Educational innovation as a communication strategy in Palliative Care (Teach-Inn Pal)

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ABSTRACT

Introduction: Society associates palliative care with "death" or "end of life", which cause them fear and anxiety. The media worsens the misunderstanding by depicting a wrong picture of palliative care. Educational innovation for university students may serve as an alternative communication strategy. Care and Society is a university course designed by and for students from non-health degrees to help disseminate the palliative care message. The first year of the Teach-Inn Pal project aims to evaluate the effects of the course and to identify areas of improvement.
Objective: to present an evaluation to determine if the course can work as a campaign to refocus the public opinion on palliative care.
Methodology: a prospective Participatory Action Research study. University students enrolled in the course (n=29) are invited to test and redesign the palliative care message. Knowledge and empathy will be measured throughout the learning process. Afterwards, qualitative, thematic, inductive analysis of the course material will be carried out.
Discussion: this study is part of a doctoral thesis. Education is used as a creative outlet, allowing rapid testing of multiple tools to create ambassadors of palliative care that may reframe the public opinion.

KEYWORDS

social change, educative communication, educational innovation, palliative care, health, strategy

1. Introduction

Palliative care is a worldwide necessity: more than 56.8 million people need specialized care for an incurable disease each year [1]. In response to this reality, palliative care started in 1967, when Cicely Saunders founded the first hospice dedicated to providing an integral support (physical, emotional, social, and spiritual) to terminally ill patients to improve their quality of life [2,3]. However, at present, the supply of palliative care is still not sufficient to meet the demographic demand [4,5]. Three examples of the inadequacy of the current services are the insufficient specialized services per 100, 000 inhabitants, the lack of legislations including palliative care, and palliative care curricula included in health-related degrees.

The European Association of Palliative Care (EAPC) suggested a minimum of two specialized palliative care services for every 100.000 inhabitants [6]. And yet, there are few countries that reach this threshold. From the 49 countries analyzed in the EAPC Atlas of Palliative Care in Europe (2019), the only country that met this recommendation was Austria, with 2.2 palliative care specialized services. Yet, the rest of the countries fell short on this requirement: on average, there only were 0.8 specialized services per 100,000 inhabitants [6]. Regarding the legislation, 76% of European countries have adapted their General Health laws to include palliative care, but only eight countries have written a law about palliative care [6]. As for the education, palliative care is increasingly being included in the curricula across European Medical and Nursing Schools. However, the percentage of Schools teaching palliative care per country and the way it is taught varies greatly [6]. Only 9 countries report teaching palliative care as a mandatory subject, and very few countries report offering over 20 palliative care teaching hours and mandatory clinical practice [6].

More specifically, in Spain there are 0.6 specialized services per 100,000 inhabitants and there are no national laws regulating the provision of palliative care [6]. Furthermore, even if more than half of the Medical and Nursing Schools offer subjects related to palliative care, only 48% of the Nursing Schools and 10% of the Medical Schools include these studies as a part of their obligatory curricula [6].

2. State of the art

2.1 Educational innovation strategy

Palliative care has a communication problem, as 54 years after its creation the concept is still misunderstood. Palliative care is currently perceived as "death" or "end of life”, and that misconception continues to generate feelings of bereavement, fear, and anxiety in society [7,8]. The media may play an important role in this misunderstanding. An analysis of 600 Spanish newspapers (2009-2014) concluded that information on palliative care does not reflect its true nature, as the narratives used to talk about it are based on ideological and moral content such as the debate of issues like euthanasia (9).

Health-related issues are frequent in the public opinion sphere. Therefore, the possibilities offered by communication for the development of a healthier society have been studied for years [10,11]. Due to its evolution and persuasive capacity, communication has become an essential component of health prevention and health promotion programs to inform and educate citizens [10,12,13]. Within the health sector, communication campaigns facilitate social education because they seek to increase the knowledge to encourage new behaviors [10,12, 14, 15]. And these campaigns have secondary goals, such as bringing attention to an issue to create an agenda [14, 16, 17].

However, the benefits also work the other way around. Educational programs such as Massive Online Open Courses (MOOC), despite not being an explicit communication campaign, have successfully started conversations around several topics and helped clarify issues [18]. MOOCS have also been widely used to disseminate research results beyond the academic sphere [19]. Specifically, the Dying2Learn MOOC demonstrated that the educational ambiance was favorable to increase participants' comfort to discuss difficult issues such as death, to foster conversations about this topic, and to explore unheard perspectives from people outside the healthcare context [20]. These results can be a foundation for the development of palliative care resources and information context [20]; which, in turn, could be the basis for formal communication campaigns.

On that line, some social studies have focused on finding new ways to overcome the confusion generated around palliative care [21,22]. The last diagnostic study of the EnPositive-PAL project conducted with university students all over Spain highlighted that it is positive to involve students when designing a strategy to disseminate the palliative care message [23]. It used the Participatory Action Research method, Design Thinking and adopted a strategy of public engagement in Responsible Research and Innovation with the idea of creating a social intervention to promote a transformative, active, and service-learning approach [23]. The result of this process is Care and Society: a four-module course aimed to create a meaningful learning experience for university students from degrees unrelated to the health sector.

2.2 Why university students from degrees unrelated to the health sector

In a health communication campaign, a desirable outcome is for the target audience to become an ambassador of the cause. Ambassadors, otherwise known as influencers, are people that can exert interpersonal influence or help reform the environmental condition that shapes the behaviors of the segment to be changed [24]. Creating ambassadors have two advantages. Firstly, they can customize the message to the needs and values of their peers [24]. Peer to peer communication has been proven to facilitate health messaging, because fellow community members are both trusted and relatable, and able to express information in an understandable and significant way [25]. Secondly, ambassadors are likely to respond to negative behaviors of those they are attempting to influence [24]. This type of engagement provides opportunities for giving instant feedback, having open dialogues, and answering questions immediately [26].

Moreover, as the issue of palliative care in the academic curricula of health-related degrees is already being tackled [27, 28], the aim of this course is to reach students belonging to areas of expertise outside the sector. Considering the two previous advantages, students with different backgrounds and areas of expertise are an ideal group to create ambassadors, as the variety of backgrounds will allow the palliative care message to be disseminated beyond the field of health. The social intervention proposes to reach the students through the Core Curriculum: an initiative designed to offer students from a wide range of degrees an integral education in core areas of study [29, 30]. Aligned with that objective, the Core Curriculum course Care and Society seeks to convey to the university students the value of caring for others within society.

2.3 Care and Society course structure

2.3.1 Module I: Transformative learning

In this module, through flipped classes, the students will receive the theory required to face the rest of the course. The students will learn to identify situations of serious illness that involve intense suffering, and to outline a set of actions that help to care for the person suffering. During this segment, the total of students will be divided in three groups to encourage participation and to adapt the class to the necessities of everyone. The groups will switch professors every two weeks, as each professor will oversee the explanation of a set of topics related to one of three categories: cancer, dementia, and neurodegenerative illnesses.

2.3.2 Module II: Active learning

Through a self-learning circuit inspired on an Escape Room dynamic, students will be the protagonists in building their own knowledge. By the end of the module, the students will be able to understand what the process of assisting, caring and alleviating suffering is like. The total of students will be divided in groups of six to facilitate and encourage the interaction of students with the environment.

2.3.3 Module III: Service learning

Students will participate individually in community service activities, allowing them to link what they have learned in modules I and II with the local context. By the end of the module, the student will have developed their personal and professional competencies, and will be able to evaluate, implement, and recommend good practices when caring for people.

2.3.4 Module IV: Multiplier learning

All students will attend a four-hour seminar titled “An introduction to rhetoric” that will give them some resources to improve their ability to express themselves and construct valid arguments on a topic. By the end of the module, the students will be able to plan a persuasive speech according to the basics of rhetoric. The seminar will be led by a teacher specialized in communication and will be taught to all students together.

3. Method

This pilot study, of the three-year multicenter project Teach-Inn Pal, is part of a doctoral thesis. The project started on November 2021 and will continue until September 2024. The pilot study took place on the second semester of the academic course 2021-2022, starting on January 2022.

3.1 Objective

Using an interdisciplinary approach, Care and Society focuses on promoting the knowledge of palliative care and increasing the empathy of students on issues related to accompanying and caring for people suffering from a serious illness. The objective of this protocol is to present the possible evaluation of Care and Society as public health communication strategy. This proposal stems from the recognition that education is inherent to communication, and therefore aims to evaluate the communicative worth of innovative education to promote a positive message of palliative care.

This research aims to address two questions:
(1) Is educational innovation a suitable solution to the communication necessities of palliative care?
(2) Can students help amplify the palliative care message?

3.2 Research design

It is a prospective study with a participatory action research framework, using multiple methods for data collection such as application of scales, satisfaction questionnaires, focus groups and direct observation. Participatory action research is composed of cyclical steps of planning, action, observation, and results, making participants evolve from the beginning [31, 32]. This allows us to receive feedback and incorporate it to improve both the course and the assessment techniques along the process before their implementation in other universities. Consequently, this is considered a pilot study, deeming the course Care and Society the prototype of the social intervention. We understand that evaluations related to the changes in attitudes and behaviors cannot be based on immediate results. Therefore, it is intended that this evaluation will be conducted over 3 years, giving us the opportunity to repeat the intervention and see its results in medium-term.

3.3 Moments of evaluation

The evaluation will assess the capacity of the course to turn students into ambassadors that can change the framework of the discussion in society. We understand as ambassadors the students who demonstrate: (1) an adequate degree of understanding of the concept of palliative care, (2) a positive attitude towards the social problem, (3) the ability to communicate the message of palliative care and (4) to retain the knowledge five months after taking the course. The overall assessment of the course will focus on four moments of evaluation.

3.3.1 Moment 1: Initial assessment

In Moment 1, one week before the beginning of the course, students will receive an email inviting them to participate in the study. The invitation will have three links: one to the initial Palliative Care Knowledge Questionnaire (PCKQ), another to a Cognitive and Affective Empathy Test (TECA), and the last to a consent form for recontact.

3.3.2 Moment 2: Learning Assessment

Following the end of Module I, students will receive links to the PCKQ and TECA of Moment 2. Furthermore, to evaluate Module II for teaching purposes, a ten-minute debriefing will be recorded at the end of the Escape Room. With their written consent, transcripts of this recording will be used to help analyze the data.

3.3.3 Moment 3: Final assessment

The final two classes in the course contemplate a seminar where students will learn the basics of Rhetoric. They will write a speech, applying the knowledge of palliative care acquired during the course and the resources given throughout the seminar. The speeches will be sent to and graded by the professor, who will forward them to the research team to be analyzed accordingly. The teacher will then proceed to select the five best speeches for a Message Transmission Experiment. For this experiment, five selected students will deliver their speech in front of first-year students not enrolled or related in any way to the course. Following the speeches, the first-year students will fill out a questionnaire to assess their understanding of palliative care after the experience.

Additionally, prior to the last day of class, students will turn in a written reflection regarding the Module III experience. This material will also be analyzed for the research with the prior written consent of the students. After the class is over, students will receive the link to answer the last PCKQ and TECA. Participants will also receive a link to provide feedback on the course through a satisfaction and commitment questionnaire that includes an open question and a learning commitment regarding an attitude change: "After what you have learned in this course, what do you intend to change in your attitude in the coming months to enhance the palliative care message?".

Lastly, all the students and teachers of Care and Society will be invited to participate in a focus group to evaluate the overall experience in this course. The first five students who respond to this request will be selected. The purpose of this focus group is to analyze the strengths and weaknesses of the methodology, the content and other aspects of the course.

3.3.4 Moment 4: Mid-term assessment

Five months after completing the course, students will be emailed a link to an online questionnaire to assess their mid-term knowledge and to indicate the extent to which they have implemented the learning commitment outlined in the satisfaction and commitment questionnaire. Students should respond to the question "You have set out to change your attitude to improve the palliative care message. Have you managed to accomplish this in the last few months? Please provide an example." Furthermore, they will receive an invitation to participate on in-depth interviews to talk about their experience on the months following the course and to confirm whether they have retransmitted the palliative care message at some point during that timeframe.

3.4 Participants

During the pilot, the course will be offered as an elective class to a maximum of 30 students in their second or subsequent years of university from the Schools of Economics and Business, Architecture, Education and Psychology. Students of fields somewhat related to health will not be admitted.

3.5 Data management

To protect the identity of the participants, every student will create his or her own code at the beginning of the study. The code will be the combination of a city and three numbers. It will be used in all questionnaires, so that the researcher is only be able to associate each questionnaire with a code instead of data identifying the sender.

Students will receive the first set of questionnaires in an email invitation sent through the university's in-house platform. The email addresses of the students who decide to participate will be saved by the researchers to send the next steps of the study directly to them. These emails will be stored separately and will in no way be linked to the answers of the questionnaires or to the generated codes.

The answers of the questionnaires will be analyzed after the course has been completed and the grades submitted. This guarantees that professors will not receive any information related to the study. Written consents about the contact will be destroyed once the project is finished and will not be associated in any way to the answers of the questionnaires. All information will remain confidential in accordance with the Data Protection Act.

The data from this study will be incorporated into a database or file without personal data and access will be available to the study personnel. A backup copy of the personal data file related to recruited participants will be kept on the hard drive of the principal investigator's university computer equipment and will be accessible to the principal investigator for 3 years. After those three years, all data will be deleted.

3.6 Ethical considerations

The study will comply at all times with the principles of the European Code of Conduct for Research Integrity. Written consents will be obtained from all the participants. The University of Navarre Research Ethics Committee has approved this study (2021.204) and will monitor that the ethical principles of research involving human subjects are adhered to.

4. Discussion

In the first year of the Teach-Inn Pal project, the protocol proposed an assessment method to evaluate the effectiveness of the course in transmitting the palliative care message to people beyond the health sector. This protocol also assessed the course capacity to create ambassadors of palliative care who can generate new frameworks for dialogue within society. To respond to these propositions, we identified two research questions that will be discussed below.

4.1 Research question 1: Is educational innovation a suitable solution to the communication necessities of palliative care?

We believe that this approach is innovative as it averts the usual health promotion programs, in which the information moves on a one-way flow from the sender to the recipients and is heavily dependent on the media as a channel [9, 24]. This social intervention shifts the trajectory in the dissemination of palliative care knowledge to society. The course was designed to be an extended experience that allowed students to see first-hand what care looks like and have dialogues with professionals dedicated to caring. Educational innovation seems to be a tailored solution to the communication necessities of palliative care, as it may leave a long-lasting impression on students, ensuring that the palliative care message is well embedded on the recipients.

4.2 Research question 2: Can students help amplify the palliative care message?

This project perceives students who are not in the health sector as potential re-transmitters of the palliative care message to society. If the information learnt through the course resonates with the students, they will serve as a conduit to amplify the palliative care message [24]. Thus, we believe Care and Society used education as creative outlet that utilized rapid testing of multiple tools to create palliative care ambassadors in society. And we are also confident that these ambassadors are potential seeds of change, as they will be able to react directly and immediately if they witness an incorrect portrayal of palliative care in their day-to-day life [25, 33]. Thus, potentially changing the public opinion on palliative care in the long run.

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