Dementia (Re)performed

Interrogating Tensions between Relational Engagement and Regulatory Policies in Care Homes through Theatre

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As an interdisciplinary group of health and artist researchers, we are concerned about the ways in which many persons living with dementia in long-term care homes are invalidated and treated as dysfunctional, thereby promoting social exclusion, depriving them of their dignity, and threatening their quality of life. We are concerned about the ways in which persons with dementia are framed as lost, robbed of mind, doomed, gutted, and the living dead. As part of this, we are conscious of the ways the "tragedy discourse" (Mitchell et al., "Dementia") is culturally produced through media and artistic representations and the ways it is manifested in care practices and policies in institutional settings, conceptualized as a kind of "social action."[1] This tragedy discourse is found in mass media, academic, and policy documents and in the reductive and dehumanizing nature of dementia care that is characterized by the management of "challenging behaviours" with mechanical and/or pharmacological restraint (Maust et al.; Dupuis et al., "Pathologizing").

Theatre and cultural theorist Anne Davis Basting discusses North American society's understanding and representation of dementia through two dominant narratives. First, earnest scientists attempt to combat an adversarial dementia, if they could only be given enough time and money to fight for and find a cure. As an example, Basting draws on the 2004 documentary film *The Forgetting*. Here Alzheimer's Disease, as the most common form of dementia, is a "slow and silent killer" that "draws the curtain over the patient's life and pulls family

1 | As critical researchers, we understand that this term generally has more positive, disruptive associations. For the purposes of this chapter, we conceptualize "social action" broadly, as "a thing done or created" following particular, normative social assumptions, in this case care practices and policies in institutional settings.

into its devastating grasp." The narrative of the film follows the scientific race to discover the cause of the disease and how to cure it, citing broken families drowning in its wake as the reason for the quest (Basting 35–36).

The second dominant storyline that Basting discusses is the loss of an exceptional, accomplished (and probably inspiring) person who is slowly emptied out by the destructive disease. She cites the example of the media's coverage of President Ronald Reagan's diagnosis of Alzheimer's Disease, which conveyed a tragic fall of Shakespearean magnitude. And while perhaps this coverage brought awareness to Alzheimer's beyond any public service announcement, magazine article or book, it also impressed the high stakes "then/now" tragic storyline deep into the North American cultural landscape.

These conceptions of dementia as produced and perpetuated through media and artistic representations have profound implications for policy development in long-term care homes. In Canada, long-term care homes are governed by provincial legislation, which attempts to standardize care and accountability and requires homes, their management, and staff members to operationalize codes of conduct through institution-specific policies and practices. In the province of Ontario, long-term care homes are expected to satisfy as many as 400 rules (Ministry of Health and Long-Term Care). For example, it is quite alarming to us that the Long-Term Care Act of Ontario has several hundred pages of standards and expectations relating to numerous aspects of care, except for a standard about meaningful relationships and supporting living. A similar critique has been articulated by Julia Twigg in the context of the United Kingdom; she argues that care time is defined in terms of easily measured tasks, where written standards pertain to the execution of tasks and the allotted time spent on any given task (Twigg, "Deconstructing"; "Carework"). Timeframes for bathing, eating, and restraining are marked out in detail, but not those for loving, relating, and thriving. As Kontos and Naglie state, citing Crawshaw: "The rationale of economic efficiency creates a system wherein the measure of care lies with the physical task rather than the quality of human interaction and, as a consequence, the relationship between the care provider and recipient is not quintessentially one of caring" (550; see also Thompson, "Towards").

Furthermore, there is a statement in the Ontario Act which implies that restraint and force are acceptable if used to complete bodily, physical care. This physical care is understood to override all other kinds of care at the risk of both the resident's emotional well-being and the relationship between resident and health-care worker. Additionally, the growing risk-aversion culture of long-term care has led to the production of organizational policies that result in the social exclusion and isolation of older adults living in long-term care homes from broader communities. As an example, research shows that some long-term care homes in Ontario have stopped all outings outside the home setting, citing that

the risks of a resident becoming injured or lost are too high for the homes to take (Wiersma & Dupuis; Dupuis et al., "Creating").

In order to disrupt the tragedy discourse that underlies both cultural production (such as media and artistic representations) and social actions (such as policy development), we embarked upon the creation of a research-informed play, *Cracked: New Light on Dementia*. *Cracked* was developed to open up a playful, social space to raise questions about current conceptions of dementia, expose unjust care practices and policies, and facilitate the envisioning and inspiring of an alternative care culture in which compassionate relationships and supporting living are at the core. We aimed to use an art form – theatre – to engage both each other and audiences intellectually *and* emotionally, by exploring stories, emotional and sensory experiences, theoretical concepts, and research findings within space and time (see Thompson, *Performance*; Boal; Rossiter et al.; Mitchell et al., "Research-Based"; Jackson; Mitchell et al., "Experience"; Kontos and Poland).

The theatrical form, when engaged for social and personal change, holds the potential to provide an aesthetic space for audience members not only to engage critically or analyze concepts and ideas intellectually but also to engage aesthetically, including emotionally, sensorily, and imaginatively. Through theatre, audience members can be provided the opportunity to reflect on how their thoughts, feelings, and senses extend to actions, including representation and policy (Gray). Critics discuss how linear, discrete educational and knowledge translation initiatives tend to overlook complex interrelationships among taken-for-granted assumptions, including what is felt and sensed, and social and personal actions (Kontos and Poland; Shor). We were therefore looking for a way for all involved to vulnerably and safely explore dominant tragic assumptions, including how individual actions (such as how one might engage a person with dementia in conversation) and social actions (such as policy) might reproduce those assumptions. We were additionally looking for a way to imagine possibilities for alternative ways of engaging with persons with dementia as filled with potential.

In this chapter, we explore two scenes from *Cracked* in order to better understand our use of the theatrical form to provide such an exploratory and reflective space. The first scene portrays residents dining in a long-term care home engaging with each other with humour, mockery, foolishness, kindness, and even some *un*kindness. The second shows a health-care provider being interviewed in comical, heightened film noir style by two "Interrogators" for using an affectionate term with a resident. We will highlight how the first scene captures the ways persons living with dementia are theatrically performed as filled with capacity to engage meaningfully and relationally, and how this sits in tension with the regulatory landscape of long-term care that suppresses this capacity in the second scene.

Cracked: Background

Cracked: New Light on Dementia was initiated by authors Sherry Dupuis, Gail Mitchell, Pia Kontos, and Christine Jonas-Simpson, all of whom are health researchers who specialize in the areas of aging, dementia, and research-informed performance (as live theatre and/or film).[2] These researchers were looking for a way to challenge the discourse of tragedy and loss that is dominant in relation to dementia and the people who live with it, as well as the corresponding dehumanizing care practices that are prevalent in so many institutional care settings. With playwright and theatre director Julia Gray as artistic leader, the play was developed collaboratively with a group of actors.[3] It emphasizes the centrality of relationships and humanity when providing care for persons with dementia and the need to recognize the dynamic and fundamental ways in which memory and self-expression are embodied. This collaborative play making, or "theatrical devising," involves an improvised creative process among those working in studio (Barton and Wells; Filewod; Mitchell). At strategic points throughout our process, we continued to invite community members, including persons living with dementia and their family members, into rehearsal for open discussion and feedback about what we were creating. For example, early on in our process we conducted a full-day arts-based workshop where the actors, playwright/director, researchers, and visual artists came together with people living with dementia and family members to interrogate the tragedy discourse and imagine and construct alternative representations based on the lived experiences of people living with dementia (S. Dupuis et al., "Re-claiming"). For more information on our development process, please see our published script (Collective Disruption).

Cracked follows two storylines, those of Elaine Carter and Vera Nolan, both of whom have been diagnosed with dementia. The play opens with Elaine's diagnosis and follows her journey with her two adult children as they navigate their changing relationships. We see Elaine becoming engaged with her community, reconnecting with her longtime friend Vera who has also been diagnosed with dementia, becoming a political advocate to improve the lives of persons with dementia, and flirting with beautiful young men. A space opens in a long-term care home, so Elaine and her family make the decision to move her

2 | For examples of our team's work, please see Mitchell et al., "Research-Based"; Mitchell et al., "Experience"; Dupuis et al., "Re-claiming" and "Catapulting"; Kontos et al., "Improving"; Jonas-Simpson et al.; Mitchell et al., "Dementia"; Kontos et al., "Presence".

3 | Actors involved in the initial creative process included Susan Applewhaite, Lori Nancy Kalamanski, Tim Machin, Mary Ellen MacLean, Mary Claire Frances Muir, Mark Prince, and David Talbot. The team would also like to recognize Jerrold Karch for his creative contributions.

into this home. From here the journey shifts as Elaine's world again opens up to meeting new people and making new friends in the home. Elaine's daughter Caroline struggles with her own assumptions of what persons living with dementia should be like; by the play's end she is able to spontaneously dance with her mother. With Vera, the second protagonist, we also witness her journey with her husband, Tom, as they work through changes in their relationship. There comes a point when Tom is no longer able to care for Vera, and she also moves into a long-term care home. As the play moves to the end, and as Vera progresses further on her dementia journey, we learn about Vera's history and life experiences through her sensuous and embodied memories of dancing, singing, joy, and fear. Through both storylines, the audience sees both characters who are living with dementia grow and learn, not only despite the disease but also because of it.

The Scenes

For the purposes of this chapter, below we have included detailed descriptions of what the actors are doing in the scene, including their posture, facial expressions, quality of movements, and so on, in addition to stage directions and the spoken text.

In this way, the following is not a traditional script, which would strictly adhere to basic stage directions (basic descriptions of where actors move and what they are doing on stage, such as moving a prop). We include more here to indicate what is missing in written form, the body and its gestures, as integral to performance. Our descriptions of actors' bodies and gestures are also integral to our arguments about dementia: that we overlook the body and its gestures because we undervalue them, and we thus overlook how persons with dementia use their bodies to continue to express and be themselves despite cognitive memory loss.

Fig. 1: Scene from *Cracked*, photographer: Dalia Katz. Actors from left to right: Andy Pogson, Mary Claire Frances Muir, Susan Applewhaite, David Talbot (standing), Lori Nancy Kalamanksi, Mary Ellen MacLean, Tim Machin

Fig. 2: Scene from *Cracked*, photographer: Dalia Katz. Actors from left to right: Andy Pogson, David Talbot (sitting), Tim Machin

SCENE 17 – Dining

Dining room.

During the scene transition, the six chairs are set up as if they are around two square tables (which are mimed/imagined) along the downstage area. All props, such as mugs of tea and meals on plates, are mimed.

SILAS, a resident, enters from the upstage right corner. Donning a sweater vest which hangs open off his shoulders, SILAS walks downstage and clutches each chair as it is placed around imaginary tables by the other actors. His face filled with intensity and concentration, he carefully limps as he walks from chair to chair, making his way to the downstage left table.

ELAINE, vibrant and active, enters from the upstage left corner. As she sees SILAS limp towards his regular seat at the table, she extends her arm and speeds up towards him so she can help him sit.

ELAINE Here you go, Silas.

ELAINE pulls back her own chair at the same table and sits with ease.

JIM, staff of the long-term care home, is helping ESMERELDA, a resident, to the stage right table. ESMERELDA's arm his hooked into JIM'S and they are happily chatting to each other as he leads her to the table. ESMERELDA's short steps are compounded by the hunch in her back, which prompts her head to slump forward slightly.

JIM *(as he helps her sit)* You're OK?
ESME Yes.

JIM bustles off to stage right to check on something in the kitchen.

HENRY, a resident, enters miming using a walker from upstage. As he makes his way to the stage right table, his steps are small and tight as he relies on the mimed walker to support him. Sitting with great weight, he nimbly folds his walker and places it behind his seat. He turns to the others at the table with a big smile.

SARAH, a resident, has entered from upstage right, and walks towards HENRY and ESME at the stage right table. She saunters into the dining room, gently fiddling with the edges of her scarf and softly humming to herself. DOROTHY, adjusting her hair and pearl necklace at her sternum, has meekly entered from upstage left and joins SILAS and ELAINE at the stage left table.

Residents acknowledge each other as they sit, some chatter to each other, some just sit and smile, some fidget. SARAH continues to hum to herself.

ELAINE *(with a laugh)* I'm so hungry I could eat the leg off the Lamb of God!

Mortified, DOROTHY crosses herself and begins to pray, and SILAS scoffs at ELAINE's absurdity. JIM enters and stands at the top of the table.

JIM So, who's for tea?
ELAINE Oh, me!
SARAH *(shakes head)*
DOROTHY *(raises hand)*
ESME Yes.
JIM Silas?
SILAS Coffee.
JIM Henry?

HENRY, who flirts head to head with ESME, does not respond.

JIM Henry?
HENRY *(looks up in surprise with a big smile)* Oh. No thanks.
JIM *(nodding, anticipating each resident's preferences)* OK, three teas and one coffee *(starts to exit)*.
ELAINE And a little sugar into it!

JIM waves at her as he exits.

ELAINE *(turns to her 'audience' of the other residents with a big smile)* So, that guy was so tight, he was tight as a frog. And you know how tight that is?
ESME No.
ELAINE Water tight! *(slaps the imaginary table, laughing)*
ESME *(with a groan)* Oh ...

SARAH, HENRY and DOROTHY laugh at ELAINE's terrible joke.

SILAS Sshh!
JIM *(enters with trolley with tea and coffee, places mugs of coffee or tea, etc, in front of residents)*. Here you go *(to ELAINE)*, and the sugar. And Silas, coffee, and some bread.

JIM moves towards the stage right table to serve tea and coffee.

ELAINE Suffering Jesus, it's hot! Can I get a little ice to cool it down a bit?
JIM *(places mug of tea in front of ESME)* Esme, some tea.
ESME Thank you.
ELAINE How about that ice?
JIM *(turning to ELAINE)* Just leave it for a minute, it will cool. I need to get the meals.
ELAINE *(pushing back her chair to stand)* Let me help you there, Jim.
ESME Yes.

ELAINE gently touches ESME's shoulder as she walks past, and she and JIM exit together.

SILAS *(having sipped his coffee, expresses in disgust)* Decaf!
HENRY *(with a smile, responding to SARAH's humming)* Oh Sarah, that's lovely.
ESME Yes!

DOROTHY quietly adjusts her pearls.

SILAS Sshh!
ELAINE *(re-entering with something in her hand)*. Got the butter.

ESME reaches towards ELAINE as she places a plate of butter at the stage right table, then walks to the stage left table.

ESME Thank you.
ELAINE *(sitting in her seat, newly discovers the tea with a smile)* Oh look, tea, that's nice.

JIM enters with another cart of plates, places the cart between the tables and starts to serve to the stage left table.

JIM *(to ELAINE as he carefully places the meal in front of her)* Here you go. Now careful, it's hot.
ELAINE *(with a wink)* Just like you!
ESME *(laughs)* Yes!

Everyone laughs.

SILAS Sshh!
SARAH *(turns in frustration towards SILAS)* Sshh!

JIM moves to the stage right table to place meals.

JIM *(places meal)* Sarah … There you go, Esme *(places meal)*.

ELAINE cheekily starts scooping up large amounts of butter onto her bread.

DOROTHY *(giggles at ELAINE)* Oh, you …
SILAS *(raises his finger in protest)* Jim, Jim, uh, she, she's taking all the butter, she's uh, she's taking all the …
JIM *(walks to stage left table)* Yes Silas, I can see that, I'll make sure there's enough for everyone. *(to ELAINE)* Now, sweetie …

Everyone freezes and, with heightened postures and expressions of shock, looks to JIM.

ALL *(dramatic intake of breath)* Gasp!

SCENE 18 – The Interrogation

As if undercover residents, members of the ENSEMBLE stand and clear the space, scattering like roaches, except for a chair centre stage and two INTERROGATORS.

JIM is pushed into the chair by one of the ENSEMBLE. Two INTERROGATORS begin their work. INTERROGATOR 1 stands facing JIM from the downstage left corner, and INTERROGATOR 2 stands facing JIM in the downstage right corner. They wait until there is stillness on stage and the whole ENSEMBLE has exited.

INT 1 What did you say?
JIM *(with a look of confusion, like a deer in headlights)* What?
INT 2 *(both INTERROGATORS slow and measured, begin to walk towards JIM in the chair)* What did you say?
JIM When?
INT 1 Just now.
JIM What do you mean?
INT 1 *(The INTERROGATORS have reached JIM in his chair and begin to circle him)* You know.
INT 2 You know what you did.
JIM *(in his own defense)* I was asking Mrs. Carter about the butter.
BOTH *(stop and turn sharply to look down over JIM in the chair)* No.
INT 2 You called her something.
JIM I did?
INT 1 *(still peering down over JIM)* Don't deny it.
INT 2 *(with seething disgust)* You have violated the rights of the resident.

INT 1 *(with increased anger and passion)* Do you know what would happen if a compliance officer overheard that?

INT 2 *(as the ultimate punishment)* We'd get a citation.

JIM Oh *(breaking down under the pressure)*, OK, I, I called her sweetie. She asked me to call her that! *(cries)*

In situating these two scenes together, both in live performance and in this chapter, the stark differences between them becomes apparent. In the first scene, persons with dementia are performed as diverse, including playful, cheeky, flirtatious, agile, physically limited, musical, spiritual, shy, outgoing, scornful, frustrated, among a raft of other qualities (and it should be emphasized, each person is unique). In the second scene, persons living with dementia are merely mentioned in the abstract ("the resident"), cast in the shadow of the Interrogators more concerned with avoiding the wrath of the compliance officer in the form of a citation.

In the first scene we see a community of people living with their differences, supporting, teasing, flirting with and testing each other, getting under each other's skin. No one is performed as though an empty shell of their former self; rather, each resident gestures and expresses themselves uniquely in the present moment. We see the care-home staff member, Jim, understanding and supporting each resident's patterns and needs, knowing who prefers coffee or tea, creating space for residents to help each other and him, as Elaine does when she follows Jim to retrieve the butter from the kitchen. But audience members come to be engaged with this community of people in large part through how the actors gesture as the residents.

Sarah saunters toward her seat, humming and fiddling with her scarf; Elaine extends her arm to help Silas to his seat; Henry brings his head close to Esme's while he flirts; Dorothy gently and daintily adjusts her pearls resting on her sternum: these things are not extraneous additions to the scene to make it more visually interesting. These gestures *are the scene*, the way in which members of this community engage with each other, and the way in which audiences come to engage with the story, central to which is the importance of author Pia Kontos's theoretical notion of *embodied selfhood*. Embodied selfhood emphasizes the importance of the capacities, senses, and sociocultural dispositions of the body for self-expression, interdependence, and relationality (Kontos et al., "Citizenship"). Based on her ethnographic research in long-term care homes with persons living with dementia, she draws upon Merleau-Ponty's notion of non-representational intentionality and Bourdieu's notion of habitus to argue that despite even severe cognitive impairment, selfhood persists in and through the body (Kontos, "Ethnographic"; "Embodied"; "Rethinking"; "Alzheimer").

Contrast this with the second scene. While filled with humour, as indicated by the heightened expressions and postures of the Interrogators, the uniqueness of each resident is all but lost in this scene, which focuses on reprimanding Jim for using affectionate language – "Sweetie" – with a (nameless to the Interrogators) resident. In their admonishment of Jim, what the Interrogators overlook, of course, is the relationship among residents and between Jim and this particular resident, Elaine Carter. The gestures between them in the dining scene include gentle teasing with playful language, flirting ("[H]ot ... Just like you!"), and Elaine helping Jim with some of the serving tasks. While Jim is not a resident himself, he is invited and accepted into the community of residents by Elaine and the others in part because of his reciprocal engagement with them. Jim using the word "sweetie" toward Elaine is not out of context, especially as we learn in the interrogation scene that Jim has previously been invited to use this term by Elaine when addressing her. He uses this term to accept her invitation of being in relation. By relying on a one-size-fits-all policy that focuses more on the avoidance of disrespecting an abstract resident, the Interrogators focus their energies on also avoiding a citation from a compliance officer, thereby negating any relationship between Jim, Elaine, and the other residents.

In this way, the performed gestures of the actors as residents in the dining scene – as full human beings living in relation with each other and in place and space despite cognitive memory loss – disrupt the abstract resident referred to by the Interrogators as a nameless recipient of policy. Through the juxtaposition of these two scenes, the policy enforced by the Interrogators is exposed as absurd; not only are the Interrogators performed as absurd in their buffoonish gestures, their exaggerated walking style, and their over-exerted passion about the imposition of policy regulation, but the policy itself, as a social action that assumes residents and staff are not able to be in relation with others, also becomes exposed as absurd through its enforcement by the Interrogators.

Both scenes have received a warm reception from audience members. In performances there is often laughter in recognition of the nuances of each resident in the dining scene, a familiar chuckle in response to particular jokes ("Water tight!"), and an affectionate sigh in recognition of forgetful moments ("Oh look, tea, that's nice"). The interrogation brings more robust laughter, and post-performance discussions have brought forth comments from audience members indicating how the scene allowed them to appreciate the absurdity of the "language police."

However, participants from a study we conducted[4] exploring how audience members working in long-term care homes engaged with *Cracked* highlight the specific tensions between attending to relationships and current policy. These

4 | This study was funded by the Alzheimer Society of Canada Research Program.

quotations from three different participants beautifully capture the importance of being in relation with residents and following their lead, as well as the ways in which policy restricts those possibilities.

> The "sweetie thing" to me was the perfect juxtaposition of institutionalized and person-centred care because institutionally, Ministry standards say that we're not allowed to do that. And to me to do person-centred care, you kind of have to be a little more personal than that. So I find a lot of times the two battle back and forth. (Participant 1) … when he called her sweetie and they're going to get the compliance officer and be cited. And I'm thinking yeah. And you know sometimes you've got to be careful, it's abuse and all this speaking like that. [But] really, if it comes from the heart, is it abuse? And these people – like are we all at arm's length and cold, you know? Like, they need love. (Participant 2)

> Well, like the first thing that the staff member got chastised around was "sweetie," being called "sweetie." And I mean, like I recognize that that can be a fine line either way. You can dehumanize someone by calling them a term they're not comfortable with. So I recognize it can be that reality. But the flip side is often when you're getting to know your residents, you know what works for them. And I just trust a lot of our staff that they get it, that they know what works. Here's someone you can joke around with and that's what they expect. If you'd be all serious with them and hands off-ish, that would not fly. (Participant 3)

Not only did study participants come to understand the absurdity of the policy they are restricted by in their daily working life but they each also understood *why* the policy might be viewed as extreme; it is extreme because it overlooks the significance of being in relation as part of being human. We would suggest that it is through the juxtaposition of the two scenes that policy is seen anew. Rules enforced by the Interrogators which might be normalized in day-to-day existence as "the ways things are" become exposed within the frame of the play precisely because audience members have witnessed positive, attentive relationships in the previous scene. Study participants reference this through language such as "you kind of have to be a little more personal than [institutional/Ministry standards]," "[residents] need love," and the importance of "getting to know your residents." This suggests that these participants, as people who work with residents in long-term care homes, know and live these tensions between attending to relationships with residents and policy that restricts them. However, in seeing these tensions enacted through the play, participants are provided the aesthetic space to reflect, attending to senses and emotions in addition to thoughts, and ultimately are able to voice it clearly.

Conclusion

In *Cracked*, and more specifically in *The Dining Scene*, we disrupt the tragedy discourse through the ways persons with dementia are performed. Actors playing residents in a long-term care home, all living with dementia, express their characters' uniqueness through their singing, flirting, scoffing, praying, giggling, helping, and egging each other on, among other gestures. We see a lively community of people engaging with each other, including staff member Jim, who supports them and creates space for them to be themselves. Policy for its own sake, as a social action concerned with avoiding citations regarding an abstract and nameless resident, is then exposed as absurd when it is personified by two buffoonish Interrogators. It is through theatre, as an art form that attends to emotions, senses, thoughts, and actions in time and space, that an aesthetic space is created to invite audience members to reflect on how their thoughts, feelings, and senses extend to actions, including representation and policy.

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