

“Before I die I want to ...”: An experience of death education among university students of social service and psychology

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Abstract

The censorship of death and dying has removed the “memento mori” practices, and in order to reintroduce this practice, some “Before I die” projects have been increasingly implemented. Running in parallel, in the syllabi of social service and psychology students, some experiences of death education has commenced. This study illustrates the results of a qualitative research conducted on the “Before I die I want to ...” Polaroid® Project (BIDIWT), which is divided into two phases. The first phase entails an analysis of the wishes collected from the United States, Japan, India, and Italy. The second phase refers to the analysis of the captions of the BIDIWT realized from two groups of undergraduates, with regard to the effect of such experience on their religiosity, representation of death, and fear of death.

Keywords

death education, death representations, memento mori, photo-therapy, terror management theory, wishes analysis

Introduction

The Spanish Basque theologian, Saint Ignatius of Loyola (1522–1524), who was greatly admired by Carl Gustav Jung (1964), considered death as the central focus for the deep meditation described in the treatise *Exercitia spiritualia* (Spiritual Exercises). His contemplation was a supreme Christian transformation of the preview Roman “memento mori,” which encourages people to remember that they have to die. Having the ability to influence the spirituality of the Middle Age and the early Modernity, the rigorous practices of reflection on mortality were means of considering the vanity of human life and the transient nature of all physical world. As an English bishop and theological writer, Jeremy Taylor (1665/1977) described in his book, “The Rules and Exercises of Holy dying,” that the “memento mori” formed an important part of everyday discipline, practiced to reinforce the virtuous character and the detachment from giving oneself up to pleasures, by orientating motivation toward immortality and the afterlife.

In the previous decades, Taylor’s perspective received special attention, thanks to the study of Robert Kastenbaum

(1979), one of the pioneers of the American Death Aware Movement, founded during the seventies in the United States. He evoked this opera while discussing on the preparation of professionals working in hospices and in palliative care, after having underlined the poor spread of reflections on these issues. As emphasized by the author, since the World War II (WWII), the recent achievements in medicine have systematically removed the power of nature on the borders between life and death, externalizing the process of dying confiscated to the family by public healthcare institutions. The exhortation to renew the “memento mori” practice was derived from the need to promote a wide conscious reflection

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on existential themes and concerns. Many things have changed since then, and especially in medicine, nursing, and psychology degree syllabi, specific formal and informal curricula have been focusing on mortality, preparing the mind of professionals to cope with death and grief (Doka, 2007).

As described by Hannelore Wass (2004), the term that indicates such kind of courses is “death education.” It refers to a variety of activities, aimed at facilitating understandings of death and bereavement. It had been practiced informally throughout all human history by religion, but nowadays in the contemporary Western culture, it is quite difficult to disseminate it, because of the fear that it could have negative effects (Fonseca and Testoni, 2011; Testoni et al., 2017a; Testoni et al., 2018). Actually, the media daily spreads themes inherent to death through sensationalistic and unrealistic events, derived from exceptional, cruel, and aggressive factors. Such broadcasts underscore the idea that death is an extraordinary occurrence that afflicts others who live in a mythical space (Gilbert and Murray, 2007). Based on all these reasons, many experiences of death education have been activated all over the world. In particular, an increasing attention has been paid to such courses for health professionals, who oftentimes had to cope with death and grieving, without competencies and adequate psychological support (Wass, 2004; Testoni, 2016).

“Before I die I want to ...”: a communitarian project on death education

Among many informal strategies of death education, two projects stand out titled “Before I die I want to,” which are the contemporary re-evocation of the ancient “memento mori.” The first form is the “Before I Die—wall.” Thousands of people have participated in a global public art project that re-makes the reflection on death topical. The first original wall was created in 2011 on an abandoned house in New Orleans by artist Candy Chang, after a long period of depression caused by the death of someone she loved. Since then, over 2000 before-I-die walls have been created in over 70 countries around the world. The wall can be produced by any group of people who need a space in their community to culturally restore communitarian existential perspectives. The project is an extension of the previous idea of KS Rives and Nicole Kenney, who realized a photographic survey on the streets of New York in 2008, asking people “What do you want to do before you die?” While the interlocutors are responding to the question, a Polaroid® photo is taken with the sentence written on the snap. Participants were contacted and involved randomly, while strolling along the streets.

Photo-based activities are useful to improve individual and community development and are widely used both in phototherapy and photo-voice techniques, whose photographic goals are, on one hand, to produce positive change in individuals, couples, families, and, on the other hand, to improve the

well-being, reduce social discrimination, isolation, and exclusion, at community, societal, national, or international levels. Social action photography and therapeutic photography techniques are useful in increasing self-knowledge and consciousness. Its activation of positive changes enhances education and expands qualitative research, by spreading many kinds of photo-based healing and learning as art-therapy (DeCoster and Dickerson, 2013; Ginicola et al., 2012; Wang and Burris, 1997; Weiser, 1990). The BIDIWT is in agreement with this.

The preference given to the Polaroid® was determined using symbolic reasons: The Polaroid® company announced the “death” of its production in 2007—1 year before the project started—and since these snaps are analog photographs, they cannot be edited or replicated. Since this camera captures a single moment in which it is impossible to intervene in post-production, as is the case with digital photos, the final upshot is a reminder that each second of being alive is irreversible. After this first performance, many Polaroid®-before-I-die experiences have been realized globally.

Terror management and the representations of death

In the last 50 years, a lot of studies which aimed to analyze death concerns have been realized, and their application has improved remarkably, especially in the knowledge of attitudes and in the management of grief. However, there is a lack of exploration about the cognitive factors which influence suffering and anxiety caused by death. An important contribution toward the explanation on the origin and the effects of the distress related to death is offered by the terror management theory (TMT; Greenberg et al., 1994). Basing their empirical studies on the work of Ernest Becker (1973), the terror management (TM) researchers have assumed that human beings would be immobilized by dread if they lived constantly with the awareness of their mortality. Consequently, individuals developed cultural worldviews with their faith and cosmological beliefs concerning the meaning of life and death, where the representation of the afterlife assumes a particular importance. The adherence to these worldviews is largely driven by a psychological defense, functional to minimize the anxiety caused by the awareness of being mortal (Pyszczynski et al., 1999). According to TM researchers, there are both proximal and distal defenses to this anxiety. The first ones are activated when thoughts of death become conscious and the buffer exigence removes them from awareness. The distal defenses are used when death-related thoughts are salient, but remain unconscious and cause the improvement of faith in one’s believe. This process includes the need to develop self-esteem, on the basis of one’s own cultural values. Across countless studies, TMT has demonstrated that when mortality is made salient, people respond by resorting to worldview defense.

Based on this, a specific reflection has been developed, inherent to the representations of death, which analyzed the role of religion and secularism in the contemporary way of managing death and dying (Solomon et al., 2017). These studies focused on the ontological dimension of such representations (Ronconi et al., 2009; Testoni et al., 2015; Zamperini et al., 2015), which aim at describing the substantial differentiation between death as passage, where souls fly up to heaven or as absolute annihilation. From a TMT perspective, these cognitions generally correspond to the negation of death as “literal” or “symbolic” immortality. The first one consists of faith in afterlives (soul, reincarnations, transmutations, etc.), common to all the world’s great religions. Symbolic immortality consists of the belief that a remnant of one’s existence will persist over time—by having children, amassing huge fortunes, being part of a great (and enduring) tribe or nation, or producing a great work of politics, art, or science (Lifton, 1979).

The studies on the ontological representations of death showed that there is a profound difference between these two forms of cognitions and their effects (Testoni et al., 2015, 2016). In fact, they are absolutely incommensurate and produce different psychological effects with respect to buffering anxiety. This study is to be read in this context of reflection.

The research aims and phases

Due to the extreme weight of social workers and being that psychologists’ function is in the field of the end-of-life and palliative care, the Italian law n. 38/2010 emphasizes the importance of death education courses in their degree programs. In Italy, the BIDIWT experience is particularly fertile and well known, so we wanted to study and utilize it as an introductory activity of formal courses of death education with Italian university students of psychology (Psy) and social service (SoS). Starting from a consideration of the role of the ontological representation of death in the construction of cultural worldviews that provide a sense of meaning, the overall objective of the whole research was to detect the main needs/desires revealed by people after the activation of the “memento mori,” such as asking pertinent questions: “what do you want to do before you die?”

The study was divided into two phases. The first one aimed at considering the international production of these photos, analyzing the texts of their captions. We wanted to investigate similarities and differences between genders and geolocation of participants; the second phase, which is a single project realized specifically for SoS and Psy university students, was further divided into two parts: the first one analyzed the captions of participants, while the second one analyzed their comments on the experience. We wanted to find identities and similarities of needs/desires between the International Groups (IGs) and the university students.

Furthermore, the first specific objective of this second phase was to consider whether and how death’s representations influence people’s desires. The second specific objective was related to the detection of how students have experienced the BIDIWT activity and what kind of similitudes and characteristics differentiated the groups of Psy students from those of SoS. Finally, since spirituality and transcendence are a prerequisite for working with dying people, a particular attention was paid with respect to the needs inherent to self-transcendence, or Being Needs (B-needs).

Methodology

The research adopted a mixed method (qualitative and quantitative). Following the COREQ checklist (Tong et al., 2007), our analysis was theory-driven, framing interpretations within the theories of Maslow (1943), TMT (Greenberg et al., 1994), and the scale by Testoni et al. (2015). In fact, the textual data have been analyzed using the framework method for thematic qualitative analysis, which allows sources to be examined in terms of their principal concepts or themes (Marshall and Rossman, 1999; Testoni et al., 2017b). Three researchers developed the analysis on prior categories and categories which only became clear as the analysis progressed. The former were the basic “pre-agreed themes” from which the latter emerged as unexpected topics. The prior categories were assumed by the motivational Maslow’s (1943) theory. Adopting the five-level hierarchical models in its bi-factorial structure, we considered these categories which are differentiated into “deficiency needs” (D-needs) and “growth or being needs” (B-needs). D-needs are divided into material and psychological. In turn, the first ones are the biological/physiological needs and the safety ones. The psychological needs are inherent to love/sense of belonging (friendship, intimacy, trust and acceptance, receiving and giving affection and love) and to the affiliative ones (family, friends, and work). In this area, a particular importance is assumed by the esteem needs, which are further distributed into two categories: esteem for oneself (dignity, achievement, mastery, and independence) and the desire for reputation or respect from others (e.g. status and prestige). Finally, the B-needs move people to realize personal potential, self-fulfillment, seeking personal growth and peak experiences. As indicated by Maslow (1968), they do not involve balance or homeostasis. Once engaged, they continue to be felt and comprise the continuous desire to fulfill potentials in becoming the most complete (self-actualization) and to improve self-transcendence.

The qualitative process of the analysis was divided into six main phases: preparatory organization, generation of categories or themes, coding data, testing emerging understanding, searching for alternative explanations, and finally, writing the report (Marshall and Rossman, 1999; Zamperini et al., 2016).

Countries	Participants	Gender	Categories	Freq.	Gender	Total %
1 India	214	127 Male 84 Female	Bodily	5	1 Male, 4 Female	3,03%
			Safety	44	28 Male, 16 Female	26,67%
			Love/membership	25	12 Male, 13 Female	15,15%
			Esteem	64	37 Male, 27 Female	36,79%
			Self-fulfillment	72	48 Male, 24 Female	16,63%
2 Japan	15 (3 Captions Illegible)	7 Male 5 Female	Bodily	0	-	0%
			Safety	0	-	0%
			Love/membership	2	1 Male, 1 Female	16,67%
			Esteem	0	-	0%
			Self-fulfillment	10	6 Male, 4 Female	83,33%
3 U.S.A	672 (1 Caption Illegible)	325 Male 347 Female	Bodily	23	15 Male, 8 Female	3,43%
			Safety	56	30 Male, 26 Female	8,36%
			Love/membership	106	45 Male, 61 Female	15,82%
			Esteem	233	103 Male, 149 Female	34,78%
			Self-fulfillment	252	103 Male, 149 Female	37,61%
4 Italy	451	135 Male 316 Female	Bodily	12	7 Male, 5 Female	2,66%
			Safety	19	7 Male, 12 Female	4,21%
			Love/membership	131	32 Male, 99 Female	29,05%
			Esteem	131	40 Male, 91 Female	29,05%
			Self-fulfillment	158	49 Male, 109 Female	35,03%

Figure 1. Frequencies and percentages of categories between countries and gender.

Results and analysis of the first phase

In the first phase of the study, Maslow's needs/desires (bodily, safety, love/membership, esteem, and self-fulfillment) were analyzed, among which are 594 males and 752 females; in particular were 214 individuals from India (127 males and 84 females); 15 from Japan (8 males and 7 females); 672 from United States (325 males and 347

females); and 451 from Italy (135 males and 316 females). Figure 1 shows the frequencies of the needs/desires on the basis of gender in the different countries.

The category called "bodily," expressed the needs/desires for food and water, sex, sleep, and the striving to survive, usually expressed with the phrase "Before I die I would like ... to get to tomorrow." This type of wishes is

the least mentioned in all IGs, and these data indicated a substantial well-being wherever the survey was carried out.

In the “safety” category, the wishes concerning the economic and family safety, health, and well-being were listed, expressed with “I would like to have a house,” “a car,” “find a job, ...” These needs have generally obtained very little relevance. It should be noted, however, that in the group coming from India, the trend was different, as it seems that this type of desires was proportionally more relevant than in other countries. On the contrary, in Italy, this instance was of very little importance. In the “Love/membership,” the needs/desires expressing the will to “know how to forgive,” to “maintain the friendships and affection in the family,” to “develop intimacy with loved ones,” and to “realize the dreams of the children” were involved. In the East (India and Japan), this need was felt much less than in the West, and in terms of percentage for the Italians, it was more relevant than others. The “Esteem” category was the most important in the Indian group. It included captions describing the capacity for “self-control,” “self-valorization,” “self-respect,” and for obtaining success “in studies,” “in sport,” “in work,” “in art,” and “in love.” There were listed also the wishes to meet specific celebrities, and famous figures in sports and show business. Also, comprised in this section were “the desire to live fully” and the opposite “do not want anything because all the desirable has already been achieved.” This is the most significant category for Indian participants. Finally, in “Self-Fulfillment,” the B-needs for “knowing the world,” of “solving the problems of humanity,” and of “guaranteeing justice and peace in the world” have been inscribed, along with “accepting the limits,” “creatively responding to losses,” and “achieving full happiness” as well. This is the most important category for the United States and Italian groups, but it is also the only category that makes sense to the Japanese group. Finally, it is important to underline that there are no major differences with respect to the gender between East and West. This suggests a progressive change beyond the tradition that took women away from the dimension of Self-Fulfillment, especially in the East.

The second phase: participants and procedure

The research group was made up of 100 students, divided into two subgroups of 50 students each, who were undergoing training for the degree in SoS and Psy. Both groups were about to take a course in death education. The characteristics of the general group were as follows: 88 percent females and 12 percent males (SoS: 95% females and 5% males; Psy: 82% females and 18% males); with an average age of 22 years (SoS 21—ds 3.9; Psy: 24.68—ds 3.2). With respect to religion, 67.3 percent were believers (35.7% worshipers); particularly among SoS, 31 percent atheist or agnostic and 69 percent were religious (54% worshipers); among Psy,

44 percent atheist or agnostic and 56 percent were religious (18% worshipers).

Each group was divided into about 10 subgroups, headed by coordinators, who had followed a specific training before actualizing the project. This part of the research utilized a mixed (qualitative and quantitative) method.

The qualitative part was realized both ways; through the analysis of the students’ captions and the texts produced at the end of the activity, when all students were invited to answer the following questions: (1) “What intimate effect does this experience have?” and (2) “What kind of existential reflections has this experience produced in your mind?”

To analyze the role of the ontological representations of death, the Testoni Death Representation Scale (TDRS; Testoni et al., 2015) was included in the questionnaire, which is a short 6-item 5-point Likert-type scale measuring the ontological representations of death, either as an annihilation (i.e. the end of everything) or as a passage (i.e. belief in an afterlife). Lower scores indicate that the individual sees death as a passage, whereas higher scores imply that the individual sees death as a total annihilation. These constructs have been used in research examining attachment (Codato et al., 2011), hypnosis (Facco et al., 2017), and palliative care (Testoni et al., 2016).

The study followed APA Ethical Principles of Psychologists and Code of Conduct and the principles of the Declaration of Helsinki. Furthermore, it was approved by the Ethics Committee of University of Padova. Participants were informed about the study aims and procedures, and were assured that participation was voluntary. The confidentiality of their responses was guaranteed. Oral and written informed consent was obtained from all participants. Data were collected between October 2016 and May 2017.

Methods and results of the first part of the second phase

The TDRS data were obtained from 96 subjects (four students did not fill the questionnaire). The *t*-test was used to compare the total TDRS averages in the two groups. Collected data were analyzed using the software SPSS 11.5. The answers to the open questions and the captions were analyzed using the software for the qualitative analysis Atlas.ti. The results emerged from the analysis of the relationships among TDRS, the answers to the open questions, and religiosity, surveyed through the socio-demographic form. The two main representations of death have therefore constituted a priori categories, in order to find which foci of Maslow’s model characterized the two different perspectives.

The results evidenced that most of the students represented death as a passage (55%). However, the comparison (conducted on an average-to-average basis) between the two groups showed a significant difference among SoS and Psy students. The first ones represented more death as a

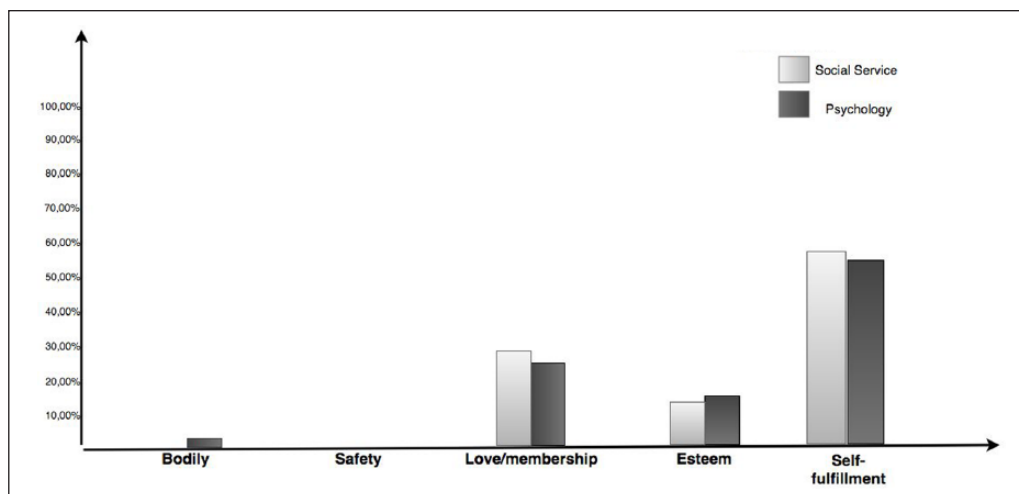


Figure 2. Needs/desires between social service and psychology student.

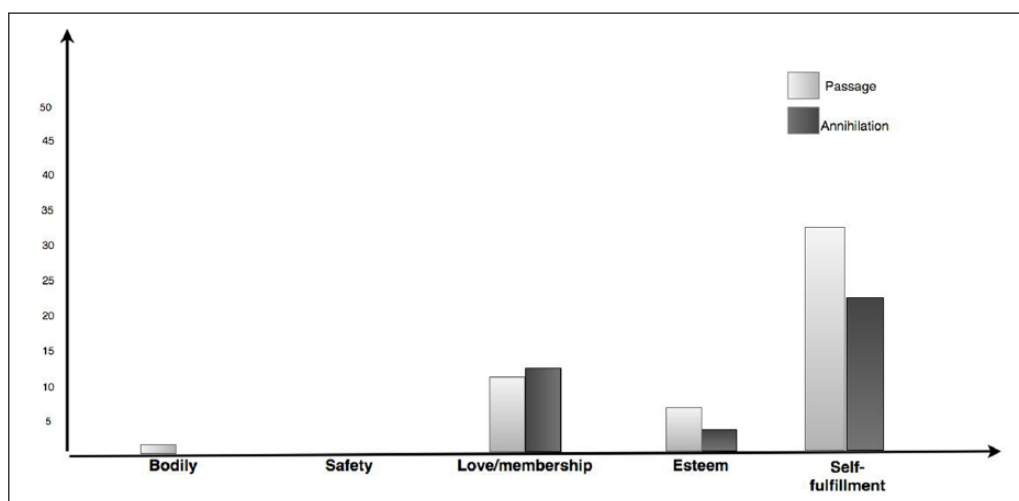


Figure 3. Frequencies between passage and annihilation.

passage (average=15.91) than the Psy students (average=19.73), and 72 percent of SoS students particularly cultivated this belief, versus 39 percent of Psy students. Nonetheless, some interesting contradictions appeared, where 33 percent of the atheist students have faith in an afterlife, while the same percentage (33%) of believers was convinced that death means total annihilation.

As illustrated in Figure 2, in the distribution of the different needs among the Italian students, the category “Bodily” obtained few preferences similar to the IGs. Only one student said “I would like to heal.” From students’ perspective, “Affiliation/love” and “Self-Fulfillment” are really important, confirming the Italian trend that was earlier emphasized. However, a more specific differentiation is inherent to the fact that, among them, “Self-esteem” presented frequencies really lower, compared with those of IGs.

The further analysis, inherent to the relationships between the ontological representations of death as a total annihilation or as a passage, showed that the second one is characterized by more frequent presence of B-needs, while self-esteem and love/membership are quite similar (Figure 3).

However, the love/membership desires evoked in both death representation categories are quite similar to those presented by the IGs: “I’d like to have children,” “to get married,” “to have a house,” “to have a family,” and “to improve my network of friends.” All the same with respect to the B-needs, which consisted of desires inherent to “know new cultures and different point of view, in order to expand my mind,” “to ameliorate the justice and the distribution of wellbeing all over the world,” and “being competent and ability to solve my problems and those of others.”

Methods and results of the second part of the second phase

The second part of the second phase was entirely qualitative, and it utilized the thematic analysis to explore connections between explicit statements and implicit meanings of discourses (Attride-Stirling, 2001). The texts obtained from the four answers were digitalized and thereafter processed with Atlas.ti. The analysis resulted in network graphs, describing logical relationships between concepts and categories identified by researchers.

In these final phases, it was possible to show that those who represented or saw death as a total annihilation described their own death as more terrifying than those who represented it as a passage. Furthermore, they affirmed that they did not want to think about their own death because it provokes anxiety: “I do not like this kind of issues because they are really distressing” (Psy 49:3); “I prefer not to think now about my death, because I want to live serenely” (Psy 29:7); “I do not like talking about death because I am very afraid of dying” (Psy 16:25); and “I’m aware that I’m mortal, despite that, the unknown scares me” (Sos 30:15).

On the contrary, those who represent death as a passage considers life: “as a preparation for existence beyond death” (Sos 4:15) and “death as a natural end of a phase of the existence” (Sos 27:18). These beliefs offer them the perspective of an endless personal development, which improves their B-needs: “I like to think about these issues because they help me remember what I need to actualize in life” (Sos 46:19); “When I think I could die tomorrow, from a fatal accident, for example, I regret not having done everything I liked” (Sos 32:9); “I want to actualize my dreams in international projects like the missionary, to help the most disadvantaged countries in tackling the problem of poverty” (Sos 3:4); and “The meaning of life helps to end it [...] because there is a consciousness that when it was beautiful it can also end without having a sense of accomplishment” (Psy 18:15).

However, all students, regardless of the ontological type of representation, are afraid to lose their loved ones: “When I think of death, fear is closely linked to the idea of not seeing the one who is my source of love. Very often, I look at M. and I tell him: I’m afraid of never seeing you again” (Psy 10: 6); “The fear of losing the person I love makes me breathless, I’m terrified at the thought of not being able to live the love, the bond, the relationship” (Psy 10: 6); “Love also means pain and I imagine how I have to suffer from loss before I die. I often think of what could be done when this occurs” (Sos 51: 4); and “I have a 6 year old son and I am afraid of dying too soon, because I would like to be present in the most important stages of his life, to see him happy, and also to be able to support him in times of suffering and frustration” (Psy 30:3). With respect to the effect of the Polaroid®-before-I-die experience, 43 percent claimed

to have become more aware of the goals they wish to achieve in their lives: “After doing this photo voice work, an unconscious feeling emerged. Having had the opportunity to talk about it made everything clearer in my mind” (Sos 35: 2) and “This experience has stimulated me to think more concretely about what I want to do, or rather, how I want to lead my life. It allowed me, in a certain sense, to be less naive towards life” (Sos 41:38). Based on this perspective, 24 percent affirmed that the finiteness of earthly life requires becoming aware of the time limit available to achieve the most important goals: “This work has made me more conscious of the limited time of life [...]. This reflection makes me want to live life better and attain happiness” (Sos 4: 1) and “I feel I do not have to put off anymore the things I would like to undertake. I realized that time passes and that we should not waste it” (Psy 40:37).

Aims and objectives were of particular importance, and 27 percent sustained the significance of the concretization of desires. Moreover, more than a third of them (33%) stated that they had been able to speak for the first time clearly about death (22%) and to have consciously thought for the first time that they will die someday (11%):

This activity inevitably has brought me to face the reality, I mean ... that I am mortal. Sincerely, I was afraid at the beginning. However, talking about death in this way minimized that fear. In fact, I could consider death as something no longer outside of me, far and dark, but think of it as an inseparable part of life. (Psy 40:17)

After rounding up with the photograph, I felt death closer to me. Before now, I saw it as something far away, now I feel that sooner or later death will come, and it is right that I live life in the best way, without superficiality, because everything is meaningful. (Sos 2: 7)

Conclusion

The research aimed at analyzing which type of needs/desires characterizes people invited to remember that they have to die. The renewal of the ancient “memento mori” was useful to introduce courses of death education among university students of SoS and Psy. This introductory activity was performed via BIDIWT, a project carried out all over the world. The qualitative analysis of the first phase of the study, realized from the IGs captions, showed that there were few differences among East and West and none between men and women. On the contrary, a significant variation was found in the analysis of the second phase, which is in line with the initial hypotheses. If there were no specific differences in the needs/desires between IGs and the students, and among the students, there was none on the basis of university course, gender, and religiosity. A dissimilar perception of the experience appeared on the basis of the representations of death. Students who

represented death as a passage declared that they went through the “memento mori” experience without concerns, while those who represented death as an absolute annihilation stated that they suffered from anxiety. Furthermore, a contradiction was seen: almost one-third of atheists represented death as a passage and almost one-third of believers represented death as an annihilation. That is why, as a whole, no differences appeared between the two groups of believers and the atheists. However, this result requires better reflection. Religion presents the most important discourses, historically rooted and developed, that discuss and indicate immortality, with a wide florilegium of reasoning and narrations. Evidently, there is a lack of education on their issues, and a noteworthy confusion is derived from this deficiency. Analyzing the desires of students who believed in an afterlife, we saw that they are more oriented toward the B-needs dimension. This result is in line with the TMT indications, and especially with the hypothesis that the cognitions inherent to the literal immortality produced a different effect with respect to the symbolic ones. As a result, it could be useful to introduce in the degree courses of health professions, some contents pertaining to spirituality and religiosity, in the area of death education.

Finally, it is possible to affirm that the idealistic perspective of almost all the captions of the students indicated that they had chosen their courses of study because they really want to help other people solve their troubles. In our opinion, such an existential proneness, based on the conviction that their personal development could be realized through the degree they were studying for, needs spaces focusing on the relationships between life and death, so that the consciousness of mortality could be better managed, especially from the perspective of end-of-life professions.

Limitations of the study

The results are quite encouraging; however, there are some limitations that should be considered. First of all, it is impossible to generalize the outcome because the research was qualitative, and the two groups of participants were not randomized. Furthermore, some essential factors should be better controlled with quantitative attitudinal instruments, that is, death anxiety and religiosity.

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