Arts-informed Research for Public Education: 
The Alzheimer’s Project

Ardra L. Cole and Maura McIntyre
Ontario Institute for Studies in Education
of the University of Toronto

We take seriously the challenge of the conference theme to “think about policies and practices that chart the course for our contemporary learning society.” We respond to this challenge with an invitation to join us in an imaginary tour of a seven-part multi-media exhibit of our research, “The Alzheimer’s Project”, displayed in a prominent public historic site in Halifax, Nova Scotia. In this venue and through our work we articulate and demonstrate a methodology that has a central agenda of making social science research accessible to audiences beyond the academy. We introduce community centred arts-informed research as the methodology that drives our research purposes of public education and community development and supports our commitment to the preservation and advancement of human dignity in the contexts of research and health care education.

The Exhibit

The venue: Pier 21 National Historic Site located on the harbourfront of Halifax, Nova Scotia; gateway to Canada for over a million immigrants between 1928 and 1971. The restored building is now a museum and tribute to those people. The Alzheimer’s Project occupies an expansive space on the second floor of the building near the entrance to the main exhibition hall. Floor to ceiling windows overlooking Halifax Harbour provide a backdrop to the exhibit creating an ambience of quiet reverence. As you approach the second floor via an escalator you cannot help but notice a free-standing clothesline running parallel along the full width of the escalator bay. You reach the top and pause to take stock of what is around you.

A large plexiglass sign at the top of the escalator grabs your attention: “The Alzheimer’s Project”. A floral arrangement on an adjacent table invites you to take a closer look. You stop at the table to look over information about the display, about Alzheimer’s disease, and about the artist-researchers and their work. A fact sheet positioned on a small easel reveals some startling statistics about Alzheimer’s disease. You learn that:

- There are 18 million people in the world with dementia.
- It is estimated that 30 million people worldwide will have Alzheimer’s Disease in the year 2025 (Post, 2000).
- In 2001, some 364,000 Canadians had Alzheimer’s Disease or a related dementia.
- More than half the population knows someone with the disease. One quarter of Canadians have a family member affected.
- There were an estimated 83,200 new cases of dementia in 2001.

1 The Alzheimer’s Project was exhibited at Pier 21 National Historic Site in Halifax, Nova Scotia from May 26-June 4, 2003. During this period we presented a version of this paper in situ as part of the CASAE Conference.
• 1 in 13 people over age 65 is affected, 1 in 3 over age 85.
• More than two-thirds are women.
• About 50% are cared for at home and most caregivers are women (Alzheimer Society of Ontario, 2001).

Your curiosity is piqued when you look to your left and see what look like free-standing refrigerator doors. You move closer and notice that there are three refrigerator doors arranged in chronological order, each reminiscent of a different era. The front of each door is partially covered with photographs secured by magnets. “Just like my fridge at home,” you think to yourself as you step closer. You study the black and white images on the first fridge door and see snapshots of a young mother and daughter—baby, toddler, adolescent—involved in a variety of everyday activities. You study the images long enough to get a sense that the relationship depicted looks quite ordinary. Mother, with horn rimmed glasses and red, red lipstick is young and vital. Daughter is infant, is baby, is girl, is teen. Mother, a young professional, is getting into the car, working in the kitchen. Daughter is baby in the bath, toddler running on the grass, irreverent adolescent sitting on the kitchen table. Together they are beside the wading pool, at the table eating, walking through the snow. You move to the next fridge and notice that some years have passed: the refrigerator door is more modern, the images are in colour, and mother and daughter are older. You see snapshots of two adult women enjoying life and each other. You take in the story being told and feel like you are almost part of it. You move on to the third and final fridge door. Immediately you realize that the mood of the story has changed and that the characters in the story have switched roles. Daughter is now feeding, bathing, and caring for mother whose illness is very apparent. You step back and do a visual sweep to read the relationship narrative laid out before you. You pause to reflect, looking out over the calm waters of the harbour, and then walk along a few steps further.

On a free-standing partition a short distance away you spot a series of large black and white photographs. They draw you closer. As your eyes sweep from left to right you read a visual narrative of a mother-daughter relationship across a life span—mother holding newborn baby to baby-now-adult holding ill mother. Immediately below the photographs on a table is a set of eight small handmade books resting on individual stands. It seems that they are meant to be read so you pick one up. It fits comfortably in your hand and you turn back the hard black cover. On each page, in hand-printed, silver lettering, is written one or a few words. You read slowly, savouring each word, turning each page with a quiet reverence. You move to the next book and the next; each one tells a different relationship story, of the intimacy of human connection. As you replace the last book on its stand you pause to look again at the photographs. The partition has two sides and so you move to see a set of eight large framed photographs hanging in a row. The matted and framed black and white photographs appear normal from a distance. As you step up to them, however, you realize that the images appear out of focus. A closer look reveals that there is another image superimposed on each that is creating a distortion and obscuring your view. It is a transparent image of an aging and ill woman with a vacant, gaunt look. Her haunting eyes draw you in, fix your gaze. It is difficult to get past that look, to see beyond to the background image. When you do, you see a little girl in old-fashioned attire standing in what might be the backyard of her home. The next image, also overshadowed by the ill woman, is of a young woman perhaps in her late teens. With chin resting on elbows she leans over a high fence, a piece of straw clenched in her broad, confident smile. You fill out the rest of the story in your mind. Each of the eight images captures a moment in a woman’s life as she grows through childhood, adolescence, adulthood, marriage, motherhood, and
grandmotherhood. This is herstory but you have difficulty keeping it in focus; the ill woman commands your attention.

As you reach the end of the partition you encounter another image of an aging and ill woman; this one is larger than life and affixed to a mirror suspended less than a metre above the floor. She is obviously in an institutional context and you recognize that same steady gaze demanding your attention. As you respond to her demand you realize that you have entered the picture. Beside her image you see your own reflection. You pause to take it in. Herstory/Yourstory the title says. You wonder.

You are closer to the clothesline now and you return your gaze to it and slowly walk its length. You trace the line of laundry from baby’s diaper to lace garter belt to multi-hooked brassiere to adult diaper. The overwashed, white, female undergarments mark the shift in personal power and changing nature of dependence across a life span. You are tempted to move closer to the adorable baby’s undershirt to see if it smells like powder; you giggle to yourself as you imagine slipping away to try on the padded push-up bra; you groan as you recognize the full-size nylon panties with the elastic waistband slightly stretched; and you pause in silence in front of the adult size diaper hanging heavily at the end of the life line. A small basket of tiny, brightly coloured clothespins sits on a small table at the end of the clothesline. You choose one, pin it to your lapel in a gesture of solidarity, and continue your tour.

Off to your right you spot a warm and inviting scene—a welcome respite from the emotional intensity of the earlier pieces. Three vintage card tables and folding chairs are clustered around a bright red, wool rug with a large heart at its centre. “Loving Care” the sign reads. You notice that a couple seated at one of the tables is hovered over a Scrabble™ game; C-A-R-E, L-O-V-E, R-E-L-A-X, S-O-F-T. You catch on to the theme. Another table is set up with pencils and tear-off pads of word puzzles. “Why not?” you think to yourself as you pull out a chair and take a seat close to the full dish of candy. You choose a word search game, pick up a pencil, and begin to circle letters. When it is time to leave the area you pass by the third table where a jigsaw puzzle is set up. You pause long enough to add a piece to the puzzle and walk on.

Two framed cross-stitched samplers hanging side by side catch your eye. In one the colours are youthful and hopeful; the border pattern of hearts and flowers suggest growth and life. The muted colours of the other are solemn, quieter. As you read the words delicately stitched into the cloth you begin to realize that each sampler tells a story. One chronicles the progress of healthy cognitive development from birth to independence; the other traces cognitive decline for a person with Alzheimer’s disease from early to advanced stages. The homely quality that drew you close to read the work evaporates as you take in its meaning.

Slightly shaken, you glance over to the final piece where you are met with an invitation to: Help us Remember…. Leave a memory (a poem, story, picture, memento etc.) about caregiving. You see a corkboard and cloth-covered table set up to collect and display memories of care and caregiving. Affixed to the corkboard and within a memory box and scrapbook are photographs, recipes, poems, scribbled reminders, torn fragments of notes and letters. The different sizes and shapes, handwriting, photo quality and paper texture displayed make it clear that the objects come from different people and places. The objects on the table—a doll, a string of beads, a Wandering Registry bracelet—give you pause. You remember your Aunt Dora and start thinking about a memento that you might bring back to add to the collection. For the time being you open the journal and write her name.
Your memories of Aunt Dora combine with your other varied responses to the exhibit. On your way out, back at the information table, you stop, pick up one of several notebooks and a pen, take a seat, and begin to write.

The Project

The context of our work is Alzheimer’s Disease and caregiving. In our program of research we have a three-fold commitment to: knowledge advancement, public education, and community development. With respect to knowledge advancement, our intention is to advance cultural and social understandings of Alzheimer’s Disease through a lens which honours the personal and socio-cultural context within which Alzheimer’s disease is situated and lived. We extend our work beyond the walls of academic institutions and into communities where we provoke and facilitate dialogue among the general public and care providers (family members and health professionals). This action is rooted in the belief that social science research must reflect a responsibility and commitment to serve the public and contribute to society as a whole.

Methodology

We describe our research approach as community based and arts-informed. By community based research we mean research that:

• is situated in communities (beyond the academy)
• conducted for communities (beyond the academy)
• acknowledges the ‘everydayness’ of knowledge construction and multiple ways of knowing
• seeks to produce data in community for both local and broader representation.

By arts-informed research (Cole, 2001; Neilsen, Cole, & Knowles, 2001; Cole, Neilsen, & Knowles, 2003) we mean research that brings together the systematic and rigorous qualities of scientific inquiry with the creative and imaginative qualities of the arts. Such inquiry processes are organic and fluid and the research representations move beyond unidimensional, text-based discourse. In so doing the process of researching becomes creative and responsive and the representational forms for communication reflect the multi-dimensional qualities of lives through multimedia forms.

Discussions about and examples of the role of arts-informed research methods in accessing and representing knowledge can be found in, for example: Bagley and Cancienne (2002); Cole and Knowles (2001); Cole, Neilsen, and Knowles (2003); Diamond and Mullen (1999); Gray and Sinding (2002); Mullen and Diamond, (2001); Neilsen, Cole, and Knowles (2001); O’Sullivan, O’Connor, and Morrell (2001). Representations of research using arts-informed methodologies in education vary according to research purposes and perspectives. When the purpose of art is “to break through the conventionalized and routine consciousness” (Dewey, 1931, p. 184) arts-informed representations become the medium for messages needing to be heard. In our research, our commitment to moving research into community drives our methodology, and we look to the arts for inspiration and guidance.

With funding from the Social Sciences and Humanities Research Council of Canada we are taking the research exhibit to three locations across the country, one of which is Halifax, where it will be displayed for ten days in a prominent public venue. In each location we invite the public and family caregivers to people with Alzheimer’s Disease to view the work and talk with us about their experiences of Alzheimer’s Disease and caregiving. In this way the exhibit both
represents and generates data thus creating an ongoing cycle of inquiry. Thematic analysis of data gathered through interview, anecdotal reports, and literature review provides the inspiration for the exhibits. Audience responses, variously gathered through focus group discussions, written comments, and/or audio-tape recording, become new data which then form the basis for subsequent analysis and new representation.

Implications and Significance

Universities and granting agencies are becoming increasingly responsive to demands that research activities be more relevant or community centred and accessible to society at large (Renaud, 1998). It is simply not enough that an inquiry is intellectually solid, that it is respected by peers, that the findings are insightful and that the researcher has developed a certain wisdom about the topic. Has the work been heard by those people for whom it is for and about? How have lives been changed for the better? How has the research cast light on problems and their resolution within individuals, families and communities? How has the work made a difference? So what? In the context of social science research in the contemporary world, the answer to the “so what” question demands the acceptance of a moral ethic and responsibility to the affairs of society at large. Social science researchers must be accountable to all those who have a stake in knowledge advancement—academics, funding agencies and sponsoring institutions, policy makers and professional and public communities. To do so requires attention to how research reaches these diverse communities. To do so requires creative and imaginative attention to what work we have to do, in practical terms, to make our work accessible to people outside the academy. To do so requires us to remember why it is important to make our work significant to others.

Acknowledgements

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References
