ORIGINAL ARTICLE

“Breaking the fourth wall”: Activating hope through participatory theatre with family caregivers

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Abstract
In a research context, Participatory Theatre (PT) has been applied to a variety of social problems from sexual assault to community building, youth socialization, and stroke education. However, it has never been used with family caregivers of persons with dementia. The purpose of this study was to explore the feasibility of using PT with caregivers in studying hope. Over the course of the study, scenarios, which were based on the realities of the participants’ lives as caregivers, were developed for the purpose of exploring strategies to deal with situations that challenged hope. Following two live performances, audience and participants completed open-ended surveys. Participants were also interviewed about their experiences of hope during the process. The results of the surveys and interviews were that using PT with this population was feasible and a meaningful experience. The participants reported that their hope was fostered through participation.

Key words: Participatory theatre, family care giving, caring for people with dementia

Introduction
Participatory theatre (PT) is a form of participatory action research (Fals-Bordo, 1991; McTaggart, 1997; Whyte, 1991) in which theatre is used to create new knowledge grounded in immediate experience and direct experiment. It transcends the theory/practice divide by considering not just “what is” but also “what might be” and what “can be” (Todres, 2008). It also transcends the objectivity/subjectivity dichotomy and moves towards inter-subjectivity by developing shared understandings through interactions that are used as a resource to interpret meanings of subsequent interactions (Holloway & Todres, 2007). Development of these shared understandings may be of benefit to populations who feel isolated, such as family caregivers of persons with dementia.

Care giving is part of the day-to-day reproductive work that is necessary to meet the physical and emotional needs of aging family members. In Canada, the cohort of family caregivers is growing. In 2003, over 1.7 million adults aged 45 to 64 provided informal care to almost 2.3 million seniors with long-term disabilities (Stobert & Cranswick, 2004) and almost three-quarters (73%) of unpaid time spent on caring for ill and disabled people was done by a family member (Zukewich, 2003). A growing body of research examines and documents the emotional, financial, and physical challenges that caregivers face (Donelan, Falik, & Deroches, 2001; Fast et al., 1999). Family caregivers report substantial feelings of guilt from having a lack of time or ability to carry out their care giving activities, particularly women who are juggling their paid work with their unpaid care giving responsibilities (Pyper, 2006).

In a research context, PT has been applied to a variety of social problems from sexual assault (Mienczakowski & Morgan, 2001) to community building (Butterwick & Selman, 2003), youth socialization (Conrad, 2006; Lee & Finney, 2004) and stroke education (Stuttford et al., 2006). However, it has not been used to study the care of dementia patients. The purpose of this study was to explore the feasibility of using PT with caregivers to study how their hope is reconstituted.

The article opens with an overview of the study’s context before moving to a description of the methodology used in the study. The study results form the main body of the article and indicate that the
methodology is feasible with this population, and has the capacity not simply to investigate but also foster hope.

The project context

The concept of hope has been a central concern as a category of experience in theology, philosophy, critical social theory, and health studies. Hope does not have a single, universal meaning: it is assembled in multiple ways, mediated by social and material conditions. However, in all of the diverse handlings of the concept of hope, there is a forward-looking, temporal element: a transcending horizon that extends beyond the immediate future. Herein lies a paradox: hope involves the unknown of which we only have the certainty of its existence. The “not-yet” aspect of hope is what is still not; it is a present lacking to be fulfilled by the future (Bloch, 1986).

Theories and conceptual models of hope have tried to capture the complex, dynamic nature of hope (Morse & Doberneck, 1995; Dufault & Martocchio, 1985). There are many definitions of hope found in the literature. For example, Maxine Greene (1988) argues that hope is a power, which we act on to become authors of our own world. For critical social theorists like Greene, hope is not a future projection of a utopian society, but a constitutive part of everyday life; hope is less an idealist, illusionary notion and more the necessary projection of the radical imagination (e.g., Freire, 1994; Leonardo, 2004).

Health researchers have proposed the following definition of hope: “hope is an essential experience of the human condition. It functions as a way of feeling, a way of behaving, and a way of relating to oneself and one’s world. Hope has the ability to be fluid in its expectations and in the event that the desired object of outcome does not occur, hope can still be present” (Farran, Herth, & Popovich, 1995). This definition has been affirmed by a recent study of hope with family members caring for the terminally ill (Holtslander, Duggleby, Williams & Wright, 2005) and for persons with dementia (Duggleby, Williams, Wright & Bollinger, in press). The participants of a grounded theory study of hope with family members caring for the terminally ill defined hope as a dynamic process that included faith, relationships, and need for connection, as well as cognitive reframing. This is similar to the findings of another grounded theory study of hope for 17 family caregivers of persons with dementia (Duggleby et al., in press). There are only two studies of hope of family caregivers with dementia. Both have described hope as important to their well-being and their ability to continue to care for a person with dementia (Duggleby et al., in press; Irvin & Acton, 1997). Ways to foster and create hope in this population have not been reported. The study described in this article focuses on how informal caregivers understand, create, and sustain hope in the context of their care giving roles.

The positive role that hope plays in health and illness has been recognized by health researchers, however, the methodological approaches taken by existing studies of hope in health research are restricted to conventional qualitative and quantitative designs using the standard data collection techniques of interviews, surveys, and other responsive strategies. This study uses an unconventional form of qualitative research, Participatory Theatre, to investigate hope among informal caregivers of people with dementia. In doing so, it responds to the need to introduce unstudied populations as subjects in health care research and explore new methods that are alternatives to the prevailing randomized control trials and systematic reviews (Chadderton, 2004).

Method

Participatory Theatre is an arts-based research technique; consequently, it is not prescriptive or codified, either in process or representational form (Knowles & Cole, 2008). As the creative arts rely less on technical expertise and more on intuition and aesthetic expression they are inherently accommodating to multiple representations and representers. Artistic forms of representation for research have included autobiography (Ellis & Bocher, 2000), photo-essays (Lapidus, 1996), and dance performances (Blumenfeld-Jones, 1995).

Theatre, in particular, has the capacity to convey meanings that pertain to the flux of social relationships because these meanings are so inherently embodied in gestures and actions (Jackson, 1996). Theatre is a unique and powerful way of accessing knowledge, because it draws out responses that are a spontaneous, intuitive, tacit, experiential, affective, rather than simply cognitive. Symbols, emotion, and performance are constitutive of human communication; by explicitly incorporating these expressive forms, theatre expands our communicative capacities (Cottle, 2006). As an aesthetic space it allows humans to make sense of, and go beyond, what they know (O’Toole & Lepp, 2000).

In PT, also known as “applied” or “popular” theatre (Prentki & Selman, 2000; Taylor, 2003), the tasks of scripting, directing, and acting are all accomplished by those with “insider” knowledge of the everyday actualities of the particular problem under investigation. The performative enactments, created by the participants themselves, are used to investigate reality in order to change it.
The techniques particular to Participatory Theatre are drawn from the work of Augusto Boal (2002, 2000). Informed by the Brazilian critical pedagogy and liberation movements of the 1950s and 1960s, Boal developed an innovative form of theatre to empower individuals to change their social reality. By democratizing the theatre-making processes, Boal transformed theatre to become a tool to be used by all individuals to enable them become protagonists of their own lives (MacKenzie, 2004). Participatory theatre is a form of participatory action research whose key features are self-reflective cycles that result in change (Kemmis & McTaggaret, 2005).

Boal was inspired by Bertolt Brecht’s political use of theatre, in which the fourth wall is broken to awaken critical consciousness. As such the research method of participatory theatre is an intervention as well as it seeks to awaken the critical consciousness. The fourth wall is the imaginary wall at the front that divides the audience from the stage. Brecht’s epic theatre broke the fourth wall by disrupting the narrative flow, often by song, to make political comments and draw attention to the theatre-making process itself. With the fourth wall broken, audiences can take a critical, analytical stance towards the action on the stage rather than being entertained as an unseen spectator of the fiction of the performance. Boal’s innovation was to break the fourth wall more directly by insisting that the spectator become active. As “spect-actors”, audience members engage in the activities of scriptwriting, directing, and acting. Participation does not require theatrical training or experience, but rather “insider” knowledge of the everyday actualities of the particular social problem under investigation.

In PT theatre-based activities are used with a core group of participants to create scenarios that depict a particular social problem with “real” characters carrying out actual everyday activities and using ordinary, natural language. The scenarios are created out of, yet transcend, the personal experience of the participants. While these participants provide the dramatic expression of the underlying stories of their community, typically they have little or no acting experience or training. The process of developing the scenarios relies on democratic decision-making, continual reinforcement of shared identities and group cohesion, and the devotion to the common goal of making the experience visible to others.

In PT the scenarios are specifically developed to have an incompleteness that seeks resolution through the actions proposed by audience members. In the performance, or “forum”, the scenarios are dramatized once in their entirety. In its second viewing, the audience is encouraged to stop the dramatic action, come to the stage, replace an “actor”, and lead the action in the direction that seems appropriate to him/her. The displaced actor steps aside until the assuming actor considers the trial to be over. Any audience member has the right to try their version without censorship, to intervene decisively in the dramatic action and change it. Proposing a solution requires working, acting, and doing, not simply talking abstractly from the comfort of one’s chair. In the course of the hypothesis testing, the other actors face a newly created situation and are required to respond to the possibilities it presents.

At the forum, all enacted solutions are subject to collective discussion and critical reflection by those on either side of the fourth wall. From the discursive interaction, led by the facilitator, alternative hypotheses, suggestions, and proposed strategies spring forth and the process is repeated. In PT, proposed strategies command respect, not by coercive force or by the authority imbued in positions or roles. Rather, legitimacy of the communicatively achieved mutual understandings is reached by the proven strength of the enacted solution. The fourth wall is broken as “actors” and audience engage in an iterative form of collective problem-solving. The continuous cycle of reflection, action, reflection, etc. distinguishes PT from other uses of theatre (e.g. Dahlberg & Ekebergh, 2008), where the drama is used to stimulate reflection and discussion, but reflection, in turn, does not guide the drama.

Participants and procedures

This participatory action research study included eight informal caregivers of people with dementia. The age of the caregivers ranged from early 20s to early 80s, currently caring for an aging parent, spouse, or grandfather, across the spectrum of care needs: some providing round-the-clock care in their own homes, others providing respite care when needed, and for still others, their family member’s dementia was already advanced enough that they required institutional care. One participant’s cared-for person had recently passed away.

Recruitment of study participants was facilitated by the local Alzheimer’s Society and other community based organizations with which the researchers had connections. The study was advertised with posters and through radio and news article announcements (Appendix A). Interested individuals contacted a research team member who described the study and informed them that the study’s workshops were for caregivers interested in exploring the use of theatre-based techniques to establish a community-based dialogue on the issue of hope. While the study was to make use of theatre-based techniques, inquiring individuals were assured that no previous theatre
experience was required. Ten family caregivers attended the first of the study’s five workshops. Two decided not to continue in the study for personal reasons.

The procedures of the study were carried out over five activation workshops, three performance forums, and post-forum interviews with participants. Owing to the study’s participatory action methodology, all the research activities of the entire project evolved over the course of the project, directed by the project “steering committee”. The committee consisted of the two researchers, representatives from the Alzheimer’s Society and a community association for seniors, and the workshop facilitator. The committee met several times, first to establish the initial direction, and then to guide the ongoing developments of the project.

Following the five activation workshops, the scenarios developed in the workshops were taken to three public forums. The first two were held at a community event on seniors’ health, the third forum was at a seniors’ residence. The audiences at each of the forums were informed of the connection of the event to the research study and at the end they would be invited to fill out evaluation questionnaires (Appendix B). The workshops and forums were then followed by semi-structured interviews with the core-participants and either video-taped or audio-taped (Appendix C). Both the survey and interview questions were purposely exploratory as very little is known about the use of PT in foster hope in family caregivers of persons with dementia. The questions were based on those used in another participatory theater study (Quinlan, forthcoming, 2009). Although the topics of the two studies are not the same, both studies incorporated an evaluation of the impact of participatory theatre on both the activators and the audience-participants. Thus, the questions pertaining to the perceived impact of participatory theatre on the audience-participants and activators are necessarily the same. The semi-structured interview questions were open ended allowing the participant to share their experience. The audio-taped interviews were transcribed verbatim. The videotapes from the interviews were analyzed using Spiers (2004) method for video analysis. Each video was viewed several times and descriptive notes were recorded into a log establishing correspondences between topic of conversation, person, and place in tape. Key sections of the tape were then transcribed verbatim. Transcripts were checked for accuracy against the recordings. All transcripts were read over several times and compared to the audio and video tapes for inaccuracies. Qualitative data were stored and managed using Word software. The analysis of data generated from the interviews with the core-participants focused on two processes in particular: (1) the individual’s perceived impact of the forum to engage audience-participants and collectively test and evaluate solutions to the challenges of hopelessness for caregivers (i.e. the breaking of the fourth wall); and (2) the individuals’ perceptions of how the PT activities (workshops and forums) helped to foster their hope in the context of their particular circumstances as caregivers of people with dementia. The transcribed video and audio data were analysed together using van Manen’s (1990) thematic analysis. van Manen discusses many approaches to thematizing data; we used the “selective or highlighting approach” (van Manen, 1990, p. 94). This selective approach asks the researcher to consider: “are there any phrases that stand out; Can we select some sentences or part-sentences that seem to be thematic of the experience that is being explored?” (van Manen, 1990, p. 94). We then took those sentences and phrases and divided them into themes. The data from the surveys and the interviews were first analysed separately, and then compared for congruency determining similarities and overlaps in the two sets of data.

**Ethics**

Prior to recruitment of participants, ethics approval for the project had been secured from the authors’ university behavioural ethics committee. At the first workshop, a number of ground rules were explained by the facilitator and discussed and agreed to by all the workshop members. The ground rules were: confidentiality of shared stories, honesty, right to pass, right to speak, and respect for and non-judgment of other perspectives, and participation was completely voluntary and exiting at any time would be unchallenged. Explicitly stating these agreements initiated a sense of safety within the group. Written consent forms were discussed and obtained from eight participants during the second workshop. The participants were informed that at the end of the project, there would be the opportunity to further contribute to the project by taking part in face-to-face interviews, but like the workshops their participation in the interviews was entirely voluntary.

**Workshops**

Four workshops were completed within a six month time frame. They were all composed of group building activities, creation of hope images, story telling sessions and identification of scenarios to be used at performances. The purpose of the first workshop was informational and to build group cohesion. A brief explanation of the aims and ground rules (see above) of the study was provided to the participants,
followed by a round of introductions. As researchers, we introduced ourselves as individuals with academic knowledge on the substantive topic of care giving, but who also come to the project with years of experience in care giving for aging parents. We declared our commitment to remaining open to changing ourselves as well as the social world we inhabit. We considered ourselves to be part of the group, not as “experts” or neutral “secretaries” to the research process, and anticipated participating in many of the workshop activities.

The facilitator’s role was identified as a guardian of the process: leading the activities and ensuring that everyone had a right to both speak and be heard. What was to happen in the workshops was described as creative work; however, we were not developing drama from fictional characters, interactions, or situations. The material that was to be used in the workshop needed to be real, typical, and representative of our lives.

The participants’ role as “activators” of the process was elaborated: they were leaders in the sense that they would be enacting the challenges to hope in order for the whole group to be able to collectively reflect on them. However, as activators they were not expected to come with ready-made solutions to the problem but to merely respond to the call to service to take up the mission of bringing the question of how hope is reconstituted to a larger collective of caregivers so that potential answers could be named, evaluated, and justified with the aim of refining action. The agreements and description of the process were followed by a series of games and physical activities for the purpose of group-building. The activities were fun, built trust, and helped us “get into our bodies”. In addition to establishing group solidarities, the games tapped into the expressive capacities of our bodies that are often under-developed within our text-based culture (Boal, 2002). Each was interspersed with a collective sharing of reflections and insights gained.

The activities of the workshops offered a means of trying out new ways of understanding their experience. The participants identified the key benefit of the workshops as fostering hope as they offered them the creative space to develop new capacities for change. Most were surprised by their ability to participate in the way that they did. One said:

I expected something different. After all, it was a research-based study. I came prepared to learn how to handle the situation I was in. And, it that hasn’t happened in the way I thought that it would. The approach was very different. And, I should have suspected—after all, it was sociologists we were dealing with and you never know what they’re going to come up with. But, we end up playing games (with incredulity) And, I knew that we were developing a trust building situation. And I thought this is really kinda weird. But, I thought I’ll go along with it and maybe something good will come of it. And, it certainly has. As we participated in the different activities, we got to know each other, we got to know one another’s other’s strengthens and possible weaknesses. I discovered lots of things about myself that I didn’t know.

The theatre-based activities of the workshops offered participants a means of trying out new behaviours within a shared enterprise of making things better for themselves and others. Seeing that change was possible within oneself contributed to their sense that anything might be possible.

Following the first workshop, the focus of the remaining four workshops were explicitly directed to the topic of hope in the context of care giving although group cohesion was further strengthened by starting each workshop with similar activities as those described above. To orient the participants to the substantive topic, they were asked to brainstorm a list of words they associated with “hope” and a subsequent list of those associated with “hopelessness”. The hope list included words such as “expectation, solutions, change, recovery, belief, connection, humour”; “fear, loss, dread, exhaustion, loneliness, end, imprisonment, anxiety, lethargy” were some of the words on the hopelessness list. The purpose of the articulation of these words was to stimulate our imaginations as we moved from a cognitive focus on hope and hopelessness to an embodied understanding of the concepts in the next activity, the image work.

The image work began with everyone standing in a circle facing outward. The facilitator asked us to

... create an image of hope. Don’t think about it too much, just let the image emerge from your body, from the deepest part of your cells. There is no right or wrong here. We are simply using our bodies to explore what hope feels and looks like. You might find you have to move a little. What does hope feel like to you? Now find the stillness in your body.

To activate the frozen images, to take the still images into action, we “sculpted” a multiple-bodied image of hope. Done in silence to allow for multiple responses, the sculpting was achieved by a volunteering participant, who positioned the bodies of other activators either directly or indirectly by mimicking the position he/she wished them to assume. Once all the other group members were positioned,
the “sculptor” put him/herself into the image. Then, another “sculptor” created a multiple-bodied image of hopelessness using the same techniques. When all groups had both images of hopelessness and hope, we “activated” by synchronizing our movements in shifting from an image of hopelessness to an image of hope over the course of three handclaps offered by the facilitator.

The work with images flowed into a session of story-telling. Those who wished to shared stories of care giving situations in which it is especially difficult to remain hopeful. In addition to making visible aspects of the substantive issue, the elements of “story” were made explicit and embellished with as much detail as possible. The story-telling session continued the group-building through the intimacy achieved by the sharing of personal story. From all the stories that were shared, as a group we picked the three scenarios that resonated to the greatest extent with everyone’s experience of trying to reconstitute hope as a caregiver. For example, the first scenario centered on the frustration of a caregiver not able to make it to work on time in the morning because his/her mother with dementia refuses to eat her breakfast. The second focused on the problem of a father with dementia who wants to help dry the fine bone china dishes after a family Thanksgiving dinner but during his drying, he forgets what he is doing and throws the dishes in the garbage. The third dealt with the difficulty of having to convince a spouse with dementia that their driving was no longer safe. The challenges to hope that were captured in each of these scenarios dealt with usual, everyday situations in the lives of caregivers. These scenarios were selected to be used at three forums.

**Forums**

Each of the three forums with audiences of other caregivers was a little longer than one hour in length. Each began with a few minutes of physical activities to break the anticipated formality. The attention of the audience was directed to the activators seated on the stage and each was introduced by name. The facilitator then asked the audience to consider their role in the event to be an active one:

The individuals here on stage felt a call to investigate how we find hope as caregivers of people with dementia. But, these individuals on the stage ARE you. They are here to reflect you and situations that are familiar to all of us. Nobody here is a professional actor. This is not Hollywood. These people up here on the stage are only one-half the equation of what is going to take place here today. You (pointing to the audience) are the other half. Over the course of our time here, you will be invited to get out of your seat and take part in what goes on up here on the stage. We have constructed an event so we can investigate how we might find hope as caregivers of people with dementia. But, we’re going to ask you to get up with us (Roy, 2007, 2008).

With this introduction, a rapport between core- and audience-participants was established and the fourth wall began to come down.

The three scenarios were presented and following each one the floor was opened up for discussion about the scenario with the facilitator asking, “Was it realistic?” The audience agreed that what happened on stage was realistic. In doing so, they offered a secondary level of validation of the lived experience represented in the scenarios. Confirmation of the reality of the scenarios consolidated solidarities between the audience and activators. It also established the credibility of the research thus far (Hallberg, 2008). Having checked and validated the scenarios for sufficient levels of “truth value” by those individuals most familiar with hope in the context of care giving, the caregivers themselves, we could move to the final and subsequent step in the research process—the testing of potential strategies to reconstitute hope.

The facilitator then focused on the specifics of the scenario: “What character was the focus? What did that character want? How did she go about trying to get what she wanted? Did his/her approach work? What prevented the approach from being effective? What else could have been done?” From the ensuing discussion, other suggestions for possible strategies arose, and with each, the initiator was invited to the stage and the action ran again, each time taking a new course.

Over the hour-long forums, one of the three prepared scenarios was enacted several times, each one emanated from a different proposal made by an audience member. After each enactment, the facilitator asked the audience “Was this realistic? What did you actually see? What was happening? Did this approach work? Why/why not?” The “actor”, who had suggested and enacted a particular strategy, was asked: “Did you get what you wanted? Were you able to employ the strategy as you intended? Why/why not?”

From the discussion following each enacted approach, other potential strategies began to surface. Rather than hypothesizing what might happen with a suggested strategy, the audience-participant who made the suggestion was invited up to the stage by the facilitator: “Would you like to come down and show us?” or “Would you like to try that?”. With the
clapping and verbal encouragement offered by the others, the fourth wall came down and the audience-participant approached the stage and stepped into the scenario to take the dramatic action in another direction. In the ensuing iterative cycle of reflection, action, reflection, etc., the scenarios opened up spaces for reflexivity and critical rational discourse, and vice versa, the discursive interaction between audience-participants fuelled further enacted proposed solutions and their enactments.

Results

Breaking the fourth wall

The results of the evaluation surveys completed by audience members indicate that the fourth wall was broken in the forums. In the open-ended questions, audience members were asked to describe their experience at the forum. Many reported feeling connected to the individuals on the stage. Typical survey responses were “I felt included—emotionally involved”, “it gave me a feeling of empathy”, and “I realized that I’m not alone”.

In describing her experience of being up on the stage, one participant reported in the interview, “As I looked out into the audience, I saw in their eyes that they could relate to the scenario”. Another said,

“I looked out into the faces in the audience and I realized that they were there for the same reasons that I was there. We were all looking for answers, for support. We were all looking”.

With the fourth wall broken, so was the isolation that family caregivers often experience.

Together, the activators and audience-participants were able to develop new ways of understanding the relationship between self and others. Their collaborative creation of representations of real-life situations made it possible for them to collectively test and evaluate their proposed modifications to those situations.

One strategy, proposed and enacted by audience-participants in different ways at the forums, was to anticipate the challenges to hope and prevent them from arising. In most instances, this strategy was found to not be realistic by the audiences. More potent strategies involved redirecting one’s attention to the cared-for person, staying “present”, and focusing on “the moment”. This had the effect of limiting the horizon of hope to the more immediate context. From the theatrically-tested ways of finding hope, as a group we learned that hope was related to an increased awareness of possibilities and choices, but that possibilities for a positive future were defined within a focus of living day by day. In doing so, we corroborated the proposition put forward by Farran et al. (1995) and noted above, that hope accommodates a changing horizon of possibilities.

Eight out of ten individuals who responded to the questionnaire agreed or strongly agreed with the statement: “the performance helped me understand the complexities of hope”. Others commented on the educational power of the forum by reporting that it allowed them to “learn alternative strategies to deal with those circumstances of hopelessness”. During the interview, an activator, reported, “I was amazed by the variety of solutions that were presented. I thought to myself “gee, why didn’t I think of that, that’s smart.” And, “I can use that”; “maybe I should be doing more of that.” It was a learning experience for me.” Witnessing the strategies being proposed and tested by audience members, one activator reflected:

I experienced something inside, what I call a ‘felt-shift’, like a gestalt. It isn’t just cognition, it’s a ‘ahh’ moment. Like, it’s knowing, ok something different has happened here. Seeing it happen in myself, feeling it happen in myself and the intervener and seeing it happen in the person that is being cared for, there was some shift happening to them. They didn’t know where it was going to go; I didn’t know where it was going to go. But, is an opening up inside.

Breaking the fourth wall resulted in the meaning and function of hope within the context of caring for dementia patients to be understood in more than intellectual ways. The new understandings were embodied and relational (Todres, 2008). As activators and audience alike watched, enacted, and recognized their shared experiences, new personal knowings were achieved.

Activating hope through PT

During the workshops, we used the image activities to “get into our bodies” to explore the emotive, visual aspects of hope. Even though the images were drawn from specific experiences, because they were not discussed and named, they could resonate with many other experiences in the group. Although the image work was done in silence, much of its power was attributable to its capacity to stimulated dialogue. By transcending the bounded rationality of the spoken word in their inception, images unlock pathways to the unconscious meanings that participants could then ascribe to aspects of their lives (Batisti & Eiselen, 2008). When the facilitator opened up the
floor for discussion of the images, the activators were better able to articulate their interpretations, tacitly held assumptions, and values.

When reflecting on the activating images, the activators easily made connections between their experiences of their bodies in motion on the one hand, and hope and care giving on the other. As one activator said,

“as long as you can move out and be with people. Even just for a walk, then you are active, you are moving and there’s hope. It is when you are isolated, alone, and in the dark. That’s scary.”

The theme of hope being connected to action and motion surfaced again when she described her experience of moving her body from being in the image of hopelessness to the image of hope. She said with great emphasis, “you took steps. You moved”.

Another activator identified a crucial element of his image of hope in terms as movement as well as having open eyes:

You have to see, you have to move and you have to move towards and as long as you can continue to do that, you’ve got hope. So, my group image of hope was to get everyone gathered around everyone around in a semi-circle with their arms stretched up and out and leaning forward as if anticipating something.

These requirements of hope, being active and having open eyes, were further elaborated when he described his feelings associated with the activity of moving from the image of hopelessness to the image of hope:

… first thing is you opened your eyes. Because if your eyes are closed, you really can’t have hope. That doesn’t mean that if you’re being blind, you can’t have hope. Because whether these physical eyes are closed or not, isn’t the same thing. Once you’re open to change, you’re open to positive things in your life, then you can have hope. It’s when you’re close to those things, when you’re eyes are closed, you’re SOL. You’re just not going to achieve it.

Reflecting on the image activities, one activator revealed,

“I found it quite remarkable that just changing my stance, changing my body language, translated into a different experience. And, then seeing others do it as well. And how that felt in the whole space, it was definitely palpable. In my heart of hearts, I believe that we are all connected, but you experience that we were working as one organism.”

Through the image work, this activator was able to feel his belief concerning the intrinsic connection between all human beings as his body in coordination with the other bodies.

During the forums, participants were able to explore the possible ways of dealing with situations that challenged their hope through the development and manipulation of the reality-based scenarios. But, in addition, the very performances themselves enhanced audience’s hope. New possibilities became apparent in the course of using the scenarios as models to test and evaluate potential strategies to reconstitute hope. An overwhelming majority of the audience members completed the survey agreed or strongly agreed with the statement, “seeing the performance has given me hope about being a caregiver of a dementia patient”.

The facilitation of hope among audience members was especially evident among those who came to the stage to enact their proposed strategy. In the survey questionnaire these audience members were asked specifically to describe that experience of engaging in the process in that way. While most reported some degree of trepidation when approaching the stage, they were made buoyant by their participation, regardless of whether their particular strategy was evaluated positively or negatively by the audience.

In the glow of the aftermath, one respondent said “it gave me a feeling of success, optimism, drawing on my own resources, a sense of freedom”.

In the forums, in which proposed solutions were enacted and collectively discussed, we learned that caregivers find hope in having practical solutions to the everyday dilemmas they face as caregivers. Hope is about possibilities that are inherently found in the reality of their everyday lived experiences as caregivers. One activator reported that, at the beginning of the workshops, he saw:

a lot of people with a lot of concerns. You could almost read it in their faces and then as the workshops progressed, you could see those layers wash away. And, I think they let themselves into it, accepted what was there, and realized that this is a help. You could see them tucking things away things in the back of their memory for use for when they got back to the people they were caring for. I think they all came away from there with their spirits lifted.

The activators and audience members agreed that, as caregivers, they need hope so they will not give up on those they were providing care for.
As one participant described, “without hope it’s like you have run out of gas, you can’t continue”. Hope is essential to deal with the ongoing demands as family caregivers to people with dementia. The object of the activators’ hope was not for things to get better—since that is not possible with a degenerative disease such as Alzheimer’s, but, their hope for things to not get worse.

Comprehensive understanding

Over the course of the project, as a group we learned that despair occurs in isolation, whereas hope occurs in collectivity and comes out of being able to take action. Since the technique of PT relies on a group cohesion founded on shared experience and purpose, participants develop a strong sense of collectivity within a short time. The very processes of the technique broke the isolation experienced by the activators before coming to the project and were replaced by a feeling of hope for themselves as individual caregivers and for other caregivers.

Within both the workshops and the interviews, the activators repeatedly described a profound sense of fulfillment from their contribution to a collective project that had potential to improve the lives of other caregivers by reducing their isolation. For instance, one expressed her sense of hope as coming from her knowledge:

... that as a group, we were forming to try to make things better for others. We all created a hopeful situation for each other in our own little niche, but we were also bringing that to others. It was a significant moment for me when it clicked for me and I realized that this is happening; this is real. We might actually bring hope to people’s lives.

The feeling of contributing to a collective good, a shared cause was felt by the activators and also by the audience-members who came to the stage to enact a proposed strategy. As one said “it was definitely a first for me—I hope I was of some use to the cause”. Being part of, and use to, a joint venture with others who share a similar problem and vision fosters people’s hope. These findings are significant as no other research studies have reported PT fostering hope in family caregivers of persons with dementia, nor described the mechanism through which hope is fostered.

Conclusions and short discussion

Our study confirms the value of various creative art forms in health care as well as in the research process, which has been advocated for some time (e.g. Eisner, 1981). Arts-based methodologies involve analyses of expressive forms such as autobiography (Ellis & Bocher, 2000), photo-essays (Lapidus, 1996), and dance performances (Blumenfeld-Jones, 1995). Arts-based methodologies involve multi-sensory exploration of the expressive domain to reveal the richness of the participants’ “lifeworlds” (Rapport, Wainwright, & Elwyn, 2005).

Performative methods, in particular, have the capacity to convey meanings that pertain to the flux of social relationships because these meanings are so inherently embodied in gestures and actions (Denzin, 2003; Gergen & Jones, 2008; Jackson, 1996). By explicitly incorporating metaphors and their inherently tentative nature, performative methods ensure that the meanings extracted are not made too concrete. Yet by showing, instead of telling (or perhaps re-telling in action), “performative enactments have the capacity to universalize” (Denzin, 1997, p. 94).

The study reported in this article used the aesthetic language of theatre as a unique and powerful tool to access caregivers’ knowledge of their lived experience and to provide a frame of reference for facilitating discussion about the abstract concept of hope: its meaning and function in their lives. The drama was created in the process of the research and used as a tool to explore how hope is reconstituted in the course of the daily lives of caring for family members with dementia. The results of the post-forum evaluation questionnaires and the follow-up interviews with the activators confirmed that in the forums the fourth wall was broken and the use of PT with family caregivers of persons with dementia is feasible, acceptable and even desirable. The processes of participatory theatre set in motion a collective investigation of the topic of hope; at the same time, the processes facilitated hope among those on both sides of the fourth wall.

We acknowledge that both sets of questions contain statements that might be considered leading questions, which might not have given enough good opportunity to express even negative experiences. More critical or neutral statements would have corrected this methodological weakness.

Acknowledgements

This project was made possible by the funding secured from the University of Saskatchewan’s President’s Social Science and Humanities Research Council Fund.
Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Appendix A: Recruitment materials

Figure A1. Newspaper advertisement.

Are you caring for a family member with dementia? If so, we invite you to be a part of an exciting, new study: Exploring the Experience of Hope.

Join us for three Theatre-Based Workshops and:

- Have FUN!
- Explore Hope and envision new possibilities
- Share your experiences
- Meet others in similar situations
- Utilize theatrical techniques
- Perform short plays and participate in a final performance
- Provide others with a better understanding of your experiences.

No acting experience necessary! Respite care provided.

For more information, please call Liz Urbanowski at 249–1368.

The Exploring the Experience of Hope Project is led by University of Saskatchewan researchers Liz Quinlan and Wendy Duggleby with theatre artist Rob Roy, a leading proponent of community-applied theatre. This project is endorsed by the Council on Aging and the Alzheimer Society of Saskatchewan. This project is funded by the University of Saskatchewan.

Radio Advertisement

Radio V/O. PSA. 30 sec.

We are looking for Family Caregivers of People with Dementia to take part in a unique series of gatherings that will use theatre games and exercises to “Explore the Experience of Hope”.

Throughout September and early October, four gatherings will be held in Saskatoon. Our intention is to build new hope by creating a community of informal caregivers in a light-hearted, nurturing atmosphere.

No acting experience is required. If you are a caregiver of someone with dementia and would like Explore the Experience of Hope, then please call: _________ at __________. That number again: ___________. Thank you.
Appendix B: Post-forum survey

To be completed after the forum.

Please fill in the blanks:

Gender: M ___ F ___
Occupation, if/when in paid labour-force: _________________________.

Please write your answers to the questions below and on the back if you need more space.

1. I benefited from seeing the performance about hope among informal care-givers of dementia patients.
   **Strongly Agree ___ Agree ___ Neither Agree nor Disagree ___ Disagree ___ Strongly Disagree ___

2. The performance helped me understand the complexities of hope.
   **Strongly Agree ___ Agree ___ Neither Agree nor Disagree ___ Disagree ___ Strongly Disagree ___

3. Seeing the performance has given me hope about being a caregiver of a dementia patient.
   **Strongly Agree ___ Agree ___ Neither Agree nor Disagree ___ Disagree ___ Strongly Disagree ___

4. What were the most interesting aspects of the performance?
5. What was it like to be a member of the audience of this performance?
6. During the performance did you participate by coming to the stage and testing a strategy: Yes ___; No ___.
   6(a) If you did come to the stage and test a strategy, describe the experience of participating in the performance in this way.
   6(b) If you did not come to the stage, what hindered your participation in this way?
7. If the performance changed your views of hope, describe the change.
8. Is there anything else you would like to tell us?

Thank you for completing this survey.

Appendix C: Interview guide

1. What was it like to take part in this project?
   Probes: Warm-up exercises, scenario building and performances

2. What was the most meaningful activity?
   Probes: Why was it especially meaningful? Any other activities?

3. Were there moments when you were hesitant about taking part?
   Probes: In the warm-up exercises? In the scenario-building? In the other activities?

4. Were there moments when you were especially keen to take part in the activities?
   Probes: Can you tell me about those moments? Why were you keen?

5. Where there times where you experienced hope?
   Probes: An activity or situation? What did hope mean to you?

6. What did the images of hope developed in the workshop mean to you?
   Probes: What was it like to form an image of hope/or despair?

7. How did participating in this project change your thoughts and feelings about hope among informal care-givers of dementia patients?

8. That is all the questions I have. But, I wonder is there anything else you would like to tell me about your experience being a member of this group?