revista de pesquisa ISSN 2175-5361

CUIDADO É FUNDAMENTAL

Escola de Enfermagem Alfredo Pinto – UNIRIO

RESEARCH DOI: 10.9789/2175-5361.rpcfo.v15.12222

'DEATH CAFÉ': PERCEPTIONS OF UNIVERSITY STUDENTS AND PROFESSORS ABOUT DEATH AND THE FINITUDE OF LIFE

'Death Café': percepções de estudantes e professores universitários sobre morte e finitude de vida

'Death Café': percepciones de universitarios y profesores sobre la muerte y la finitud de la vida

Fernando Ribeiro dos Santos[1]
Lucimeire Aparecida da Silva[2]
Dulce Dirclair Huf Bais[3]
Adailson da Silva Moreira[4]
Fabiana Bolela[5]
Juliana Dias Reis Pessalacia[6]

ABSTRACT

Objective: : this study aimed to identify the perceptions of students and university professors in the health area about death and the finitude of life, after participating in a "Death Café" type activity. **Method:** descriptive research, with a clinical-qualitative approach, carried out with 17 university students and 6 professors in which content analysis was used as a method of data analysis. The results were discussed from the point of view of logotherapy. **Results:** four categories emerged: Quality of life and death, Death and transcendence, End-of-life preferences and Breaking taboos. **Conclusion:** there was a change in the participants' understanding of the meaning of life and death at the end of the proposed activity.

DESCRIPTORS: Death; Palliative care; University; Teaching; Logotherapy.

[1,4,6]Federal University of Mato Grosso do Sul (UFMS), Três Lagoas, MS, Brazil.
[2] University of Grande Dourados (UFGD), Dourados, MS, Brazil
[3]Federal University of Paraná (UFPR), Curitiba, PR, Brazil.
[5]University of São Paulo (USP), Ribeirão Preto, SP, Brazil.

Received: 01/12/2022; Accepted: 06/05/2023; Published online: 30/11/2023

Corresponding Author: Lucimeire Aparecida da Silva meiresilvino@gmail.com

How cited: Santos FR, Silva LA, Bais DDH, Moreira AS, Bolela F, Pessalacia JDR. 'Death Café': perceptions of university students and professors about death and the finitude of life. *R Pesq Cuid Fundam* [Internet]. 2023 [cited year mouth day];15:e12222. Available from:

https://doi.org/10.9789/2175-5361.rpcfo.v15.12222

RESUMO

Objetivo: este estudo teve como objetivo identificar as percepções de estudantes e docentes universitários da área da saúde sobre a morte e a finitude da vida, após participarem de uma atividade do tipo "Death Café". **Método:** pesquisa descritiva, de abordagem clínico-qualitativa, realizada com 17 estudantes universitários e 6 professores em que se empregou a análise de conteúdo como método da análise de dados. Os resultados foram discutidos a partir do referencial da logoterapia. **Resultados:** emergiram quatro categorias: Qualidade de vida e morte, Morte e transcedentalidade, Preferências de fim de vida e Quebrando tabus. **Conclusão:** evidenciou-se uma mudança na compreensão dos participantes sobre o sentido da vida e da morte ao final da atividade proposta.

DESCRITORES: Morte; Cuidados paliativos; Universidade; Ensino; Logoterapia.

RESUMEN

Objetivos: este estudio tuvo como objetivo identificar las percepciones de estudiantes universitarios y profesores del área de la salud sobre la muerte y la finitud de la vida, después de participar en una actividad tipo "Café de la Muerte". **Método:** investigación descriptiva, con enfoque clínico-cualitativo, realizada con 17 estudiantes universitarios y 6 profesores en la que se utilizó como método de análisis de datos el análisis de contenido. Los resultados fueron discutidos desde el punto de vista de la logoterapia. **Resultados:** surgieron cuatro categorías: Calidad de vida y muerte, Muerte y trascendencia, Preferencias al final de la vida y Romper tabúes. **Conclusión:** hubo cambio en la comprensión de los participantes sobre el significado de la vida y la muerte al final de la actividad propuesta.

DESCRIPTORES: Muerte; Cuidados paliativos; Universidad; Enseñando; Logoterapia.

INTRODUCTION

The training process of health professionals promotes few spaces for discussions about death, directing the gaze of students to the detachment of humanity and finitude of the patient, focusing primarily on the care of the physical body from a curative perspective. This approach does not prepare undergraduates for the confrontations related to death, fostering a denial about the terminality of life and preventing its discussion and approach in a solid manner.1 The unpreparedness of the health professional to initiate end-of-life conversations and provide effective Palliative Care (PC) is evidenced in the literature.[2-3]

An integrative review study[1] about the vision of death and dying from the perspective of health professionals concluded that interventions should be made with them, so that they can deal with the theme in a more natural manner, and thus assist patients in terminal situations in a more human way. Thus, they will be able to base themselves on the principles of PC established by Cicely Saunders, having a holistic view of the patient in PC, investing in integral care, giving due value to the complexity and the various dimensions that this care implies.[4]

According to the World Health Organization (WHO), PC aims to ensure the quality of life of people living with life-threatening diseases, including their families. Such care aims at the prevention and/or relief of suffering through early identification, correct assessment, and treatment of pain and any other physical, psychological, and spiritual problems. Moreover, they help the patient to achieve maximum autonomy over the course of his own life and treatment, by allowing him to choose, for example, the place of his death, to be informed, to have emotional support, and to have access to Diretivas Antecipadas de Vontade (DAV) and comfort measures.[5]

Thus, the Advance Directives of Will emerge as an instrument capable of facilitating the resolution of possible conflicts arising from indecisions regarding the conduct to be taken by health professionals, which proposes to minimize the dilemmas faced in issues related to the end of life. Through this documentation, the individual can make his wishes explicit, in case he is unable to express his will in the future due to illness.[6]

In Brazil, according to a mapping conducted by the National Association of Palliative Care (ANCP) in 2018, it is evident that 50% of the services offered appeared after 2010, making it clear that this is still a very recent practice, and that besides few trained professionals, there is no diffusion and adequate understanding of its concept.[7]

In this context, actions aimed at raising awareness and sharing experiences involving death and the finitude of life, such as the 'Death Café' movement, become relevant. The model was developed by the Swiss sociologist Bernard Crettaz and consists of informal meetings whose topic of discussion is related to terminality. It became a movement through Jon Underwood, who realized the importance of the model and transformed it into something bigger, having held more than 1000 meetings around the world.[8]

Thus, the use of the 'Death Café' model as a means to discuss death, dying, and the aspects involving finitude, aiming to approach the theme to health students and its demystification, presents itself in a promising way.[9] Thus, this study aimed to identify the perceptions of health students and professors about death and finitude of life, after participating in a 'Death Café' activity.

METHOD

This is a descriptive study, with a clinical-qualitative approach, based on the Logotherapy10 framework, carried out with 17 students and six professors from undergraduate health courses (nursing and medicine) participating in an activity based on discussions about death and finitude, during an afternoon coffee type meal.

The clinical-qualitative method prioritizes the psychological and psychosocial interpretation of the study agents, in the healthcare setting. For this, it is based on three fundamentals: the clinical approach, which employs the clinical knowledge of the researcher in the analysis of the research participants; the existentialist approach, arising from the existentialist material brought by the sample members; and the psychodynamic approach, which resorts to psychological principles for the construction and application of instruments, techniques, and theoretical references in the discussion of results.[11]

The qualitative research referential used was the Logotherapy and Existential Analysis proposed by Viktor Frankl, in which his ideas about the meaning of life as the center of man's motivation in his life choices were put into practice when he became a prisoner in the Auschwitz concentration camps during World War II. During the time he was held captive, he could prove through observation of his fellow prisoners that the lack of meaning made a difference in their lives, because those who had a reason for living were more resilient than those who had no such reason.[10]

The sessions were developed following the guidelines expressed in the Facilitators' Guide on the official website of the 'Death Café',[12] being held in the first semester of 2019 and consisting of face-to-face meetings with a maximum of 15 people, with an average duration of two and a half hours, in a relaxed environment, being offered tea, cakes, breads, and cookies to the participants, at a single large table, and mediated conversations about the theme of death and the finitude of life. Due to the climatic conditions of the location, tea was offered, not coffee, due to the possibility of offering iced tea.

The participants of the activity were invited to participate in the study after the sessions, and a semi-structured interview was conducted, recorded, in a private place, with the following questions: What is the meaning of Death for you? How do you understand Palliative Care? Tell me about the experience of participating in the meeting. What is your perception about the methodology used (place, planning, time etc.)? Had you heard about DAV before participating in the activity? How was the experience of thinking about DAV?

The interviews were transcribed in full, and the transcripts were presented to the participants for confirmation of the transcribed content. The participants' speeches were coded, where E1 represents student 1 and consequently E2, E3...the others; and P1 represents teacher 1 and subsequently P2, P3...the other teachers.

The transcripts constituted the corpus of the research, in which the thematic content analysis approach was used for its deepening.[13] The content of the interviewees' statements was grouped and associated according to thematic affinities, which were raised in an inductive manner, that is, based on the data and not considering the frequency of the analysis units.

For this process the following steps were followed: 1- a database was created with the complete transcription of the recorded interviews; 2- reading of the transcribed material, accompanied by notes of comments and impressions about the statements; 3- identification of the units of analysis, by thematic affinity, according to the motivations and purposes of the study; 4- coding of the material; 5- categorization, by grouping the meanings highlighted in the content of the reports.[13]

The research was evaluated and approved by the Research Ethics Committee of the Federal University of Mato Grosso do Sul, under CAAE: 20624819.4.0000.0021 and opinion number: 3.727.528, on November 26, 2019. The participants were invited to participate in the research after a clarification process and subsequent signing of the informed consent form.

RESULTS

From the analysis of the participants' speeches, four thematic categories emerged: 1. quality of life and death; 2. death and transcendentality; 3. preferences at the end of life; and 4. Breaking taboos.

Category 1. Quality of life and death.

When asked about their understanding of PC, most participants associated PC with extending the quality of life close to death, that is, the quality of death of patients who receive this type of care.

> *I understand it as a specific end-of-life care, but with the objective of giving quality death to the person, so that he and his family suffer as little as possible.* (E5)

> *I understand Palliative Care as an appropriate, humanized and indispensable way to provide comfort, serenity and acceptance of death to people who are in the process of finitude of life. They enable quality of life in the dying process.* (P1)

However, some participants, even after the experience, remain with the concept that PC are those intended only for the comfort of physical pain in the last moments of life.

> *This is the care that should be provided to the dying person so that he dies in the best possible way, ensuring dignity and well-being. From the moment there is nothing to do from a medical point of view until the final hour.* (P4)

For other participants, the concept of PC was expanded, contemplating the multidimensional aspect.

> *Palliative care, I understand as a way to make the patient as comfortable as possible, both physically and spiritually.* (E10)

Further emphasizing that, PC should go beyond looking at the patient to include family members, participant D3 mentions that:

PC is like a warmth for those who need it, not only the patient... it's like a warmth, that last warmth that the person and family needs. (P3)

Category 2. death and transcendentality.

When asked about the meaning of death, the participants were divided into concepts such as "the end of life", "end of a cycle", "natural process".

The meaning of death for me... I rarely stop to think about it. But sometimes in my life I've come to some conclusions... I think that death, for me, I don't believe in religions or anything like that, I think it's an end, like, it's an end really, an end of a life that ended there. You know, I don't believe that there is a paradise or an afterlife." (E1)

It is associated with a closing stage in the life cycle. (P6)

However, the mentions that most emerged in the speeches of the participants considered death as a passage (45.8%). When discussing PC, which directly involves the concepts of terminality, it is impossible not to have an empathic look, in which we put ourselves in the place of the one contemplating the proximity of death. The various conceptions of death are based on the individual's cultural baggage, but the vision of terminality as a transition is imbued with the spiritual character of the human being.

For me death represents the end of life here on earth, where it will be a passage to eternity. (E5)

For me, death is the end of the process of living, it is the possibility of our spirit (mind/energy) passing into another dimension, where our physical matter is no longer necessary. (P1)

Category 3. End-of-life preferences.

During the interview the participants were asked about their knowledge about DAV. Most of them (66.6%) had no knowledge about this instrument and had not even allowed themselves to think about this possibility.

So I had never heard of it, this is the first time I really heard about it, it was at the Death Cafe. And I didn't stop to think if... it's this, or that, so I can't really say what my experience would be." (E7)

I did not know about DAV, it was important to know because it opened a new horizon to think about my own death, as well as to orient my family and other people of my acquaintance about these guidelines. (P1)

However, some professionals do not understand the real purpose of DAV, associating this tool with euthanasia or assisted suicide.

Yes, no. Isn't it that thing where you know what the patient's will is? That business of euthanasia, you know those things?... (P4)

On the other hand, even though they understand the concept, professionals have difficulty in accepting the predominance of patient autonomy over attempts at a cure, even though these are unfounded and impossible to achieve.

...I confess that for me it was a very difficult feeling. As a future health professional, we always think that we should fight until the end for life. .. (E6)

Another point mentioned by the participants, when commenting on DAV, was the legal aspects related to the instrument, in which the lack of a national legislation does not give the instrument the importance it deserves.

... And I had already thought about it because of American movies that talk about it a lot, I think it is interesting, but in Brazil it is not worth much, unfortunately, not yet. So, you think that you would do it, but you stop and, as it is not worth much in Brazil, you don't think much about it.. " (E14)

Nevertheless, participants demonstrated an understanding of the benefits that conversations about end-of-life and DAVcan bring to PC patients.

...it is a support that the patient has at the end of life. And you respect the ideologies and wills of this patient, improve the quality of life in this final stage and that he stays close to his family, close to what he likes, without a doubt, is the way for him to have a better quality end of life.". (E2)

Category 4: Breaking Taboos.

The participants were asked about their experiences and perceptions when participating in the methodology. There were many answers, but the mentions concentrated on two main subjects: the change in the professional vision of terminality (41.6%) and the breaking of the concept of death as a taboo (37,5%).

Thus, the 'Death Café' contributed a lot in the aspect of knowledge about death and also about knowing how to respect the limits of each one, when they want to talk about the subject. Just as society deals with death in an attempt to exclude it from daily life, generally health professionals also seem to use this escape, many still have limitations when working with death, they feel like failures in doing their job, and this, many times, contributes to their denial of the death process. (P3)

Another issue that was highlighted in this category, was the changing understanding of death by the participants:

It provided me with important information and led me to reflections that became knowledge and new perceptions about the dying process, knowledge and perceptions that I will be able to discuss with the students who attend my courses, as well as serve as support for eventual professional and/or personal participation with people in the dying process. (P2)

DISCUSSION

PC when inserted into the training of future health professionals allows them to develop their cognitive and affective tools, so that when they are faced with real situations of death of their patients, they do not suffer in a dysfunctional way.[14] Thus, the understanding of PC brought by most participants after the activity, as observed in the category "Quality of life and death", converges with the literature, because they realized that PC can increase the patient's comfort and improve the family's decision--making process regarding issues of health procedures at the end of life, the decrease of aggressive procedures, the increase of death in the home environment and the decrease of admissions in intensive care units; therefore, increasing the quality of life near death.[15-16]

Another point addressed in the category "Quality of life and death" by the participants is the involvement of the family in end-of-life issues. Thus, it is necessary that the team takes into account the family and the patient as a unit of care, seeking an attention guided by the facing of finitude, and the minimization of physical, psychological and spiritual suffering.[17-18] In this scenario, it is fundamental that the family understands the end-of-life process, since if the patient is not able to express his wishes, it will be the family that will guide the actions that will be offered to the individual, which can lead to insistence on unnecessary investments by the team, prolonging the patient's suffering if the family is not clear enough.[19-20]

In their reflection on the duality of life and death, in the category "Death and transcendentality", the participants show the different perspectives on terminality. Most of them, however, meant it in a transcendental way, considering that man is a multidimensional being, containing the physical, mental, emotional, and spiritual dimensions.[4,21] The latter is explained in part by the search for a superhuman force, unattainable by tangible understanding that connects us to the sacred. From this angle, man is apt, by nature, to connect with transcendentality, representing the sacred, manifesting his faith.[22]

According to Logotherapy, there is in man the noetic dimension, which corresponds to the spiritual dimension.10 However, this human aspect permeates transcendentality through consciousness, which Frankl calls "transcendental consciousness", in which the "voice of consciousness" would actually be the "voice of transcendence". Through "unconscious religiosity", there is the unconscious tendency to search for the sacred.[10,23]

Belief in a higher power that transcends human existence is a favorable attitude for dealing with stressful scenarios. According to the literature, belief in a transcendental being helps with mental health, stress, and even with coping with death.[24-25] A qualitative study conducted in two Danish hospices aimed to explore the feelings of elderly people over 65 years old about death, dying, and their meaning. One of the points investigated was what they thought about what would happen after death. About this, the researchers reported that the hope for a better life after death was very present and relevant in the interviews, even though, according to the study, the Danes are characterized by skepticism and little religious compared to other societies.[26]

Another important aspect brought by the study in the category "Preferences at the end of life" was the notorious lack of knowledge that the participants had about the DAV - an important tool for the exercise of autonomy by patients, especially those in PC, therefore, bringing quality of life near death, by avoiding invasive procedures that will not bring real benefits to the quality or prolongation of life.[27] This knowledge gap, on the part of the participants, converges with the literature that still points to this deficit as one of the barriers to the application, by health professionals, of the Advance Care Planning (ACP), which are discussions about the wishes and desires of patients near the end of life that result in the DAV.[27-28]

When considering the legislation related to DAV in Brazil, one of the points raised by participants in the category "End-of--life preferences", it is noteworthy that the country does not have a federal law on this issue. However, in this area, there are two resolutions (Resolution 1995/12 of 2012; Resolution 2232/2019) of the Federal Council of Medicine (CFM), which support this practice.29 However, knowledge about the legislation related to VAD is relevant for professionals, because it leads them in the application of ACP, considering that it aims at DAV, and allows respect for patient autonomy within the law.[30-31]

This study showed how a simple educational intervention, but on a complex subject can change the look of both students and teachers, and make them reflect on the care provided to the other and on their own lives, as shown in the category "Breaking Taboos". Despite being a subject that brings several negative feelings such as sadness, fear and anguish, for denoting the unknown, the end of life is one of the certainties that life brings, due to the mortal characteristic of our existence.[14] Thus, converging with studies that used the "Death Café" as a tool to address the terminality with health students,[8-9] this strategy was considered beneficial by the participants, because they identified it as a safe environment in which they felt confident to discuss the finitude.

CONCLUDING REMARKS

After the 'Death Café' intervention, it was possible to identify the change in the perceptions that students and teachers presented about the issues related to PC, death and the finitude of life.

The changes highlighted in the study, through the words of the participants, allow us to infer that the investment in dealing with issues related to death and finitude of life, whether with students, or even professionals, causes the pre-established prejudices on the subject to be undone, impacting positively on the care of patients who are in situations close to finitude. Thus, the need to train professionals in practice and in training on the subject is highlighted, in order to break the taboo about death, thus ensuring that the needs at the end of life of the patient are met, and also the presence of a professional who provides biopsychosocial and spiritual support, acting preventively and/or curatively, contributing to the patient's survival with quality and a dignified death.

FINANCING

This study was financially supported by the Scientific Initiation Scholarship Program of the Federal University of Mato Grosso do Sul (PIBIC-PROPP-UFMS).

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