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INFORMATION IN PURSUIT OF THE "GOOD DEATH": LIBRARIES' ROLE IN THE DEATH POSITIVITY MOVEMENT (Paper)

Abstract:

The Death Positivity Movement (DPM) is a recent social and activist movement seeking to change the North American "culture of silence" surrounding death and dying. Seeking to engage with the conference theme of "conversations across boundaries," this presentation presents arguments as to why libraries should be involved in the movement and also outlines more specifically actions that they can take to be involved. In this presentation, a short introduction to the DPM will be provided, followed by a brief discussion of the concept of the "good death". Arguments will then be made explaining why libraries should be involved in the DPM and then the last section explores more specifically how libraries can be involved through collection development, community assistance and programming.

1. Introduction

The Death Positivity Movement (DPM, or sometimes Death Positive Movement) is a recent social and activist movement seeking to change the North American "culture of silence" (Doughty, 2019b) surrounding death and dying. The modern DPM is relatively novel, and until now has been primarily driven through the publishing and sharing of content on social media (Hayasaki, 2013). However, as the movement grows, libraries are well positioned to be involved in the movement through their role as information providers and community builders. In turn, the pursuit of the goals of the DPM fulfills the mission of libraries. In engaging with the CAIS/ACSI 2019 conference theme of "conversations across boundaries," this presentation explores the current and future relationship between the DPM and libraries to bring awareness to it and to further promote its growth. This presentation offers conversations across boundaries through intersecting the fields of Library and Information Science (LIS) and Death Studies, as well as connecting research to outreach through library practice. In this presentation a short introduction to the DPM will be provided, followed by a brief discussion of the concept of the "good death" which acts as a diagnosis of modern death culture and sets the context for the reasons why libraries should be involved. Following this, arguments explaining why libraries should be involved in the DPM are made. The last section explores more specifically how libraries can be involved through programming, community assistance, and collection development.

2. What is the Death Positivity Movement?

Seeing the problems of pervasive cultural death anxiety, the DPM aims for the restoration of death to its true place as a part of one's life (Doughty, 2019b) "through educating the public as to the benefits of confronting and accepting death" (Jorgensen Skakum, 2018, p. 24). Brennan (2014) notes that these beliefs are pursued because the DPM believes in the "the primacy,

inevitability, and naturalness of human mortality as well as a...belief in the potential risk posed to social relationships and psychological well-being if issues of death, dying, and bereavement are not addressed or engaged with in a fully transparent, honest, and mature fashion" (p. 138). The modern figurehead of the movement is Caitlin Doughty, a Los Angeles-based funeral director, activist, author, and host of the YouTube channel *Ask a Mortician*. The modern usage of the phrase "death positive" derives from a 2013 tweet wherein Doughty (2013) questioned "why are there a zillion websites and references to being sex positive and nothing for being death positive?" Analogous to the idea of sex positivity, or being sex positive, the term "death positive" is meant to describe those who embrace openly the many aspects of death in a healthy, tolerant, progressive, and shameless manner. The movement is loosely marshalled around an organization called *The Order of the Good Death*, founded by Doughty in 2011. The Order is a collective of scholars, artists, scientists, educators, and funeral industry professionals aimed at fulfilling the goals of the DPM. Librarians are also counted amongst the members of the order, notably Megan Rosenbloom who runs the event arm of the Order, called *Death Salon*.

3. What is the "Good Death"?

"Death and dying became almost unmentionable words over the course of the last century" (2013, para. 1) Samuels notes. Death, dying, and bereavement have become hidden away. This recognition encompasses not merely speaking about death but extends to the almost total medicalization and professionalization of dying and post-mortem care. Northcott and Wilson (2016) write that "Death and dying were removed from the context of normal life and instead largely placed in the context of health care institutions to be managed by health care professionals" (p. 93). This hiddenness manifests as well as unfamiliarity with the mechanics of a variety of end-of-life activities such as creating advanced medical directives or determining powers of attorney (Silveira et al., 2000). Individuals have also become ignorant of the workings of the funeral industry. Mitford (1963) notes "the buyer's almost total ignorance of what to expect when he enters the undertaker's parlor" (para. 29). The DPM and its goals are a response to this culture of hiddenness and ignorance. They posit awareness about death so that people can have a "Good Death" where they exercise an informed autonomy over their dying and deathcare as well as have a planned death with personal, financial, medical and legal affairs in order. An important factor in the "Good Death" is information.

4. Why should libraries be involved?

There are a variety of reasons why libraries should be involved in the DPM and subsequently in helping individuals have a good death. First, because death is a mysterious part of the human condition. Brenda Dervin (2003/1980) sees "a direct connection between the kinds of situations people see themselves as being in and the kinds of questions they ask" (p. 45). Our present human life is such a situation. It necessarily gives rise to questions about its nature. "Our very being becomes a question for us" (p. 67), Batchelor (1983) suggests. The interrogatory nature of questions and questioning points to their function as eliciting information (Searle, 1969), so information can serve as an answer to these questions. In many ways, information is the only thing one can use to understand and make sense of death until one experiences death themselves. Staudt (2009) writes, "The only genuinely unmediated death we will know is the one that we will all eventually experience at the ends of our lives. Until then we have to be satisfied with second- and third-hand reports and limited understanding of what it means to die" (p. 8).

Relatedly, there have been studies of the information needs of dying individuals or of individuals who have information needs concerning death within LIS. For instance, the author's doctoral dissertation (Chabot, 2019) investigated the existential information needs of 20 Buddhists of the New Kadampa Tradition. He found that seeking answers about death was one of the reasons why New Kadampa Buddhists sought spiritual information. Other scholars have also found that death elicits questions and requires information. Donat and Fisher (2002) conclude that "information is critical at different stages and to many different actors involved in the process" (p. 184). Baker (2004) and Fourie (2008, 2012) also found that dying people have information needs even as they approach death, especially about existential issues.

Libraries should also be involved because death positivity is a matter of social justice. Rich (2016) writes:

> Death positivity is social…If death positive advocates are truly concerned with creating a more just culture around death and dying, we must position ourselves clearly and loudly as social justice advocates. (para. 16)

Libraries are far from neutral institutions. The pursuit of social justice is frequently allied with librarianship (Jaeger, Shilton, & Koepfler, 2016). Largely, libraries pursue social justice through enabling universal access to information. As was mentioned, the DPM movement is in large part an informational one. It presents information about death, dying, bereavement, and corpses to people who are seeking answers. Information about death and dying empowers individuals to make more informed decisions in regard to their end-of-life activities. It allows them to take control over certain aspects of how they die, even if they cannot control the fact that they will die.

Last, there is also a very practical reason for libraries to be involved in the movement as a large part of populations in the Western world age and begin to die over the next thirty years. Samuels (2013) warns that "we remain very unprepared for the approaching tsunami of death as the largest generation in history begins to die off in great numbers....[we] need to individually and collectively come to terms with mortality if we are to avert a major social crisis over the next couple of decades" (para. 1).

5. How should libraries be involved?

While there are obvious limitations to libraries' abilities to enable the DPM (for instance, librarians are often not trained counsellors), there are still ways in which libraries can help facilitate the movement's goals by continuing their collection and community-building missions. Doughty (2019c) writes that the primary avenues of change for the DPM are "discussion, gathering, art, innovation and scholarship" which are avenues that libraries already engage with. Libraries can be involved primarily by being a "third space" (Oldenburg, 1989) for information exchange about death and dying to take place while simultaneously helping build community through bringing people together. A programming event that is relatively easy to put on, and gaining in popularity, is the *Death Café*, an event founded by Bernard Crettaz in 2004 (Fong, 2017). Death Cafés are informal, group-led discussions about death and dying (usually accompanied by refreshments). They are not group grief or counselling sessions but provide a safe space for discussion. Libraries are ideal places for Death Cafés because it is "a neutral location where there is no perception of impropriety" (Inklebarger, 2015, para. 4). A library

could offer space, a staff member to facilitate, and provide the refreshments. The Regina, Okanagan Regional, Vancouver, and Toronto Public Library systems all held Death Cafés in 2018, demonstrating the applicability of this idea in libraries across Canada.

Next, much like their support of those finding employment and providing government information, libraries can also help ease the burden some of the bureaucratic elements at the end-of-life such as facilitating access to government information and providing workshops on filling out necessary forms, like advanced medical directives. Kirchhoff (2014) suggests that "patients' preferences about their future health care should be elicited during an advance care planning discussion in a less stressful setting and time than during hospital admission" (p. 11). Libraries could also be prepared to make referrals to professionals when needed through maintaining or collecting local lists of counsellors, lawyers, funeral homes, and death doulas.

The avenues of scholarship and art to combat the culture of silence surrounding death can also easily be taken up by libraries through the through the collection of death positive materials. Death and dying can be approached scholastically from a variety of different perspectives (e.g. historically, sociologically, scientifically) so a death positive collection can and should be multi-and interdisciplinary since death touches on many aspects of life and culture. Public libraries could be more inclined to collect materials on self-help matters related to death acceptance and grief as well as juvenile and young adult works. Doughty (2019a) has compiled quite an extensive bibliography of death-related and death positive works which can act as a starting place.

6. Conclusion

By actively participating in the DPM, libraries can fulfill their mission to be of service to others through the provision of information and through facilitating community-building. Furthermore, by supporting the DPM through programming, support, collection development, libraries can help challenge the unspoken authority of the culturally dominant ways of approaching death. They can help individuals to a place of strength, empowered by information and a facility of talking about death. In this way, the library can continue to make an impact on society outside of its walls by helping people pursue the "good death".

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