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Dying Matters – Innovating Spaces to Foster End-of-Life Discussions with Applied Theatre

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Abstract (100 words)

Increasing evidence highlights the benefits and importance of discussing End-of-Life (EoL), yet many people struggle to talk openly about death and dying. This practice-based report details the development of *Dying Matters*, an applied theatre performance designed to encourage EoL conversations with loved ones. The combination of lived experience monologues and reflection activities appeared to provide an inspiring and supportive experience. The team observed many attendees actively taking moments during the performance to ponder and write their response to EoL preferences prompts. Further application of this work is recommended to engage a broader community and to enhance healthcare professional training.

Keywords: end-of-life discussion, applied theatre, lived experience, death preparedness, compassionate communities.

“Death is like a burglar, catching us when we least expect it. It felt like (and still feels) like coming home, finding the front door opened, realising that something has been taken and it is irretrievable and irreplaceable.” – an excerpt from a monologue in *Dying Matters*

Introduction

When is the right time to consider and discuss our End-of-Life (EoL) with our loved ones? What happens if our EoL preferences are not made known to them when they need to act on our behalf? How do we initiate such conversations? Discussing death and dying can feel daunting. Many people associate these conversations with later life or consider them as the responsibility of healthcare professionals. However, everyone is susceptible to experiencing death and loss. Discussing EoL preferences with loved ones offers opportunities to share and obtain information that could provide clarity and aid decision-making regarding treatment and care arrangements (Wright et al., 2008). Avoiding EoL discussions can diminish the quality of life for patients and their families (Roscoe & Barrison, 2018); compromise the dignity of the dying (Parks et al., 2011); result in regret among the bereaved (Kim, 2018); and hinder bereavement adjustment (Schulz et al., 2015). Additionally, a lack of information on patients' treatment preferences can cause healthcare teams to experience moral distress and grief. Without sufficient information, healthcare professionals can feel conflicted, helpless, and concerned that the care provided was not in the best interests of the patients or might be even against their wishes (Boulton et al., 2023). Despite the known benefits of having EoL discussions, the taboo surrounding death and dying in many societies prevents many people from initiating these conversations (Rawlings et al., 2017).

This practice-based report introduces *Dying Matters*, an applied theatre performance aimed at encouraging EoL conversations with loved ones. It seeks to complement ongoing efforts to foster death preparedness in communities. Death preparedness involves taking actions to accept mortality broadly (Kastenbaum & Moreman, 2018). This may include recognising symptoms of decline and understanding what dying entails, as well as processing death-related emotions and grief responses. It also involves accessing support to manage, plan, and provide care around death (Durepos et al., 2019). Death preparedness promotes

acceptance of unexpected death as part of the continuum of life (Park et al., 2023) and offers several benefits such as reducing death-related anxiety and stress; fostering a positive awareness of death; supporting decision-making related to death; and encouraging people to appreciate their lives (Chapple et al., 2017; Mohammadpour et al., 2018; Nan et al., 2018; Shah et al., 2013). The positive death movement and compassionate communities are examples of ongoing initiative to foster death preparedness. The positive death movement, a social and philosophical movement that addresses the culture of silence around death and dying by promoting open discussion (Leland, 2018). While compassionate communities strive to enhance death literacy by providing practical information and support in palliative and end-of-life care contexts (Kellehear, 2013). *Dying Matters* explored ways which an art-based approach could promote engagement and encourage EoL discussions.

The project leads are full time staff members at Sheffield Hallam University. One is a creative health practitioner and academic at Lab4Living, an interdisciplinary research group focusing on creative health and wellbeing. The other is an academic at The Performance Lab, specialising in theatre, with a particular interest in theatre and health. The project was offered as an option for third-year undergraduate acting students enrolled in an acting and performance programme. Seven students chose to participate in the project and collaborated with the two project leads to develop the performance. This report shares the authors' reflections on the design and execution of the project and concludes by highlighting several potential areas for future application.

Programme rationale and goals

People with a high level of death literacy – familiarity with knowledge, skills, and understanding of EoL and death care options – can adapt more easily when circumstances require them to make choices and decisions on care or treatment arrangement (Noonan et al.,

2016). Despite the known benefits of discussing death and loss with others, many people seldom prioritise such conversations, particularly with their loved ones, and find themselves coping with unresolved issues related to death (Chan & Yau, 2010).

Applied theatre refers to forms of dramatic activity occurring outside conventional theatre settings, aimed at benefiting individuals, communities, and societies (Nicholson, 2014). Applied theatre techniques often serve as catalysts for social action, supporting community capacity building, empowerment, and social transformation. Much of this involves performances that prompt or challenge audience responses, encouraging active engagement in exploring various themes identified by communities as important to them (Prentki & Preston, 2013). Such approaches have been widely used in arts and health contexts for health education, delivering health information, highlighting health inequalities affecting communities, and promoting well-being (Baxter & Low, 2017). Some projects have focussed on death and loss for example, *This Grief Thing* by Fevered Sleep – a multimedia creative project encouraging public engagement with the notion of grief (<https://www.feveredsleep.co.uk/project/this-grief-thing>), and the *Kicking the Bucket Festival* – an annual festival exploring death, bereavement and life through community activities like workshops, performances, and film (<https://www.kickingthebucketfestival.co.uk/>).

Responding to the need to expand efforts in community-based death preparation and education (Kim et al. 2016), *Dying Matters* utilised applied theatre techniques to foster social action and change in individuals' capacity to discuss EoL (Thornton, 2015; Wong & Clammer, 2017). It aims to provide a space that stimulates critical thinking, inspires discussion, and encourages individuals to consider, capture, and initiate conversations about EoL through an immersive, introspective, and interactive experience. The 90-minute performance weaved together a series of monologues developed by performers from their lived experiences, reflection activities, and a conversation segment (Figure 1).

[Figure 1. Monologue presentation in the opening scene by a performer near here]

Description of the programme

The project was offered as an option for third-year undergraduate acting students in the module Drama in Education and the Community. Seven students voluntarily opted to undertake this project. They were motivated by experiencing the death of someone close or have an interest in EoL. Six students were 20-21 years old, and one was 40 years old. The content and format of *Dying Matters* was co-developed by the project leads and the students through a series of workshops, and all appeared in the subsequent performance. At the initial monologue development workshop, the participating students were invited to share their reasons for choosing the project and their views on death, loss, and grief. Following a discussion, they were tasked to write a monologue using the free writing technique (writing without a prescribed structure) to capture their initial thoughts and ideas. This technique encourages the writer to tune in to and follow impulses and stream of consciousness without premeditation that can take place over a predetermined amount of time. The students were free to use any writing style for the monologues and to write from a first or third-person point of view. Subsequent workshops were used to discuss tone and to consider Geese Theatre Company's degree of distance advice about whether to work at one-step removed or at a personal level (Baim et al., 2002). Through this process, most of the students expressed a desire to work at a personal level and to speak about their own experiences, and this led to an aesthetic decision for them to read their stories, as if they were testimonies. A rehearsal was conducted with students also enrolled in the course but not participating in *Dying Matters*. It

was held towards the end of the semester, as a segment of the course content to promote peer learning.

Since premiering in November 2022 at Lab4Living in the UK, the project has welcomed audiences such as retirees; students; social workers; and nurses. It was showcased at Dying Dialogue Symposium 2023, Toronto, and Dying Matters Awareness Week 2023 in Sheffield, UK. The performance schedules were publicised online using Eventbrite for members of the public in the different locations to register for attendance. Given the sensitive topic of death and loss, viewer discretion information was included in the publicity material and announced at the start of each performance. The audience was informed that they were free to excuse themselves or approach team members if they distressed or uncomfortable at any point of the performance. Leaflets containing contact information for crisis support services (e.g. the Samaritans Helpline) were prepared and distributed at each performance. Similarly, group check-in sessions were held at each project meeting for students and project leads to express and discuss any concerns or emotions arising from their work on the project. Throughout the presentations, the project team did not encounter any instances of participants leaving sessions prematurely or experiencing unexpected distressing emotions.

The staging for the performance was intentionally minimal to blur the boundaries between performers and audience, symbolising the interconnectedness of life and performance. We were also interested to convey the universality of death between strangers and to foster a shared communal experience. The stage was a circular space framed by a ring of chairs. The performers were placed among the audience, participating in all activities, dressed and behaving in ways that did not draw attention to them until they delivered their monologues, revealing they were performers. This approach has similarities with Augusto Boal's concept of Invisible Theatre (Boal & Epstein, 2013), in that it blurred the distinction between performer and observer and played down any sense that this was a rehearsed

performance. It also served as a deliberate reminder of 1) the unexpected nature of death, 2) death's inevitability, and 3) the continual experience of death and loss. More significantly, the work highlighted the invisibility of grief and loss among us and questioned our capacity to support one another. Between the monologues, several performer-led reflection activities provided the audience with opportunities to contemplate who and what matters to them, and to write down messages they wished to leave for others (Figure 2). At the conclusion of the performance, audience members were invited to join the performers in a collective dialogue and learning space, where they could voluntarily share their thoughts, feelings and experiences related to death and loss.

[Figure 2. Reflection activity for audiences led by a performer near here]

The minimal staging allowed the project to be readily adapted to different environments and formats. Based on post-show debrief sessions and audience feedback, adjustments were made over time to enhance the work's ability to immerse and engage the audience, thereby enhancing the flow and tension between the monologues. Some of the adjustments we made include allocating more time for audience members to reflect and write. It is important that they feel unhurried. We learnt also that it is also useful for the facilitator to indicate the duration of an activity and check in the audience if they require some extra time. We also reviewed and adjusted the order, pace and rhythm of the performance, to enhance its capacity to hold space for introspective activities and to sustain attention.

Key learning points

Thinking about and discussing EoL is something many people feel uncomfortable and reluctant to consider, both personally and with others. This section presents the key observations the authors made regarding the qualities of an art-based approach and its ability to stimulate and encourage reflection on EoL. It also identifies several opportunities for future application.

A moving, engaging, and thought-provoking hour

The authors observed that the performance had a compelling and evocative effect on the audience. The audience was intrigued by the unique performance format where the performers were embedded among the audience. The audience was kept in suspense, not knowing where the next story would come from, which effectively contextualized that death affects everyone. Many audience members expressed curiosity about the authenticity of the monologues, which was an element that kept them engaged. Upon learning that the narratives were personal experiences during the conversation segment, they felt emboldened by the performers' vulnerability, honesty, and courage to share upon learning that the monologues were associated with the performers' lived experiences. The capacity for writing, vocalising, sharing, and listening offered by the work to support processes of realisation, foster a sense of resolution and healing, and facilitate a call to action were appreciated by both the audience and performers.

The audience recognised the need for and importance of discussing death and loss openly, yet many have not taken those initial steps. They appreciated *Dying Matters* as an alternative approach. The project also led people to recognise a need to make time to reflect on their experience of loss. The performance and the two activities led attendees to reflect on dying and many were seen taking moments to

write during the performance. Additionally, the performance inspired several attendees to write letters to their loved ones.

Fostering compassionate communities

The immersive experience of having the audience and cast sit together in a circle served as a reminder that the experiences of loss narrated are shared by all humankind. There is no fixed time period for grieving a loved one, and thoughts about a lost loved one can arise unexpectedly. The performance highlighted the pervasive and elusive nature of grief, prompting questions about our ability to support each other and the availability of spaces for such support.

Grief is often viewed as an individual, internal psychological process (Breen & O'Connor, 2007). Macdonald (2019) warned that taboos around death can heighten grief experience. Social contexts and processes (Macdonald, 2018) and the prevalence of “socially-awkward, and maladapted responses to grief” (Breen et al., 2022, p. 425) can exacerbate grief. Audience reactions underscored the importance of compassion in daily life, highlighting the performance's supportive and caring qualities in fostering a space for sharing, introspection, and learning about end-of-life experiences. The audience's view of *Dying Matters* as communal and supportive also suggests its potential contribution to ongoing efforts in grief literacy, which aims to enhance community and societal support for grief (Breen et al., 2022).

Expanding context and promoting intergenerational exchanges

Discussions on EoL often focus on later life and care settings such as hospitals and hospices.

Dying Matters broadened EoL discussions to a wider community context and audience.

Audiences included community care workers, healthcare professionals, academics, retirees,

and university students. The discussion segment provided an opportunity for the audience to share their perspectives and opinion on EoL. It also enable a diverse views of death audience from various backgrounds and ages offered a nuanced perspectives of death and dying. These exchanges underscore the universality of death and loss and its transcendent nature.

Future plans for creative activity

The encouraging responses the authors observed of audience and the capacity of *Dying Matters* to stimulate reflection on EoL also prompted the team to consider opportunities in the following areas.

Further community outreach. The positive reception and emotional impact that the team observed from audience at *Dying Matters* suggests its ability to inspire and engage audiences of different backgrounds and ages to discuss EoL. Given the limited platforms for sharing lived experiences of loss and the community-building potential of the work, the team was encouraged by community care professionals in the audience during post event reception to expand its reach to the wider community. The team is keen to collaborate with public libraries and community centres to explore workshops and presentation opportunities. We also received a recommendation to adapt the work to support legacy-making activities that offer opportunities for loved ones together to create or do something with the intention of remembrance (Allen et al., 2008).

Enriching health professional training and healthcare practice. Applied theatre is increasingly used in healthcare professional training to develop communication skills, address health stigmas, and promote empathy (Reeves & Neilson, 2018). The “direct engagement” and “felt” qualities of *Dying Matters* have led health practitioners and educators

in the audience to recommend further application in the healthcare training curriculum to cultivate compassionate practitioners. The team was also encouraged by healthcare professional and academics in the audience during the conversation segment of the performance to present the work as a learning encounter for healthcare professional through seminars or extra-curricular events. Additionally, the introspective nature of the project suggests that there is potential and opportunities for the work to be adapted in several areas. These include 1) Research-based Theatre (RbT) (D'Alessandro, 2023; Lea et al., 2011) to present research findings in a captivating, imaginative, and engaging manner; 2) dignity therapy - individualised psychotherapy intervention aiming to alleviate psychosocial and spiritual distress in the final stages of life (Chochinov & Montross, 2021); and 3) stimulating reflection and discussion of ethics in healthcare settings on issues and experiences of healthcare workers with death/dying such as supporting understanding of moral distress-dilemmas arising from morally challenging situations (Elpern et al., 2005). Lastly, the increased interest in participatory theatre as a methodology to facilitate transformative social research (Erel et al., 2017) also prompted the team to consider the possibility of deploying the work as a creative method in participatory research with the community to further explore concerns and barriers surrounding EoL planning and bereavement.

Conclusion

Conversations on death and EoL are crucial, yet many struggle to initiate them with their loved ones. Through *Dying Matters*, an art-based approach appears to have the capacity to inspire, ease, and engage people to reflect on important EoL considerations. The emotive quality of the lived experience inspired monologues reminded the audience that everyone is vulnerable to death and loss. While the introspective space afforded by the performer-led reflection activities were seen

encouraging the audience to pen their thoughts and wished. As communities explore ways to foster compassionate communities and enhance death preparedness in the community, *Dying Matters* could provide a space for starting conversations about EoL.

Declaration of interest statement

The authors report there are no competing interests to declare.

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