THE DYING ROLES: A CREATIVE AUTOETHNOGRAPHIC EXPLORATION OF ROLES AT THE
END OF LIFE

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ABSTRACT

THE DYING ROLES: A CREATIVE AUTOETHNOGRAPHIC EXPLORATION OF ROLES

AT THE END OF LIFE

ÉMILIE CORMIER

I chose to conduct a creative autoethnographic exploration to better understand the implication of roles at the end of life and the possible creative interventions that can be built on the use of roles. To do so, I created a short animation film based on roles that emerged from my analysis of the verbatim of Elizabeth Kübler-Ross interviews with dying women included in the book *Death and dying* (1969/2005). I used Robert Landy's role method (1992), role taxonomy (1991a) and role theory (1991b) as well as his artwork to frame my exploration of these emerging roles. The creation of the short film gave me insight on how roles can be linked to some suffering experience as well as how they can contribute to positive outcomes at the end of life. I discovered how roles are deeply anchored in social relation and in the body, two aspects of life greatly threatened at the end of life. I realized that roles can be seen as metaphors of our relationships to the world and therefore cannot only express but create our reality. I consider how roles and Landy's method could be used as a reflective tool for caregivers for more ethical practices. I discovered how roles and their expression within a multimodal environment could be used as a pretext to facilitate the act of storytelling that can be challenging at the end of life for dying individuals. Leaning into the creative process, I also realized as an artist and becoming therapist the power of art, creativity and intersubjectivity to relate to the world we live in and challenge it. The autoethnographic aspect of the quest showed me how transformative this type of research process can be.

Key Terms: roles, end-of-life, role method, role taxonomy, Robert Landy, metaphor, animation short film, dying, Elizabeth Kübler Ross

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Chapter 1. Introduction

This research project was conceived and carried out continuously over the course of a single academic year, which nevertheless seems to have been composed of two eras. Conceptualized in the fall of 2019, most of the exploration and creation that the project involved took place in 2020 during the COVID-19 pandemic. The purpose of this inquiry is to explore personal roles at the end of life. Within our cultural landscape, death as shifted from a distant, hidden and taboo concept to a daily reality in the news and in the lives of our neighbors, relatives and friends. How in these circumstances does one reflect on individual's reality at the end of life? How can we think about creating more sensitive support tools for people at the end of life when the health system is struggling to offer basic care to the dying individuals? How to put aside for a moment the lightning lethality of this disease, to try to understand the slowed down temporality of contemporary end of life? Sometimes, breaking off to acknowledge death is a way to dramatize life, suggests Luce DesAulniers (1997) inspired by the words of Christophe Tison (1989). Perhaps, despite the violence of the trauma experienced collectively this stop in motion, the shock of death as a reality that concerns us all, can push us to reposition ourselves, and instead of flying away from the void, create in tension with the vacuum meaning and purpose (DesAulniers, 1997). Therefore, the relevance of the present exploration is anchored in this will to dramatize life by putting forward at the very end of it, flexibility, adaptability and creativity. In the circumstances of the pandemic, adapting the means taken to pursue the creative exploration testify, first of all, to a desire to continue this research which may show its usefulness in the short term, but also act as a way to keep a necessary aesthetic distance from dying in these times of collective mourning.

Byock (2002), a contemporary flagship figure in palliative care, more than fifteen years ago stressed the need to constantly consider creative ways to improve support for people at the end of their life. The reminder of this recommendation is particularly timely in the political and legal context of Quebec where the Law on end-of-life care was adopted in 2014 (http://legisquebec.gouv.qc.ca/fr/ShowDoc /cs/S-32.0001). This law, which received lot of attention, especially in relation to the legalization of medical assistance in dying (MAD), also called for obligations with regard to the development of adequate and accessible end-of-life care for all. One year after the report on the situation of end-of-life care in Quebec in the spring of 2019 (Commission sur les soins de fin de vie, 2019), considering innovative practices to ensure optimal relief of the sensitive suffering of motivating MAD requests in people at the end of life seems more relevant than ever (Bourgeois-Guérin et al. 2018; Ohnsorge et al., 2019).

The development of this research project is therefore inspired by the association of the social, legal and political context of the end of life in contemporary Quebec, the under-representation of dying individuals' point of view on their experience (Ohnsorge et al., 2019), the need to develop innovative interventions (Byock, 2002), and the significantly reduced presence of drama therapy in the palliative care field which contrasts with the marked interest of the same field for the concept of role (Lowrie et al., 2019b; Redhouse, 2014). It is also motivated by intrinsic aspects of who I am as an artist approaching death in her artistic work, a student and researcher interested in these questions, a therapist in training in palliative care settings, a human having accompanied her father at the end of life and a citizen concerned by the legislation surrounding end-of-life care.

From then on, the possible combination of cultural, scientific and intimate aspects of the experience guided the choice of a methodology in qualitative research nourished by these different facets, namely autoethnography.

The objective of this research is therefore to explore roles at the end of life, through a creative autoethnography, as a response to this imperative to develop creative and innovative interventions. By aiming to participate in the emancipation of the dying as well as in the transformation of the end-of-life experience and the culture in which it is lived, this project is definitely part of a critical paradigm. From an ontological point of view, reality is seen in the context of this exploration as co-constructed and contextual. Finally, the axiology of the adopted approach is anchored in community and humanistic values.

Chapter2. Literature Review

Informed by this positionality, the literature review which follows seeks to give an account of the writings relating to the experience of the end of life from the point of view of the dying person, the known and probable contributions of drama therapy in the context of end-of-life care and the concept of role in this specific context, in general and in drama therapy.

Emic perspective on end of life

Since the fundamental Elizabeth Kübler-Ross' *On death and dying* (1969/2005) which encompasses numerous testimonials of patients at the end of their life, very few articles adopting an emic perspective, namely recounting the point of view of the dying on their own experience, seem to have been produced. In general, the articles that serve as a voice for this population denounce at the same time the significant absence of their perspective in the description of the experience of dying. The article by Fleming et al. (2016) is a good example of this awareness-raising work. By specifically giving voice to elderly at the end of their lives, it highlights the impression of not being themselves dying people have and the perceived impact of this identity change on their loved ones. In addition, the article by Mckechnie et al. (2007) seeks to compensate for this lack of representativeness of the dying by collecting accounts of lived experiences of palliative care. These stories highlight the disconnection felt by the dying and the difficulty in maintaining certain social roles. The study also highlights the lack of agreement between the roles made available to the dying and the characteristics of their lived experience. Based on interviews with end-of-life patients suffering from various incurable diseases, Ohnsorge et al. (2019) provide an essential forum for the dying to express characteristics of their experience that may possibly motivate a request for medical assistance in dying. Interviewees name isolation, the loss of agency and identity, the experience of liminality, and the impression of being trapped between two states as difficult aspects of their lived experience of end of life. Bourgeois-Guérin (2010, 2013) based on interviews conducted with 10 dying women articulates the implication of temporality, communication and the experience of the body in suffering at the end of life. Finally, studies by McKinlay (2001) and Yedidia and MacGregor (2001) illustrate that, by giving voice to people at the end of their life, it makes it possible to identify aspects of their experience that could benefit from more sensitive and adequate support. McKinlay (2001) with their "Circle of Care" highlights the central importance of recognizing the identity of people at the end of life and Yedidia and MacGregor (2001) succeed in highlighting seven patterns (struggle, dissonance, endurance, incorporation, coping, quest, volatile) as many perspectives on the end-of-life experience described by patients.

Extended temporality of contemporary dying

For several decades, we have observed an increase in life expectancy in Quebec. At the same time, the causes leading to death have also changed significantly. Since the early 2000s, malignant tumors

have supplanted diseases of the circulatory system as the leading cause of death. According to the 2018 Quebec demographic report published in 2019, 33.6% of all deaths are attributable to malignant tumors (Institut de la statistique du Québec [ISQ], 2018). In addition, technological and medical advances have made it possible to develop protocols that relieve pain more effectively, which also has had the effect of extending the temporality of contemporary dying (Lipsitt, 2016). This extension of the end-of-life period brings its share of consequences for those who live it (Emanuel et al. 2007). First, the social scripts that support the end of life do not seem to have evolved in parallel (Lowrie et al, 2019b). There is therefore a contrast between the perception of caregivers who see the person as dying and the latter who in order to adapt to the prolonged liminality of their situation seeks to oscillate between the living and the dying (Breen et al, 2018; Kellehear, 2009; Lowrie et al., 2018 as cited in Lowrie et al, 2019b). The single and fixed change in status from living to dying cannot sustainably serve the contemporary reality of end of life and the personal and relational aspects of it (Lowrie et al., 2019b). Furthermore, it is interesting to emphasize that the prolonged awareness of living their last moments allows the person to have more time to carry out these primordial transitions and reorganizations in their role system (Lowrie et al, 2019b).

Definition of role as a concept

The famous sociologist Erving Goffman was one of the first in 1959 in the book *The presentation of self in everyday life* to introduce the metaphor of the theater to illustrate the dynamics of social life and of the human as an actor playing a role to understand the psychological processes that drive them. These metaphors have since more generally intruded into the field of sociology and psychology to give birth to numerous role theories.

Different definitions have shed light on the many functions that roles can serve. Thus, the role can be considered as a set of characteristic behaviors adopted by a person in a given context (Emanuel et al., 2007). It is also used as a normative guide to social expectations relating to the status of the individual (Emanuel et al., 2007). Adopting a role and associating it with a set of roles already assumed by the person can also contribute significantly to the construction of their identity (Lynch, 2007 as cited in Lowrie et al., 2018). In this sense, the role repertoire which is frequently presented as a constellation of sub-roles overseen by roles is reminiscent of the central self-schemas in the field of social psychology (Vallerand & Rip, 2006).

Finally, the rituals accompanying significant life events generally have the function of facilitating the transition from one role to another (Lowrie et al, 2018). Because dying is the last significant event in life, the legitimacy of the concept of role in the context of the end of life is manifest.

Role at the end of life

Already in the important work edited by Feifel in 1959 *The Meaning of death*, the psychiatrist Gerald J. Aronson speaks of the need for dying individuals to maintain a certain continuity in their

repertoire of roles. He invites caregivers to promote therapeutic and human actions that contribute to this continuity. Since then, a whole conceptual current based on the concept of the role and the dramaturgy of end of life has been developed. Through a systematic review of the references included in articles related to this movement, it has been possible to identify the most significant literature and reach a point of saturation in presenting what has been written over time on the subject of role and dying. Therefore, the articles reported here cover the period between 1977 and 2019. This longitudinal interest for the role seems to reflect the relevance of the concept in palliative care, the need to work even more actively to resolve certain problems linked to this concept and to the imperative to create tools to address them.

Noyes and Clancy (1977/2016) speaks of the principle of confusion between the sick and the dying roles. This confusion can be fueled by the environment and the attitude of caregivers. Open communication of the prognosis to patients makes it possible to facilitate a healthy transition from the role of a sick person to a dying one, which can, in turn, allow the completion of meaningful tasks for the person at the end of life and leave room for the creation of meaning. Howe (2016), in a commentary on this article, talks about access to end-of-life care as a social breakthrough that eases this transition from the sick to the dying role. In a second comment on the same article, Lipsitt (2016) puts forward the pharmacological framework of symptoms which allows room for other types of treatment to ensure an adequate experience for the dying person. To complete this care, palliative care workers must develop a malleable system of roles. A system which unlike a defined script that promotes rigid behavior and limits creativity, flexibility and freedom, would be able to take into account the personality and the developmental stage of the dying.

Parker-Oliver (2000) used Goffman's dramaturgical model to account for the experience of dying. The article provides a definition of certain fundamental elements of the dramaturgy of the dying: the roles, the co-staging of the drama of dying, the necessary centrality of the dying role, the possible implications of the other scenic elements such as the sets, props and costumes in the maintenance of roles that preserve the dignity of the dying.

Emanuel et al. (2007) analyzed the main role of the dying person by dissecting it according to three dimensions: the practical dimension, the relational dimension and the personal dimension which involves the integration of losses and the redefinition of deep identity. A better understanding of these dimensions can, according to the authors, support the development of therapeutic approaches that promote a better quality of life and that stimulate personal growth at the end of life.

In other studies, flexibility of roles is emphasized as a factor of resilience (Lundquist, 2017). Storytelling and creative interventions are suggested to promote this flexibility and maintenance of certain roles to sustain the relational, cultural and environmental aspects of the dying (Leonard et al., 2017). Based on the definition of suffering according to Ricœur, the study by Bourgeois-Guérin and colleagues

(2018) suggests that the loss of certain roles can threaten the person's power to act and that it is this impotence that causes suffering in the person at the end of life.

Finally, in a series of three articles Lowrie and colleagues (2018; 2019a; 2019b) explore the nature of the dying role and its implication in the dramaturgy of the end of life. In a first article, they relate that dying scripts have always been culturally present. These scripts are frequently presented as evidence of the power issues that affect the dying (Lowrie et al., 2018). In this sense, they warn against the definition of the roles of the dying by the living which can undermine the power to act of the dying and incidentally their dignity. The ambiguity pertaining to dying role, the living and the dying not being mutually exclusive status, is also named. The authors suggest that the dying roles repertoire represents an intrinsic part of the living roles repertoire and that the task of the dying is not to adopt a new set of roles at the end of life, but rather to reorganize their repertoire of roles. In the first segment of an anchored theorization which aimed to understand the causes and implications of alignment or mismatch of roles at the end of life, the researchers emphasize the contemporary reality of dying which frequently involves prolonged experience of the ambiguous reality of the living dying or the dying living (Lowrie et al., 2019b). The account of this research highlights the advantages of a continuity or an extension of the repertoire of the roles of the dying in this liminal space. The disadvantages, such as distress and anxiety, caused by role mismatches are also discussed (Lowrie et al., 2019a). Since liminality is inherent at the end of life, flexible and open approaches must help avoid the negative consequences of role incompatibility (Lowrie et al., 2019a).

Despite this marked interest in the concept of role in the development of palliative care field, Lowrie et al. (2019b) deplore the fact that very little work has focused on the role as an intervention tool as well as on the influence of contemporary roles on the experience lived by people at the end of life.

End of life and drama therapy

Given the preponderance of the concept of role and the use of dramaturgical language in the literature of the dying, it is surprising to find so little research looking at drama therapy intervention in palliative care. Redhouse (2014) explains that drama therapy, like art therapy and music therapy, must find its way in the field of palliative care. She suggests that it may be reduced mobility, physical condition or generational preferences for certain art forms of end-of-life patients that could potentially explain this gap in the implementation of different creative modalities. Open environment that accommodates new practices could benefits the development of drama therapy in the context of end-of-life care. Rigidity of some medical setting is also proposed in this perspective as a potential constraint to the implementation of drama therapy in palliative care.

However, the benefits of the dramatic modality appear to be very promising. Drama therapy allows, among other things, the dying person to revisit their life story, explore the liminal space and

maintain communication when spoken language is inaccessible (Redhouse, 2014; Russo, 2018). Hartley and colleagues (Hartley, 2013; Hartley & Payne, 2008) and the systematic review of creative interventions by Archer et al. (2015) demonstrated effectively the benefits of other creative arts therapies in the context of palliative care. Paired with researches on drama therapy interventions for populations sharing many characteristics with people at the end of life these demonstrations can undoubtedly serve as theoretical foundations for the development of drama therapy in palliative care (Jaaniste, 2011; Jaaniste et al., 2015; Porter, 2003).

Role in drama therapy

Drama therapy consists of the use of dramatic processes for therapeutic purposes (Landy, 1991b). The dramatic experience according to Landy (1991b) is based on the actors' ability to play a role, that is, to be themselves and someone else at the same time. It is from the historical foundations of the theater that Landy draws one of the most powerful therapeutic mechanisms of such an incarnation: taking a role allows humans to exercise control over the uncontrollable, to experience transcendence (Landy, 1991a). One of the great functions of the role, "from the early dramatic ritual" has been "to assert power over that which is inherently more powerful than human being (e.g., destiny, birth, life, death, afterlife" (Landy, 1993, p. 16).

Robert Landy's conceptualization of role within drama therapy will be central to this investigation. As one of the most important drama therapists and theorists, he successfully established the concept of role in drama therapy through developing the fundamental elements of the role taxonomy, role theory and role method (Landy, 1990; Landy, 1991a; Landy, 1992).

For Landy, the role system is a structure allowing the organization of the personality. Role system helps to predict how the individual will interact with the world. It also allows the individual to build their identity and make sense of their experience. The system is composed of roles that are accessible and can be performed by the person. However, a set of "intra-psychic" roles remains available. These "intra-psychic" roles can be activated under favorable circumstances (Landy, 2001 as cited in Frydman, 2016). Frydman (2016) talks about the flexibility of the system by reiterating the principle of identification with roles which operates around a fundamentally dramatic juxtaposition between *to be* and *not to be*.

Landy's drama therapy role theory
Role taxonomy

The role taxonomy developed by Landy is intended to be a tool to facilitate the exploration of personal material using fiction. Inspired by Western dramaturgy, Landy's taxonomy provides a set of roles organized around six domains: somatic, cognitive, emotional, social, spiritual and aesthetic (Landy, 1991a). It is enriched by the characteristics specific to each of these domains, the archetypes associated with it, the subtypes relating to each archetype, the qualities and alternative qualities associated with these

types as well as by three examples of characters from different dramaturgical periods in addition to a list of functions and styles of interpretation.

All of this information allows the therapist to lead the individual with whom they work to explore the gaps between the roles played, the characteristics of the lived experience and the dilemmas that arise from the embodiment of certain roles (Landy, 1991b). Whereas in drama the actor's job consists in using personal material to serve the fiction he plays in, in drama therapy it is rather the fictional which is put at the service of the lived experience of the client (Landy, 1993).

Role method

The role method aims to explore the salient roles in the life of the individual, the counterroles that are overshadowed by the former as well as guide roles that can allow negotiation between the two (Landy, 2008). The relationship between roles and counterroles is not reduced to an antagonistic relationship. Each role can have several counterroles and each counterrole can be related to several roles (Landy, 2008).

The aim of the role method doesn't concern the resolution of the essentially human ambivalence between the roles which inhabit the individual, but rather the reestablishment of a state of flexible equilibrium in the repertoire of roles (Landy, 1991b).

Concretely, the role method offers a path of non-linear guidelines defined by its creator. To name them concisely the steps imply invoking a role, naming it, playing or working it, exploring its alternative qualities, reflecting on the exploration of the role, relating it to the everyday life, integrating it into one's role repertoire then, finally, molding it socially (Landy, 1993).

Chapter 3. Methodology

Autoethnography

Autoethnography is defined as a scientific method that conceptualizes lived experiences simultaneously from a cultural, social, political and personal perspective (O'hara, 2018). Both analytical and evocative, autoethnography can vary slightly on this continuum depending on the emphasis placed on observation of self (auto), culture (ethno) or process (graphy) (Ellis and Bochner, 2000, as cited in Chang, 2008). Autoethnography is based on the idea that language not only reflects reality, but also serves to construct it. According to this idea, the individual is defined according to the elements of the discourse, which is made available to them, the self and the social being influenced in a dynamic of co-creation (Chang, 2008).

O'hara (2018) identifies six steps in the conduction of a good quality autoethnography. The first step is to conceptualize and contextualize the autoethnographic research with regard to its analytical (scientific) or evocative (artistic) aim, the collaborative nature of its process as well as the singularity of its contribution. In the second step, the researcher addresses the ethical considerations specifically related to their research protocol. The third step is to determine the theoretical foundations that will serve as benchmarks for conducting the research project. The fourth, fifth and sixth stages respectively involve the traditional research steps of data collection and analysis as well as dissemination of the results.

Creative analytical practices

The creative analytical practices of which autoethnography is a part (Richardson, 2000) are also understood on a continuum of research methodologies going from the more analytical pole to the more creative or evocative pole (Ngunjiri et al., 2010). When presented in the form of artistic manifestations, autoethnography, in addition to stimulating the empathy of the interlocutor, makes it possible to simultaneously exploit the creative and analytical furrow of this methodology (Spry, 2001). Performative artistic work allows a dialogue with the other, an exchange with the public who can add their voice to that of the researcher which enriches the data pool and to its analysis (Anderson, 2006; Dubé, 2016). This enrichment contributes to the crystallization of the results, the ethnographic equivalent of triangulation, a criterion of rigor in qualitative research (Richardson, 2000). More than anything, referring to Spry (2001) freely, the performance of ideologies and experiences makes it possible to replace the cadaverous rigidity of academic writing with the living embodiment of social criticism.

Artistic performance: from the body to the screen

The performative nature of this research was first reflected in the creation of a theatrical object. However, the pandemic that is affecting the whole world has called for radical measures to limit the contagion. Therefore, the need to maintain physical distance to decrease the contagion made it impossible to hold a theatrical event. This unprecedented situation also induced in me an increased modesty in my

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exploration of the end of life and a will to maintain a certain emotional distance from the subject. The concept of aesthetic distance inherent to drama therapy has therefore been at the forefront of the creation to allow a sensitive and ethical exploration of the topic. This concept of distance was also a way to self-care by taking into account the impact of the trauma experienced collectively in the context of a pandemic. From the conception of a really embodied performance, the exploration was finally transposed into a filmic creation borrowing from animation techniques.

Aesthetic distance

The concept of aesthetic distance was first introduced by Scheff who described it as the central point of a continuum between emotion and distance or as "a moment of balance when the past can be remembered with a degree of feeling that is not too overwhelming, where intense emotional expression can be tempered by cognitive reflection" (Landy, 2008, p.101).

Landy, in translating this concept to drama therapy, sought to use the approaches of different theorists of theater and acting. By contrasting the methods of Stanislavsky anchored in the exploration of the emotions and those of Brecht who valued rational thoughts he created a similar continuum of drama therapeutic interventions going from *underdistance* to the *overdistance* with in its center aesthetic distance (Landy, 2008). The use of various projective techniques allows the participant an optimal emotional and cognitive involvement by offering the opportunity to project certain parts of themself into a creative medium. These techniques include photography, the use of objects, puppetry, masks and video to name few (Landy, 1994).

Distanciation as a continuum logically echoes the continuum between an analytic pole and an evocative one pertaining to autoethnography and creative analytical practices. It is therefore a question in the context of this creative autoethnographic exploration of being a little more in emotion than in cognition, but to measure the emotional implication given the current weight of the subject explored.

Animation as a film technique

Film work and animation technique have emerged as alternative resources to theatrical performance under the circumstances. Video is an element recognized in drama therapy to share affinities with storytelling and to allow, as a projective tool, great flexibility on the distanciation continuum. The screen can be referred to as *it*, *you* or *I* (Landy, 1994).

Animation also has a strong evocative power since it can succeed in transmitting the testimony not of the experience but of *an* experience which is both singular and unique while encompassing a more universal reality (Napier, 2005). These techniques give the opportunity to combine thoughts and emotions and to blur the boundaries between what is true and what is fictional (Napier, 2005). Napier (2005) argues that it is the fluidity associated with the medium that allows it to arouse simultaneously an emotional, aesthetic and intellectual commitment in the observer. Ehlrich (2015, as cited in Oldford, 2016) talks

about the political aesthetics of animation by referring to the same oscillation between affect and intellect that provokes engagement and even mobilization of the viewer.

Rational for the use of creative autoethnography methodology

In the context of research that focuses on the emancipation of the dying and the transformation of the end-of-life experience by exploring the concept of role which is at the same time a personal, a relational and a cultural construct, such a methodology appears more than appropriate. More so, evocative autoethnography "may have far greater impact […] [f]or researchers attempting to offer a new and challenging way of understanding human action, to illuminate potentials, to foster social action, or to combat injustice" (Gergen & Gergen, 2018, p. 284).

Since one of the main sources of data collection in this type of methodology is the experience of the researcher, such a method is increasingly widespread and recognized as valid in research in the health field. Its value is based on its ability to provide access to rich and deep data by streamlining the research ethics verification processes for the most vulnerable populations (Chang, 2008; O'hara, 2018). This value is even more noticeable in the case of a creative autoethnographic exploration which uses writing and film work as the main investigative tool, locating at the same time the researcher's experience in a separate reality governed by generally more flexible ethical standards (Pentassuglia, 2017). Furthermore, strongly anchored in a critical paradigm, this methodology is well suited to serve the emancipation of marginalized populations and allow research to act as a voice for generally underrepresented individuals (Chang, 2016; Spry, 2001). Since identity is a social construct and the roles that make up this identity are an integral part of the culture in which they are defined, the use of artistic processes to serve the dissemination of results could have a direct impact on the issues related to roles at the end of life by injecting new cultural elements in the culture accessible to the dying (Spry, 2001).

Finally, the film work and the need to engage the body to gather images and to explore my environment strongly anchors the exploration in my reality which turns out to be completely in sync with characteristics of autoethnographic work. The bodily mobilization implied by the artistic work inherent in this autoethnographic work which aims the emancipation of the dying makes it possible to let the body, that is to say precisely the place and the vehicle of dying and of the role, the possibility of disseminating, in a roundabout way through the short film, the results (Spry, 2001).

Ethical considerations

Given the projective and creative nature of a creative autoethnography where the data are extracted from the researcher's lived experience, this kind of research is immediately oriented towards the most evocative pole of the continuums relating to ethnography and creative analytical practices. Therefore, the ethical considerations are generally greatly simplified (Chang, 2008; O'hara, 2018). However, it is important to mention that exploration must have stayed sensitive to the power relationship

between the living and the dying in order to ensure that the exploratory work is indeed at the service of the emancipation of the voice of people at the end of life and not an additional tool use by the living to control the dying (Lowrie et al, 2018). Researchers, using narrative form of inquiry always have to stay aware and transparent to who owns and tell the story and stay humble and reflective on their own positionality the privileges that comes with is and the assumptions they have on the investigated subject (Pinnegar & Daynes, 2007). They also have to be aware of not only tell their own story but let the one of the participants be heard in the process (Trahar, 2009 as cited in McGarrigle, 2018). On the other hand, using their own lived experience to dig into sensitive topic can trigger strong emotional response, including grief, sadness, hopelessness and so on, for the researcher. "Vulnerability is part of what makes reading autoethnographic works so compelling as researchers expose their pains, hurt, grief, heartbreaks, and other emotions experienced as they travel through events in their lives" (Ngunjiri et al., 2010, p. 8). Being psychotherapeutically supported and the inherent artistic aspect of creative analytical practices can act as tools to conduct the process ethically.

Nevertheless, if the creative autoethnography implies a collaborative phase which involves public feedback, approval of the research protocol by the ethics committee of research-related institutions is needed. Means to assure participants confidentiality, how the benefits overcome the potential risks associated to the participant in the research project as well as how the data provided by the participants will be used should all be described in the research protocol.

Criteria of rigor

Validity in qualitative research can be ensured by a process of data crystallization which consists of the multiplication of points of view and sources (Tracy, 2010). The use of primary data collected from people at the end of their life, along with emerging data from the researcher in dialogue with the literature on roles at the end of life can contribute to the crystallization of the data and therefore to the increased validity of the final research results (Dubé, 2016).

Transparency in regard to the creative research process help provide all the necessary tools to anyone who wishes to reproduce the research and thereby increase the fidelity of the research.

Furthermore, although very widespread in the scientific literature, these criteria of rigor are not the criteria of excellence put forward in qualitative research in general and with regard to autoethnographic approaches in particular. Chang (2016) proposes the criteria of authenticity, transparency of the process, ethical concern, the socio-cultural character of personal experience and the contribution to literature to judge the quality of autoethnographic approaches. Spry (2001) reminds us of the transgressive validity related to the critical paradigm of Morrow (2005), when speaking of the transgressive character of performance as an evaluation criterion. These criteria are also well served by

the steps of a good autoethnography conceptualized by O'hara (2018) and which served the creation of the research design.

Data collection, analysis and dissemination processes

Chang (2008) notes that producing culturally meaningful and engaging autoethnography usually involves a tangle of data collection, analysis and interpretation. Thus, the movement of the spiral has been used at first as a conceptual diagram for the current research project in an attempt to iteratively link together the three large loops of the exploration, each bringing together the traditional research steps of data collection, analysis and dissemination. The pandemic context and the inductive nature of the chosen methodology significantly transformed the initial plan. Therefore, the original formulation of this process will be described below, while the next chapters will give an account of the process that actually took place.

First loop

In the first loop, data collection was to consist of extracting characteristics of the end of life experience from the dying individual's perspective. The interviews conducted by Elizabeth Kübler-Ross in the essential publication *On death and dying* (1969/2005) would be used as basic material for the data collection. These interviews constitute one of the only sources of integral and direct testimonies of people at the end of their life in contemporary literature. In addition, even though the four female interviewees were all of different ages and came from a different era and culture, they shared an important part of my reality, that of gender identity. A creative association on my part with their testimonies and their universe seemed to be facilitated by this similarity. Also, all of them were under the age of 80 and therefore belonged to the age group most likely to die from a disease causing a prolonged end of life in present-day Quebec (ISQ, 2019). In fact, 3 out of the 4 women suffered from cancer and the youngest of the four suffered from an autoimmune disease.

The analysis would consist of coding gathered extracts from the interviews using the six domains of Landy's role taxonomy (somatic, cognitive, emotional, social, spiritual, aesthetic domains) as code categories. From there, excerpts would be reorganized inside each domain and coded using tentative role names. The creation of a first partial repertoire of roles would be illuminated by the organization of characteristics within the six domains and considered to be the first dissemination of the results.

Second loop

During the second loop, the first partial data dissemination was to serve as a basic data pool for the collection of secondary data. These data would be generated by the creative organization of all the roles in the first repertoire through an exploration inspired by Landy's role method of the counterroles and guide roles which are linked to it. Scriptwriting, filming and filmmaking would then be used to analyze the data, allowing refining of emerging data, eliminating duplicates, naming and giving form to

significant roles. Sharing the film creation with a selected audience would act as a second step in disseminating the partial results.

Third loop

Ultimately, the third loop would use public feedback as collected data. Through a creative activity inspired by Robert Landy's art series *Squaring the Circle* (https: //www.robertlandy.com/) viewers would be asked to organize their own end-of-life constellation of roles by participating in a collaborative online blog. Data analysis is collaborative. Members of the public would be invited to name the emerging roles in their work. These extra data would be then compared to those included in the short film.

Figure 1. The research process diagram (From the bottom)

Due to the pandemic the creation of an embodied performance was transformed into the filming of a short movie
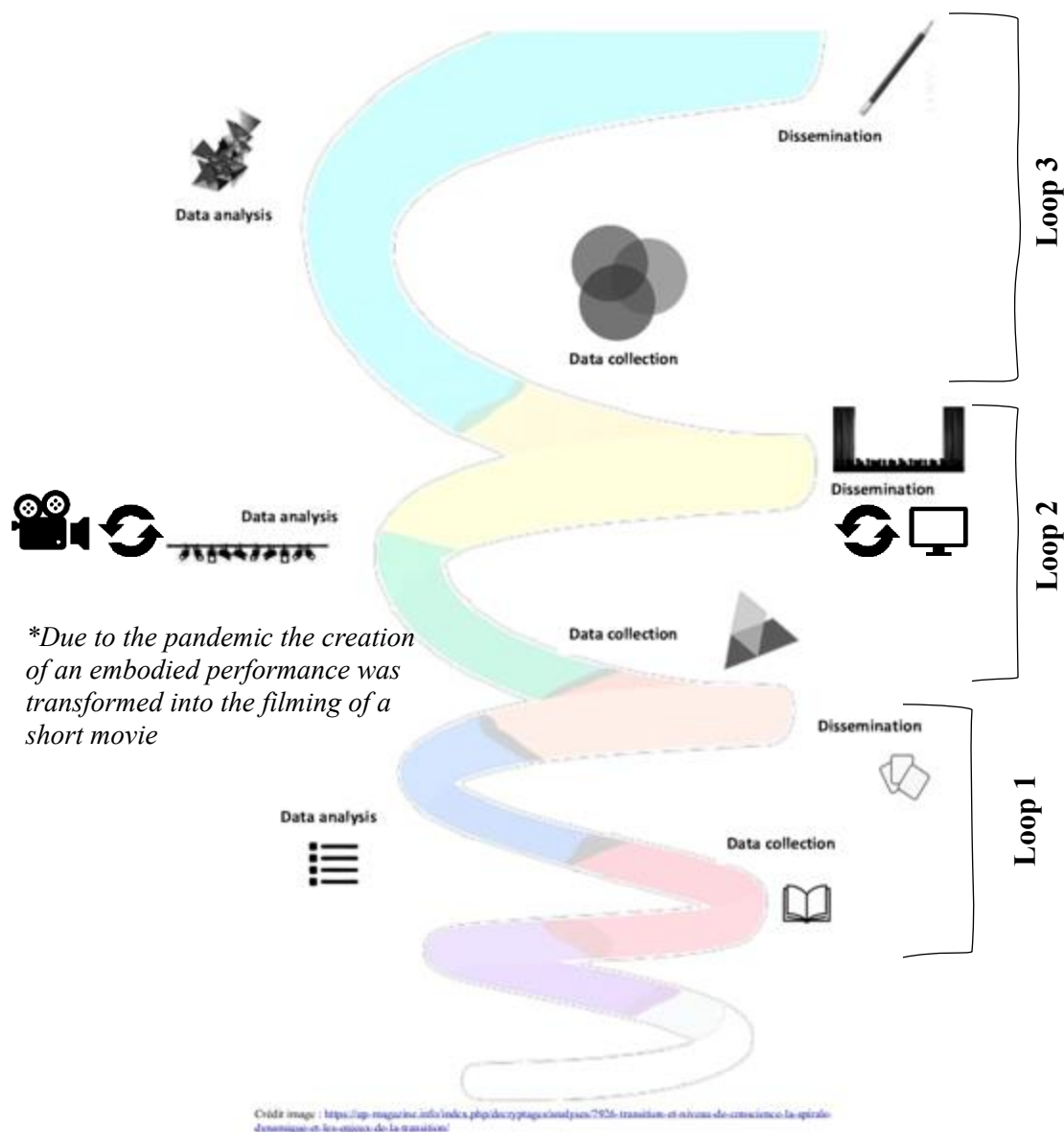
Chapter 4. Creative Research Process

Tami Spry (2011) in their book *Paper, Body, Stage*, which aims to be a guide on performative autoethnography, speaks of the need for anyone who wants to embark on such an investigative process to identify a personal experience that "has collided with, interrupted, or embraced larger social issues " (p. 124). This identification, this parallel between the intimate and the social could also be linked to what Luvaas (2019) calls the phase of "consumption" which "establishes a relationship between subject (the con-sumer) and object (the consumed), a relationship that gradually begins to blur the line between the two " (p. 252).

For me, this shock between the experience and the ecosystem in which it was lived has been without any doubts the death of my father in May 2016 just a few months after the adoption of the law on end-of-life care in Quebec and all the debates that had ignited the public arena with regard to medical aid in dying and the concepts of suffering and dignity. Since autoethnography calls for great transparency on the part of the researcher, I think it is relevant to clarify the circumstances surrounding the death of my father since they profoundly changed my point of view on suffering and dignity at the end of life.

My father became quadriplegic in January 2015 following a work accident. Before this event he was already living with challenging mental and physical health issues that were affecting his quality of life. Because of this difficult background, my mother and I were not anticipating his choice to fight the rehabilitation battle and the appetite for life he regained in the process. However, during 2015-2016, this is what he decided to do, diligently repeating his physiotherapy exercises and working hard with the nutritionist to correct dysphagia and regain the possibility of eating without an ostomy. Completely dependent on the care received, while the accident continued to inflict on him unsuspected physical and psychological suffering and deprived of what many of us attach to dignity, my father seemed to find his life worthier than he had for a long time. Our explosive relationship, capable of generating the greatest anger and the most gigantic love, made us face the adversity together; first at the rehabilitation center, then at the cancer center. Because at the intensive care unit, among the many scans, the doctors had made a "fortuitous" discovery, they said. Beyond the blatant success of the operation between C6 and C7 vertebrae, there was also on the images of my father's inside body, clearly visible, a lung cancer. That summer, I alternatively spent it running dozen and dozen kilometers as if to compensate for his steps and accompanying him to the radiotherapy sessions. He lived an autumn and a winter until his body, weakened by quadriplegia, finally succumbed to cancer at the beginning of the magnificent spring of 2016. May 11. I remember my mother's call on the morning of May 7. "It's now". I remember not being able to discern well who should own this moment that I was about to live: was it the death of my father, the disappearance of my role as a daughter, his death, the outcome of his story or a stone in mine? A 5-day watch. Days that seemed like years to me. A death at home, the pains of his disabled body added to

the suffering of dying, rudimentary palliative care, my mother and I who did our best to accompany him in these last moments. Again, what I thought I understood about suffering and dignity was turned upside down.

Jankalévitch (1977) talks about death in the first, second and third person. Death in the third person is distant and anonymous: *he dies*. Death in the first person is always mysterious in the living, the dead abandoning him on the threshold of life: *I die*. Death in the second person blurs the tracks: *my father dies*. The death of a loved one is almost like ours, almost as heartbreaking as ours; the death of a father or a mother is almost our own death (Jankalévitch, 1977). I was consumed. Definitely, the line between me the subject as researcher-artist-therapist and the end of life as an object had become blurred.

If the death of my father is without any doubt the catalyst for my interest in end-of-life care, I think it would be fair to say that I have unconsciously chosen as my guide for my first investigation in regard to end-of-life care a father figure in Robert Landy. Beyond the value of Landy's work as a theoretician and drama therapist, it is, although I do not know him personally, the human being he seems to be who led me to draw inspiration from his art, his work and his theories.

Karnakakis (2017) in an issue of *Dramatherapy* journal dedicated to Robert Landy describes him as

> a name, a creator, an innovator, an artist, a scientist, a drama therapist, a greatly ambivalent man, a thinker, a legend, one of a kind.[…] Sensitive, vulnerable, wounded but also strong, ready to fall apart in million pieces but also to pull himself back together, he abandons himself to the poetic chaos of emotions, but always find the thread of Ariadne to lead him back, a trickster prepared to challenge the system and effect change. (pp. 19-21)

How not to see in this description a perfect guide for an autoethnographic and creative exploration of a subject as emotionally and existentially charged as the end of life. It is therefore all of his work from his pictorial artistic work, to his theory, method and taxonomy of roles passing through the imprint that was left by two short workshops on the *Voyage of the Heroes* to which I had the chance to participate that fueled my research project. Kranakakis (2017) talks about the feeling when you come in contact with Landy's work of building a relationship with its author. He attributes his talent as a writer to the fact that Landy remains first and foremost an artist and that it is through this role of artist that "we connect with his persona, his shadow, his hero, his self, the source of his thinking" (Kranakakis, 2017, p. 22).

Thinking back to the creative process at the heart of this research, it now seems clear to me that these three iterative loops discussed previously in the methodology section could be more eloquently organized through Landy's role method non-linear stages (Landy, 1993). Therefore, it is by following these eight stages that the creative research process will be explained in this chapter.

1) Invoking roles

"The role is invoked to help the client immediately focus on one aspect of the personality" (Landy, 1993, p.46). Conversely, while at this ultimate stage of life, everything contributes to bringing the focus back to the fact that the person is dying, my intention was to exhaustively invoke roles in order to draw up the fullest portrait of people at the end of their life. To do this, I was going to use the interviews with four women at the end of their life led by Elizabeth Kübler-Ross (1969/2005). These four interviews as initial data could be considered as extracts from the "social drama" of dying; "social drama" is an important source of roles (Landy, 1993). These extracts served what Landy (1993) poetically called inspirations for a "creative search for meaning" (p. 16), an expression which interestingly echoes the titles of the important works on the end of life from Feifel (1959/1965) *The meaning of death* or the very existential book from Frankl (1959/2006) *Man's search for meaning*.

To make these roles explicit, I used the inverse of the strategies used by Landy in the creation of his role taxonomy (Landy, 1991a). Landy scoured Western dramaturgy for recurring roles and then classified them within six domains that shared common characteristics: social, somatic, cognitive, emotional, aesthetic, spiritual. Instead, I first used the six domains as codes for the first analysis of the interviews using qualitative research software InVivo. Systematically, when a verbatim extract from the interviews expressed a characteristic specific to a domain, the extract was encoded under this domain.

Once I finished coding the four interviews, I asked the software to generate a diagram showing the proportions specific to each domain relative to all the selected extracts. In the graph the somatic and social domains occupied a significantly larger part.

Figure 2. Proportions of excerpts pertaining to each domain diagram

This observation is interesting on multiple levels, from a drama therapy perspective to the lens that tries to understand the implication of roles in the end-of-life experience and to the research process serving the present exploration.

From a drama therapy perspective, the somatic and social domains are also those which Landy (1993) describes in greater details in his book *Persona and performance.* The importance given to these

types of roles in the interviews coded mimics this preponderance. Also, in another work *The couch and the stage* (2008), Landy notes that the roles relating to these two domains are roles that are generally imposed on us. Although we perform these roles in our own way, our body and its state largely dictate our somatic roles and social structures very early on assign us a set of social roles which are greatly influenced by these somatic characteristics. The salience of these two categories of roles makes sense, however, if we consider that the roles mainly fulfill a social function. Since we relate to each other through our bodies, the importance given to somatic and social roles is in phase with the intrinsic social nature of human beings. Furthermore, Landy (1993) in his description of somatic roles first speaks of "survival roles" putting forward the primacy of this type of roles over others. In the context of the end of life, when vital energy is mainly invested in survival, the importance of somatic roles therefore seems to be obvious.

Moreover, the equal importance of these two categories of roles for the living individuals and the dying ones makes it easier to grasp the possible implication of role in the psychological and/or existential suffering experienced by the dying. If through our lives we mainly define ourselves by roles imposed on us, if at the end of life we are no longer able to perform the actions that these roles required, if our roles are then mainly reduced to survival functions, is there, in these circumstances, any remained space to live? While it may be easy in these conditions to put the other types of roles aside, they may also allow the dying individual to define themselves more freely and preserve a form of agency on their own dying experience.

More specifically related to palliative care research, Lowrie et al. (2019a) describes the "social death" by bringing together characteristics from the somatic and social domains and associating it to an inability for the dying to engage in meaningful roles at the end of life. "The concept of social death is generally used to describe a loss of identity and social connectedness, as well as bodily disintegration experienced by ill or dying persons prior to the event of their actual biological death (Borgstrom, 2017; Kralova, 2015)" (as cited in Lowrie et al., 2019a, p. 7). The series of articles by Bourgeois-Guérin (2010, 2013) which on the basis of interviews conducted with 10 women at the end of their life draws a parallel between suffering, dysfunctional communication and embodied experience also helps to highlight the possible implications of social and somatic roles in the psychological and existential suffering of people at the end of life, more specifically in women lived experience.

Finally, this first analysis validated my basic intuition with regard to the relevance of a creative autoethnographic approach which is by definition a strongly social, relational embodied methodology and therefore completely aligned with the subject explored (Luvaas, 2019; Mermikides & Bouchard, 2016; Spry, 2011).

2) Naming the roles

Again, at this stage, my exploration consisted in performing conversely the approach used by Landy in the constitution of his taxonomy. Within the six domains, I paid attention to the common characteristics that emerged from the extracts gathered within them. By reorganizing the extracts from the 6 domains in this way, I obtained a first set of 44 roles (see Appendix A). Spontaneously, to code the different sub-sections that would become the first roles to explore, I used the preposition "The one who ...". When speaking of the role naming stage, Landy (1993) points out that it is possible for the client to name the roles with very realistic, utilitarian names, but also in a more abstract or poetic way. Obviously, the code that I proposed at this stage had an evocative quality more related to abstractions and poetry.

In this sense, it is interesting to reflect on the underlay poetry of the preposition "The one who ..." and the choice of a verb that it calls to make. Speaking of semantic choices while conducting an evocative ethnography, Gergen & Gergen (2018) argue that "[e]very description opens a way of understanding, valuing, or approaching the world and thus the range of intelligible actions. […] In this light, and ethnographic account that relies on traditional, or sedimented language use is conserving: it sustains our existing ways of understanding and acting" (p. 275). Using a more poetic form to name the roles already opened up possibilities. "[W]e owe a large part of the enlarging of our horizon of existence to poetic works" (Ricoeur, 1983 as cited in Helenius, 2012, p. 150).

Furthermore, Helenius (2012), speaking of Ricoeur's thought, suggests that the poetic form could potentially favor a certain form of empowerment: "The poetic language expresses, but it also makes by speaking out our experience of the world and ourselves" (p. 151). To be whole, the metaphor I used to name the roles had to combine a verb to the poetic preposition "The one who ...". For Ricoeur (1960 as cited in Helenius, 2012), metaphor itself has a deeply active nature, always developing in the present moment, in the action of bringing together scattered pieces. On the other hand, the verb "is" carries a highly relational and existential meaning. Two case figures imposed themselves in the naming of the roles here: the one who *is* something and the one who *does* something.

Naming the roles in this manner therefore allowed me to have a hold on them while preserving a great flexibility which left the possibility for multiple interpretations to emerge. In this way "tacit knowledge remains unarticulated until an appropriate means 'could' be found for explication" (Moon & Hoffman, 2014, p. 172). In addition, the active nature of the metaphor coupled with the need to use a verb in this metaphor seemed to have an empowerment effect on me. If I say that I am the one who does an action, is it possible that the simple fact of naming it partly compensates for the fact of taking the action in reality? It's seems that I really experimented what the power of the poetic images that "becomes a new being in our language, it expresses us by making us what it expresses" (Helenius, 2012, p. 151). Agency and flexibility are two realities difficult to access for people at the end of their life according to

the literature that seemed at hand for me through one of the first stages of the role method process by a sensitive and free use of the language.

Despite the fact that in relation to the role the "counterrole is not in objective opposition, [and that] its creation is forged from the individual's subjective experience" (Frydman, 2016, p. 44), I still tried initially to extend the first set of 44 roles by adding to it what was for me their literal opposite as counterroles (see Appendix A). Even if the choices of counterroles were, of course, not purely objective, I tried to bracket my own subjectivity which I would rather explore in the next stages of the process.

Beyond all these explanations in relation to my approach, I believe that above all it is to project myself into a reduced future, confronting my own mortality which led me to name the roles in this poetic, active and evasive, way. With this nomenclature I was able to create configurations that were both able to define myself well without revealing myself too much while allowing me to redefine myself. If I use these "The one who…" roles to describe myself today and die tomorrow, these roles were able to preserve my memory without exposing more intimate aspects of my identity in a shameless manner. If I use the same roles to describe myself today and continue to live tomorrow, even at the end of my life, these roles allowed me the necessary latitude to continue to evolve and grow.

3) Exploring alternative qualities in sub-roles

The role method globally calls and even more markedly at this stage for a "search for ambivalence, even as an initial role […] shifts to its apparent opposite" (Landy, 1993, p. 51). The idea here was to subjectively explore the 88 roles and through this exploration manage to more or less halve the repertoire that I was going to use for the rest of the research process. I wanted this reduction to respect as closely as possible the proportions corresponding to each of the domains identified by the analysis conducted in InVivo. Gergen and Gergen (2018) referring to Ricoeur's "surplus meaning" note that the purpose of evocative ethnography is to allow the maximum possible interpretations through the object rendering the research. I had, then, to discern which roles were the most evocative. Still according to Ricoeur (1975 as cited in Helenius, 2012), the "is" contains both "is like" and "is not". To reflect on this idea of the role and counterrole encapsulated in one, we can use "The role profiles" assessment method which uses the categories "This is who I am", "This is who I am not", "I 'm not sure this is who I am" and "This is who I want to be" (Landy & Butler, 2012). In general, according to this method, if I put a role in the category "This is who I am" good chances are that its literal opposite will be in the category "This is who I am not". For many roles, the use of the preposition "who" and the verb "is" to name the role meant that the counterrole I added to the set was already contained in the role. This inclusion immediately allowed me to reduce the first set. However, the possibility of defining oneself in the negative remained and this is why in the context of this exploration certain particularly significant opposites have been retained. For example, "The one who lives" and "The one who dies" or "The one who is sick" and "The

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one who is healthy" stayed included in the set of roles used for the following steps of the creative research process. Thus, taking into account the proportions relative to each domain as well as the evocative power of roles kept, the first set of roles subjective exploration enabled its distillation to 45 roles (see Appendix B).

4) Integrating roles to create a functional system

In the application of the role method the goal of this stage is to "to help the client construct a viable role system—one that is able to tolerate ambivalence and acknowledge the importance of both negative and positive roles" (Landy, 1993, p. 53). While roles tend to "become entangled in one another" (Landy, 1993, p. 54) the aim of Landy's (1993) method is to "unravel some of the knots and separate one role from another" (p. 54) for me, it was a question of going upstream and making knots between the emerging roles of the first stages. While Landy (1993) speaks of reorganizing or reconfiguring the role repertoire, I had to rather initially organize and configure the repertoire of roles by projecting myself in the "as if" reality of my own end of life.

To work on roles, Landy (2008) suggests alternative ways of invoking them. The process does not have to rely exclusively on the verbal expression; it is not essential to play the role as one would play a character. Roles can be explored using non-verbal and/or projective techniques. I chose such a projective, non-verbal modality to organize the role system. Landy's pictorial artistic work inspired me to do so. For me his series *Squaring the Circle* represented a great metaphor of his drama therapy theories. One circle, the counterrole, overshadowing another circle, the role. The dynamics between the two revealing a third circle, the guide.
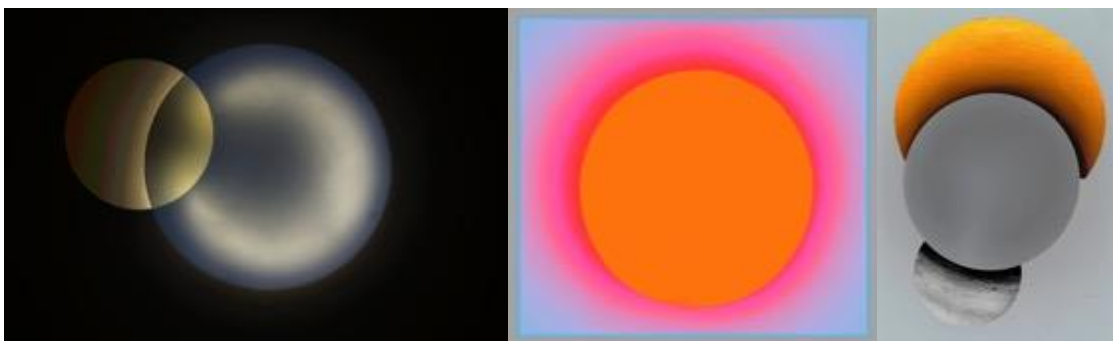
*Figure 3. Communion; Tyger,Tyger, Burning bright and Totem from the series Squaring the Circle, Robert Landy (*https://www.robertlandy.com/*)*

The work *Communion* referred to as the .jpeg name *Eclipse* has been particularly significant in my journey. I started to use the metaphor of the eclipse to reflect on the link between living and dying. The reference to something infinitely great that it contains, —the notions of light, shadow and darkness that it supposes—made sense to me in the delicate yet complex context of the end of life which calls for a relationship with something that is beyond us and includes us at the same time.

Moreover, the image of a circle in itself seemed meaningful to me. In a post on *Psychology Today* titled "Why do I make circles?" Landy (2017) suggests many symbolic interpretations that could be linked to the image of the circle. Through his text he speaks of his Jungian analyst who interprets the circles that he draws as attempts to express his "wholeness". He remembers his friends who think that he is rather trying to collect scattered fragments of his life inside these circles. He talks of himself noticing that he is splitting the circles and he questions whether he is in this way expressing his duality or the "doubleness" of his life. He concludes his post by putting forward the following hypothesis: "Maybe it's my way of holding together the things that keep falling apart-relationship, understanding, tolerance, complexity, kindness, beauty, justice, love. Maybe it's my way of attempting to return home after generations of wandering. Maybe it's my way of squaring the circle" (Landy, 2017). The circle as a symbol of a never resolved existential quest. The circle which contains the two faces of Janus "the symbol for the theater, the symbol for transitions, the symbol for the dynamic interplay between truth and fiction" (Kranakakis, 2017, p. 22) seemed to me perfectly appropriate to explore this final stage of life.

I chose to cut circles of similar sizes from newspapers, scrap paper, photos, wrapping paper, etc. to make a bunch of items similar to the role card deck used in the role assessment method (Landy & Butler, 2012). I instinctively associated each of these circles with a role that I indicated on the back of the image. Then I started to assemble them on a large cardboard according to the dynamics I perceived between them. I started from the role "The one who lives" which was overshadowed by that "The one who dies". Sometimes a guide role stood between the two. Once the duo or trio was formed, I chose one of the three roles and questioned its relation to the remaining roles until my pack of circles was completely distributed on the cardboard. This collage of the circles on the cardboard represents what I have from that moment called my constellation of roles. This constellation is conceptually similar with regard to the role method to the configuration of the role repertoire. At the level of the autoethnographic approach to which it served as a tool, it was the equivalent of the idea of the mindmap suggested by Spry (2011) to organize the creation of an autoethnographic performance.

Besides, in order not only to organize the roles, but also to frame the artistic object that I was about to create, I transformed the different associations of roles into tableaux that were going to compose my short film. I was able to identify 25 roles dynamic that seemed meaningful to me, linked to each other and that I wished to explore creatively.
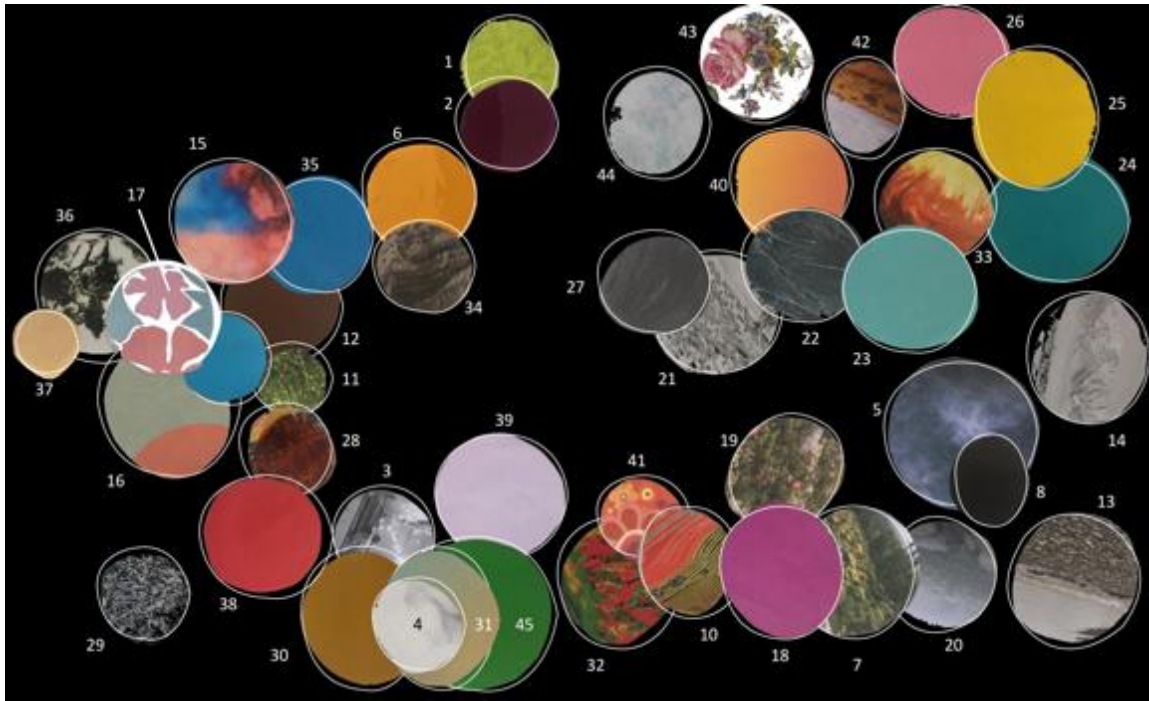
Figure 4. My constellation of roles (numbers refer to the list of roles available in Appendix B).

The metaphor of the circle and the image of the constellation allowed me to preserve a certain flexibility rather than imposing a rigid narrative framework. What Ricoeur calls according to Helenius (2012) a "'healthy circle' of discordant concordance and concordant discordance" (p. 149). By invoking all the roles at once in this loose structure, I could emphasize the ambivalence of human experience while at the same time succeeding in ordering and honoring chaos. Already, at this stage, there was an antidote to the two-dimensional vision that pits the living against the dying. Already, there was a political criticism in this bursting, this dynamism and this refusal of order and calm to approach the roles at the end of life.
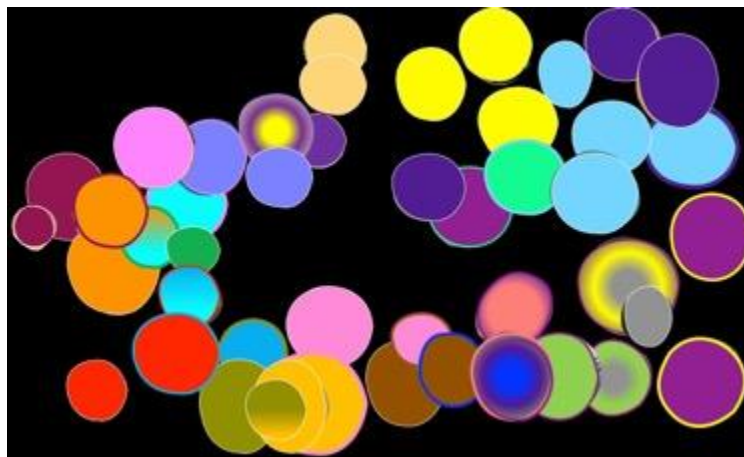
Tableau 1-25	Tableau 7	Tableau 14	Tableau 20
Tableau 2	Tableau 8	Tableau 15	Tableau 21
Tableau 3	Tableau 10	Tableau 16	Tableau 22
Tableau 4	Tableau 11	Tableau 17	Tableau 23
Tableau 5 & 9	Tableau 12	Tableau 18	Tableau 24
Tableau 6	Tableau 13	Tableau 19	

Figure 5. My constellation of roles with tableaux highlighted (all the circles that contain the color associated to the tableau are part of it).

5) Reflecting on role

In the role method, this step represents the opportunity of "stepping back from the actual drama and discussing its meaning" (Landy, 1993, p. 51). It's also usually the step that ends the process. Here, however, it was the first manifestation of this kind of hindsight which within the iterative process of autoethnography would ideally repeat itself multiple times along the way (Chang, 2008). Rather than terminating the process, this reflexive space made it possible to root it in the lived experiences and by doing so give depth to my exploration (Spry, 2011).

At this point in the creative process I approached the research done with people at the end of life. These articles and the excerpts from testimonies some of them included became voices I let my imagination and my creativity converse with. To organize the dialogue, I compiled in a table significant parts from the literature that were linked to the roles and dynamics included in each of the 25 tableaux. This dialogue would facilitate the oscillation between evocation and analysis. It would oxygenate my creation and allow me to avoid solipsism by making visible the dissonances between my imagination and the experience lived by other individuals at the end of their life or the analysis of researchers who had listened to them (Dubé, 2016; Spry, 2011).

"Autoethnography […] often works best when it's accompanied by the perspectives and vantage points of others" (Luvaas, 2019, p. 25). This contribution of the literature became at that time primordial to my research process given the sanitary measures which were now making it impossible to hold a live embodied performance followed by a creative workshop to collect the public feedback. The transition from performance to the short film was demanding and the adaptation of the methodology in a given time frame complex. It became increasingly clear that my creative exploration process would not be able to include the contribution, even virtual, of the audience members points of view to crystallize my own results. Despite the grief of not being able to pursue the dialogue with my contemporaries who are sensitive to issues surrounding end of life the situation has, however, imposed a real face to face with the subject of my exploration. This mandatory isolation forced me to plunge radically into my autoethnographic exploration and forced me to demonstrate my "patience for living on someone else's timeline" (Luvaas, 2019, p. 248). This dialogue has been so significant in the process that, in the intention of making it visible, I inserted footnotes inside the script of the short film to testify to its importance (see Appendix C).

6) Relating the fictional role

As reflexive as the preceding one, this step of the role method invites one to "return from the reality of the imagination to that of the everyday, and look at the connections between the two" (Landy, 1993, p. 52). For me, this step supposed a mechanism that was both inverse and complementary to what is proposed by Landy. By taking up the roles that emerged from the analysis of Kübler-Ross interviews

(1969/2005), I needed to use my creativity and my imagination to make connections with the prospective reality of my own end of life. However, my imagination inevitably nourished by my experience as a living being, the creative object which would result from it would inevitably testify to the links between my imagination and my current reality. It appeared to me at that point that my work as a creative autoethnographer was very similar to that of the therapeutic actor who "is given permission to move in and out of two contiguous realities, that of imagination, the source of unconscious imagery, and that of everyday, the domain of grounded daily existence" (Landy, 1992, p. 7).

To establish these bridges between these different realities and feed my exploration, I, once again, created tables. Inside the first one I listed all the roles and indicated images, objects, actions, and places that each of them inspired. In the second table, I brought together the 25 tableaux and I allowed myself to freely write about the dynamics that I sensed between the roles. These tables allowed me to collect fragments and group them into a "cluster" as suggested by Spry (2011) who, while referring to Denzin (2006), indicates that such an approach feeds a "critical reflection" on the subject.

The fact that these tables made it possible to gather fragments in the form of objects or what one could call artefacts in addition to free writing drafts certainly helped to open the possibilities while anchoring the approach in my reality and my imagination. "Objects can often symbolize complex issues and experiences causing us to make deeper associations and connections. Metaphors can be objects, places, ideas" (Spry, 2011, p. 148). Free writing manifests itself in a flow that promotes both effusion and a very dynamic analysis of the subject (Paillé & Mucchielli, 2012 as cited in Dubé, 2016). In fact, Ricoeur (1975 as cited in Helenius, 2012) speaks of semantic dynamism by indicating that metaphor by amplifying meaning also amplifies being. This dynamism of free writing and metaphor, this capacity of the object to present itself as a metaphor and the evocative power that this possibility assures are all aspects that enriched my autoethnographic exploration of roles at this stage by making it possible to build links between the dispersed fragments.

Moreover, these links, these connections—if they are of the greatest therapeutic importance as for the role method—are also the reason for being part of the performative autoethnographic approach according to Spry (2011). "Performative autoethnography is about connections; it is about our connections to one another personally, socially, historically. We are, in a sense, writing to one another about these connections and about the pain of disconnection" (Spry, 2011, p. 125). Having experienced the grief of mourning, being temporarily isolated due to sanitary measures, prematurely removed from my internship environments where I accompanied people at the end of their lives, I strangely felt at the right place to explore through the story of these women the relationship between the living and the dying roles and my relationship with all of them.

7) Playing out /working through roles

"The working-through stage is a time of enhancing one's commitment to a role and extending it beyond expected behaviors" (Landy, 1993, p. 49). For me, this phase of the process would manifest itself through the redaction of the script for the short film. Luvaas (2012) speaks of production, the second stage of autoethnography according to him, as the actualization of the initial phase of consumption: "[i]t replicates the kinds of objects, media, and sensations consumed. It alters the relations between the consumed from reception to reproduction" (p. 253).

The process of "fictionalization" also seems to follow a similar path which reflects my exploratory creative process (Iser, 1997 as cited in Leavy, 2015). Based on the selection of a subject to be explored, fictionalization consists in the association of various elements related to the theme to create an object that will then openly be identified as fiction. In my case, I had to join elements of my life to aspects of my prospective dying reality, with elements of the interviewees' end-of-life experience to the experience of other people at the end of their life that were reported through the literature. The creation of a short film through these multiple associations would inevitably belong to fiction.
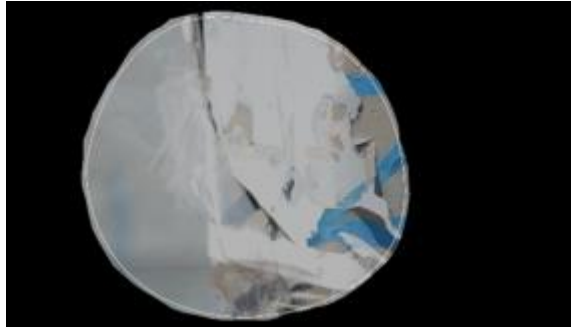
It is therefore by utilizing the various tables that I had created which list fragments of all these realities that I started the writing of the script (see Appendix C). A script that I wished to be flexible, free and evocative; an intimate script that I was going to write in a second language, I for whom French is the mother tongue. Once again, poetry has emerged as a response to these imperatives of accessibility, flexibility and evocative power. "The profundity of existence is disclosed in a poetic statement that works as a metaphorical image" (Helenius, 2012, p. 154). Poetic writing allowed me to bring together several perspectives not in a polysemous way, but rather in an organic way through metaphor. Metaphor just as fiction makes the highlighting of alternative interpretations possible (Frank, 2000 as cited in Leavy, 2012).

Using poetic writing in the empty space of the nascent script with these images, these words and these artefacts as unique tools, everything seemed possible. I really believe that, as Ricoeur (1975 as cited in Helenius, 2012) inspired by the thought of Bachelard points out, metaphor has not only an expressive power, but also a deeply active one. Through the writing process, I discovered less obvious parts of myself and redefined other aspects. I was in a way creating or "making" myself.

For Spry (2011), autoethnographic writing is highly embodied. "We want the body to 'perform' on the page" (p. 141). Contrary to my apprehensions and despite the transition from the staging of a performance to the creation of a short film, the writing work remained deeply rooted in the body. Moreover, from the preponderance of the body in the writing process emerged three greatly embodied roles which were afterward added to the set of roles namely "The one that contains", "The one that is contained" and literally "The one who is a body".

26

It is also through the body that an important aspect of the experience of dying and of this stage of the role method expressed itself: the ongoing shifts from one role to another. As Landy (1993) clearly indicates, it is not for the client to "focus upon a single role and work it through until the process is concluded" (p. 49). In this sense, the work of Yededia and MacGregor (2001) has been helpful in translating these transitions. Using the adaptive motifs identified in their research with people at the end of life, I created the directions for actions bridging together the images of the film.

Table 1. Motifs definitions and their associated actions

Motifs	Definition	Action	
Struggle	"living and dying"	To burn	
Dissonance	"dying is not living"	To look at from	
Endurance	"triumph of inner strength"	To breathe	

Incorporation	"belief system accommodates death"	To pick up	
Coping	"working to find a new balance"	To hold	
Quest	"seeking meaning"	To drop	
Volatile	"unresolved and unresigned"	To let slip	

8) Social modeling

"Change of role system is not enough. That is generally an internal matter. The client must be able to play out a revised version of dysfunctional role in order to influence others within their social sphere" affirm Landy (1993, p. 55). Similarly, as Brook pointed out so well, one can think of the "[w]ords as a small portion of a gigantic unseen world" (1968/1996, p. 12) within the creative process. I had to assume my "response / ability" and put my artistic skills at the service of the cause of the people with whom I wanted to work in order to make their voices heard (Sadjnani et al., 2012). I had to leave the world of words to let it incarnate on the screen and thus make my exploration accessible.

28

The work of certain animation artists has fueled and solidified my artistic intuitions regarding the aesthetic choices for the production. Ishu Patel's short films *The bead game* (1977) and *Afterlife* (1978) and Caroline Blais's *Les Vêtements (Clothing)* (2019) probably add the most major influence on my work. Partly because the themes tackled in all of these were strongly linked to the themes of my exploration. They were touching, through seemingly simple visual effects, on existential concerns, oscillating between reality and transcendence, everyday life and memory, contrasting the microscopic to the gigantic.
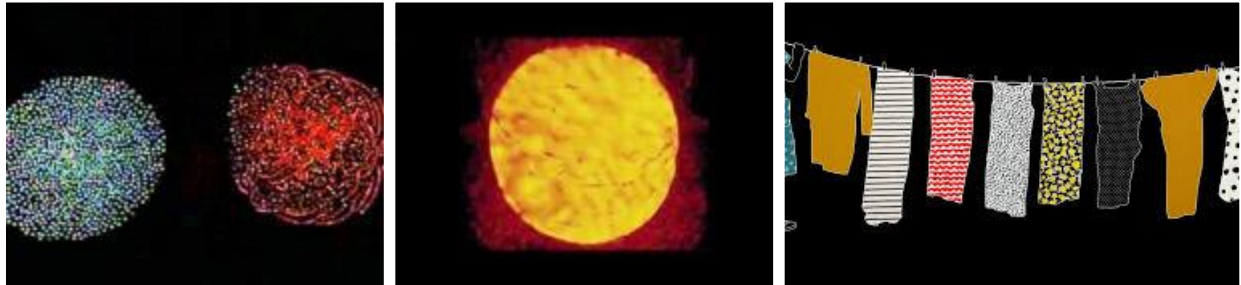

Figure 6. Screenshot of (from left to right) The bead game (Patel, 1977), Afterlife (Patel, 1978) and Les vêtements (Clothing) (Blais, 2019)

In *The bead game* (Patel, 1977) I recognized the playfulness and symbolism of the circles that I had manipulated on a blank surface. I also recognized in the object of the bead itself the source of the link that I had established between repertoire of roles and constellations. I had already explored the role method with a client, using a bead game as projective material with which we had playfully organize her role repertoire in the image of a solar system. In Blais' film (2019), the inlay of textures, testifying of the "real" world, inside naive illustrations which left all the space for this life between their lines were corresponding to what I had in mind when writing the script.

The combination of these two universes, shaped by my own creative landscape, gave inspiration to the short film through which my exploration of end-of-life roles would be translated. Technically, the idea was to shoot a limited number of sequences. I would then be able to juxtapose, frame and superimpose in a metonymic way the images on the text which would be accessible in the voice over. The black canvas of the film would in a way be my ultimate playground for this exploration and act as a "transitional space" as Winnicott (1971 as cited in Landy, 1993) would say, an "empty space" as Brook (1968/1996) would suggest or an « as if » reality, according to Ricoeur (Helenius, 2012).

These textures, these fragmented transparent images would be used in a similar way to the poetic work of the text, to evoke rather than to dictate.

An evocative ethnography is designed not to constrain the reader's attention but rather to invite a richer more expansive appreciation of the possible. For the evocative ethnographer emotionally

arousing discourse plays a central role. The hope, for one, is to engage the reader in a more fully embodied experience. (Gergen & Gergen, 2018, p.276)

In the context of an autoethnography, stimulating the public's emotional and sensory involvement is desirable (Dubé, 2016). The construction of an engaging soundtrack had also served this purpose. The tracks of the artists Godspeed You! Black Emperor, A Silver Mt. Zion, Max Cooper, Giles Corey, Seraphim, Émérance and Sophie Hunger allowed me to express emotional aspects linked to the exploration of these roles. Aiming for a stimulant sensorial experience and in a desire to accurately translate the complexity of these words and the role they convey which fuse from multiple and unsuspected places, in a contradictory way or in harmony within a whole, I made a rudimentary spatialization of the voice in the sound editing work.

Olford (2016) suggests that "auteur animation's constructed nature foreground its subjectivity and, thereby, can be seen as a transparent representation of reality. Yet, what a personally authentic representation is for one filmmaker is not necessary so for another" (p. 15). According to this author's thought, I would go so far as to say that the authenticity of the representation is not only dependent of my point of view, but, from my perspective, at the precise moment when I created the short film. The different fragments to assemble inside the flexible structure that I put in place for the exploration is such that if I had to return and re-edit the film today it would result in a significantly different short film.

I sincerely think that this observation regarding the impermanence of the film object created justifies the relevance of the process by giving the evidence of the personally generative aspect of autoethnographic work (Spry, 2011). Autoethnography, even more so when it is anchored in a critical paradigm and when it uses creative resources to achieve its end, makes it possible to question the world in which we live, to bring out other possibilities and to contrast our lived experience with those of others (Spry, 2011). In this sense, because it upsets our vision of the world, autoethnographic exploration is profoundly transformative (Luvaas, 2019). It is from this logical point of view that my representation of roles at the moment it materialized simultaneously changed. However, beyond the transient nature of the representation remains a renewed meaning, shared with the one who witnessed the representation, shaped within the encounter (Spry, 2011).

Chapter 5. Discussion

If the exercise of writing on the research process supporting this creative autoethnographic exploration served a purpose it is the one of reconsidering from a different angle the aspects that I first perceived as limits. At different moments in the process, I questioned the relevance of my approach including the role method as an intervention method at the end of life and the choice of a creative approach to investigating the subject. I discovered that what I had originally considered as limitations could have a strong generative potential in terms of understanding the implication of the concept of role in end of life experiences, of developing role-based interventions for dying individuals as well as their caregiver, while giving access to more empathic and ethical practices. I will therefore present in this section, in a way that reflects the exploration that I conducted, the research limitations and on the flip side their possible implications in all their ambivalence and paradox. I hope that these contrasts will fuel creativity and once again, open up the possibilities.

The one who is a body

Figure 7. "For me this destination. / This home. / It is my own body. / I am the one who is a body." (Cormier, 2020)

The book *Performance and the medical body* links performative arts and medicine in their quest for knowledge by observing the body. In a chapter of this book, Pynor (2016) argues that

> Language can approach the end-of-life (but never arrive) perhaps only by enacting its own breakdown—words sliding down the page or seeping through paper form slow spreading stains, menacing lumps, senescing meanings and rotting syllables. Falling apart, perhaps absorbed eventually into other bodies. (p. 178)

I believe that in the circumstances, the creative autoethnography which seeks to break down the mind/body partitioning by making their polyphonic knowledge heard (Spry, 2001) was a really suitable methodology to explore roles at the end of life. The concept of role itself undergoes this tension between semantic and somatic. There is the one who says they are and the one who is in their body which is their vehicle to relate with the world (Spry, 2001). Autoethnography "provides embedded and embodied insights that cannot be gleaned from other kinds of inquiry" (Luvaas, 2019, p. 248). In addition, in the case of a creative autoethnography, the creative process as an integral part of the methodology is a process intrinsically embodied in sensory memory of the body projected into a fictitious, imagined situation.

Health restrictions limiting in-person contact and the need to transform the performative process into the creation of a short film first made me fear of losing the body as an investigative tool. Rather, the opposite has happened. The constraint made me more attentive to the possibilities linked to this knowledge of the body and to question myself in relation to its implication in the performance of the roles. I discovered that the body carries both important limits and endless possibilities.

The body is what is living and what is dying, a simple, yet fundamental observation. Spry (2011) with reference to Gale and Wyatt (2008) and Pollock (1999) speaks of the hope that arises from bodies performing theory, defying codes in the liminal space between who we are and who is the other. She talks of these keenly felt sensations in the body which allow both to inhabit and transcend it. By transforming the body into a role, by creating the role "The one who is a body", it seemed possible to change the narrative framework of the body as a source of limitations. Undoubtedly, the dying body transformed, generating worry, anxiety and suffering (Hurd, 2000, 2002; Beauvoir, 1970 as cited in Bourgeois-Guérin, 2013). However, it seemed accessible through the dislocation, the superposition, the repetition of words and sentences, through the juxtaposition of images and the amplification or the calming effect of certain parts of the soundtracks to succeed in giving meaning to these transformations. Consequently, my body was no longer the one who underwent or the one who causes the suffering, but rather became the one who is the path to this new emerging meaning. By othering my own body, I was able to "reabsorb" it and learned to relate differently to the world through it.

"In autoethnographic performance, the body is like a cultural billboard for people to read and interpret in the context of their own experience" suggests Spry (2001, p. 719). Using all my senses to tell how I relate to these roles gave the necessary backdrop to express myself. I believe the projective process of the role method that honors different ways to relate through the body has a strong emancipatory potential for individuals at the end of their life as it allows the dying person to reclaim their body. A body which despite everything that is imposed on it in our lifetime as in our dying moments remains until the very end the way of the living to enter into contact with the world (Merleau-Ponty, 1945).

The one who is an artist
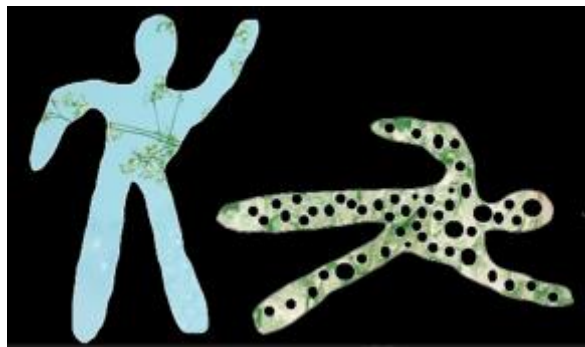
Figure 8. "With him parts of me realized that I am, as well, a dying being." (Cormier, 2020)

"Intersubjectivity offers a useful conceptual framework to understand the way in which the self of the performer and the spectator dialogically relate in their mutual search for meaning" (Jacques, 2016, p. 104). Already, the event that was the catalyst for my interest in the end of life and the precursor of this research, is deeply intersubjective. The death of my father, the confusion between our roles of living and dying in his last moments called for a search for meaning which we lived together influencing each other.

While Landy speaks of the role as the primary medium, as an unbreakable element of dramatic art, for Brook it is the encounter in which they reveal themselves, the presence of and to others that is fundamental to performing art (Jacques, 2016). In this encounter, subjectivity is beneficial and opens meanings, possibilities or new knowledge rather than imposing limitations. This type of relational knowledge which put one's subjectivity and creativity to the service of the relationship with other is fundamental for therapists (Moon & Hoffman, 2014).

However, the goal of this research project was to honor an emic perspective on the experience of roles at the end of life. I feared that the subjectivity inherent to creative autoethnography would not contribute to making the voices of people at the end of their lives heard. I was afraid that my living words would overshadow theirs. I was scared to add noise that could make it even more difficult to listen.

Although, at the end, I believe that it is in this resonance process by which I referred to my own sensitivity to understand the nature of the other that the process took on its meaning (Hefez, 2010). As an artist I was able to open in this intersubjective space a real dialogue between my creative voice and the artifacts testifying to the experience lived by the people at the end of life. In the creative process I felt that their voices through me were more and more audible. As Spry (2001) so eloquently points out (2001) "[…] autoethnographic methods recognize the reflections and refractions of multiple selves in contexts that arguably transform the authorial 'I' to an existential 'we'"(p. 711); an existential quality that is more than welcome in the context of this kind of inquiry and not easily accessible through other methodologies.

Furthermore, the idea of the role method is not to discover new roles, but rather to reorganize those that already inhabit us. This way of looking at work around roles is consistent with the research of Lowrie et al. (2019) with people at the end of life who underlines that a malleable repertoire of roles capable to honor the living and the dying can reduce the psychological suffering at the end of life. Above all, the intersubjective experience of creation using the experience of others and my own prospective experience allowed me to tolerate more ambivalence and "clash of feelings engendered in the taking on and playing out of conflicting roles" (Landy, 1993, p. 13).

In these troubled waters between who I am and who I am not, between the one who lives and the one who dies and by revisiting my repertoire of roles and projecting myself in the end of my own life, I think I have been able, despite my status as a living individual, through artistic expression to conduct a close to emic exploration of roles at the end of life.

The one who is a caregiver

Figure 9. "I tend to stiffen around my eyes. / My vanish point. / There is no such thing as a good death. / I do not have to fit in a rigid mold." (Cormier, 2020)

Landy (2012) suggests that by putting ourselves in the shoes of our clients, not only do we get to know them better, but we also get to know ourselves better. These discoveries, these connections between those we support and ourselves are the foundations of the empathetic therapeutic relationship while also calling for greater reflexivity (Williams, 2017). Landy (2012) talks about the possibility of using investigation processes based on art not only as treatment, but also in all facets of the accompaniment, including as a reflexive tool. Williams (2017) takes this opportunity to put the role method at the service of the caregiver by proposing its use as a framework for self-assessment. As we saw earlier, the intersubjective aspect of the creative encounter is not inherently problematic, but it does imply what Jacques (2016) calls responsibility for our own subjectivity. It is therefore imperative for anyone in a caregiving relationship to reflect on their attitudes, feelings, presuppositions related to those they support, and the situation experienced by them. The verb to accompany etymologically refers to the fact of "being with". Châtel (2010) underlines that to have this real presence to the other it is necessary to clearly distinguish our stories from the stories of those we care for. This ability to discriminate elements of our narratives is based on an authentic and honest self-knowledge (Châtel, 2010).

Williams (2017) suggests that reflecting on the roles of those we support and trying to make room for these within our own system can serve these ethical responsibilities of reflexivity and self-awareness. The exercise makes it possible to realize which roles are more sensitive or less acceptable for us as companions, which roles within our own system are overshadowed or difficult to access and how these less reachable roles influence our ability to be present to the other. Reconnecting with all of these roles in addition to contributing to better self-awareness also helps to nurture our empathy.

As part of my autoethnographic exploration of end-of-life roles, I anticipated the danger of imposing my conception of a "good" death in the narrative bringing together the roles (DesAulniers, 2017). I feared that sharing this vision, tinged with my values, my living experiences and my culture, would undermine the relevance of my approach, which aimed to truly listen to the voices of people at the

end of life (Lowrie et al., 2018). In retrospect, I believe that the process allowed me to lower my guards and explore my implicit bias in complete transparency, which is in fact essential as a caregiver. I hope that this authenticity will inspire other caregivers to take up the challenge of exploring the roles that inhabit them. Like Williams (2017), I believe that the role method can serve this kind of reflexive work which would promote more sensitive and ethical practices in the end-of-life care.

The one who is a therapist
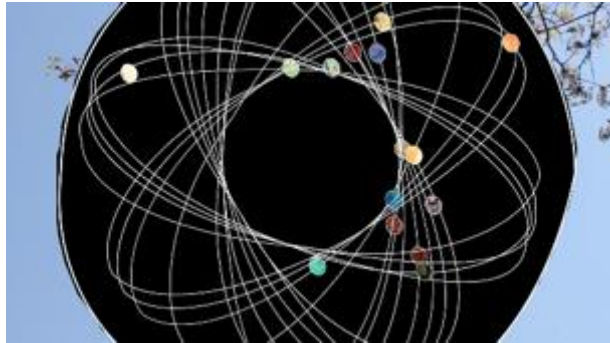
Figure 10. "Roles as anchors. / Role to understand the fundamental paradox of human existence."

(Cormier, 2020)

The trauma of facing their imminent death can make the narration of oneself difficult for individuals at the end of their life (Bourgeois-Guérin, 2010). In this perspective, I suggest that the use of roles as a fundamental element of the narrative could facilitate the process. Facilitating the narration of their story could have a positive impact on people at the end of their life. "Narrative, the imaginative linking of experiences and events into a meaningful story or plot, is one of the primary reciprocal processes of both personal and social efforts to counter this dissolution and to reconstitutes the world" (Good, 1994, p. 118 as cited in McKechnie et al., 2007, p. 368). A story can both give meaning to past experiences and help in "the anticipation of an event that has not yet occurred, such as one's death" (Landy, 2008, p. 107). Also, since dignity, recognition and respect of identity and uniqueness are central concepts in palliative care, facilitating storytelling could contribute to the affirmation of oneself and promote agency (McKinlay, 2001).

Nguyen (2012) emphasizes that by getting to know better how the end-of-life individuals define themselves, it is easier to understand how they envision and experiences the end of their life. Moreover, this knowledge makes it easier to offer an optimal support to the person in their last moments by honoring their uniqueness despite the limitations that illness and death impose on them (Nguyen, 2012). This exploration of roles can also result in a better understanding of the dynamics that inhabit the dying and could therefore allow to discern more effectively among the adaptive motives and thus propose interventions that are attuned to the person's needs (Yedidia & MacGregor, 2001).

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I was able to notice how the role method favors this kind of storytelling which affirms the identity while respecting the blurred areas and the gaps. Even if, at first, the goal of the exploration was not to tell a story I found myself telling one. By organizing the roles, a narration emerges, almost by itself. According to Landy (Minerson, 2017) we chose our guide according to our destination. It seems that choosing the dynamic between roles and selecting a guide role to facilitate the transition was slowly indicating the destination and, by doing so, was telling the story of the journey that leads to it.

Moreover, the main discovery of my inductive exploration of roles at the end of life is that whereas I thought that it would highlight what one could call a taxonomy of the roles of the dying individuals, it is rather the fluidity of the role method that help structure the narrative without making it immutable which appeared the most relevant aspect to better support people at the end their life. It is this radical flexibility in the transitional empty space of "as if" reality (Brook, 1968/1996; Helenius, 2012; Winnicott, 1971 as cited in Landy, 1993) which made it possible to take action in stillness. It is the abundance of mediums that made accessible, through the use of simple words superimposed with images and music, highly liberating fantasies. Perhaps it is in this flexibility, in the multitude of creative ways to express oneself which leaves room for uncertainty and shifts that the method turns out to be the most significant since it is "in these splits that human beings discover their humanity" (Landy, 1993, p. 21).

The one who critiques

Figure 11. "Let us be an exquisite corpse. / My eyes with your hands. / My story with your body. / The sensation that I feel and your voice. / It takes a village." (Cormier, 2020)

> Many of course do not choose their roles. […] For those people, balance implies a capability to conceive of themselves beyond the limits of their disabilities or abilities, reaching out to other parts of themselves and to others who are similar and different from them. Imbalance, leading to a more limited existence, means the opposite—a definition of self and a view by others as one—dimensional person, locked into a prison of one's own construction. (Landy, 2008, p. 110)

Throughout the process, this concern for the margin kept coming back to me. I was wondering if my exploration could concern any individual at the end of life or if it only addressed a normative and privileged death. I was wondering if it could be used for individuals with a cultural background different

from mine. I was also wondering if it could serve people living with diverse physical or cognitive realities at the end of their lives. I feared that my desire to make the voices of people at the end of their lives heard would only contribute to listening to the narrative of privileged people for whom death was already in many respects already eased.

I wrote this essay and script in English, a language that is not my native language. At the beginning of the process when I was coding the interviews conducted by Kübler-Ross (1969/2005), the formula "The one who…" rather imposed itself in my mother tongue, French, as "Celle qui…". Therefore, the voice that has been heard in the short film is a feminine one, which would have been obvious if the exploration had been conducted in French. I realized through this research that not only was my positioning critical, but that it was rooted in critical feminism. My approach tended towards the emancipation of dying women amongst other marginalized populations. My weapons of rebellion were privacy, identity, poetry, art and the body. My investigation tools were non-traditional (Sikka, 2019). "A poet figures a possible world while challenging the real one with a tragic plot" (Helenius, 2012, p. 149).

Critical feminist "is aimed at interrogating, challenging and providing an alternative to dominant ways of knowing and thinking" (Sikka, 2019, p. 11). I think that this autoethnographic exploration, creative, intimate, yet formally free and abundant can show the way for us to consider how by using the role method it is possible to deploy different ways to relate. The role is a concept very connoted and strongly defined by the culture in which it is performed (Howe, 2016). I believe that the flexibility of the method of roles, because it is partly anchored in fiction, offers the space necessary to turn away from stereotypes and free oneself from a rigid vision of the role giving way to individuality (Leavy, 2012). I also firmly believe that by allowing the invocation of roles through various sensorial modalities, such as images, sounds and textures makes storytelling more accessible for individuals with varied physical and cognitive realities. "[A]s long as a person is conscious enough to imagine himself as other, in another space, there is drama and thus hope of change" (Landy, 2008, p. 107) and it seems to me that the sound or visual textures of the short film alone can tell a story. From my artist-therapist-researcher perspective, it is possible to envisage how simple words can contain more than one reality and manage to construct and deconstruct the world. Everyone, depending on their sensitivity, their capacities, their inclinations, could choose one of the mediums used in the short film to say who they are and to somehow "make" themselves (Ricoeur, 1960 in Helenius, 2012). Remaining free in the adventure, as Landy (2008) suggests, to transcend their own limits by gleaning from others and their creativity the pieces that are lacking to be able in this association, this exquisite corpse, to be more whole.

The one who becomes

Figure 12. "I will cook a meal. I will cut the food. Let it bake as if I have many more tomorrows. I will take my time and offer it to you as if I have too much. / Letting living on my own transform into gathering together to caring for each other." (Cormier, 2020)

Luuvas (2019) with regard to the existential risks linked to autoethnography says that:

In many cases, there is no leaving the field anymore. We take the field with us. […] We may think we are finished with them, but they are not finished with us. We linger in autoethnographic present indefinitely. (p. 257)

Spry (2011) talks about the unsuspected ways in which such an approach transforms the researcher. This transformation is at the heart of the narrative investigation and inevitably changes the relationship between the researcher and the object of their investigation (Pinnegar & Daynes, 2011). An influence that continues to be effective for the researcher as well as for those who witness the results of it (Moon & Hoffman, 2014). In the case of a creative exploration, the researcher is also an artist. As part of this creative exploration, I was in addition to a researcher and an artist, a therapist in training. The observers of my investigation will be, you are, I imagine, caregivers and living individuals interested in the end of life. Perhaps also the dying individuals in search of other voices to join theirs.

Congruently, if the ultimate goal of an autoethnography is transformation, I think it would be appropriate to conclude by reflecting on how I think these transformations will manifest in us (Luvaas, 2019; Spry, 2001).

Death made me become somebody else through the experience of caregiving for my father at the end of his life. I became somebody else through this creative autoethnographic exploration by being in closer contact with my own ambivalence and paradox. I will continue to become somebody who tries to reconnect with forgotten, sometimes almost dead, parts of herself in order to relate more fully to others. This project will continue its latent transformative work by reminding me of the power of creativity and subjectivity as well as the flexibility that these artistic skills make available in supporting people at the end of their life and will support me in becoming a more sensitive and equipped therapist.

The context of the pandemic made the inclusion of the viewers creative feedback impossible in the current research process. However, it is my intent that the process itself will continue to become and that further investigation with regard to the reception and impact of the short film will be conducted.

Meanwhile, this journey and the short film that keeps traces of it will hopefully resonate in you. I hope that through this resonance you will become caregivers sensitized to the importance of exploring your own constellation of roles, the stories it tells in the moment and the biases that these stories impose on our vision of the world.

I hope that we will all become living and dying beings more aware of the value that we must give back to creativity at the end of life so that, as Miller (2015) so powerfully says, we let "death be what takes us. Not a lack of imagination" (18:27). Or as Ricoeur articulated it near to his own death "living up to death as a living against death in the sense of removing death's victory so that life continues in others, through others, for others" (Kearney, 2011, p. 225).

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Appendix A

#	Roles	Counterroles
	Spiritual	
1	The one who lives	The one who dies
2	The one who prays	The one who keeps silence
3	The one who dies	The one who lives
4	The one who is devoted	The one who free herself
5	The one who believes	The one who doubts
6	The one who have faith	The one who is atheist
7	Somatic	
8	The one who transforms	The one who stays the same
9	The one who is able	The one who is disabled
10	The one who is stuck	The one who is free
11	The one who is sick	The one who is healthy
12	The one who is weak	The one who is strong
13	The one who takes a lot	The one who collapses
14	The one who stocks	The one who counts
	Social	
15	The one who takes care	The one who is taken care of
16	The one who doesn't work	The one who works
17	The one who is a neighbor	The one who is a patient
18	The one who is a partner	The one who is a burden
19	The one who is a parent	The one who abandons
20	The one who is lonely	The one who gathers
21	The one who is an orphan	The one who is the child
22	The one who is the child	The one who is an adult
23	The one who is a friend	The one who dissapears
24	The one who is fair	The one who thinks about herself
25	The one who is bereaved	The one who abandons
26	The one who depends	The one we can count on
27	The one who helps	The one who is being helped

28	The one who is a sibling	The one who is a single child
	Cognitive	
29	The one who knows	The one who ignores
30	The one who obeys	The one who rebels
31	The one who ignores	The one who faces
32	The one who decides	The one who endures
33	The one who accepts	The one who rebels
	Affective	
34	The one who is optimistic	The one who is pessimistic
35	The one who liquifies	The one who stiffens
36	The one who worries	The one who meditates
37	The one who is not afraid	The one who is frightened
38	The one who is a number	The one who is unique
39	The one who is depressed	The one who is happy
	Aesthetic	
40	The one who enjoys	The one who endures
41	The one who hopes	The one who is bitter
42	The one who jokes	The one who is serious
43	The one who arrives	The one who leaves
44	The one who belongs	The one who frees herself
45	The one who loves	The one who hates

Appendix B

% and proportion*	Domains	Roles	Proportion and % 1**	Proportion and % 2***
9% 5/52	**Spiritual**	1-The one who lives 2-The one who dies 3-The one who has faith 4-The one who doubt 5-The one who breaks free	**5/45 11%**	**5/48 10%**
29% 15/52	**Somatic**	6-The one who transforms (>>>The who stays the same finally encapsulate I the one who stiffens) 7-The one who moves 8-The one who is stuck 9-The one who is free 10-The one who is sick 11-The one who is healthy 12-The one who is strong 13-The one who counts 14-The one who stocks (>>>The one who collapse finally encapsulate in the one who liquifies) 46-+++The one who is a body 47-+++The one who contains 48-+++The one who is contained	**9/45 20%**	**12/48 25%**
28% 14/52	**Social**	15-The one who is a kid 16-The one who is a citizen 17-The one who is a patient 18-The one who depends 19-The one who is a partner (Encapsulate The one who is a lover & The one who is a friend) 20-The one who grieves 21-The one who belongs 22-The one who is alone 23-The one who gathers 24-The one who cares 25-The one who is egoist 26-The one who is fair 27-The one who abandons	**13/45 29%**	**13/48 27%**
9% 5/52	**Cognitive**	28-The one who faces 29-The one who ignores 30-The one who knows 31-The one who decides 32-The one who undergoes 33-The one who rebels	**6/45 13%**	**6/48 12%**
17% 9/52	**Affective**	34-The one who stiffens 35-The one who liquifies 36-The one who is unique 37-The one who is a number 38-The one who is terrorized 39-The one who is depressed 40-The one who is happy (>>>The one who is imperturbable encapsulated in the one who stiffens) (>>>The one who is optimistic switch category)	**7/45 16%**	**7/48 15%**
8% 4/52	**Aesthetic**	41-The one who jokes 42-The one who hates 43-The one who loves 44-The one who enjoys 45-+ The one who hopes (originally the one who is optimistic)	**5/45 11%**	**5/48 10%**

*% of excerpts coded for each domain and the equivalence in role on a repertoire of 52 roles Number of roles for each domain on a repertoire of 46 roles and the approximative equivalence in %
**Number of roles for each domain on a repertoire of 45 roles and the approximative equivalence in %
***Number of roles for each domain on a repertoire of 48 roles which include the one who emerge in the creative process and the approximative equivalence in %
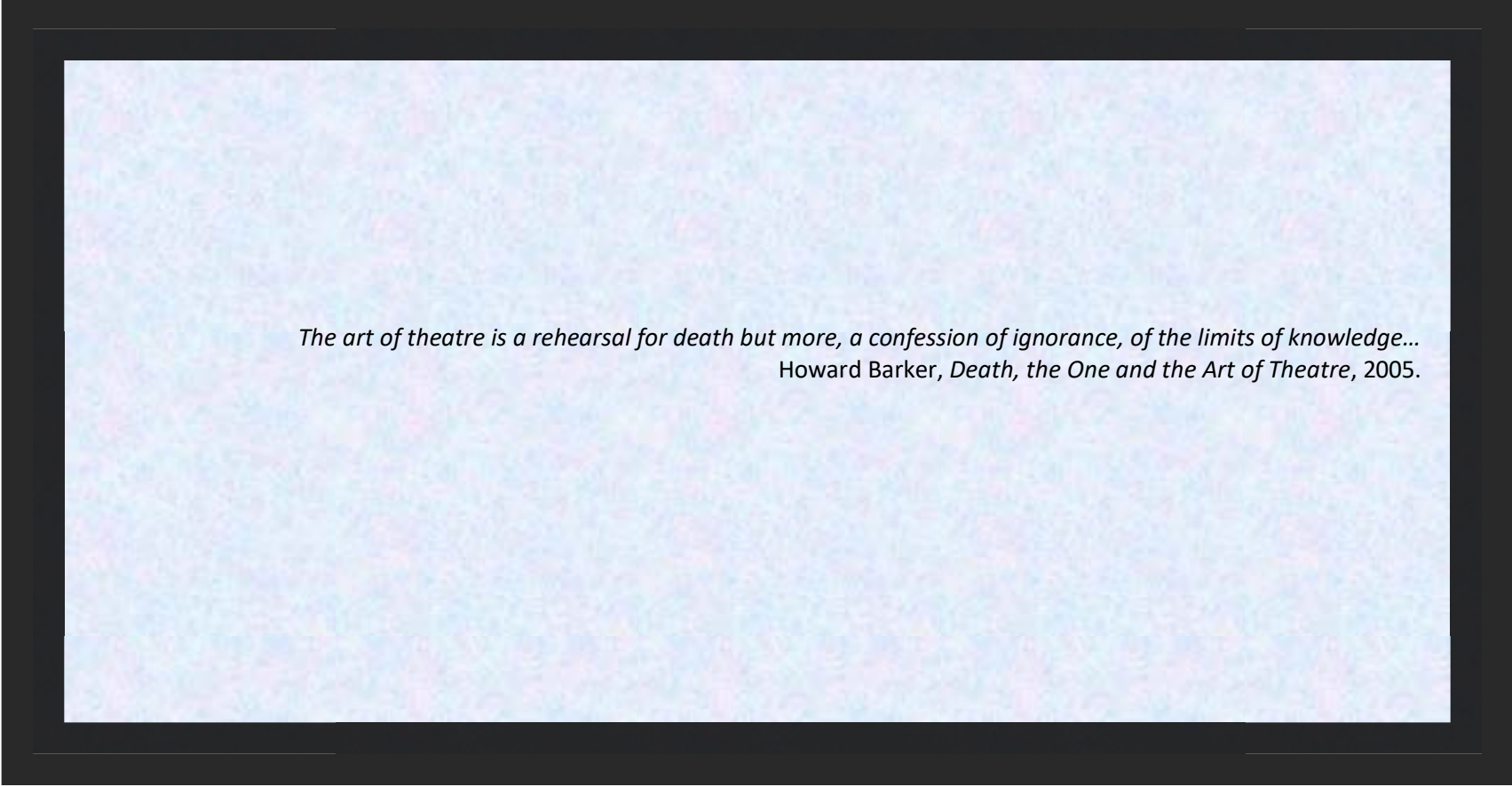
THE SCRIPT FOR THE SHORT FILM

THE DYING ROLES: A CREATIVE AUTOETHNOGRAPHIC EXPLORATION OF ROLES AT THE END OF LIFE

Juxtaposed to a superposition of images that will be part of the film, as an epigraph to the short movie:


The art of theatre is a rehearsal for death but more, a confession of ignorance, of the limits of knowledge…
Howard Barker, *Death, the One and the Art of Theatre*, 2005.

PROLOGUE

A drawn circle on a black background. Filled up with moving images. The circle and the images in it appear and disappear. The line that form it is craftily changing the shape of the circle, letting us see that it is actually many circles that appear and disappear with a new moving image in each of them. The line changes into a body shape. The moving images pile up inside the lines. The body duplicates and split apart. One next to the other. Black circles gradually appear in the second body. When the body is almost full of these black circles the containing lines transform back into two circles. The first body transforming into a circle. The second body all the dark circles pile up in his middle and escaping from there into what looks like a constellation while transforming itself into a circle as well. The first one is the one who lives. The second one is the one who dies. All the other circles are roles that we will slowly discover throughout the film.
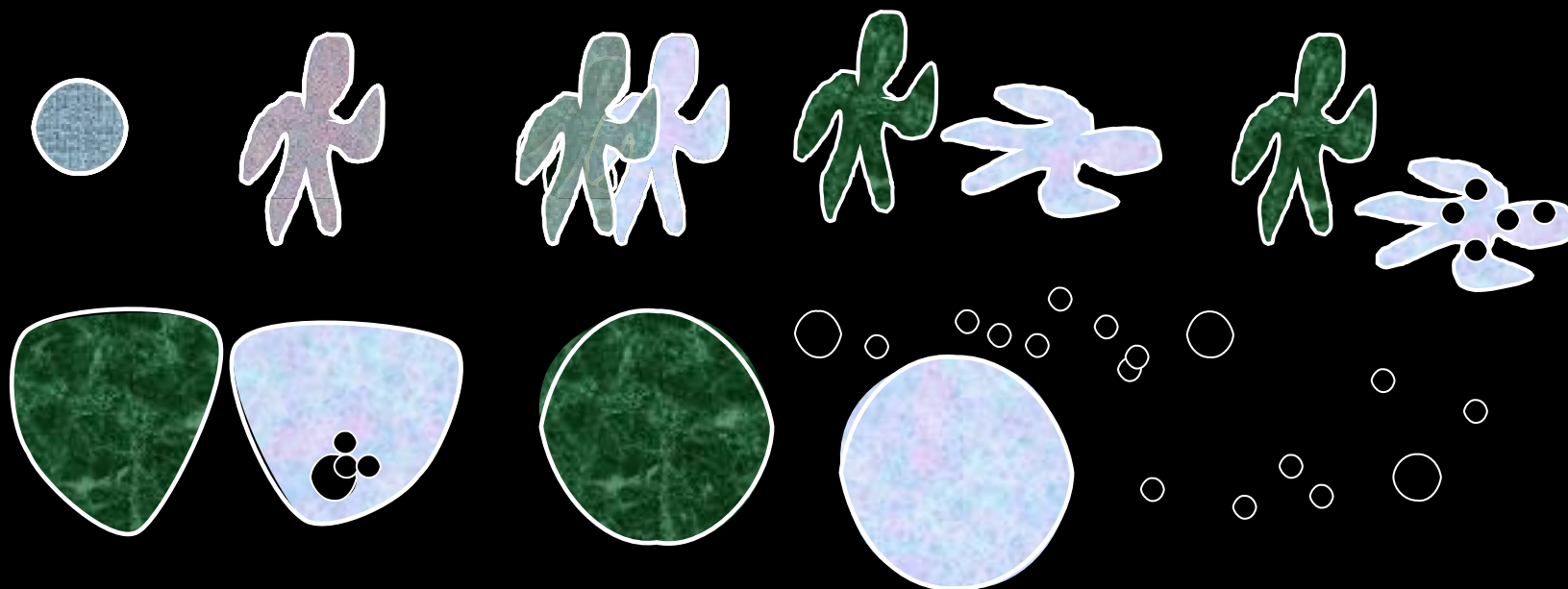
A cell.
A moving circle.
Full of life.
One cell multiplies.

One cell dies.

One cell grows.

A human being.

Me.

Full of life.

My body.

My body next to his.

Next to his dying body.

I'm alive because my cells keep growing and dying.

Apoptosis.

From the beginning I was dying.

And now his damaged cells that refuse to die.

They multiply.

What makes us alive is the fact that from the beginning we are dying; when we stop dying, we start to die.

He's dying.

My father is dying.

With him parts of me begin to realize that I am as well a dying being.[1]

That ambivalence between my living role and my dying role becomes the lens through which I envision all other ambivalence.

Life complexity.

Dynamics.

Maybe as a performative artist I was already used to living in a world "written on the wind".[23]

Aware that I was playing many roles.

That I am and I am not at the same time.

Role as the actor primary medium.

Role as anchor.[4]

Role to understand the fundamental paradox of human existence.

---

[1] "Aussi la mort d'un être cher est-elle presque comme la nôtre, presque aussi déchirante que la nôtre; la mort d'un père ou d'une mère est presque notre mort, et d'une certaine façon elle est en effet la mort-propre" says Jankélévitch (1977, p.29) when talking about what he calls death at the second person, between the anonymity of a death at the 3rd person and the tragedy of 1st person.

[2] The task of the actor is to embrace life and death at the same time. The paradox of drama is be and not to be, simultaneously) (Landy, 1993, p.12).

[3] Brook (1969/1996) talking abouth the deadly theater: "theatre is always a self-destructive art, and it is always written on the wind" (p.15).

[4] Landy(1991b) talks about the role as an anchor in the psyche.

"The role is like the cell or the atom. It is a primary building block, diminutive at first glance yet expansive in terms of its own substance and function, as well as its powerful effects on the system as a whole. Speed up the atom or modify the cell and a radical, irrevocable force may be unleashed. Alter the role and a psychological counterpart to the physical and biological may also burst forth."[5]

What happens when the dying role takes all the place?

Broken homeostasis.

What are the psychological effects of altering the role dynamic?

If the cells invading my body are slowly making me die what are the psychological effects of the dying role slowly shadowing every other planets of my very own constellation of roles?

My personality.

My identity.

My belief system.

I matter because I am me and I matter till the end of my life. [6]

The drama of contemporary dying is longer than ever.[7] I do not only want to be helped to die peacefully, but also to live until I die.[8]

Dying while living and living while dying.

[5] (Landy, 1991a, p.422).

[6] The original sentence is: "You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die." (Saunders, 1976 as cited in Nguyen, 2012, p.2).

[7] (Lowrie et al.2019a).

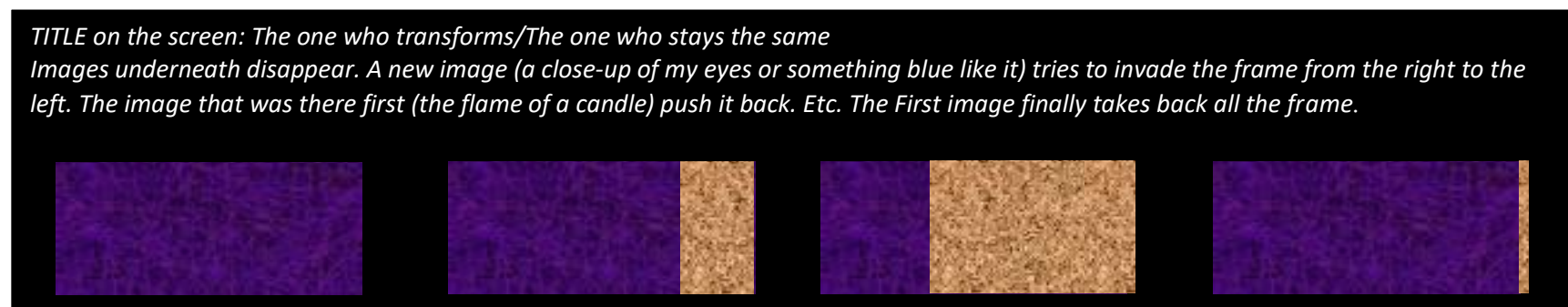[8] Saunders, C., *op.cit.*

TABLEAU 1

TITLE on the screen: The one who dies/The one who lives >>>The one who transforms
Close-up on the two bigger circles. One circle at the back that will slowly fill up with another image and gradually overflow the line to invade all the frame. The circle becomes bigger coming over the first two ones. The black background slowly disappears. Leaving the superposition of 3 images and 3 drawn circles.

I am the one who dies.
Walking doctors said it.
Able specialists said it. [9]
I know it.
But I'm also still the one who lives.
I am mostly the intersection between both.[10]
Reframe my roles.
Transform them as my body transforms.
Learn from my cells.
Embrace liminality.[11]

---

[9] The doctor is seen as the gatekeeper in the drama of dying, the one who announce the transition as explained (Lowrie et al., 2018).

[10] "Dying people and those closest to them also lessened the emotional burden associated with the dying role by leveraging the conceptual overlap between living and dying. This overlap allowed key elements of the dying role to be enacted under the guise of a focus on living" (Lowrie et al. 2019b, p.606).

[11] "A further possibility is that dying may not be a status in its own right, but rather representative of the liminal phase between the statuses of the living and dead (Froggatt, 1997; Seale, 1998)" (Lowrie et al., 2018, p.332).

TABLEAU 2

TITLE on the screen: The one who transforms/The one who stays the same
Images underneath disappear. A new image (a close-up of my eyes or something blue like it) tries to invade the frame from the right to the left. The image that was there first (the flame of a candle) push it back. Etc. The First image finally takes back all the frame.

I remember my skinned knees in the backward.
The pain.
My body kept a trace of it.
Transform.
Transformation happen whether we like it or not.
Transformation defines me as a living being.
I do not always choose how I transform, but I can always choose how I tell the story of these transformations.
Putting different meanings on the same things.
Scars as symbols of bravery.
Scars as symbols of loss.
My body changes, reminding me that I'm not the same. [12]
My daily ritual changes, reminding me that my life is not the same.[13]
Perpetually having to adapt.
To my new body.
To new rituals.
Having to reinvent who I am. A mutant.[14]
The pace getting faster. And faster. And faster.

[12] "[...] individuals' sense of self can be challenged when and if their physical bodies are altered" (Parker-Oliver, 2000, p.506).
[13] "Illness or disability disrupts life by altering the regularity and the routine of habitual behavior" (McKechnie, et al., 2007, p.368).
[14] What she calls « le corps éprouvé » is linked to suffering for the women interviewed by Bourgeois-Guérin (2013). Amongst other things through their body women experience repeated pain, may find their feminine identity fragilized and have worries concerning upcoming transformation.

I am slower and slower.

What is still me in this ever-changing being?

The eyes of my father.

The same.

Until the end.

I know that my eyes. Identical to his. Will be the same. Till the end.

My eyes.

Immutable.

Through life and at the crepuscule of it, these eyes.

Which carry anger as well as tenderness bigger than us.

Immutable.

Invasive.

TABLEAU 3

« As [my] body develops it is affected by and forms the basis for the construction of social relations. [As my] body refuses to be reconstructed, the prospect of my own death becomes real."[15]

Sclerosis.

I tend to stiffen around my eyes.

My vanish point.

There is no such thing as a good death.[16]

I do not have to fit in a rigid mold.[17]

In order to evaporate, ice needs to be water first.

Letting all the molecules of sadness loosen up.

Allow the flow of liquids.

Urine, blood, sweat, tears.

Let it go.

[15] (Shilling, C., 2002 as cited in McKechnie et al., 2007, p.368).
[16] ""good death" places powerful pressure upon the dying to swiftly and effortlessly transition to normalized expectations and behaviors associated with the dying role" (Lowrie et al., 2018, p.339).
[17] Some people can feel the pressure of having to conform to a normalized way of dying (Emanuel et al, 2007).

TABLEAU 4

I remember stiffening all the muscles of my body as I was standing in cross in the doorframe of my bedroom to respond to injustices.

I remember crying all the available tears of my entire life before I was 5.

All I have left at the end is the tenderness of childhood and the laughs I didn't back take then.

My body which opposed is exhausted and the rivers flowing on my cheeks dried up.

My eyes are burning, my body is hurting, I'm smiling.

Just like the kid I used to be, let myself be the one we take care of, the one who furiously cries without shame, who spontaneously expresses herself and her emotions.[18]

The one whose mother tucks her in at night. With heavy blankets.

Tucked. Listen to the sounds of life without me actively in it.

Imagine.

Even there.

At the end of my world.

Imagine.

Thinking about growing tomorrow.

The same curiosity for what will be this tomorrow.

My imagination, my narration.

My gentles and powerful weapons against dissolution. [19]

---

[18] Inspired by the shared story Wilder-Craig (2004).

[19] "narrative, the imaginative linking of experiences and events into a meaningful story or plot, is one of the primary reciprocal processes of both personal and social efforts to counter this dissolution and to reconstitutes the world (Good, 1994, p.118)" (McKechnie et al., 2007, p.368).

TABLEAU 5

TITLE on the screen: The one who's sick/The one who's strong >>> The one who faces
A structure of plain Mikado sticks. Some sticks are gently and carefully removed. Some branches being planted in the soil like a fence.

Redefining strength in the face of death.

The crocus growing in the last snow of March.

Everything calls to repress that desire to show off, but it grows in the mud and the white blanket without caring about common sense.

I am this crocus.

Strong and vulnerable.

Strong because I'm vulnerable.

Strong because when everything calls to close my eyes, I decide to open them.

TABLEAU 6

TITLE on the screen: The one who's sick/The one who's healthy
Concrete. Asphalt. Grey bark. Growing grass. Bark covered with green moss.

I'm sick.
I do need to get better.[20]
 I do not feel the enemy in my blood.
I do not feel these extra cells.
No more space.
Bumps.
I lost my battle.
But I feel ok.[21]
Enjoy how well I'm feeling.
Or.
Scan my body all day from head to toe to find something abnormal.
Transformed.
It pinches here.
My skin is a little warmer there.
Connected.
And disconnected.
Who's the liar?
My body?
The doctor?
The disease?

[20] "The "sick role" and the "dying role" share a common ground in the sense that they both have rights and obligations. But in the case of sickness, the person is obligated to get well, while in the case of dying, the person is obligated to die" Parker-Oliver, 2000, p.494). Therefore, incurable disease means that the person failed at reaching the only goal of their "sick role" i.e. get better.

[21] "Toutefois, cette invisibilité et le fait que son cancer est asymptomatique font que son entourage et elle-même ont eu de la difficulté à croire qu'elle est atteinte d'un cancer" (Bourgeois-Guérin, 2013, p.159) on the difficulty experienced by some women to grasp the reality of their end of life while they do not notice any symptoms.

My loved ones?
The mirrors?
Me?
I should drink another smoothie.[22]

TABLEAU 7

TITLE on the screen: The one who's sick/The one who's a citizen >>> The one who is a patient
Grey bark. Layers of tape on a light post. Hands. Flowers in a pot.

Is this world still mine?
Do I need to leave a print on it?
Noticing the traces of time and people.
The layers of tape on the light posts.
The spray paint on the wall.
All of it wasn't just a dream.
There is too much texture. Too much depth. Too many bonds.
The scene is too big.
There is no neighbor.
I do care about the future. Can I do care about the future?
I don't know what my value as a citizen has been.
I don't know what my value as a sick citizen is.
I do not resemble the picture on my identity card anymore.
I do not recognize the light posts on my street. The spray paint on the wall of my neighborhood.
Socially dead and still alive.[23]
Belonging to everything and nothing at the same time.
A new world without light posts, identity cards, sprayed walls.[24]
A neighborhood where rooms are like homes and hallways are like streets and hospital gowns are like suits.
Citizens with greasy scalp who smell sickness.
Between us we don't smell it.
An ultimate wolfpack.
Root ourselves here one last time.
Create bonds.

[23] The concept of social death is related to loss of identity, social connectedness, body disintegration before the actual biological death. The experience can "hamper the enactment of important interpersonal dimensions of end-of-life roles and compromise the ability of the dying person to negotiate dying role relations" (Borgstrom, 2017; Kralova, 2015 as cited in Lowrie et al., 2019, p.8).
[24] In palliative care "acknowledging death is a general practice, patients are more apt to become involved in each other's lives as there is no need to keep the dying separate and invisible" (Charmaz, 1980, p.181 as cited in Parker-Oliver, 2000, p.501).

I always liked the turquoise color they use for hospital fabrics.
I will sew our flag from the fabric of our curtains.
A nation of lame person who wants to live before it's too late.
We would organize the chaos.
We would vote laws to destroy them the day after.
We would scream from the windows of our rooms: "Aren't you tired of dying bunch of idiots"[25]
I would help build a new world in which I can engage and be sick and die and still be a citizen.
How can we call it?
A patient?
Somebody who patiently engage in her life, in her world, in her last days.

[25] Free translation of the famous sentence by Claude Péloquin carved on the outside wall of the Grand Théâtre de Québec by the visual artist Jordi Bonet in 1971: "Vous êtes pas écoeurés de mourir bande de caves. C'est assez !".

TABLEAU 8

TITLE on the screen: The one who is a patient >>> The one who's unique/The one who's a number
Hand lines. Flower dropped like Mikado sticks. One flower is a different color. Mikado sticks in a flowerpot.

Patiently draped in my hospital gown flag I do not want to be a number.

I do know all my numbers.

CORE28608401-room-101-do-not-live anymore-at-2521-do-not-answer-anymore-514-758-3492-can-be-reached-at 514-932-0786-will-answer-if-not-sleeping.

Again.

I do know that I'm doing more and more naps. 3,4,5,6,7,8,9. For one day.

I hate and I love being a number.

65 pulses per minute, systolic tension 110, diastolic tension 70, 36.9° Celsius, 94% O2 saturation

I hate and I love being the summation of all these statistics.

There is something about anonymity that makes it easier to grieve.

People do forget numbers.

Numbers are replaceable.

Switchable.

I'm unique and similar to other dying patients.[26]

Sometimes I find the turquoise gown comforting.

Sometimes I wish the gown is the color of my own identity.

---

[26] Inspired by testimonials from discharged hospice patients in Mckinlay (2001).

TABLEAU 9

TITLE on the screen: The one who's strong/The one who's sick >>> The one who faces
Only one Mikado stick. A broken mikado stick. Tree bark. Travelling to tree crown.

Blink my eyes. Open it. I'm there.
I do not want to be a warrior.[27]
I do not want to perform my own death.
I just want to live my days.
Finish my very own story.
Being strong prevent me to face the fact that I'm incurably, fatally, deadly sick.
I am not this fighting character.
This is not my story.
I'm the other one behind.
Discreet and fragile.
Blinking my eyes. Open it. Tear off like a translucent layer of starch.
I'm there.
Fragile and discreet and so much more.
Eyes wide open. [28]

[27] "Cette valorisation de l'attitude héroïque dans un combat contre la maladie peut aussi avoir comme effet de taire les souffrances ou les peurs vécues, et c'est d'ailleurs pourquoi certaines femmes âgées atteintes d'un cancer vont refuser d'endosser ce rôle (Sinding et Gray 2005) " (Bourgeois-Guérin, 2013, p.155).
[28] The image of eyes wide open is suggested here as a metaphor of what can be perceived as acceptance. Acceptance of dying according to Zimmermann (2012) analysis of palliative care literature discourse is "regarded as a necessary precursor to effective contemporary end-of-life care" (Lowrie et al., 2018, p.338).

TABLEAU 10

TITLE on the screen: The one who faces/The one who's terrorized >>> The one who ignores
Tree crown. At day. At night. Day. Night. Day.

I'm not afraid to die.
I close my eyes. I open my eyes. [29]
I'm afraid to live.[30]
I close my eyes. I open them.
I'm afraid to suffer.
I'm afraid to lose.
I close my eyes.
My quality of life.
My next camping trip.
The light of tomorrow morning.
I open my eyes.
I'm afraid.
I close my eyes.
To not be able to walk to my bed.
To not be able to read my favorite poem.
To not remember the name of my favorite human.
To not recognize what and whom makes me who I am.
I open my eyes.
I'm afraid of what comes after.[31]
I close my eyes.

---

[29] As a counterpart to acceptance, the image of closed eyes is suggested here as a metaphor of what can be perceived as denial. " Zimmermann (2012) highlights that, while acceptance of death is welcomed by health workers, perceived denial of death will be met with professional resistance and offers of psychological assistance" (Lowrie et al., 2018, p.338).
[30] "I'm not afraid to die. I'm afraid to live. One thing leads to another." Excerpt from interviews made with terminally ill patients by Yedidia and MacGregor (2001, p.812).
[31] "What will happen when I die? What will happen after I have died?" said a patient while describing their fears with regard to death (Wilder-Craig, 2004, p.57).

I'm afraid of eternity.[32]
I open my eyes.
I'm afraid of the fear of others.
I close my eyes.
I'm afraid that nobody believes that I'm dying.
I'm afraid of *their* closed eyes.[33] [34]

[32] "Dying is forever" *ibid*.
[33] Inspired by the testimonials of patients reproduced in Nguyen (2012)and Grumann and Spiegel (2003).
[34] Covert acknowledgment of the dying status often results in distress for the dying person according to Lowrie et al. (2019a).

TABLEAU 11

TITLE on the screen: The one who faces/The one who's terrorized >>> The one who has faith
A circle with images of hands in the soil. Hands in ashes. Hands in white confetti.

I open my eyes.

To see a wall or to see a hole. To see a hole in the wall. Infinitely deep.

In time of uncertainty one little goal after the other. I have great faith in small steps. I have small faith in big trees. Devotions. To the microscopic and the gigantic. Digging into the dark to find light. Poetry.

TABLEAU 12

TITLE on the screen: The one has faith/The one who knows >>> The one who doubts
Tree crown. Travelling on grass soil then abruptly asphalt.

I knew that I was sick.
I know that I am now dying.
Doctors are searching for the exact name of what is killing me.
I'm searching for meaning. I'm searching for the travel map of my disease to be able to make the trip my own.[35]
Noticing different smells.
The vertigo of traveling and the encounters that comes with it.
Seek to others.
Diving into myself.
Unpredictability. Uncertainty. Doubts at every corner.
Doubts as my luxury.
What will happen with my pain, my body, my soul, my time, my identity?
Doubts that nourish my anguish and my curiosity.
Doubts that freeze me and make me move forward.
Maybe it will be terrible. But it may be wonderful also.
Faith.
Faith into something beautiful.
I remember constructing a small altar beside my bed and putting objects that were valuable to me: a small shiny rock, a Virgin Mary, a silky scarf.
I remember my knees on the floor in front of it. I remember my desire to offer my imprecise words to something bigger than myself.
I remember the impression of being connected to something bigger than myself.
I remember my knees often landing on the floor.
The repetition.
The daily rituals.
The vertigo of large spaces. The soothing feeling of the small ones.
The impression that a thread exists between all of these.
The sensation that if I happen to explode the thread will somehow contain me.

---

[35] "Doctors aim to diagnose a disorder; the patient attempts to find meaning and understand the illness" (McKechnie et al., 2007, p.368).

If the world's going to explode the same thread will contain it.
It might be terrible. But it may be wonderful.
Witness it with my own eyes.
Doubts fulfilled by a wish for autonomy.

TABLEAU 13

Taking power over my doubts. Reframing my anxiety as curiosity. Make decisions.

I'm not as hopeless as doctors can say.[36]

Goals as hopes.

Meaningful hopes to me.

Reasonable hopes that acknowledge the fact that I'm dying while giving me the opportunity to live until then in a meaningful way.[37]

Hope to be able to attend my loved ones' birthday and bake a cake for them

Hope to see the beach one more time and swim alongside my dog.

Hope my body will help the advancement of science.

Hope I will be free of physical suffering.

Hope I will have the chance to listen to somebody sorrow and help them.

Hope I will laugh many times again.

Hope I will sleep in the same bed as my lover for as long as possible.[38]

---

[36] "Dying individuals are often deemed "hopeless" by physicians" (Parker-Oliver, 2000, p.500).

[37] The notions of meaningfulness in living and transforming hopes as achievable goals and vice-versa are inspired by Corr (1991) as referred to in Parker-Oliver (2000, p.500).

[38] Hopes inspired by patients' words reported by Nguyen (2012).

TABLEAU 14

TITLE on the screen: The one who hopes/The one who's depressed >>> The one who jokes
Dropped flowers juxtaposed to dropped Mikado sticks. Sprinkle with colorful confetti.

Humor as a vital counterpart of the experience of dying.[39]
There are hopes.
There are goals disguised as hopes.[40]
The daily life of the dying.
A list of treatments, baths, movies, smoothies, small activities.
Depression. When list of hopes transforms into list of goals.
Shred all my list. Shred all my prayers.
Confetti.
A joke.
After my death mix it with my ashes to spread it in the wind. Just wind.
Absurdity.
If life is absurd, I want to laugh at it. A way to celebrate. To soothe me and others. To gather. To form bonds.
Colorful laughter like sparkling confetti in the grey ashes.

---

[39] McKinlay (2001) identifies humor as an important part of the dying experience as a counterpart to tears and sadness.
[40] Living day-by day or goal-by-goal is describe as a coping strategy to transition from the living to the dying (Lowrie et al., 2019b).

TABLEAU 15

Taking different roles.
If goals can disguise as hopes, I can also pretend.
I am and I am not at the same time.
Dying.
Living.
Joking.
Laughing.
A way to take "[transcend, assert] power beyond certain proscribed limits".[41]
From undergoing to freeing.
Flying.
A mass of ashes mixed to colorful confetti in the wind.

---

[41] (Landy, 1991b, p.39).

TABLEAU 16

The "I can". The "I can't". The "I need".

The relation between what I can control, what I can't, what I need from others and my own sense of freedom.

I can close and open my eyes. I can move many parts of my body. I can tell my story. I can feel skin sensations, smell odors, hear sounds.

Let us be an exquisite corpse.[42]

My eyes with your hands.

My story with your body.

The sensation that I feel and your voice.

It takes a village.

Tuck the kid in at night.

Tuck the dying in at night.

Tuck me in at night.

Let me tell you my story.

---

[42] "A game in which each participant takes turns writing or drawing on a sheet of paper, folding it to conceal his or her contribution, and then passing it to the next player for a further contribution. The game gained popularity in artistic circles during the 1920s when it was adopted as a technique by artists of the Surrealist movement to generate collaborative compositions." Museum of Modern Art definition. https://www.moma.org/collection/terms/138

TABLEAU 17

TITLE on the screen: The one who depends/The one who is a partner
Only the image of the neck stays. It fades out as the text goes.

Be vulnerable in the eyes of others.
A desire to run away.
The injured animal instinct.
Instead, letting myself depend.
Holding necks. Adopt a slower pace.
Letting myself loose tiny parts of my intimacy.
A different type of electricity is making a wall between us- the electricity of all my nerve endings firing up.[43]
Let me be hurt by your touch.
Let me be touched.
I will care and be there until the end.
Let me caress your forehead.
Let me fold your clothes.
Let me love you even if it hurts.
Let me be disappointed.
Let me be alive.
Let me be a friend.
Let me be a colleague.
Let me be a lover.
Let me be a child.
One more time a single child. Whom knows they will be profoundly alone even together. A single child who still can be a partner.
An endlessly leaving partner.

---

[43] "None were able to tolerate being touched because of the sensitivity of the nerve endings and various levels of pain such touching caused, which had a severe effect on intimacy with their husbands" (McKechnie et al., 2007, p.371).

TABLEAU 18

Leaving. Walking. Running. Rolling. Dancing. Moving.

From point A to point B.

Moving.

Holding necks.

Leaving and having to stay too close at the same time.

Having to depend.

Walking, running, rolling, dancing, moving less and less.

Depend.

Losing tiny parts of my intimacy. Of my liberty.

Depend.

A violation to my dignity.

Being a burden.

Stream of thoughts that is constantly in [my] mind. [44]

Losses that are "constantly on [my] mind and about which [I have] been thinking on a moment to moment, hourly basis, turning it over in an almost obsessive fashion".[45]

In a grieving fashion.

Invasive.

I slowly mark down the path from point A to point B.

From refusal to acceptance.

I grieve.

[44] (Byock, 1997 as cited in Parker-Oliver, 2000, p.507).
[45] *Idem*.

TABLEAU 19

And I grieve all the other losses at the same time.[46]

The eyes of my father.

The music and the pancakes of my grandfathers.

The friendships that have disappeared.

All the past, present and future losses smashed together.

Smashed on me.

The violence strokes me.[47]

Unable to move.

Even with a neck to hold on to.

Stuck.

In a time that has nothing to do with the past.

Nothing to do with the present, the future.

Nothing to do with time.

Stuck in the violence of losing.

With a pile of heavy rocks around me.

Slowly marking with those rocks the path from point A to point B.

The final journey.

Disengaging.[48] Breaking free. Transcend.

Shift perspectives.

Something that ties and unties at the same time.

---

[46] Facing death calls for talking and revisiting prior experiences with death and dying and significant losses amongst other relatives' ones according (Craig, 2004; Nguyen, 2012).

[47] "All of them experienced and expressed an intense sense of loss in all sorts" (McKechnie et al. 2007, p.372).

[48] To disengage is one of the privileges of the dying (Noyes & Clancy, 1977/2016).

Weightless.

Throwing things that disappear as I'm throwing them out.

Nothing breaks.

Just possibilities.

Breaking free.

TABLEAU 20

TITLE on the screen:
The one who stocks/The one who counts >>> The one who breaks free
The one who grieves>>>The one who moves
The one who's a partner/The one who depends >>> The one who belongs
Hands that pick up things that were dropped in other part of the film: Mikado sticks, the flowers, the branches, the bark, a rock. Hands that hold these things. Hands that drop carefully these things in a really organized way on the neutral background.

Build memories.[49]   Count days.
Blow birthday candles.   Put crosses on the calendar.
The blessing of having more time than expect.
The burden of living longer than the prognostic.[50]
Stocking up.   Counting down.
Half-full.   Half-empty.
I am.   And I am not.
Breaking free.
Losing and integrating.
Making a new me from these old gathered parts.[51]
From what's left of it: the one who moves, the one who depends, the one who is a partner.
Allow meaning to emerge.
Allow grieving and belonging to converge.

---

[49] Oscillating between a focus on the living and the dying can serve the dying by contributing to important dying tasks such as building memories (Lowrie et al., 2019b, p.607).
[50] *Ibid.*
[51] "With each loss and each adaptation to that loss, the meaning of what has been lost and its place in the person's identity can be integrated" Emanuel et al., 2007, p.163).

TABLEAU 21

Alone together.
From the beginning to the end.
What is new.
The vivacity of the feeling.
Aiming for inclusion and isolation at the same time.[52]
I am and I am not part of this world.[53]
Iteration. Loops. Exponential cycles. Existential cycles.
From time to time, choose isolation.[54] Like an animal. Hibernation.
Create the myth.
Transcend the story.
Adapt to what feels like a new role but was there from the beginning.
Transform the old ones.
Be the observer.
Outsider.
Something has to die in order to honor the cycle.
I will, somehow, blossom.

---

[52] Dying individuals experience a tension between the fear of social exclusion and the appreciation of "alone time" (Lowrie et al., 2019a, p.6).
[53] According to Samson (1999): "Illness prompts a feeling of disconnectedness, as the focus changes from being in and part of the world to a turning inward in an attempt to negotiate and reconnect to a new world that is unfamiliar" (As cited in McKechnie et al, 2007, p.368).
[54] Chosen isolation as a coping strategy (Mckinlay, 2001).

TABLEAU 22

TITLE on the screen: The one who's alone/The one who's gathers >>> The one who rebels
>>> The one who hates
>>>The one who cares
A branch in fire in the day. A branch in fire in the night. A lighted candle.

Living on my own.[55]

I rebel against circadian cycle. I live in the night and sleep in the day.

I rebel against the protective bubble for the dying.

I rebel against sadness and oversensitivity.

I rebel against photo collages and nights to remember.

I rebel against peace and ease. And calm.

Anger transforms into a beautiful and joyful rebellion.

Normalized hate. Which allows me to access deep love. [56]

Life is unfair and so death is.

I rebel against death.

Makes me scream from my guts.

Makes me move forward.

I rebel against circadian cycle. I live in the night and sleep in the day. Follow me in my dreams. I had planned a dinner.

Gather. Put together. I had planned a dinner in the middle of the night with all of us together.[57]

---

[55] Rebel the traditional script of a "good death" and engage in life can allow the person to enact important roles and complete important living tasks which serve the dying process without too much focus on the dying according (Lowrie et al., 2019b, p.607).

[56] "Even though people tend to seek balance and order much of the time, that order cannot be realized unless one is willing to listen to oppositional voices. To seek peace, one must negotiate with one's tendency to disturb the peace. To do that, one needs to give voice to one's anger and listen carefully to the message. In choosing peace, a place needs to be found for war" (Landy, 1993, p.14).

[57] Echoes the reality of relational appetence describe by Michel de M'uzan (1977) which refers to the intent of the dying person in her last moments to be in relationship with other beings.

I will cook a meal. I will cut the food. Let it bakes as if I have many more tomorrows. I will take my time and offer it to you as if I have too much.[58]
Letting living on my own transform into gathering together to caring for each other.

[58] A phantasmagoric scene that could mirror a desire hidden behind the limitation lived by a woman interviewed by Bourgeois-Guérin (2013, p.162): "Tu ne peux plus rien faire. Tu ne peux plus avoir de projets, tu ne peux plus même cuisiner. Moi qui adorais cuisiner, c'est fini. [Elle pleure.] [...] tout est trop fatigant. Je m'épuise à rien faire, alors tu te dis en toi-même, [souffrir], c'est de dépendre des autres, de plus être capable de faire rien par soi-même".

TABLEAU 23

TITLE on the screen: The one who depends/The one who cares
The one who's egoist/The one who cares
The one who's egoist/The one who's fair
The one who's partner/The one who abandons >>>The one who breaks free

Juxtaposition of many images in different transparency in a mosaic: the neck, the Mikado stick, the held flowers, the grey bark, my eyes, the white confetti, the ashes, the hair in the wind, the fire of a candle.

The same hands will hold your neck and cook you a meal.
The same hands will caress your neck and will close up.
The same closed hands will open up to give you back.
Alleviate your suffering.
Giving meaning to my own life.
You take care of me I take care of you.[59]
In my way. Taking care.[60]
Be a partner.
Don't give up on you.
Be a partner.
Dropping you off. Carefully.
Breaking free.

---

[59] Being taken care of as another privilege of the dying as listed by Noyes and Clancy (1977/2016).
[60] Disease can make the performance of the social roles difficult. Women tend to keep their social roles of mother, grandmother, sister, daughter, etc. but fulfill these differently (McKechnie et al., 2007).

TABLEAU 24

TITLE on the screen: The one who breaks free>>>The one who stocks/The one who counts>>>The one who enjoys
>>>The one who's happy
>>>The one who loves
>>>The one who transforms

A circle in the same moving image(the fire of a candle) we saw at the beginning. Around the black background slowly fade in erasing other layers of images.
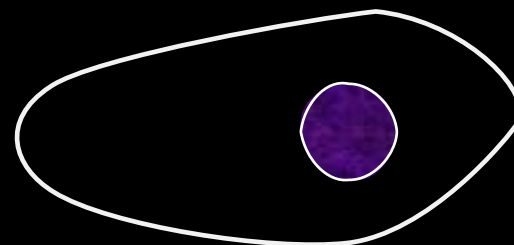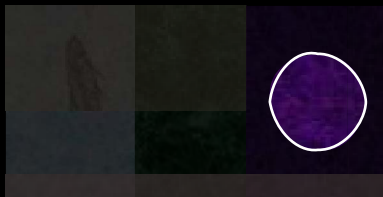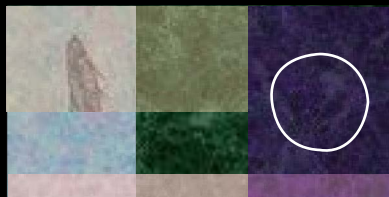
Add years.   Burn hours.
Bake cakes.   Take sips.
Throw plates.
Drop glass, pot, container.
Let things break down.
Let things disappear.
Let the disappearance duplicate the pleasure.
Enjoy it.
Let my hands settle in this new land.
Let them happily plant some seeds.

Let them gather the fruits of the love I nourished.[61]
Let this love transform me.
Let me the observer of my own transformation.
Let growth continue.[62]

---

[61] "It is hard to explain happiness to someone unless they face death. That is when one realizes what makes them happy. […] So few people realize how lucky they are in life. There are so many things to be thankful for, but one realizes it until it is too late" (Parker-Oliver, 2000, p.506).
[62] "Even when people are close to death, personal growth may continue" (Emanuel et al., 2007, p.164).

TABLEAU 25

TITLE on the screen: The one who transforms >>>The one who dies/The one who lives
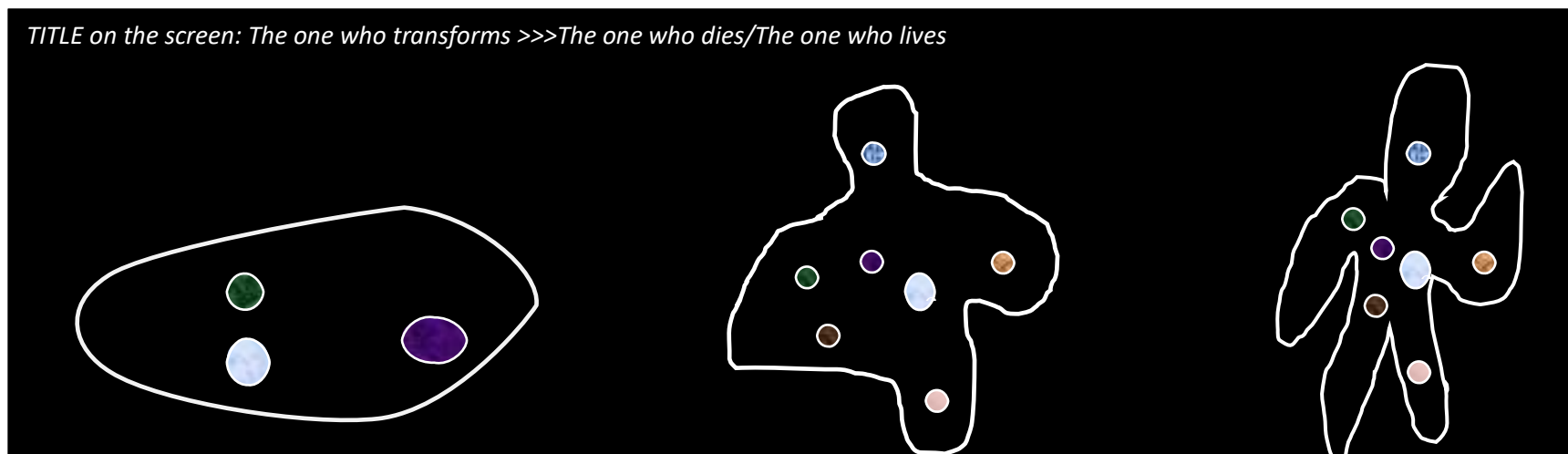
From dying to living. From living to dying and again.

Whole. [63]

Every role of mine engaged in the action. Integrated in the play. Balanced in the fragile equilibrium of this drama that is mine.

Living while dying. Like it always has been.[64]

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[63] "Be whole" as one of the six elements of a "good death" identified by terminally ill patient in Nguyen (2012).

[64] "If we are able to adhere to the paradoxical nature of our role system, we can gain a sense of integration, allowing all roles to be at our disposal. With choice comes balance and with balance comes stability" (Frydman, 2016, p.43).

EPILOGUE
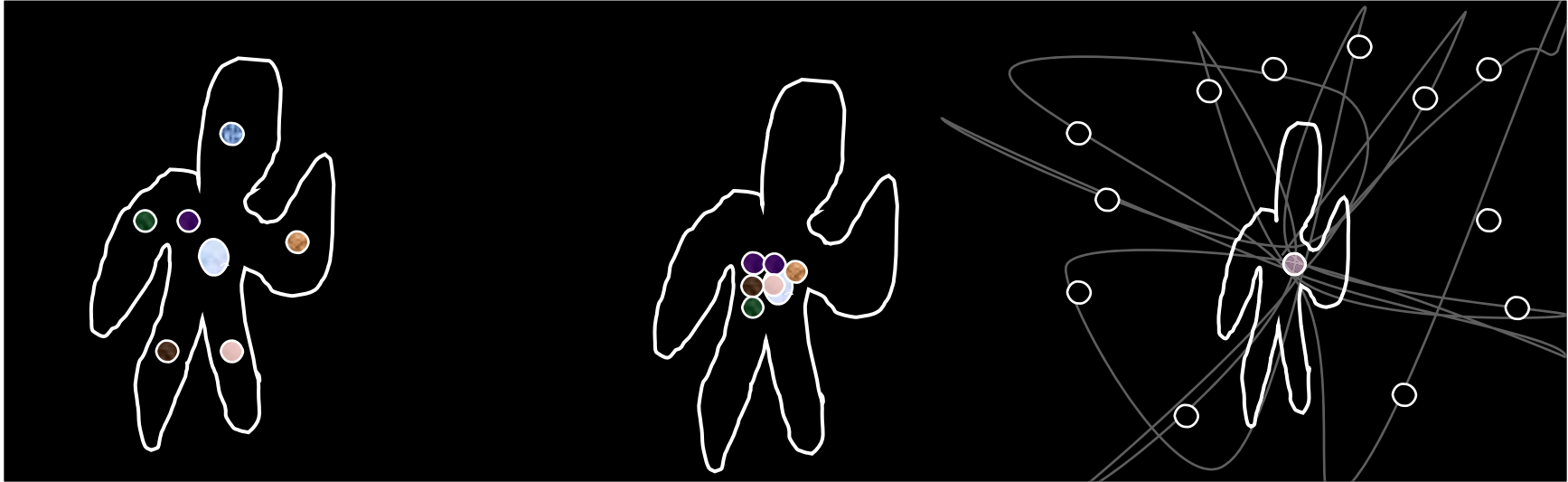
We all chose our guide according to our destination.[65]

The destination is like our home.

The circle of all circles.

The cell of all cells.

There is no guideline.

"Everybody dies differently and individually".[66]

For me this destination.

This home.

It is my own body.

I am the one who is a body.[67]

As I will slowly fade, I aim to softly implode.

[65] Robert Landy interviewed by Minnerson (2017).

[66] (McKechnie et al., 2007, p.373).

[67] Inspired by the phenomenology of perception (Merleau-Ponty, 1945)

Bringing all my roles, these circles into a microscopic dot from which multiple lines[68] will reach out for linking me to things that were meaningful to me.

I will therefore contribute with my absence to the thread that prevents people and the world to explode.[69]

I am the one who is contained and the one who contains.

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[68] (Landy, 1991b, p.35).

[69] "Ricoeur's dying words, in short, were about living up to death as a living against death in the sense of removing death's victory so that life continues in others, through others, for others" (Kearney, 2011, p.225)