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Acknowledging bereavement, strengthening communities: Introducing an online compassionate community initiative for the recognition of pandemic grief

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Abstract

Despite public health measures and collective efforts, millions of individuals have unfortunately died from COVID-19 complications worldwide, leaving several million family members at risk of developing bereavement complications. In the Canadian province of Quebec, where substantial deaths were associated with COVID-19, we established an online support community for bereaved caregivers who lost a loved one during the pandemic. We explain how we created a community that recognized pandemic grief and advocated for its wider acknowledgment. We discuss "compassionate communities," the theoretical underpinning of our initiative, as a means to foster solidarity, normalize finitude, create and maintain a safe social space through group sharing, and challenging capitalist principles. We then describe the eight areas of activities inspired by the Charter of Pallium Canada: education and training, hospices and nursing homes, media and social media, commemoration, celebrations, artistic practices and storytelling, marginalized populations, and review and evaluate. We propose that online communities constitute a powerful space for community members to gather and advocate for greater awareness of the inequities found in end-of-life care and bereavement services, to denounce abusive situations experienced by many individuals who died from COVID-19 complications, and to fight against the lack of recognition experienced by numerous caregivers.

KEYWORDS
bereavement, compassionate communities, COVID-19, pandemic grief, research-creation

Highlights
- Pandemic grief is neither normal nor "complicated."
- End-of-life is an experience that is part of every life and which could be lived as "healthy."
- The CC model represents an accessible and equitable model of health promotion and support.
- There is value in further expanding this empowering initiative within and beyond palliative care.

INTRODUCTION

Since the beginning of 2020, most nations and countries around the world are facing the spread of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and its recent variants, causing the contagious coronavirus disease (COVID-19). To prevent virus transmission, several measures have been recommended by the World Health Organization (WHO) such as physical distancing, use of fabric masks and frequent hand hygiene. Despite these preventive measures, 4,762,089 individuals have unfortunately died worldwide due to COVID-19 complications as of September 30th, 2021 (WHO, 2021). A number of these deaths occurred in particularly tragic circumstances (e.g., in isolation, following a very fast decline and lacking basic care required such as proper hydration;

Castonguay, 2021), which consequently left several million individuals at risk of developing bereavement complications (LeRoy et al., 2020; Vachon et al., 2020). In the context of both substantial deaths associated to COVID-19, as well as a scarcity of bereavement support services in the Canadian province of Quebec, we established an online support community for caregivers who lost a family member during the pandemic inspired by the theoretical framework of "compassionate communities" (Kellehear, 2005). In this article, we will describe our initiative and explain how we created a community that recognized pandemic grief and advocated for its wider acknowledgment so that it could potentially inspire similar initiatives. We will first address the problematic and specific context of the Canadian province of Quebec that necessitated the development of this project. Second, we will draw a general portrait of our online support community as well as its main partners, and reflect on our theoretical foundations: the compassionate communities' framework. We will conclude by expressing how this kind of community allows bereaved individuals who share pandemic grief to come together to denounce abuse situations and to break the lack of recognition surrounding the particular challenges associated with this bereavement experience. The scope of this article encompasses how we first conceived and implemented our project: it does not report on the research findings which are being published in further papers.

PROBLEMATIC: PANDEMIC GRIEF IN THE CANADIAN PROVINCE OF QUEBEC

In Canada, 27,819 individuals unfortunately died due to COVID-19 complications, and almost half of the deaths (11,369 as of September 30th, 2021) happened in the province of Quebec, the second-largest province in terms of area as well as population located in Central Canada (Government of Canada, 2021; Institut national de santé publique du Québec, 2021). In this province, we estimate that more than 100,000 individuals have faced the loss of a relative, since every death from COVID-19 leaves approximately nine bereaved (Verdery et al., 2020).

In Quebec, public health measures implemented in addition to those recommended by the WHO (e.g., the complete prohibition of outside caregivers visiting residential aged care facilities from March to May 2020) must be considered within the broader context of a long-standing underfunded health care and social services system, especially regarding officially-designated elderly care facilities (known in Quebec by the acronym "CHSLD," which translates to residential aged care facility). The lack of personnel in these facilities has been overlooked for decades and already represented a chronic social problem when the COVID-19 pandemic began. Residents of these facilities, as opposed to other health care environments, faced long-standing inequities regarding access to quality care. These facilities continued to function only because of family caregivers who provided critical care to their sick relatives, with almost no psychosocial services (e.g., psychological counseling) available to neither residents, caregivers nor relatives. Thus, in March 2020 when these facilities suspended visitation, thousands of elderly individuals stopped receiving complete decent care (Castonguay, 2021). Further, end-of-life care is unfortunately often reserved for patients on a cancer trajectory (Vachon, 2019), even if there are many other reasons to receive this type of care. Considering this context of understaffing and mismanagement, during the first waves of the pandemic, many healthcare professionals were forced to work in poorly equipped facilities, even if they were sick with the coronavirus. Under these conditions, the virus spread rapidly and infected many residents, especially the most vulnerable. Healthcare professionals were overwhelmed and could not care for every resident, nor contact families with updates about their relatives' health. A first consequence of this situation was that many individuals died in outrageous conditions of negligence due to a lack of basic care such as hydration (Castonguay, 2021). A second consequence is that many caregivers did not receive news from their relatives nor the staff, including information on their relative's condition and when they had died. Many caregivers and family members learnt about the deteriorating situation in the facilities through various media outlets: they heard that the situation was out of control, that outbreaks were occurring more frequently, and that deaths were accumulating. In addition to the general lockdown situation that impacted everyone's mental health (Ho et al., 2020), the catastrophic situation surrounding residential aged care facilities resulted in a high level of stress among family members. To sum up, thousands of caregivers and family members have had to endure their grief during the three lockdown periods (spring 2020, winter 2021, and spring 2021), following a stressful and isolating period during which outside contact was not possible.

The context of the pandemic has indeed led to particular adversity conditions (LeRoy et al., 2020; Vachon et al., 2020) that have resulted in an increase of requests from bereaved individuals for professional and/or community support services. However, it is largely recognized that bereavement services in Canada were not sufficient to meet community needs even before the pandemic. In addition, several community organizations offering bereavement group support have stopped their in-person activities since the beginning of the pandemic. Individual, professional, private services could be offered through teletherapy, but there are associated obstacles, both in terms of accessibility and equity given the high cost of such services and the waiting time before actually accessing such services (Rémillard, 2020; Vachon, 2021a). Consequently, bereaved individuals are increasingly using the internet and social media to cope with the loss of a family member (Wakam et al., 2020).

PRESENTATION OF "J'ACCOMPAGNE," AN ONLINE SUPPORT COMMUNITY INITIATIVE

As two researchers with a psychology background and former clinical experience in palliative care, we shared the same concern when in March 2020, severe measures were put into place that barred visits to residential aged care facilities: bereaved individuals would need additional support and we knew that this would be extremely difficult to obtain. This was our main motivation when we launched the online support community "J'accompagne" [I'm with you] anchored in the compassionate communities' framework (Kellehear, 2005, 2013, 2016). A compassionate community is "one that recognizes all-natural cycles of sickness and health, birth and death, and love and loss occur every day within the orbits and of its institutions and regular activities" (Tompkins, 2008, p. S118). Further, the compassionate communities charter was developed by applying the Ottawa Charter for Health Promotion to palliative care and is available online (https://www.phpci.org/tools). Aligned with these theoretical frameworks, the mission of "J'accompagne" comprises the following: to develop a better understanding of the experience of pandemic grief; to break the isolation of bereaved individuals by creating an online support community; to offer guidance for individuals in search of support; to raise awareness and educate the wider community regarding end-of-life caregiving issues and the recognition of pandemic grief. From the beginning, we established a reciprocal collaboration with the four following partners: (1) The Canadian Virtual Hospice, which provides support and personalized information on the internet about advanced illness, palliative care, loss and grief to people living with illness, family members, people working in healthcare, educators, and researchers; (2) the "Au Diapason" Hospice that offers bereavement support services; (3) the RANQ, a national representation of 21,000 caregivers throughout Quebec; and (4) Pallium Canada, a national non-profit organization focused on building professional and community capacity to help improve the quality and accessibility of palliative care in Canada as a best practice framework.

Methodological aspects

Anchored within a constructivist-interpretive paradigm (Morrow, 2005), the overall research design was informed by a participatory research approach, which emphasizes research as a collaborative, practical, emancipatory, critical, and reflective social process between researchers and participants (Wang, 2016). The research component of our online support community aims at developing a better understanding of the experience of pandemic grief. About one year after its creation and at the time of this article's writing, our community (see details in Table 1) comprises 35 individuals (31 women), aged from 21 to 78 years old

TABLE 1 Sociodemographic characteristics of the participant ($N = 35$)

Characteristics	N (%)	M (SD)
Sex/gender		
Women	31 (88.6)	
Men	4 (11.4)	
Age (years; range: 21–78)[a]		56.39 (17.2)
Time after the loss (days; range 12–315)[a]		116.37 (84.9)
Relationship with the deceased[b]		
Parent	27 (71)	
Spouse	5 (13)	
Grand-parent	5 (13)	
Sibling	1 (3)	
Civil status[a]		
Single	8 (22.9)	
Married/cohabiting	20 (57.1)	
Separated/divorced/widowed	7 (20)	
Country of origin		
Canada	30 (86)	
Other	5 (14)	
Place of residence		
Montreal	18 (51)	
Laval	1 (3)	
Laurentides	3 (9)	
Capitale-Nationale	3 (9)	
Outaouais	1 (3)	
Mauricie	1 (3)	
Estrie	3 (9)	
Gaspésie-Îles-de-la-Madeleine	1 (3)	
Other	4 (11)	
Religious affiliation		
Christian (Catholic or Protestant)	16 (46)	
Judaism	1 (3)	
Not specified	18 (51)	
Socioeconomic background		
Retired	9 (25)	
Full-time position	8 (23)	
Part-time position	5 (14)	
On sick leave	5 (14)	
Unemployed	1 (3)	
Student	3 (9)	

(Continues)

TABLE 1 (Continued)

Characteristics	N (%)	M (SD)
Homemaker	1 (3)	
Not specified	3 (9)	
Death location		
Hospital	23 (65.7)	
Residence for elderly	9 (25.7)	
Domicile	3 (8.6)	
Cause of death		
COVID-19	25 (71.4)	
Other cause	10 (28.6)	
Commemoration[a]		
Nothing	10 (28.6)	
Virtual	19 (54.3)	
In person	6 (17.1)	
Possible visit at bedside		
No	16 (45.7)	
Yes	19 (54.3)	
Interview length (minutes; range: 11–94)		62.08 (15.18)
Number of interview(s)		
1	19 (54.3)	
2	10 (28.6)	
3	3 (8.5)	
4	1 (2.9)	
5	2 (5.7)	

[a]Information at the time of the first interview.
[b]Some participants unfortunately lost more than one family member during the pandemic.

($M = 56$) who have lost a family member (27 people lost their parent, five lost their spouse, five a grandparent and one a sibling) due to COVID-19 complications or during the COVID-19 pandemic. Some caregivers unfortunately lost more than one family member during this period. Most participants spontaneously joined the community by word of mouth between 12 and 315 days after the loss (mean of four months); no formal recruitment effort was needed. Our participants shared their stories and experiences through in-depth interviews (mean of 62 min) mainly conducted through video conference by clinical psychologists with expertise in both palliative care and qualitative interviewing. Almost half of our participants expressed the wish to participate in more than one interview, as they had a lot to share with us (between two and five interviews per each of our 16 participants). Many participants spontaneously shared that they felt a sense of belonging to a community by participating in the project. Through our email exchanges and on social media, we expressed heartfelt words, received updates about our participants' respective psychological states and the progress of their relatives' funerals, offered referrals to psychological services, and most importantly gave them the opportunity to be part of a group that facilitated exchanges with other bereaved participants. Concerning ethics, we conducted the research according to the institutional review board approval obtained from the two institutions where the authors are affiliated. We analyzed, transcribed and verified (checked for accuracy by an independent transcriber; Kvale, 2007) all the interview data as well as written exchanges following the main principles of interpretative phenomenological analysis (Smith et al., 2009), as this approach allows for an interpretative standpoint that particularly fits our initiative. So far, empirical findings have been presented in three articles: we reviewed the literature on bereavement and described in greater detail the genesis of our online support community (Vachon et al., 2020), we described the trajectory of pandemic grief through four main stages: (1) caregiving journey, (2) narrowing of the temporal window of dying, (3) death occurring often suddenly and unexpectedly, and (4) pandemic grief, and discussed similarities and differences between pandemic grief and disenfranchised grief (Doka, 2002; Ummel & Vachon, under review). Finally, we analyzed the metaphors family caregivers used to report their experiences and described three metaphorical dimensions: (1) the search for social connections, arising from multiple "cut-offs" experienced with others, (2) the search for narrative coherence, arising from the caregivers' "disrupted" ability to visit their relatives and a "blocked" grief, and (3) the search for recognition, arising from a need to express, share and make sense of the "shockwaves" felt throughout the pandemic (Guité-Verret et al., 2021). Based on those empirical findings, we developed the following qualitative definition of "pandemic grief": neither normal nor "complicated," pandemic grief is a hushed mourning process suspended in time, punctuated by public health measures, with little social recognition for the suffering it causes (Vachon, Ummel, Lessard, et al., 2021). We use this definition of pandemic grief throughout this article, and thereby do not treat it as a syndrome of dysfunctional grief (Sherman & Neimeyer, 2020).

THEORETICAL AND CONCEPTUAL BASIS

Death and bereavement have only recently become medicalized and professionalized in Western societies. However, these events are part of the natural life cycle, and individuals still have the capacity to love, surround themselves with loved ones, live and sometimes even work with an incurable and serious disease (Vachon, 2019). The compassionate community (CC) philosophy suggests the advent of community palliative care, where dying, loss, grief, bereavement and care become everyone's

responsibility, and not only those individuals directly involved or health care professionals. We embraced these principles within our online support community to compassionately support bereaved people using reparative writing, storytelling, and testimonials sharing which resulted in strengthening their creativity, resiliency, and empowerment at an extremely difficult time to experience grief. In the following section, we describe CC's underlying key principles and use examples from both our initiative and Quebec's particular context as illustrations.

Compassionate communities: Fostering solidarity

Normalizing finitude

The rise of the caring professions (e.g., medicine, nursing, psychology, and social work) in the last century has made consequent changes in community care praxis. It is now assumed that professionals mediate and express the care response for and of the community, and consequently, community care, including solidarity, becomes privatized and domesticated. Community care has become informal, privately motivated, a support role for the "more appropriate" professional response to social and physical troubles of individuals and communities (Kellehear, 2005). For Kellehear, a sociologist and professor of palliative care, formal organizations of care under the guidance of diverse health care professionals channel the common informal desire to be involved in care for others and connected to each other. Volunteers, support groups, and service club activities are all examples of how this informal impetus to help each other in solidarity is integrated into fund raising or other support duties bound to care services (Kellehear, 2005). Indeed, care for the dying throughout the past has been normal and routine matter for families and communities. Today, direct, personal experiences of death are rare, although direct personal encounters of loss are arguable not so rare. Nevertheless, where experience cannot guide or give confidence to communities, education can. There is an important role for public education in the normalization and routinization of the modern experiences of death.

Solidarity versus scarcity

Solidarity is often opposed to scarcity (e.g., Turner & Rojek, 2001), a concept that could be considered within different perspectives. First, scarcity could be generated by a limited amount of resources in the world, which engenders competition to access those resources (Kellehear, 2005). This is precisely the case with palliative care in Quebec over the past twenty years, where accessing palliative and end-of-life care has been and continues to be fraught with difficulty (Commission sur les soins de fin de vie, 2019), and bereavement support services remain extremely insufficient to meet basic needs. Within our online support community, the concept and practice of solidarity

allowed for reciprocal support and echoed individual grief experiences, thus linking solidarity to compassion, the foundation of CC. On a scholarly level, we emphasize compassion as a universal core value to better understand similarities and nuances in the grieving experiences and to propose a qualitative definition of pandemic grief. Second, in current postmodern societies, we are experiencing a scarcity of (religious) meaning due to secularization, which leads to a crisis of meaninglessness (Turner & Rojek, 2001). This crisis can be seen in the following factors and symptoms of death denial in Western societies: the medicalization of death, the reluctance to speak of death in public, the perception of death and dying as failure, and the segregation of the sick or elderly in hospices, etc. (Callahan, 2017; Lafontaine, 2008; Tradii & Robert, 2019). In this context, one can more easily understand the tensions that persist between the solidarity expressed in relatively abundant community care practices and the scarcity of individualized end-of-life care and bereavement services. As recently asserted by Breen et al. (2020, p. 2), "the community is often 'in the dark' about the illness, the death, and then the grief of those left behind," which is why some researchers refer to our societies as grief-denying ones (Macdonald, 2020). Considering this, normalizing human finitude seems to be an important step toward alleviating scarcity, because it may increase solidarity among people who, together and compassionately, acknowledge grief and death.

A safe social space through sharing

On a more individualist perspective, Turner and Rojek (2001) argue that scarcity exists because human desire is infinite, elastic, and rapacious, as well as relative and historical depending on the cultural production of the desire to consume. On the other hand, some sociologists (e.g., Durkheim) consider solidarity as created by the sharing of common rituals (e.g., sacrifice, Turner & Rojek, 2001). Concretely, within our online support community initiative, we witnessed the creation of solidarity and compassion through expressive and creative activities pertaining to the grief experience. This analysis meets Turner and Rojek (2001)'s consideration of citizenship as a form of civil religion which does for modern societies what organized religion did for premodern societies: create a web of solidarity based upon common beliefs and practices. Indeed, we truly believe that common or shared values are crucial to the creation of social solidarity and agree with Turner and Rojek (2001) when they state that individuals must be motivated to co-operate in a social environment that they regard as safe and legitimate, and, we add, compassionate.

While competition constitutes one way that individuals and communities cope with scarcity, other social activities could rather be privileged and implemented. For instance, within our online support community, we encouraged co-operation, reciprocity, and other forms of social sharing, and witnessed how our members expressed empathy, compassion, and solidarity toward one another. Indeed, during the pandemic, many bereaved individuals lacked

such a social safe space to share their grieving experience, partially due to the number of deaths that occurred at the same moment, and the violent comments they would often receive in that context (e.g., "your mother was old and would have died soon anyway," Vachon, 2021b).

Challenging capitalist principles

On a more macro and economic level, we cannot ignore the fact that in most Western societies, market economies rule our lives, and consequently there is a need for addressing the political and social changes linked to inequalities created by this capitalist system (Kellehear, 2005). These inequalities and their associated health consequences have been a long-standing concern of many public health initiatives, and yet they persist. Uneven distribution of risks and hazards exist for the poor and the marginalized both locally and globally, and access to help is also compromised by economic market forces. The CC approach, which emerged in the early 2000s, is rooted in these theoretical underpinnings and based on the principle that health is not limited to the absence of illness or disease and that quality of life does not equal the absence of problems. Further, end-of-life should not only be considered as an experience one would absolutely avoid, but rather as an experience that is part of every life and which could be lived as "healthy" (Kellehear, 2005; Vachon, 2019). This revised approach to palliative care implies that rather than focusing on patients whose death is imminent, early, compassionate, and effective palliative care that focuses on physical, cultural, psychological, social, and spiritual needs should be accessible for patients and families (caregivers) regardless of age or disease trajectory, to better support their quality of life (Tompkins, 2008). We completely endorse this initiative and wish to contribute to its further development. Indeed, in most Western and industrialized societies, it can be challenging to promote dialogue around death and grief, and to confront inexorable human finitude (Zimmerman, 2007). Thereby, to foster solidarity, compassion, and community care and to counter scarcity and inequities in end-of-life care and bereavement services, we used the CC Charter of Pallium Canada (Tompkins, 2008), which constitutes a best practice framework designed to be expandable and flexible for creating a CC in any setting, to facilitate the creation of our online support community "J'accompagne." In addition, we were inspired by Aoun et al. (2018) who published results suggesting that informal social support is considered helpful by bereaved individuals when there is an emotional bond (attachment), practical assistance (tangible alliance), and a perceived sense of belonging (social integration). Illustrated in Figure 1, our community is based on eight of the 13 original areas of social changes that are described in the following section.

Eight areas of activities co-constructed within our online support community

We co-constructed the activities of our online support community based on the following eight aspects: (1) education & training, (2) hospices & nursing homes, (3) media & social media, (4) commemoration, (5) celebrations, (6) artistic practices & storytelling, (7) marginalized
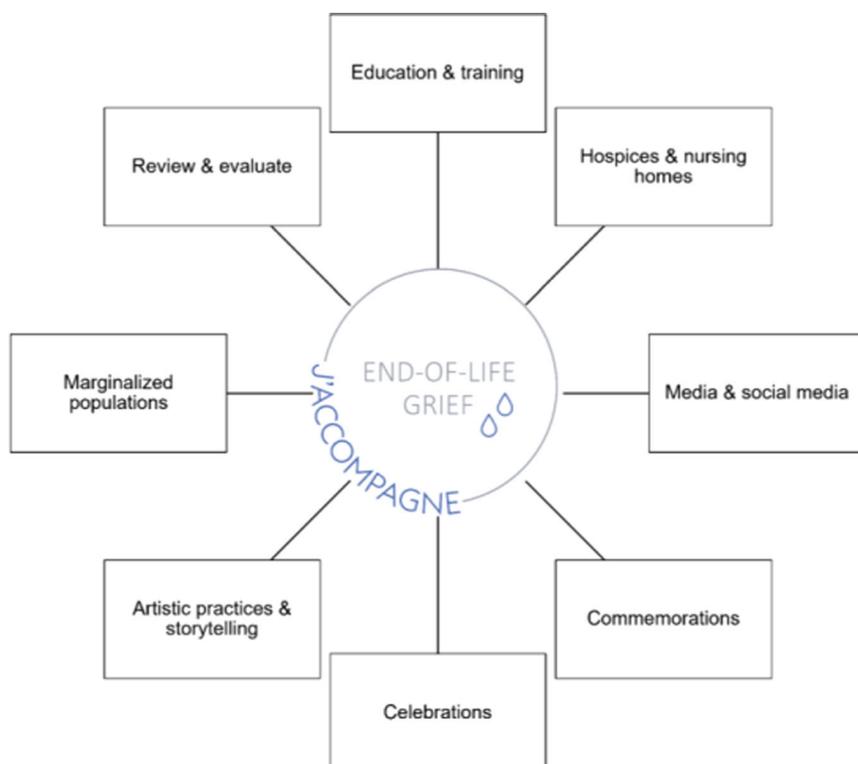

FIGURE 1 Areas of social change implemented within the "J'accompagne" online support community. Adapted from "Compassionate communities in Canada: It is everyone's responsibility" by Tompkins, 2018, *Annals of Palliative Medicine*, *7*, p. S121 [Color figure can be viewed at wileyonlinelibrary.com]

populations and (8) review & evaluate as illustrated in Figure 1. Five components of Tompkins' (2018) model (workplaces, trade unions, faith communities, museums & art galleries, and understand diversity) were not include as they were considered less or not relevant within our initiative. We also adapted some of these (e.g., annual memorial parade was modified in commemoration) to better fit the community and its members' needs. Lastly, the CC Charter comprises both the areas where social changes can occur and vehicles for those social changes (e.g., media and social media). Below, we describe the current state of the different activities accomplished at the time of this article's writing.

Death education and training

Death education, encompassing everything people learn about death (e.g., meanings and attitudes toward death, processes of dying and bereavement and care for people affected by death), has been practiced informally throughout the history of humanity (Fonseca & Testoni, 2012). Despite the inexorable truth that everyone will die and that everyone needs to deal with bereavement, there remains an important gap between the theory and practice of death education, partly due to social attitudes toward death, but not exclusively. In many countries, public health authorities have not established end-of-life policies, and if this has been the case, there are issues in practical implementation, resulting in the fact that death is rarely discussed, even in palliative care facilities (Fonseca & Testoni, 2012). In our online support community, we place a strong emphasis on death education, especially with objectives of raising awareness and educating the wider community regarding caregiving issues in end-of-life and pandemic grief. We published four articles of knowledge transfer (Ummel & Vachon, 2020; Vachon & Ummel, 2021; Vachon, 2020; Vachon, Ummel, Lessard, et al., 2021) and performed eleven webinars with several community organizations addressed to diverse audiences (e.g., health care practitioners, bereaved family members, caregivers, etc.). With these various activities, we aim to amplify the testimonials shared by our community participants and advocate for their needs and particular experiences during this pandemic time, with the hope of supporting the development and financing of further initiatives inside social and health care services and within communities.

Hospices and nursing homes

Hospices and nursing homes constitute key stakeholders in the effort to implement positive social change. To ensure the fastest and best possible transmission of our empirical findings regarding pandemic grief to as many bereaved individuals as possible, we are working in close collaboration with our four partners: (1) The Canadian Virtual Hospice has been able to document pandemic grief based on some of our empirical findings; (2) the "Au Diapason" Hospice has received our support and learned from the experiences of our online support community to adapt its bereavement support services to a virtual setting; (3) the national representation of caregivers throughout Quebec, RANQ, has used some of our empirical findings to inform its member organizations about pandemic grief; and (4) Pallium Canada has been able to spread information and document, on an international level, the development of and the results obtained from our online support community. All of these collaborations are mutually beneficial, as while we have been able to better understand pandemic grief and quickly offer training to first-line health care providers, with modalities that best matched their needs (e.g., we facilitated eleven webinars for various partners since the beginning of the project), the feedback we received from these organizations allowed us to continuously adapt the project, remaining in line with its participatory action research perspective.

Media and social media

We used traditional media and social media as transversal vehicles to strengthen social changes that were occurring in other areas, especially education and training, and artistic practices and storytelling. In the first year of our online support community, we participated in 27 interviews with Canadian media outlets (written press, radio, and television, complete details are available here: https://www.jaccompagne. ca/prsence-dans-les-mdias). One especially notable example is the participation of the second author (MV) as an expert in the program entitled "une (autre) vie" (one [other] life), which was broadcasted on public television in primetime to the Canadian francophone population across Canada and which showed the changes in our lives due to the COVID-19 pandemic, in addition to featuring some touching stories. Among these touching stories were end-of-life and bereavement experiences from members of our community who had agreed to provide public testimony of their experiences.

Regarding social media, we used different features (e.g., private and public group pages) of *Facebook* to encourage the development of storytelling and artistic practices regarding the pandemic grief experience. We also frequently posted meaningful and touching quotations, and information regarding the community's activities as well as available resources, the last of which was particularly hard to access in the pandemic. As an example of our outreach, for Father's Day in 2020, we shared the following quotation, by the French writer Bernard Werber: "In another life, Dad, I would like to take you as a father again," which touched almost 1200 *Facebook* users. At the time of this article's writing, our page has more than 600 subscribers.

Commemoration

Together with members of our online support community, and through our numerous public comments and

interviews in the media described above, we publicly advocated for the acknowledgment of pandemic grief. This resulted, for instance, in the government of Quebec declaring a national day of remembrance for victims of COVID-19 on March 11th, 2021, one year after the WHO's declared COVID-19 a pandemic, pointing to the 118,000 cases of the coronavirus illness in over 100 countries and territories around the world and the sustained risk of further global spread (Ducharme, 2020). While some of our members considered this commemoration meaningful and important, others found it rather challenging. Indeed, when this event happened, Quebec was still in lockdown, and some bereaved participants had still not been able to organize a funeral ceremony for their deceased relative, given the restrictions of the public health measures. This extract from a letter that Odile, a member of our community who consented to be identified, wrote to her deceased mother, for her one-year death anniversary, illustrated this struggle:

> I can count on my fingers how many hugs I received since you died, except from my sons, luckily. We still cannot hug without feeling that we are risking our health and acting in a certain illegal manner. This is a weird time. Since your departure, we still cannot kiss our friends when we cross them on the street. For this reason, I still haven't organized your funeral, Mom. I haven't yet resigned myself to having just 10 or 25 people in a room, at a 2 meters distance, with masks, and the interdiction of touching each other. I don't want such an absurd ceremony that does not resemble us. I don't want to cry without a true and authentic reassurance.

Commemorations and funeral rituals have been regulated by strict public health measures in Quebec. To begin with, they were simply banished, then postponed and they are now allowed if they respect the frequently changing and complex public health measures. In that sense, when they could occur, those funeral ceremonies have been grandly modified, which resulted in at least two major consequences on the psychosocial level for individuals experiencing pandemic grief. First, like Odile described above, to be prevented from the possibility to honor, commemorate, and make sense of the loss of a family member, and second, to be deprived of the social recognition of the loss and the social support associated with meaningful collective funeral rituals (Bacqué, 2013). To preserve its restorative component, a funeral ritual must be meaningful (religious or not) and aligned with personal values and beliefs. Together with our community members, we will continue to advocate for the possibility to organize meaningful commemorations for bereaved families and co-coordinate some commemorations on a community level. For example, to commemorate the two-year anniversary of the start of the pandemic, on March 11th, 2022, we are collectively organizing an exhibition featuring artworks from our community members (see below), paintings created by a professional artist inspired by our participants' experiences and a short film we made to honor the pandemic grief experiences of our members. The film and the exhibition will then tour across Quebec. In line with the death education area described above, we believe that artworks constitute an effective and innovative way to raise awareness of pandemic grief in particular, but more generally of death, dying and bereavement.

Celebrations

Within a grief trajectory, which is often captured with the image of a roller coaster, moments of sadness and sorrow alternate with less difficult times (Worden, 2018). The absence of a family member at meaningful moments during the first year after the loss (e.g., Christmas or other New Year celebrations, according to religious beliefs) are often particularly challenging. For this reason, we celebrated and acknowledged the deceased's departure with a six month and one-year death anniversary, as well as other meaningful times (e.g., the first Mother's Day without his or her mother) by exchanging personal communications with our community members as well as publicly on our social media page. The underlying intention was to consolidate the connection between the online support community and its members, as according to the original CC Charter (Tompkins, 2018), recognition and celebrations are central. The vast majority of our community members responded very positively. A few participants told us that in this particular pandemic time, they received only a few wishes of condolence from their social circle, and that made our celebration even more nourishing and meaningful.

Artistic practices and storytelling

With the physical distancing measures and lockdowns, many bereaved caregivers are using the internet and social media to share their experiences, break their isolation, and virtually celebrate the life of their family member (Wakam et al., 2020). Some research on these practices conclude that online grief communities may provide a space for bereaved individuals to share their personal story of deep loss and their memories, to validate their grieving experiences, to negotiate their stories of loss, and to find hope (Harting & Viola, 2016; Robinson & Pond, 2019; Smartwood et al., 2011; Varga & Paulus, 2014). Additionally, as Giaxoglou (2015) suggests, sharing one's story on social media can be considered an act which allows bereaved individuals to begin to make sense of their loss. Thus, within our online support community, we encouraged bereaved individuals to experiment expressive and reparative writing, storytelling and testimonial sharing. This suggestion was based on the hope that these creative processes could support the elaboration of the experienced loss, and even its symbolization and

integration. It turned out that this was actually the case for many members of our online support community. Because many bereaved individuals experienced anonymity around the end of their caregiving journey, due to the strict measures prohibiting visits to residential aged care facilities, and that, unfortunately, many deceased men and women were alone at their time of death, several members of our community struggled deeply to integrate a loss that they have not been able to actually witness (e.g., seeing the body or attending a funeral ceremony). To facilitate the integration of a loss remaining unreal or abstract, a greater acknowledgment from the surrounding community, including an online community, has shown a relieving effect on the grieving experience.

Marginalized populations

Given the isolation, weakened mental health, and important pressure within the health and social services due to the pandemic context, we consider that our online support community represents a service that is fair and accessible for some individuals who would otherwise not have had access to such support. In addition to the direct support, completely free of charge, that we provided with our online support community, we offered further guidance by providing a 126-page resources directory on our webpage, organized according to services offered (e.g., therapeutic consulting, funeral cooperatives, telephone helpline) and geographical region. We have also offered personalized guidance to 31 individuals (bereaved individuals as well as health care practitioners) who contacted us directly.

Further, we chose purposefully to use the social media platform *Facebook* to host our initiative, as this is the most commonly used platform in Quebec. Despite our reservations concerning the use of such a commercialized and privately-owned tool, the potential to reach the most diverse and marginalized populations convinced us to use it, in addition to our own website developed for the community. Indeed, while we recognize political influences associated with our social media platform's choice, we chose to give precedence to the possibility of meeting individuals where they already were, even if this meant reconsidering some ethical values and assumptions. We also welcomed every request for membership into the group, which resulted in a community comprising individuals with various religious beliefs, socioeconomic backgrounds, and geographical localizations (see Table 1). Being inclusive and sensitive to marginalized individuals remains at the core of our considerations for the further development of our activities. Indeed, other authors have emphasized the need to include the exploration of social and structural vulnerability that shapes bereavement experiences (Bindley et al., 2019; Moore et al., 2020; Mulheron & Inouye, 2020). When studying pandemic grief, which is akin to disenfranchised grief (Doka, 2002), it appears all the more important to consider the structures of inequity associated with psychological distress and social disenfranchisement. As a participatory project anchored in CC, our initiative contributes to the development of inclusive frameworks that provide multiple ways to cope with bereavement (Bindley et al., 2019).

Review and evaluate

Kellehear (2005) strongly emphasizes the importance of reviewing and evaluating CC initiatives for reasons such as: to assess effectiveness in an organized and credible way, to help build political and social support and to obtain feedback for future planning. Thus, a careful and rigorous examination of our online support community, based on the principles of developmental evaluation (Patton, 2010) and including both qualitative data (e.g., interview transcripts, electronic communication) and quantitative data (statistical information from our website and our social media page) represents the major next step of our process and will be completed by an independent research team. Indeed, not only does this process allow for a better understanding of the underlying principles of our online support community, but the stronger the evidence of its efficiency, the higher are the chances of the longevity of this initiative as well as its chances to be replicated in another context.

COMPASSIONATE COMMUNITIES AS A TOOL TO TACKLE SOCIAL INJUSTICE?

Between March and May 2020, when the SARS-CoV-2 was still largely unknown, a large number of elderly deaths occurred in Quebec in the pandemic context of physical distancing, lockdowns, and the complete prohibition of outside caregiving visits in residential aged care facilities. This meant that thousands of caregivers and family members faced their grief in especially tragic conditions (e.g., the loss of direct contact with their dying relative). When the government announced the prohibition of all visits in residential aged care facilities, we knew, based on our clinical experience and knowledge about bereavement, that caregivers would need critical support. From this activist standpoint, we created the CC initiative. At many points in the process, we prioritized our community members' wellbeing beyond gathering research findings (e.g., offering more interviews when participants needed and asked for them) and we maintained relatively close connections with our 35 participants, which is an untraditional way to conduct research. We broke down the barriers of scientific knowledge by sharing the results of our research with numerous audiences very early in the process, which constitutes an important democratization of knowledge transfer. As clinicians with experience in palliative and end-of-life care, we knew the importance of connection and relationships in bereavement care, and so the origin of our project is directly derived from our clinical intuition and expertise.

Based on the experience of our online support community aiming at supporting bereaved individuals experiencing pandemic grief, we propose that online communities, especially when developed within the framework of CC, could constitute a powerful space for community members to care for themselves and each other while simultaneously advocating for greater awareness of the inequities in end-of-life care and bereavement services, denouncing abusive situations experienced by individuals who have died from COVID-19 complications or during the pandemic or their caregivers, as well as fighting the lack of recognition of this event experienced by numerous caregivers. Indeed, as the pandemic context amplifies isolation, weakens individuals' mental health and adds pressure to an already insufficient health and social services system, the CC model represents an accessible and equitable model of health promotion and support (Wallace et al., 2020). During this project, we were touched to witness how strong and resilient our community members became when they shared their experiences within a safe space, even though it was virtual. There is definitive value in further expanding this empowering initiative within and beyond palliative care, as other marginalized communities could benefit from an accessible, equitable and powerful space to share their experiences and build communal resilience. Individuals naturally have the impetus to express solidarity and come together to compassionately support each other and can do so in a way that also tackles wider social injustices, an issue that professionalized, privatized help cannot solve. Empowering, accompanying and supporting communities within the CC framework constitutes an inspiring manner to support the development of meaningful alliances and coalitions.

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