

Death education at a federal public school: a Brazilian experience

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Introduction

According to Association for Death Education and Counseling, death education can be defined as a set of resources and methods for acquiring and disseminating knowledge concerning the subject of dying and death, bereavement and palliative care.¹ Considering the importance of such topics being widely discussed throughout society, international associations around the world have developed educational interventions open to all society, involving governments, public and private institutions, schools, orphanages, hospitals and other institutions. When we talk about palliative care, especially in developing countries such as Brazil, which still have numerically disproportionate palliative care services, if we consider the number of the population,² community education strategies are very relevant to demystify misconceptions and to increase knowledge about civil rights to the end of life, increase knowledge about palliative care, advance directives, control of pain and other symptoms, as well as emotional, psychological and spiritual care of people at the end of life.

Created by Dame Cicely Saunders in 1967, St Christopher's Hospice in England has been developing a death education project for many years, which involves students in elementary and middle schools in London, involving the academic community with patients and professionals who they work at the hospice. Based on St Christopher's Hospice's Schools of Death Education and Health Promotion, we carried out a project with the same purpose in order to bring the community of students, parents and teachers together in the philosophy and practice of palliative care, bereavement care and thanatology.³ The project was supported by the school board and the parents 'and teachers' association. During the year 2016, activities were carried out during the school year, namely: Project discussion, at the beginning of the year, with teachers, parents and students; campaign to collect hygiene items and children's books for sick children from various hospitals; workshops and activities with active methodology on the subject of death, dying and palliative care, with 45(n=45) primary and secondary volunteer students; two visits to the support institution aimed at adolescent children with cancer, involving the whole community, such as students, parents, teachers, professionals and patients.

The intervention: death education school's project

According to the belief that in order to begin to unravel the complexities of death education and community involvement, vital and pressing questions for hospices and end of life care services should be based on how communities become engaged in such matters,⁴ we began our project of death education. After receiving the approval of the school board and the parents and guardians, we presented the project to a body of 1200 students, of whom 45 showed an interest in volunteering in the extra-class period. We divided the project into four phases of intervention:

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- i. Phase approaching the theme of death and dying and presentation of the hospice philosophy with students and teachers. At this stage of our intervention, six workshops were held for two months. In these workshops, the philosophy of palliative care was presented, as well as stories of patients in palliative care, in order to demystify concepts and help students realize that it is always possible to do something for the seriously ill, abandoning the idea that "there is nothing to be done". The resource of life histories was very important to facilitate the discussion, so that it was not in the purely theoretical field, and the use of songs and poetry was employed, in order to facilitate the approach with the theme. Three stories were selected, taken for didactic purposes from Elisabeth Kübler-Ross's book *To Live Until We Say Goodbye*.⁵ The concept and principles of palliative care were presented, according to the World Health Organization, and discussed the difference between palliative care and end-of-life care.
- ii. Phase of intervention with the whole school and students, carrying out a campaign of collection of children's books and hygiene products to be taken to an institution chosen by the group of students, near the school, for poor children and adolescents with cancer. At this stage, the students began a campaign, involving the entire school, teachers, parents and caretakers. An extensive campaign to collect donations has begun. Then, an institution for poor children and adolescents with cancer was selected by the students who were part of the project. Through this phase, students were able to integrate into the care of patients and their families through a sense of community and solidarity.
- iii. Visitation phase for children and adolescents for an afternoon of joint activities. At this stage, researchers, parents and teachers came together to make it possible for the students to visit the patients and bring them hygiene items, just as they could meet and share their life experiences. Students were instructed to take musical instruments and read poetry or short story books for patients. The visit lasted a few hours, and caused deep marks in the minds and hearts.
- iv. Reflection on the philosophy of palliative care together with the philosophy lessons of the school, discussing issues such as mourning, death, dying, symptom control and community support to cope with difficult times in life

This last phase involved a discussion on existential themes, such as the meaning of life, the use of time, the connection with other human

beings, and the need for us all to build a life full of meaning. We also talk about how illness can bring about a break in the meaning of life, but that we can also grow through it, keeping us connected with everything that makes sense to our lives. We discuss how palliative care can facilitate the search for meaning in our lives or the lives of those we love, giving them the means to live a dignified life even in the face of a serious or potentially fatal illness. The philosophy classes were the complement of this work, which counted on the support of the philosophy teachers of the school to introduce existential themes in the classes, proposing reflections on time, finitude, solitude, bereavement and love.

Conclusion

This one-year intervention proved to be effective in facilitating the discussion of palliative care, death, and the needs of dying in the community involving people of varying ages. High impact activities allowed students to carry out solidarity activities, benefiting patients and their families. In the final evaluation, this activity was described as a very significant experience by the students, patients, teachers and health professionals involved.

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None.

Conflict of interest

The author declares no conflict of interest.

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