partnership, whilst funding for developing the dramatic production came from: the Canadian Breast Cancer Foundation, the Canadian Cancer Society, Novartis Canada, Pharmacia and Upjohn; Zeneca Pharma, Rhône Poulenc Rorer, and GlaxoWellcome Inc.

References

- 1 Ivonoffski V, Gray RE. *Handle with Care?: Women Living with Metastatic Breast Cancer*. Toronto: Toronto-Sunnybrook Regional Cancer Centre, 1998.
- 2 Gray RE, Greenberg M, Fitch M, Sawka C, Hampson A, Labrecque M. Information needs of women with metastatic breast cancer. *Cancer Prevention and Control*, 1998; 2 (2): 57–62.
- 3 Gray RE, Fitch M, Sawka C. The perspectives of medical oncologists regarding women's experiences with metastatic breast cancer. (theatre script, in preparation).
- 4 Richardson L. Writing. A method of inquiry. In: Denzin K, Lincoln Y (eds) *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage, 1994; 516–529.

- 5 Mienczakowski J. Theatre of change. *Research in Drama Education*, 1997; **2** (2): 159–172.
- 6 Denzin N. *Interpretative Ethnography. Ethnographic Practices for the 21st Century*. Thousand Oaks, CA: Sage, 1997.
- 7 Conquergood D. Rethinking ethnography: Towards a critical cultural politics. *Communication Monographs*, 1992; **58**: 179–194.
- 8 Mienczakowski J. An ethnographic act: The construction of consensual theatre. In: Ellis C, Bochner A (eds) *Composing Ethnography: Alternative Forms of Writing*. Thousand Oaks, CA: Sage, 1996.
- 9 Watkins P. All the world's a stage. *Nursing Times*, 1990; **86** (21): 47–48.
- 10 Bates RA. Popular theatre: a useful process for adult educators. *Adult Education Quarterly*, 1996; **46**: 224–236.
- 11 Filewood A. *Collective Encounters: Documentary Theatre in English Canada*. Toronto: University of Toronto Press, 1987.
- 12 Jackson T. *Learning Through Theatre*. New York: Routledge, 1993.
- 13 Mienczakowski J, Smith R, Sinclair M. On the road to catharsis: a theoretical framework for change. *Qualitative Inquiry*, 1996; **2** (4): 439–462.
- 14 Ellis C, Bochner A. Telling and performing personal stories; The constraints of choice in abortion. In: Ellis C, Flaherty MG (eds) *Investigating Subjectivity: Research on Lived Experience*. Newbury Park, CA: Sage, 1992.
- 15 Paget M. Performing the text. *Journal of Contemporary Ethnography*, 1990; **19**: 136–155.
- 16 Paget D. Verbatim theatre: Oral history and documentary techniques. *New Theater Quarterly*, 1987; **12**: 317–336.
- 17 Saldana J. Ethical issues in an ethnographic performance text: The dramatic impact of juicy stuff. *Research in Drama Education*, 1998; **3**: 181–196.
- 18 Mienczakowski J, Morgan S. *Busting: the Challenge of the Drought Spirit*. Brisbane: Griffith University Reprographics, 1993.
- 19 Mienczakowski J. *Syncing Out Loud: a Journey Into Illness*. Brisbane: Griffith University Reprographics, 1992/1994.
- 20 Mienczakowski J. Ethnography in the hands of participants: Tools of dramatic discovery. In: Walford G, Massey A (eds) *Studies in Educational Ethnography*, Vol. 2: *Explorations in Methodology*. Oxford: JAI Press, 1999.
- 21 Ontario Breast Cancer Information Exchange Project. *Living with Metastatic Breast Cancer. A Resource Guide*. Toronto: OBCIEP, 1998.
- 22 Mitchell RG, Charmaz K. Telling tales, writing stories. *Journal of Contemporary Ethnography*, 1996; **25**: 144–166.
- 23 McClaren P. *Critical Pedagogy and Predatory Culture: Oppositional Politics in a Post-modern Era*. London: Routledge, 1995.
- 24 Gray RE. Four perspectives on unconventional therapies. *Health*, 1998; **2** (1): 55–74.
- 25 Richards TJ, Richards L. Using computers in qualitative analysis. In: Denzin NK, Lincoln YS (eds) *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage, 1994.