

CONFRONTING NARRATIVES OF LOSS: *Art and Agency in Dementia and Dementia Care*

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DEMENTIA HAS FOR MANY centuries been understood as a condition of old age, making it a time of loss and decay; that is, in the words of William Shakespeare, “sans teeth, sans eyes, sans taste, sans everything.” While in more recent decades dementia has been brought into public view as a form of illness framed in terms of declining brain function, this narrative of loss has persisted. It is seen in the atomistic focus on the emergence of *symptoms* such as loss of inhibition, loss of capacity, and loss of memory. People with dementia are framed as *tragic figures* – patients, residents, or clients who are in need of care to treat and combat their functional and cognitive limitations. This view through a lens of pathology brings *disability* and *incapacity* into focus, perspectives that are well understood within biomedical and/or psychological models of illness.¹ They serve as the master narrative fuelling the belief that dementia and its associated symptoms of loss define the person’s experience, their relationships, and their identity.

These commonly held assumptions can lead to significant harmful social consequences for people living with dementia and their families. Indeed, a diagnosis of dementia can be socially maligning,² leading

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¹ Sherry L. Dupuis, Elaine Wiersma, and Lisa Loiselle, “Pathologizing Behavior: Meanings of Behaviors in Dementia,” *Journal of Aging Studies* 26, 2 (2012): 162–73. In this study of long-term care homes in Canada, Dupuis and colleagues challenge the predominant biomedical understanding of behaviours in dementia, which often overlook the root cause of a person’s response to specific circumstances, leading to unaddressed need and unnecessary suffering. The authors’ arguments help to shift the debate by forwarding a multidimensional understanding of responsive behaviours in dementia that considers the interactional and broader socio-political levels. In so doing, this article challenges the prevailing understanding of dementia based in discourses of pathology.

² Thomas Kitwood, *Dementia Reconsidered: The Person Comes First* (Buckingham, UK: Open University Press, 1997). Kitwood’s seminal work on personhood in dementia in the mid- to late 1990s challenged maligning care practices in dementia care settings. This work, alongside that of his colleagues at the Bradford Dementia Group, United Kingdom, set the stage for

to the person being “unjustifiably rendered shameful, excluded, and discriminated against,”³ denied opportunities for choice and inclusion, and denied her or his rights and entitlements as citizens.⁴ Proponents of the notion of social citizenship in dementia have significantly contributed to problematizing this dominant “narrative of loss.” Bartlett and O’Connor define social citizenship as “a relationship, practice or status in which the person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible, [with a sense of] purpose and community.”⁵ Rather than focusing on individual needs, this is a rights-based discourse that challenges the structural stigma surrounding aging and dementia. It recognizes that although people with dementia might need particular kinds of support, as human beings they have the right to demonstrate agency to make decisions and participate as active citizens.

Recently there has been growing recognition that the arts might play an important role in supporting social citizenship for people with dementia. Though arts programs in dementia care settings have a much longer history, research has focused mostly on the therapeutic question, asking how art might serve as a form of remedial care. Two recent Canadian studies have instead framed the question through a lens of social citizenship. One project conducted in British Columbia examined the role of public art to facilitate the inclusion and social citizenship of people with dementia.⁶ Researchers observed that, when people with dementia were

worldwide efforts to humanize dementia care (i.e., person-centred care), emphasizing positive conceptualizations of dementia, the importance of the social context to well-being, and valuing the subjective experiences of individuals living with dementia. Yet, while these efforts have significantly contributed to reshaping the narratives of loss, the biomedical discourse based in pathology as observed by Dupuis et al. “Pathologizing Behaviour” remains a powerful force by which dementia is understood and witnessed.

³ World Health Organization, *Reducing Stigma and Discrimination against Older People with Mental Disorders* (Geneva: WHO, 2002), 8.

⁴ Ruth Bartlett and Deborah O’Connor, *Broadening the Dementia Debate: Towards Social Citizenship* (Bristol: The Policy Press, 2010), 37. Whereas Kitwood’s work centres on the micro-level context, including immediate interpersonal relationships and care environments, Bartlett’s (UK) and O’Connor’s (CA) foundational work on social citizenship in dementia expands the focus from the individual to the social and political context vis-à-vis a rights-based discourse that considers larger macro-level enablers and barriers to meaningful participation in civic life.

⁵ *Ibid.*, 37.

⁶ Elizabeth Kelson, Alison Phinney, and Glen Lowry, “Social Citizenship, Public Art and Dementia: Walking the Urban Waterfront with Paul’s Club,” *Cogent: Art and Humanities* 4, 1 (2017): 8–12, doi: 10.1080/23311983.2017.1354527. Along with Sherry L. Dupuis, Pia Kontos, Gail Mitchell, Christine Jonas-Simpson, and Julia Gray, “Re-Claiming Citizenship through the Arts,” *Dementia* 15, 3 (2016): 358–80, Kelson and colleagues’ important work applies the notion of social citizenship to the context of art viewing and art making. This work reflects the growing interest in participation in the arts as a way for individuals living with dementia to

afforded access to public art, they were enabled to more fully participate as members of a community. Work conducted by Dupuis and colleagues in Ontario also focused on outcomes related to citizenship.⁷ This project brought together people with dementia, family members, visual and performance artists, and researchers to co-create artistic reflections on what individuals with dementia and their families wanted the world to know about them. Eight visual and poetic expressions were created, illustrating that, despite loss, people with dementia remain active, engaged, and contributing members in relationships and in society.

While these studies hint at the potential for art to support the social citizenship of people with dementia, for the most part, arts practice in dementia and dementia care remains on the margins where it is under-valued, under-funded, and under-subscribed. In this position, it is uniquely vulnerable to pressures of discourse around evidence-based practice. In other words, for the arts to become a full and valued partner in enhancing the lives of people with dementia, there needs to be research showing its benefit.

As scholars committed to knowledge development in this area of arts practice in the context of dementia and dementia care, the purpose of this article is to offer a novel contribution to the growing evidence-based discourse on the use of visual arts in dementia care. Specifically, we present a dialogue between the authors discussing a recent project, *Making Art for Making Place*, that explored the impact of visual art for people with dementia in a transitional care facility located in Surrey, British Columbia.

This article began life as a jointly authored essay, but we quickly became bogged down in formalities and structures that were not doing justice to the complexity of the ideas we wanted to explore. With some inspired direction from our colleagues, we took the narrative turn as a way to better expose the cross-current of scholarship and ideas by which we have each been informed and inspired. GP is a postdoctoral researcher at the W. Maurice Young Centre for Applied Ethics (UBC), whose program of research involves the development of arts-based methodologies in end-of-life dementia care, and AP is a nurse whose research has examined arts-based approaches for supporting people living with dementia. She was also the primary investigator of the research component of this project.

reclaim agency, participate in and contribute to community, and disrupt the tragedy discourse, as referenced earlier.

⁷ Dupuis et al. "Re-Claiming Citizenship."

The dialogue below has its origins in a lively daylong conversation between the two authors. This conversation was recorded, transcribed, printed out, cut into parts, and reorganized. We met twice more to read it together, introducing pictures and additional related literature, and engaging in further conversation that allowed us to incorporate new ideas that had emerged and to pursue other ideas in greater depth. GP took the lead in knitting this all together into a coherent narrative.

We begin by first orienting the reader to *Making Art for Making Place* and to the broader British Columbia context in which it unfolded. We then move into a conversation about the process and what was learned through the placement of original, newly created artwork within this transitional care facility. Finally, by way of conclusion, we reflect on the impact of this project.

GP: This project, which was conducted between 2013 and 2016, brought together an architect, an artist, and a nurse – an unusual trio with different disciplinary commitments coming together for a common purpose. Can you describe the inception of the project?

AP: As British Columbia’s fastest growing city, Surrey has long identified the need for a new hospital. By 2013, the regional health authority had plans in place that included a facility for patients designated as “Alternate Level of Care” (ALC). Many of these are older people with dementia who are ready to be discharged from hospital, but because they are no longer able to live independently at home they remain in care, waiting for a nursing home bed to become available. Given the pressures of British Columbia’s aging population and the ever-increasing numbers of people with dementia, it was well understood at the time that there was an immediate and pressing need that could not wait for the new hospital to be finished in three years’ time. A temporary solution was found in Yale Road Centre, a 1970s-era nursing home that would be repurposed to serve as a 140-bed transitional care unit (TCU).

Michael Wilson, as senior facilities planning leader with the health authority, was responsible for the renovations. The budget and timelines were very tight. The team was given six months before patients were due for admission, and most of the budget was devoted to physical upgrades to meet safety requirements. Apart from the selection of paint colours for the walls, there was no budget for anything that might be considered an “extra.”

Given these restrictions, Michael conceived the idea to partner with Emily Carr University of Art + Design (ECUAD) to create original art for the patient units and common areas. His idea was not only to create a welcoming milieu but also to provide a more supportive environment for the high proportion of patients who were living with dementia. With his educational background in architecture, Michael had been deeply influenced by the work of Kevin Lynch,⁸ an urban theorist who had written about how different elements of a space allow people to find their way around. Michael was also a strong proponent of evidence-based design and advocated for the project to include a research component. So he acted as a broker, bringing together Landon Mackenzie, an artist and teacher from ECUAD, and myself, a nurse and researcher from the University of British Columbia (UBC). We were both excited to join this project in creating art for this transitional care setting and studying its impact. Of course, the timeline was not completely under our control. Landon designed this as a class project, which meant that we were working within the confines of an academic term, and it was several more months before we were able to secure research funding and recruit doctoral students to assist with the project. Ultimately, it all happened quickly. The art was created in the space of a few months, the residents moved into the newly renovated facility, and the paintings were installed all before we had really pulled together our ideas for how the research component would be conceived to include the perspectives of people with dementia, and certainly before we had all the resources in place.

GP: To clarify, the transitional care unit in Yale Road Centre was thus a repurposed unit to help alleviate congestion in the hospital setting – specifically by reducing the number of ALC-designated beds in Surrey Memorial Hospital. Yet we do know that this congestion was influenced by a confluence of a number of provincial home and continuing care policy reform decisions over the past twenty years or so. Namely, the prioritization of home-based care in the late 1990s (*Closer to Home* and *New Directions*) without significant investment to support this priority,⁹

⁸ Kevin Lynch, *The Image of the City* (Boston: The MIT Press, 1960).

⁹ Donna Vogel, “Unfulfilled Promise: How Health Care Reforms of the 1990s Are Failing Community and Continuing Care in BC,” in *Without Foundations: How Medicare Is Undermined by Gaps and Privatization in Community and Continuing Care*, ed. Marcy Cohen and Neil Pollak, 17–54 (Vancouver: Canadian Centre for Policy Alternatives, 2000). Along with the policy analyses cited below, Vogel critically examines policy changes in long-term and continuing care in British Columbia, which had a significant impact on access to services for

and the introduction of the policy *Continuing Care Renewal*,¹⁰ which resulted in the closure of over three thousand nursing home beds, to be replaced by an assisted-living model in the early 2000s. Concurrently, eligibility criteria for nursing home care shifted to higher levels of complex care needs,¹¹ and eligibility criteria for assisted living excluded many people living with dementia owing to safety concerns and the need for supervision beyond what an assisted-living facility may be able to provide. As such, these policy decisions resulted in individuals living with dementia who needed more support than what could be offered in their own homes, ineligible for assisted-living or nursing home services – notwithstanding the shortage in appropriate nursing home beds. It comes as no surprise then to observe persons living with dementia waiting in the hospital until something appropriate became available. And, given the congestion in hospitals, their having to wait for health authorities to search for more cost-effective solutions such as the opening of the transitional care unit at Yale Road Centre. Given this background, can you describe the residents of the transitional care unit?

AP: As a facility for people who were “in transition” between hospital and nursing home, the assumption was always that they would not be staying long – a week or two perhaps. Indeed, the unit itself was labelled a “short stay unit.” But of course this was all happening at a time when support for home care was being dialled back, and the bed supply in long-term residential care was stagnant. So, it was taking time, and people were staying for several months before a permanent living situation could be found for them.

These were people who needed help with their activities of daily living – preparing meals, getting dressed, even going to the bathroom. Many of the residents were in wheelchairs and did not have the upper-body strength to move about independently, and the vast majority also had some degree of cognitive impairment. For example, they experienced problems with their short-term memory and were sometimes disoriented. Their daily routine was simple: they slept in single- or double-bed rooms and ate their meals together in the main dining room. They watched

individuals living with dementia (i.e., they had no place to go when their home environment was no longer suitable to support their needs).

¹⁰ Marcy Cohen, Janice Murphy, Kelsey Nutland, and Aleck Ostry, *Continuing Care Renewal or Retreat? BC Residential and Home Health Care Restructuring, 2001–2004* (Vancouver: Canadian Centre for Policy Alternatives, 2005).

¹¹ Marcy Cohen, Jeremy Tate, and Jennifer Baumbusch, *An Uncertain Future for Seniors: BC's Restructuring of Home and Community Health Care, 2001–2008* (Vancouver: Canadian Centre for Policy Alternatives, 2009).

television in a small communal sitting room, and those who could, passed the time walking up and down the hallway. Occasional recreational activities punctuated their days – crafts and games organized by a recreational therapist.

There was lots of activity going on around them. The care staff were constantly on the move, and family members were coming in for rushed meetings during the day to discuss “placement plans” with the staff. But the residents themselves seemed apart from all this flurry. There was little for them to do.

GP: One of the goals of the project was to do research that would show the value of the arts in enhancing the lives of people with dementia who were living in a transitional care unit. How was this overarching purpose reflected in your research questions; and, considering the different disciplinary perspectives, did these questions change? And, if so, how?

AP: With the funding in hand, we conducted a focused ethnography over the following year to explore how people with dementia responded to the art on the walls. The research was organized around two questions: *Would these paintings help residents orient themselves in the environment? And would the paintings be emotionally and socially engaging?*

It took some time to land on these questions. Early on, Michael and I had thought it might be useful to explore the effect of art on patient aggression and irritability, and we envisioned an intervention trial to determine if these kinds of problems would diminish after the paintings were installed, asking, in effect, if art could be an effective “non-pharmacological intervention.” If art could show reduced behavioural incidents, that would be a very powerful argument. Eventually this approach was abandoned, in part due to the difficulty of gathering suitable data.

But the questions were also deeply influenced by the particular interests of the project team. Landon had questions about the content, about what the paintings depicted and how the art looked in the space, but these did not make it into the explicit questions we asked, in part because they were not necessarily posed as researchable questions. Given his background in architecture, Michael wanted to understand how art might aid in wayfinding for those with dementia. And, as it turned out, this was difficult to study in this setting as people were not allowed free reign of the space; their movements were tightly controlled and it was a fairly simple space to negotiate, being just a long single hallway. From a nursing perspective, the doctoral students and I were drawn to issues of

social and emotional engagement in the context of the care environment. We wondered how viewing art as an individual and social act contributes to place-making.

The research questions were thus an intersection of ideas, questions, and values; and, in some sense, they were undergirded by the different ways disciplines conceptualized or “language[d]” a particular idea. For example, by what psychologists would call “orientation,” by what architects or urban designers might call “wayfinding,” and by what is found in my own conceptual work, which draws upon phenomenology and Tim Ingold’s work on “wayfaring” (this being the idea that it is by walking or moving through an environment that one actually *creates place*).¹² These different languages sparked our way of framing the questions and the kinds of methods we used in looking at them.

GP: Before we come to that, I would like to address this conceptual piece about wayfaring and place-making, as it was these concepts, more so than orientation or wayfinding, that grounded this project. Place-making is about the co-creation of space and place that promotes people’s well-being through active participation in place;¹³ and wayfaring is about the primacy of movement and that intimate co-constitutive connection between the person and her environment as she moves through it. Some of your previous published work is about meaningful activity and the importance of physical activity and,¹⁴ more specifically, walking. And, your research with Paul’s Club specifically highlighted how walking was a way of being in the world and that it promoted social citizenship.¹⁵ Were there any learnings from your previous projects that inspired or informed this work at Yale Road?

AP: From those previous projects, we learned that people need to move, they want to move, they feel able, and they have the capacity. In addition, we knew that being out in places that are beautiful, and being connected in the world with others and doing something that could give back to

¹² Tim Ingold, *Being Alive: Essays on Movement, Knowledge and Description* (London: Routledge, 2011), xii, 9–13, 146–53.

¹³ Janine Wiles, “Conceptualizing Place in the Care of Older People: The Contributions of Geographical Gerontology,” *Journal of Clinical Nursing* 14 (2005): 100–8.

¹⁴ Jennifer McDuff and Alison Phinney, “Walking with Meaning: Subjective Experiences of Physical Activity in Dementia,” *Global Qualitative Nursing Research* 2 (2015): 1–9, doi:10.1177/233393615605116.

¹⁵ Alison Phinney, Elizabeth Kelson, Jennifer Baumbusch, Deborah O’Connor, and Barbara Purves, “Walking in the Neighbourhood: Performing Social Citizenship in Dementia,” *Dementia* 15 (2016): 381–94.

the community, was important. In *Making Art for Making Place*, we were not just interested in people who were physically able to walk, but this idea that people could move around in their world was hugely important. So that informed this study, even though Yale Road Centre was a much more impoverished and restricted environment than what I had previously researched. In this project, we made just this one change to the environment. We put really beautiful art on the walls and looked at the experience for those people who were moving about in that environment, even in this very restricted, tightly controlled way.

GP: The artwork then helped facilitate place-making in the sense that it gave an opportunity for residents to engage with objects of beauty while they walked through those hallways. This highlights the intersection of the built environment and the aesthetics of place. You mentioned earlier that the project began as a renovation of a 1970s-era nursing home. Adams and Chivers argue that these kinds of buildings are not only “dull in their gestures to unimaginative contemporary commercial hotel and motel structures,”¹⁶ but they are also influenced by the design of acute care hospitals to reassure families that the space provides care that is not available in the home environment. As such, these spaces have a particular “look” about them: recessed from the street, they look like small hotels, and inside there are long corridors, central nursing stations, with the dining room and recreation areas on the main floor, and resident rooms on upper floors. I can imagine that a key part of this project then was to transform an unimaginative space such as this into something more aesthetically pleasing. Can you give us a sense of what this space looked like?

AP: It is very much as you describe. You enter the main floor through secure double doors, the reception area is on your right, and a large dining room on your left. Really, it’s a somewhat unremarkable space. This dining room served all the residents of the facility who had access only when accompanied by staff who would unlock the elevators and bring them down for meals. On the far side of the dining room was a recreation and physiotherapy area, including an enclosed outdoor garden space, that was specifically used for residents of the acquired brain injury program (ABI), which was then not accessible to ALC residents. The ALC residents were located on three floors, which were

¹⁶ Annemarie Adams and Sally Chivers, “There’s No Place Like Home: Designing for Long-Term Residential Care in Canada,” *Journal of Canadian Studies* 50, 2 (2016): 273–98.



Figure 1. Yale Road Centre corridor. Photo by Michael Wilson.

basically indistinguishable from each other: long narrow hallways with private or semi-private rooms on either side, cinder block whitewashed walls, poor lighting, and a very low ceiling. Half of the width of the hallway was taken up with equipment: a lot of laundry, clean and dirty (Figure 1). It was so narrow that there would be just barely enough room for two wheelchairs to pass. A small seating area was located off the nursing station and there was no access to outdoor spaces. It was like a prison. The reason the nursing home had sold the space was because the building was in desperate need of renovation, but those renovations did not happen because of asbestos. And so, the health authority used this as a temporary place – though here we are, six years later and it has only just recently closed.

GP: Just the intervention of hanging beautiful art on the wall then contributes to place-making, in the sense that it has the potential to transform an impoverished space. Yet considering such an uninspired place, there was considerable pressure for the art to “stand out.” Can you describe the limitations of the space and how that relates to experiencing the art that was hung on the walls of the transitional care unit?

AP: This was a visually noisy place. There was a lot of signage: signs about infection control, about rules and regulations, and guidelines for

working in that environment. Pieces of paper that were behind plastic enclosures pinned up on the walls, and that would be beside a painting of downtown Vancouver, for example. When I use the word “noise,” that’s the kind of thing that I’m thinking about, but also the fact that there was a handrail along this wall and the art had to be above the handrail, which meant it was too high for people in wheelchairs, and that made it a big issue. The handrail needed to be there, but it created another kind of noise and barrier. You could see it in some of the video data that we gathered, someone straining their head back to look up to see the art. In terms of the limitations of the space, that was probably one of the important ones. The narrowness of the hallways, there were a lot of doors, and of course all the equipment littering the hallways. I describe the space as aesthetically impoverished. It wasn’t visually impoverished – there was a lot going on – but aesthetically, it was an impoverished space, very busy, and lighting was poor. These felt like very dark hallways. I’m reminded of all the research that has been done showing how lighting levels in nursing homes are appallingly low. This would be one of those places. I felt the art was not shown to its full effect.

GP: I’m reminded of the idea of visual noise and the Canadian composer and writer Murray Shafer’s notion of noise pollution and soundscapes,¹⁷ and how it’s difficult to be attuned to the acoustic or aesthetic environment because it’s overwhelmed and disrupted by all this noise. This is what seems to be happening in the visual sense. That the gentleman could not pick out the aesthetically pleasing bits among all the other visual noise is thus not surprising. This not only speaks to the competing aspects of the physical/aesthetic environment and the potential for the institutional environment to mute more home-like attributes but also to the challenge of implementing (and evaluating) this kind of intervention in these spaces.

AP: I think that’s quite important. Our findings are overwhelmingly positive and we really wanted to articulate and describe in some detail about how this was a “good idea” to put art here. However, the findings downplayed some of the challenges of the physical environment and hanging art in those spaces, except by way of contrast, saying that this was not a nice-looking space and so art was important. But that idea of something getting lost – when you think about, and pay attention to, the

¹⁷ R. Murray Schafer, *Soundscape: Our Sonic Environment and the Tuning of the World* (Rochester, NY: Destiny Books, 1977), 3–12.

noise, as in the auditory environment, in health care this is recognized as being very damaging for people, and there has been some work done in response to that, reducing the noise at least at night so people can rest. Clinicians have become more attuned to auditory environments and have made efforts to reduce noise stimulation; however, this is less so in terms of the visual environment, notwithstanding reducing stimulation in relation to safety. This is an area that needs much more attention and careful consideration, and makes us think of the visual environment in different ways. This has implications for why we might want to think about these aesthetics in long-term care and bring in things or experiences of beauty.

GP: While this research was not theoretically grounded in the notion of orientation or wayfinding, was there any impact in terms of physical environment that goes beyond the creation of a more aesthetically pleasing place?

AP: Yes, I think so. The paintings also acted as landmarks and way-stations, which served as distinguishing cues for residents. This was particularly important for those with impaired mobility who used the paintings as resting places along the facility's long halls. One gentleman talked about how moving from one painting to the next was as far as he could make it and he'd say, "Well, I'm going to stop for a rest by the 'sheeps,'" for example. So, he would move slowly down the hallway and that was his meaningful marker.

Part of what Michael was thinking about was creating a sense of being at home and how the paintings could be used to stimulate this. The residents didn't really speak about the paintings in terms of orientation, in part because they never saw any of the other units: they went back and forth between the main floor and their own floor.

However, one student had made a painting of a roll of toilet paper that had been placed in the hallway next to the public bathroom so it *could* serve as a sign. Residents sometimes had trouble finding the bathroom, and the thinking was that maybe a good piece of iconographic art would work to show them. And it totally did not. First of all, people had strong opinions about that image; it was not always their favourite. Second, the bathroom moved, and that roll of toilet paper, after the first eight months, was outside the nurses' station, which of course is quite ironic.

This says a lot too about trying to do a "rigorous" study when art is an unfolding process and when the health care context of the research

is itself unfolding. So it becomes a funny story to tell, not only in what people said about the piece but also because the intent was that it was to be used as an orienting cue. But as the nature of the practice and the real life context unfolded, it was not possible that it be used in that way.

GP: This brings us to the role of the artists. This was not just any art on the wall. The artwork was created specifically for this project by students from Emily Carr University of Art + Design. In this sense then, students themselves were integral to place-making. How did the students come to be involved in this project?

AP: When Michael first conceived the project, he had no preconceived notions about the kind of art that would be suitable, but with Landon Mackenzie on board, the choice made itself. As a renowned Canadian painter and teacher, she made this a class project for her third-year painting students in the fall of 2013. She drew the attention of sixteen ECUAD students who chose the class because they wanted to learn painting with her, only discovering that it included this special project once they were enrolled. It was a fairly diverse group of students of different ages and backgrounds. But all were at the point in their growth as artists of trying to define their artistic identity, exploring and developing themselves as serious artists. In some sense, this project took them away from that; it was for a particular social purpose, which was a dramatic departure from their usual headspace. Up to that point their education has been all about looking inward, expressing their inner self. But for this project, they were confronted with the need to be looking outward; they were going to learn about who this art was for.

GP: Given the shift in focus – from cultivating an artistic identity to the focus on arts for social change – how did the students respond to this project; and, how did they learn about creating art for a specific purpose, that is, for people living with dementia residing on a transitional care unit?

AP: Some of them really welcomed that, while others struggled with it a bit more. The diversity of the group meant they came with a wide range of experience and understanding about aging, mental health, and dementia. For example, one young woman had never really given much thought to old people and had a sense that she was creating art for “little old ladies.” The art needed to be “safe” she said. Others had life experiences that led them to think differently. One man, for example,

described how his own experience of mental illness allowed him to see the value in having the “cognitive layer stripped away.” He saw the potential for people with dementia to actually encounter art in a much more real and immediate way, and he really appreciated the opportunity to create something for that audience.

Michael and I came in to one of the early classes to explain the project and the ideas that lay behind it, and Landon brought in others to provide additional background from their perspectives as perceived experts in the field. This included a physician who talked with the students about dementia, and representatives from the health authority who explained some of the policies and guidelines governing what was considered appropriate subject matter for art in health care facilities, and for people with dementia specifically. As far as I am aware, no consideration was given to the idea of inviting someone with lived experience, either a person with dementia or a family member. While that might have been a missed opportunity, throughout the semester, Landon herself shared freely her own experiences with her mother, who had dementia and who had recently moved in to live with her. Landon’s personal observations and interpretations of her mother’s experiences were hugely influential for the students.

As a group they engaged in regular critiques, examining each other’s work and providing feedback, and in this way came to shape each other’s ideas about what would be “good art” for people with dementia. Much of this was what they imagined would be the case since the students never had the opportunity to meet the residents of Yale Road Centre or their families. However, there was a more public critique where the nurse researchers and health care facility design people were invited to provide some feedback, guidance, and opinions on the work. This was meant as a way to further guide the process, to see what was happening in the studio, and to come back to the purpose of the project by providing a different kind of commentary on how this might work in that kind of space and for those kinds of residents.

GP: There is a large body of evidence on design for dementia, particularly as it relates to colour, lighting, contrast, and the physical design of space. Were there any evidence-based guidelines on what kind of art would be most engaging for people with dementia? And were the students given any guidance or restrictions on what they could create?

AP: The health authority had rules about what could go on the walls: no religious iconography and no people, as there were concerns about exclusion. We were also counselled to not have foreground images of water – which has to do with the concern that people would feel they were “falling” into the space – and no abstraction because people with dementia would find that distressing. However, while we were doing this work there was evidence to suggest that these guidelines might not be right. The project *Meet me at the MOMA*,¹⁸ for example, has shown very clearly that abstract art is doing something rather special in the context of people with dementia. However, that was not the guideline given to the artists.

The guidelines were taken very seriously, although the students pushed these rules a little – a painting of a tree had water in the foreground, but the artist insinuated a bridge right in front. The limits on abstraction got some pushback because Landon had seen that her mother was quite captivated and intrigued by particular patterns in her environment, and she thought it would work, particularly with women who had a history of craft-making, creating visual objects that are quite structured, such as quilting, for example. So, she encouraged the students to think about abstract *patterns*, and what we learned was that those pieces were powerful (Figure 2).



I do like that one. It's kind of light and flowery, and it makes you feel light and flowery.

Figure 2. Cherry Blossom Pattern. Artwork by Wei S. Chen.

¹⁸ This is an artmaking and art-viewing project for individuals living with dementia and their care partners held at the Museum of Modern Art in New York City. See Francesca Rosenberg, “The MoMA Alzheimer’s Project: Programming and Resources for Making Art Accessible to People with Alzheimer’s Disease and Their Caregivers,” *Art and Health: An International Journal for Research, Policy and Practice* 1, 1 (2009): 93–97.

GP: We've touched upon how art, in of itself, contributes to place-making and the role the students had in creating art for a *specific* purpose. This brings us to thinking about place-making in the context of the interactional environment and the methods you used for this study. You took a more participatory approach to data collection. The doctoral students from UBC conducted "walk-along" interviews with ten residents with mild to moderate dementia. Can you describe how these kinds of methods prompted conversation and the kinds of conversations that occurred?

AP: I should tell you first a little about who these residents were. They were six women and four men. They ranged in age from seventy-three to ninety-five, with the exception of one person who was fifty-three years old. We purposely selected people to reflect some of the diversity we saw in the facility. So, for example, they came from a variety of cultural backgrounds, and as is typical in BC care homes, a good number of them had grown up in other places. They had different abilities – some could walk and some could not. Some had hearing impairment and some wore glasses. Everyone could speak, although they had varying degrees of cognitive impairment and different kinds of dementia.

Recruitment for the research was easy. Everyone we asked agreed to take part, and the dialogues were richer than what we thought we would get. The nature of the conversation was really powerful, and it goes back a bit to the methods we used. We were informed by work done with older adults and people with dementia in gallery settings; for example, the aforementioned MOMA project. Adopting the methods of walk-along interviews, the interviews ended up being a kind of gallery tour, with the student walking with the resident, engaging in conversation as they went along, asking open-ended questions like, "What do you think of this one?" and "How does it make you feel?" So, there's a lot of time spent with a painting, dwelling on it, looking at it, talking about it, then moving on to the next one.

Many of the conversations were about travel, freedom, and a desire to be elsewhere. This made immediate sense to us, given the fact that the residents were in effect being held in this place with no opportunity to leave until the system had found them a place. But it was more than that too. These findings remind me of the work we did previously with Barbara Purves on CIRCA-BC.¹⁹ In that project long-time residents of

¹⁹ Barbara A. Purves, Alison Phinney, Wendy Hulko, Gloria Puurveen, and Arlene J. Astell, "Developing CIRCA-BC and Exploring the Role of the Computer as a Third Participant in Conversation," *American Journal of Alzheimer's Disease and Other Dementias* 30, 1 (2015): 101–107.

You can see yourself going down that road. I like that ... We used to go down south every year for two months and it just reminds me of that. The highway.



Figure 3. Rocky Mountains. Artwork by Olivia Meek.

British Columbia were asked to identify photographs that they thought would be meaningful prompts for reminiscence, and images of travel featured prominently. The idea of “going places” seems to have particular cultural resonance in this large province of recent immigrants. For example, one woman looked at a small painting of a highway disappearing into the mountains and spoke wistfully of her memories of travelling south through Oregon with her family (Figure 3).

In this project, people moved from one painting to the next, telling stories and sharing memories that told something about who they were and where they came from. While the facility itself was in a large metropolitan centre, many of the residents were from elsewhere. For example, we learned that several had grown up in farming communities across western Canada. This is not surprising – unlike in other regions in Canada, older people in British Columbia are much more likely to have moved from another province²⁰ – but what this meant was that the paintings that were more pastoral were really important. The painting of the horse (Figure 4), for example, prompted numerous richly detailed stories.

GP: This speaks to the art as invoking storytelling and remembrance and therefore is a place/object for individual expression. Yet the walk-along interviews do much more than seek to solicit the individual’s perspective; rather, they offer a method of understanding the participant’s experience

²⁰ Andrew V. Wister, Andrew Sixsmith, Raymond G. Adams, and Danielle Sinden, *Fact Book on Aging in British Columbia*, 5th ed. (Vancouver: Gerontology Research Centre, Simon Fraser University, 2009).

RESIDENT: The horse. I'd like to get up on its back and ride it. I've been riding horseback since I was two years old. And I rode bareback most of the time and I had a bucket of sandwiches in one hand, and I'd bring the bucket of sandwiches out and I'd bring a pot of coffee and I'd set it down. Taking it up to the men in the field and I never used a bridle or a saddle. I just told the horse where we were going. And I think I was nine then.

Research Assistant: Wow ... that was freedom. Was it?

RESIDENT: That was freedom all right. I miss the farm.



Figure 4. Ma Ma Knight. Artwork by WeiYu Chen.

through social interaction and shared engagement in the environment. This process appears to be more organic than traditional interviews in the sense that the researcher does not necessarily have control over the conversation. In terms of place-making, the art then served as a place for dialogue.

AP: The spirit of the interview was dialogical in the sense of prompting talking about the artwork *together*. The interviews also were video-recorded, and the camera was focused on the painting and not the participant, which positioned the researcher and the resident in a more egalitarian way as the video focused on what was viewed together. People were meeting as equals to talk about the painting, no one had more expertise than the other, and they were able to engage in authentic conversation/dialogue. The paintings then created places where people could come together to talk, exchanging ideas and opinions, feelings and perceptions.

As mentioned earlier, to some degree, on the units especially, the art didn't stand out as such because it was a visually noisy space, and one of the gentleman we interviewed said, "I never really noticed these until you pointed them out." But when they were brought to his attention, there was something to see and something to talk about. It was not just physical space, it was also social space. And to some extent, for some of the residents, it was through the research that the social space was created that allowed those paintings to be important.

It was also important for the staff. We held a group interview with eleven staff members to explore their impressions of how the art had affected residents, and they told us “the art impacts them, and it impacts us too.” Staff members expressed that they would have very little to talk about with the residents. They were there to do a task, and the task shaped the content of the conversation; it would be all about “medical things,” they said. But with the paintings there was something else to talk about, and whether it was “naughty squirrels” or “life on the farm,” it was thought to be more real in the sense that people shared their personal memories and had a conversation together. One person commented that they felt the art brought them closer. They explained that it was no longer a resident and a helper, but two people enjoying a meaningful exchange. Alison Shields, who was a teaching assistant with this project, has spoken of the “passage” of these paintings, pointing to the idea these are not mere objects on a wall but, rather, that they function as part of a social network, creating opportunities for learning to occur and relationships to be fostered.²¹

GP: As the art promoted a place for dialogue, how did the students as artists factor into these conversations, or did they?

AP: Many of the residents had some understanding that students had created these paintings for them, which mattered to them. It meant something to the staff as well. This wasn't so-called “Walmart art” purchased by the health authority. Everyone knew that this was art that someone had created for them. It was striking how people were really quite moved by the idea that this had been done for them. But after having produced it, the students were gone. Most were close to the end of their program, and so they had moved on in their lives. There was no opportunity for them to meet the residents. Moreover, there were no names with the art. The paintings were not signed and they did not have any description beside them. This had been done on purpose. Landon argued that people don't encounter art as authentically and with such immediacy if there are descriptions; they tend to read about the art instead of really seeing it. And she explained how the signature on the front is an old-fashioned idea; artists don't do that anymore. But of course, many of the residents were old-fashioned people and many

²¹ Alison Shields and Alison Phinney, “The Passage of a Painting: The Learning Process of Students Creating Art for People with Dementia,” *International Journal of Education through Art* (in review).

were curious about who had made this art. Some of their conversations were about imagining the person behind the painting and wondering at the skill of it all.

It didn't always mean that they liked it; for example, one person thought these were created by students for children – “this is art for children.” There is one painting, a painting of sheeps, that invoked all sorts of different comments, and that was one of them, where someone thought it was painted for children, and other people really liked it – they liked it aesthetically, it was a way-station for someone.

GP: In describing walk-along interviews, Myers describes the participants as “percipients” who direct the process as they go along²² and, in so doing, actively contribute to place-making. What you have described in terms of the art prompting storytelling and dialogue suggests that residents were intrigued by the paintings and were eager to share their opinions. This is a great example of the way art could promote everyday citizenship in the sense that it prompts the sharing of narratives of self – stories and anecdotes that would otherwise have been inaccessible or unvoiced. In addition, and perhaps profoundly so, the art engaged a critical voice. Below, you share an example of the abstract art (Figure 5) and some of the interesting conversations that transpired as different people felt free to imagine whatever possibilities emerged for them in that moment.

It is so much more than what was being said then. The art promoted creative expression through storytelling, and so there is a sense of agency in engaging with the art. I wonder if you could talk about this a bit more.

AP: I have thought about that in the context of imagination. This goes back to my very first study where I was brazen enough to ask people where they saw themselves in five years. Some people had trouble imagining the future, or they were reluctant to talk about it, but there was one woman who had no trouble going there. She told me about how she used her imagination to think about a meaningful future for herself, which was really a kind of gift to me. It helped me think about this idea of imaginative possibilities, and that's what I see in these stories. Some of them were wistful, imagining different possibilities, as right now they were not in a good place, metaphorically or physically. But to imagine other possibilities for one's life is also a real act of creative agency. This

²² Misha Myers, “Walk with Me, Talk with Me: The Art of Conversive Wayfinding,” *Visual Studies* 25, 1 (2010): 59.



Figure 5. Red and Gold Road Pattern.
Artwork by Na Lam.

RESIDENT: That picture is very beautiful ... counted the lines ... what it represents ...

Research Assistant: Those little shapes? So they seem to blend into the walls a bit don't they?

RESIDENT: Oh yes, different shapes ... different lines ... I know what it is but I can't say what it is ... like a country, a country it represents (moving his hands across the width of the painting) a country.

RESIDENT: This one, I have a feeling that this, is a woman's bum (both laugh).

Research Assistant: Oh yeah, yeah I see.

RESIDENT: Well, you use your imagination eh?

Research Assistant: Hhm.

RESIDENT: (little laugh).

Research Assistant: And it's a nice shape.

RESIDENT: Yeah (little laugh).

Research Assistant: And look at the waist. Nicely toned. (pause)

RESIDENT: And with some of the other colours drawn into the yellow. It's nice. Or orange. It changes colour. (little laugh). It's very nice.

is not a passive space; people were being asked what they thought and they were very eager to share their thoughts and feelings.

The counterpoint to this is that these were people who had lost a whole lot of power in their lives. They weren't having a say in what happened next. It was families and staff who were busy negotiating the next phase of their life, and the person seemed to have so little agency in that. But the conversations around the art showed something different.

GP: That is really significant. Through the interaction and dialogue about these pieces of art, residents (re)claimed agency. This is significant, partly in the sense that it disrupts the powerlessness fostered through the environment and policy/practices of the transitional care unit – something that often deprives persons of their rights to agency. But more broadly speaking, it also confronts the narrative of loss and the stigma surrounding people living with dementia, the perception that agency is lost, and the perception that individuals cannot engage in acts of creative imagination or engage the “critical voice,” so to speak. Art can promote creative agency as it offers opportunity for place-making, and in this sense promotes social citizenship.

AP: It is interesting to think about it in that light. When we asked the question “What does this make you think of?” we often heard comments that related to that idea of place. People saw the paintings as reminding them of the outside world, and they commented on their desire to be somewhere else (Figures 6 and 7).

This reminds us that this was not a study about art in a hospital or in a nursing home. It was about art in a transitional care unit, and these people all had some degree of awareness that they were in a holding place. They had been in hospital but could not return home, so now they were being held in this place, a kind of “no-place” really, just waiting and wanting to be free (Figure 8).

GP: So the notion of transitional care permeated all their stories?



I was thinking it looks like Hawaii, but it should have a palm tree. I want to go back to Hawaii. My sister lives there.

Figure 6. Afternoon at Sunset Beach. Artwork by Richard Heikkilä-Sawan.



Figure 7. White Flowers. Artwork by Christiann Kennedy.

It makes me feel like getting out of here so I could see the actual flowers.

RESIDENT: It's bright. I like blotches, how it just kind of blotches everywhere? I like it. And then they've come up with something. I actually quite like this picture.

RA: What do you like about it?

RESIDENT: It's simple, but effective.

RA: Effective, what do you mean?

RESIDENT: It captures what it's meant to, you know? There's just a certain vibrance to it that I enjoy looking at. It's just a nice picture.

RA: How does the picture make you feel?

RESIDENT: Free. I think that's what it does.



Figure 8. Sheeps. Artwork by Andrew Jacobs.

AP: I think in some way, yes. People were hearkening back to places from their past, but they were also thinking about how they don't want to be where they are now, and they were imagining a better place for their future. We've thought about the art as being a kind of bridge, allowing people to create a more meaningful and enlarged sense of place at this time in their lives when they are undergoing such a significant transition.

GP: You mentioned earlier that the transitional care unit was a temporary solution, yet it was only until very recently – the spring/summer of 2018 – that the program closed, more than five years after its inception. The art was then only envisioned as something temporary in that space and therefore was taken down after the project. Can you tell us more about that?

AP: The way the project was structured was with the agreement that the art was on temporary loan and would be there for three years, after which it would be returned to the students. We had expected that the building would be closed in that time. But of course, it wasn't. We were left with having to remove the art, and the ethics around that were troublesome. Some of this was the result perhaps of bringing together the cultures of research and art and the conflicting responsibilities that resulted. We hadn't really thought it through, and when the time came to remove the art it created a lot of distress. On the one hand, we felt we were getting rid of an effective intervention (to use research terms), while on the other hand the art belonged to someone else and we had a moral obligation to these artists. This was the creative expression and property of a person who had the right to make a decision about it. This project had not just been about creating something that then became part of the facility: it was the student's art, and it had value. For me, this had been a hidden part of the project, and the removal of the art forced me to consider questions about ownership and how we value art, and how all this intersects with the structures in the health authority in terms of how artists' work is monetized and how they make a living.

GP: What happened after the art was taken down? Did something else fill its place?

AP: After the project, the recreation therapist, who had no money for supplies, very quickly had those spaces on the wall filled with art objects that had been made by the residents. There was a wonderful abstract piece that was made out of found materials, and some really beautiful paintings by people who clearly had an artistic background. It was so curious about how this had come to be, but at this point we had extended the grant and as a researcher I needed to pull the story together. So, it remains something of an epilogue. But interesting to think that removing the art that had been done *for* them is what allowed art to be done *by* them. Perhaps we might argue that the students' art had not only created a

(temporary) space of beauty but had also produced a more lasting kind of cultural imperative in this environment. Staff and residents felt compelled to bring art back and, in so doing, reclaimed that space.

GP: That is an important, and perhaps an unintended, outcome of the project, in the sense that art opened up the possibility for the residents and staff to claim that space as their own. Although, as you say, art was created for them and was the primary “object” of study, that staff and residents organically continued to contribute to the aesthetic of place seems to speak volumes to the impact of a project such as this. This project underscores the relevance of the arts in supporting social citizenship; that is, it opened up the possibility for residents to shape their environment – or actively participate in place-making – in ways that were not otherwise available to them, thereby fostering inclusion and participation. What would you describe as other key impacts of this work?

AP: In our report we have argued that this project provides evidence that art makes a positive difference in the lives of people with dementia who are living in care. It creates a sense of place and is a focus for social and emotional connection. The paintings served as a kind of landmark, providing meaningful resting places in an otherwise aesthetically impoverished environment; and they helped orient the residents to time and place by prompting them to reflect on how they were living in a kind of “no-place,” in between the stories from their past and those of an uncertain future.

The evidence also speaks to issues of inclusion and the importance of “hearing the voice of dementia.” By engaging directly with the residents themselves, we heard things that challenged some of the existing design guidelines and assumptions held by the students; for example, that art in dementia care environments must be “safe” and “easy to read.” The extent to which residents actively engaged in these conversations demonstrates that people with dementia could and should play a more active role in engaging with art in care facilities. It was apparent that the paintings engaged residents’ emotional responses in many different ways, with the interviews providing opportunity for their critical voice to be heard. While it was not always easy to get an immediate sense of what people were trying to say (some participants had word-finding difficulties that made verbal communication more difficult), these conversations were themselves probably the most important finding from the study. The paintings, and particularly the landscapes and abstract patterns, evoked

richly detailed stories and provided meaningful social connections as people shared their ideas, opinions, feelings, and perceptions.

I guess my final thoughts would be something about how we should be moving this forward. Certainly, we took the opportunity to present our findings to organizational decision-makers, the facilities-planning people, and those who had responsibility for selection and placement of art in the health care environment. But this work has also made me think about how for a long time we have been making decisions on behalf of people with dementia. I do believe that their readiness in this project to share their perceptions and opinions indicates that it is time to consider how people with dementia can be better involved in decisions around the selection and placement of art in care settings, and to contribute their perspectives to institutional design guidelines. This certainly aligns with current policy directions around patient engagement – the BC Ministry of Health’s *Patients as Partners Initiative*, for example – and reminds us that people with dementia do not always need someone (e.g., a family member) to speak on their behalf.²³ As the recent Canadian Charter of Rights for People with Dementia points out, people with dementia have the right to “participate in the development and implementation of policies that affect their lives.”²⁴

GP: Twenty years ago, rare would it be to hear a statement that advocates for people living with dementia to be involved in decisions related to art in care settings and to contribute to the development of institutional guidelines. In a place where policy decisions, as noted earlier, have a far-reaching impact on the lives of individuals with dementia, positioning individuals as active agents in collaborative decision making such as the development of design guidelines seems to be a way to support social citizenship to a certain extent. Moreover, your research findings go far beyond the “feel-good factor” of having artwork on the walls. Rather, it demonstrates this intervention’s capacity to create a provocative and stimulating aesthetic experience and to promote creative and imaginative agency. In turn, art facilitates well-being and social connectedness and citizenship in institutional environments that are otherwise quite impoverished. Thank you for sharing your insights on such important and effective work!

²³ British Columbia Ministry of Health, *Patient, Family, Caregiver and Public Engagement Framework* (Victoria, BC: Ministry of Health, 2018). <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/patients-as-partners-framework.pdf>.

²⁴ Alzheimer Society of British Columbia, “Read the Charter,” <https://alzheimer.ca/en/bc/Get-involved/The-Charter/Read-the-Charter>.