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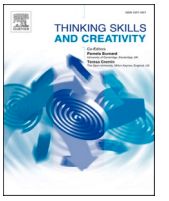

Combining interdisciplinarity and creative design - A powerful strategy to increase palliative care awareness within a university community

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ABSTRACT

Society's understanding of palliative care has room for improvement. Although the World Health Organisation highlighted palliative care as a human right, many people still lack access to this crucial form of treatment. The paucity of understanding and social discussion surrounding palliative care has, moreover, negatively impacted its development and implementation. This study therefore aims to construct a strategy that will empower a specific community to solve their own palliative care-related misunderstandings. Using Participatory Action Research and Design Thinking methodologies and adopting the strategy of Public Engagement in Responsible Research and Innovation, a design group worked for three months through five virtual focus groups. Moving through the phases of empathizing, defining, ideation, prototyping, and testing, the design group generated 33 ideas to address palliative care-related problems. Ideas related to self-learning, the use of technology, and the exchange of personal experiences are highlighted as innovative ways to promote palliative care. The design group adopted a variety of strategies, used disruptive tools, and created and tested rapid prototypes to discover novel solutions. This method of working, centred on interdisciplinarity and creativity, presents an efficient way to involve the members of a community in solving their own problems.

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1. Introduction

Over the last five years, several social and health studies have attempted to find new ways to convey a positive message about palliative care to society (McIlfatrick et al., 2021; Reigada et al., 2021b; Wallerstedt et al., 2019). Across society, the concept of palliative care is still associated with feelings of fear, anxiety, and death, rather than with compassion and support or appropriate care (Carrasco et al., 2019; McIlfatrick et al., 2021). However, the definition of palliative care, which impacts the scope of practice, has not always been understood in a uniform way, which in turn poses a barrier to the design, understanding, delivery, and access to palliative care for society at large. Different definitions of palliative care have been presented between countries and even between leading institutions in the field, such as the World Health Organization or the National Council for Palliative Care (Russell, 2015). It is interesting to highlight the search for consensus in the definition of key terms (Xiao et al., 2021) between palliative care stakeholders worldwide (Radbruch et al., 2020). Radbruch et al. (2020) define "palliative care as the active holistic care of individuals across all ages with suffering when it is associated with illness or injury of any kind. Health-related suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social, spiritual, and/or emotional functioning) because of severe illness (severe illness is a condition that carries a high risk of mortality, negatively impacts the quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress), and especially of those near the end of life. It aims to improve patient families', and caregivers' quality of life". The triad consists of the patient, the caregiver – usually a family member – and the palliative care professional, all of whom share a real vision of palliative care. These stakeholders see integrated into their daily lives the conceptual facet of palliative care (what is understood or perceived to be 'palliative care'), the procedural and instrumental facet (how to interact with palliative care), and the attitudinal facet (how palliative care is experienced and felt). In contrast, the general population approaches palliative care from a mainly theoretical approach.

Globally, 45% of countries have no current access to palliative care; in Spain, slightly less than 0.6% of the population have access to such services (Arias-Casais et al., 2020). Thus far, most palliative care awareness strategies have been linked directly to education and communication campaigns, courses, academic and social events, and they are frequently presented in the literature as having immediate positive effects (Seymour, 2018). From an educational point of view, there is a perceived lack of adequate training on what is meant by palliative care. While for the stakeholders that make up the mentioned triad an important road is being travelled towards a better understanding of the term (Alcalde & Zimmermann, 2022; Ryan et al., 2020; Zimmermann et al., 2016), recent studies suggest that society at large still lacks an understanding of palliative care (Fliedner et al., 2021; Law, 2019; Mallon et al., 2021b; Reigada et al., 2021b). This misunderstanding may generate stigma or misperceptions in the general population (Grant et al., 2021; Patel & Lyons, 2020) on when the palliative approach should start, which patients should receive it, or on how it compares with curative care (Pastrana et al., 2008). Misunderstandings among the general population include associating palliative care with end-of-life care only, associating it with a greater social stigma related to death, confusing it with hospice activities, portraying it as a last resort with a consequent lack of hope, and therefore not promoting treatment in the early stages of a disease or seeing palliative care as an alternative to further treatment. These misunderstandings about the meaning of palliative care, along with priorities and beliefs, can be potential barriers to care, since stigma regarding what is meant by palliative care can be perpetuated by those who think they know what it means (Zimmermann et al., 2021).

Few studies and initiatives target the non-palliative care public to improve their knowledge in this area (Hoerger et al., 2017; Mallon et al., 2021a; Zimmermann et al., 2021). Some analyse the state of knowledge of the general population about the definition and that population's attitudes towards palliative care. The results indicate that a better knowledge of palliative care can help to reduce stigmatization (Zimmermann et al., 2021) and improve perception of it (Akiyama et al, 2016). The improvement of palliative care knowledge thus seems to be linked to the attitude referred to below. Some research has analysed the attitudes that palliative care evokes in the general population. Affective predictions attempt to predict how patients and others will think and feel about the topic in the future. Biases in affective predictions, however, may serve as barriers to optimal palliative care delivery (Ellis et al., 2019). It seems, therefore, appropriate to devote efforts to improving awareness improving among the general population.

Perhaps palliative care education is not yet as integrated as it should be in the academic sector and, perhaps, should be worked on as a life-long learning skill (Ellis et al., 2019). A recent study by Reigada et al. (2021b) concluded that undergraduate students tend not to talk about palliative care, as they assume it equals death and believe it is of little concern to themselves, since they are young. Surprisingly, the students also reveal that the consequent lack of knowledge of the subject causes them distress, and for that reason they find it necessary to learn about it. In our day, thanks to the opportunities afforded by new forms of education, nursing students alerted by the literature can actively help clarify the social understanding of palliative care topics in society (Noguera et al., 2018). Studies centred largely on students in health disciplines showed that medical students are highly sensitive toward this topic (Dimoula et al., 2019; Miltiades, 2020). Also, one recent study revealed that young university students from non-health-related disciplines such as social work, law, communication, and design, can provide an active voice when building counter-narratives to the negative social perception of palliative care, as well as when defending it as a human right (Reigada et al., 2021b). While it is important for any group that lacks expertise in palliative care to gain adequate knowledge of it, young people are the population group that is characterized by a maturing psychological and social awareness, by a lack of experience in many areas of life, yet at the same time by their high commitment to the values they defend. They are therefore key to facilitating behavioural change (De Leeuw et al., 2015). For this reason, young people, including university students, seem to be particularly vulnerable to a lack of competent reflection, in particular towards aspects related to control of the fear of death (Testoni et al., 2016). However, young people, whether in health care or any other field, may experience first-hand the suffering and/or death of loved ones in tragic events (Cupit & Kuchta, 2017). As a result, and despite being self-educated in matters relating to death (Liu et al., 2019), this group may be the most vulnerable group. Nonetheless, they are also the most interested in learning to respond to what they experience first-hand, which can be achieved, by providing a

foundation of positive experience of palliative care that will affect their life trajectories and enable them to make the personal commitments required to successfully navigate their lives and the lives of others in the future. On the other hand, helping young people to express their ideas about palliative care as a group helps to minimise the effect of avoidance or hesitancy and to highlight their misunderstanding and failure to address it in their usual narrative (Mallon et al., 2021; Zimmermann et al., 2021). The fact that more university students are being encouraged to learn about values-based work leads us to think that they may be the group to whom the issue of palliative care should be work with to allow them to elevate the issue into a social discussion (Reigada et al., 2021b).

Small-group interventions have been shown to be particularly suited to transformative change in learners as the goal of education and to be particularly appropriate for use in palliative care education (Macauley & Billings, 2011). The literature argues that a process of constant cognitive and emotional discussion can lead to good-quality ideas that are both feasible and focused on a specific context (Cox et al., 2021). The prevalence of this mechanism in academic settings explains why universities are often privileged places in which to collaborate, communicate, and, through creativity and critical thinking, solve social complex problems through innovation (Manalo & Kapur, 2018). It follows that there is a fundamental necessity to co-design hybrid environments, both physical and digital, while using design as an integrative discipline. Further, this must be accomplished while bearing in mind that students are the main asset. The overall process is well-summarised by Ezio Manzini (2017), who declared that "every co-design process includes the co-creation of shared ideas about what to do and how to do it, ideas that emerge from the interaction between the social actors concerned."

Not having the opportunity to discuss this topic on a social level can be considered a significant barrier to implementing quality care within the health system and to gaining access to what the World Health Organisation (WHO) recognises as a human right for those facing life-threatening illness (WHO, 2014). Given this need to bring fresh thinking to increasing palliative care awareness, Design Thinking methodologies stand out as a prominent method of empowering specific communities to construct effective awareness-boosting strategies. Drawing on a range of individual experiences, Design Thinking can help to develop innovative products, services, or models. In addition, Design Thinking often uncovers strategic solutions to complex problems, a quality that helps discover how to better communicate and understand palliative care (Altman et al., 2018; Brown, 2008).

Building from these insights, this study employs a person-centred methodology that incorporates university professors, researchers, and undergraduate students from a university environment. It does not employ experts in palliative care, nor is it focused on persons who work with patients or who are direct recipients of palliative services; the clinical and educational approach to palliative care aimed at primary/integrative care on this topic is therefore neglected (Mroz et al., 2021). The aim of this study is to find a novel strategy to empower a specific university community to solve their misunderstanding around palliative care. In the first diagnostic phase prior to this work, the misunderstandings of a group of university students concerning palliative care were explored (Reigada et al., 2021b). An exploratory qualitative focus group study was carried out with the participation of a team of experts composed of palliative and non-palliative researchers, physicians, and nurses. Firstly, students were diagnosed as having an ambiguous understanding of palliative care. This ambiguous understanding causes them distress, in that they hold stereotypes reported in many other studies; that is, they associate palliative care with the end of life and specifically with death and dying. Secondly, and derived from the previous stigma, students report little urgency to learn about palliative care because they feel young and consider the subject to be of more interest to those who have some connection to the field of health (See Table 1).

Once this point has been reached, a methodological strategy is required to enhance the understanding of these theoretical parameters.

2. Methods

2.1. Research design

This multimethod study is based on a Participatory Action Research (PAR) model, a progressive set of research phases that include planning, action, observation, and results, with the aim of understanding and transforming socio-educational realities and practices. This method allows practical knowledge to be obtained based on constant reflection on a problem and allows interaction and dialogue with and among participants, which enables the negotiation and construction of new meanings and interventions (Adelman, 1993; Lewin, 1946). We then combined this approach with Design Thinking, a recursive methodology marked by flexibility and creativity in the phases of empathy, definition, idea, prototype, and testing. The empathy and definition stage allow us to understand the context and the reality surrounding a problem. Basically, it helps to identify the specific problem that needs to be solved. Ideation is the phase where, through brainstorming, many ideas are produced, and insights are generated. These ideas are understood as possible solutions

Table 1
Understanding-strengthening the Definition of Palliative Care (Reigada et al., 2021).

STEREOTYPES TO BE ELIMINATED	UNDERSTANDING – STRENGTHENING THE DEFINITION OF PALLIATIVE CARE
Synonymous with death, a place where people go to die	- Palliative care gives hope and quality of life - Palliative care helps patients maintain dignity - Palliative care relieves pain and other symptoms - Palliative care is delivered by a team of professionals
Associated with older people	- Palliative Care is an issue relevant to more than those directly affected. - Palliative care is an issue relevant to your life today. - It is a universal right.

that, at the end of this phase, can be prototyped and tested. Design Thinking is a concept that allows ideas to be generated and organised to find the best solution to a problem. Whether it succeeds depends on the implementation of the creative idea and its evaluation and whether it helps to solve the initial problem or not (Walker et al., 2019).

Finally, we also adopted a Public Engagement in Responsible Research and Innovation (PE-RRI) strategy, engaging the research subjects themselves as co-researchers and making them participants starting from the research design stage, as recommended by the European Commission (2015). Responsible Research and Innovation is a dynamic process that means caring for the future by collectively managing science and innovation in the present. It is the ongoing process of aligning research and innovation with the values, needs and expectations of society and in which decision-making is increasingly collective and transparent. All actors involved in research and innovation become mutually active, responsible and representative. Together with researchers, the general population engages in mutual learning and agrees on practices to develop joint solutions to social problems and opportunities (European Commission, Directorate-General for Research and Innovation, 2015).

We used several data collection strategies, such as virtual focus groups (FG), direct observation, virtual tools including Miro (https://miro.com/about/), virtual conversations (chats), brainstorming, and brainwriting. FG transcriptions, field notes, visual thinking exercises (e.g., an empathy map and affinity diagrams), documentation, videos, and notes from non-verbal communication were also used to collect and analyse data. This use of a creative, multi-methodological approach has served not so much to find anticipated solutions operating in already-existing spaces but instead to break down certain initial prejudices with 'the simple but revolutionary idea that people can be considered (also) an asset and that they should see themselves as an asset in the first place' (Manzini, 2017). Towards this end, we used the problem-solving strategy detailed in Table 1, below Table 2.

2.2. Context

This study is part of the second phase of a large project (EnPositive-PAL) to implement a social intervention with the students of the University of Navarra to promote a creative way to enhance positive attitudes toward palliative care (Reigada et al., 2021b). The University of Navarra is a private, Christian-inspired institution with 16 faculties, offering 37 degrees and with an enrolment of more than 12,000 students. The university's academic goal until 2025 is to contribute to the resolution of society's challenges regarding sustainable development and to care for people and their environment in an interdisciplinary way.

2.3. Participants

From September to December 2021, individuals from University of Navarra were invited to work together to design an innovative solution to improve palliative care awareness and to form a focused team deemed the design group. Researchers and university professors joined this research group, and students were recruited. The recruitment sought up to ten undergraduate students at University of Navarra studying towards both health and non-healthcare degrees, 23 years old or younger, who understood the Spanish language and agreed to work directly with university professors and researchers during five virtual FG, once a week, for a maximum of two hours each. Our call specifically targeted individuals who see themselves as creative, curious, and disruptive. Students from the Faculties of Medicine, Nursing, Communication, Architecture, Education and Psychology, and Business programs of University of Navarra were invited to integrate into the design group by email, social media, and internal student newsletter. Those who agreed to participate received detailed information about the study and an informed consent form.

Five researchers, four university professors, and seven undergraduate students (n=16) participated in five focus groups. Eleven members participated in a sixth FG. The average age of the group was 32.6 years (range 18-55). Social Work, Economics, Design, Nursing, Education, Palliative Care, Journalism, Nursing, and Medicine were the areas of knowledge represented in the group. Student participants were enrolled in both health degree (n=2) and non-health degree (n=5) programs and had a mean age of 20.7 years (range 18-23).

2.4. Data collection

The design group participated in five virtual focus group (FG) meetings in three months. Each FG included four facilitators and two observers. The lead facilitator (author SH) moderated and dynamized the group, introduced topics, asked questions, and launched creative 'games' to encourage participants to feel confident sharing their ideas. The support facilitators (authors AA, AT, CR) recorded

Table 2
Problem-Solving Strategy.

Problem	Palliative care still faces a problem of understanding and social acceptance. Strategies to inform the public implemented thus far seem to lack long-term effectiveness. Specific problem: Undergraduate students tend not to talk about palliative care as they assume that it is the same as death, and they reveal that the lack of knowledge about palliative care causes them distress. Moreover, undergraduate students believe that palliative care is of little concern because they are young.
Main strategy	We invited the university community to address the specific problem. We used multi-methodological strategies in a dynamic, interdisciplinary and creative approach based on Design Thinking.
Research question	Is it possible for a specific community, hampered by a lack of understanding and dialogue about palliative care, to solve its own problem through interdisciplinarity and creativity?

participants' comments and ideas, supported them with virtual tools, managed the meeting times, moderated the Zoom and WhatsApp chat, and supervised the FG in general. Observers (authors SR, AC, AS) helped reorient the FG, when necessary, by giving feedback on the topic, alerting the group when it was time to go deeper into an issue, pointing out any non-verbal behaviour among members of the group, and transcribing each FG (e.g., writing field notes). The observers turned off the camera ten minutes after the start of each FG. Beginning from the third FG, observers and facilitators actively contributed to the discussion.

During all FGs, the Design Thinking methodology was used, following its five phases: Empathise, Define, Ideate, Prototype, and Test (Altman et al., 2018). Each phase progressively adopted different strategies and tools in light of the ongoing FG results. The visual platform Miro (https://miro.com/) was used to dynamize and record design group outcomes. Techniques such as brainstorming, storyline creation, empathy mapping, and actor mapping, among others, were used. In each FG, the emphasis was on generating a rich understanding of palliative care in the university context in a free, fast, and intuitive way. The starting point of the first FG centred on the specific problems arising from the project's initial phase (Reigada et al., 2021b) (see Table 1). The subsequent FGs were systematically reorganised and planned to meet the goals for each Design Thinking phase. Each FG was simulated in advance via role-playing between facilitators to test the exercises and timing, maximizing participants' learning and sharing experiences, and consequently obtaining optimal outcomes in the following FG. A design assessment was done in a sixth FG to validate the findings, to list barriers and opportunities that resulted from the work dynamics and methodology used, and to share experiences bearing on strategies and perspectives from different areas of knowledge.

2.5. Analysis

In Design Thinking, outcomes are analysed systematically (Walker et al., 2019). During the FG, all materials produced through tools such as post-it notes, drawings, or diagrams were organised into blocks of ideas and discussed directly within the design group. This first analysis and synthesis stage aimed, in a continual and participative way, to reach an agreement about the meaning of what was felt and thought in the design group. Forty-eight hours after the end of each FG, the facilitators performed an affinity analysis of the materials. This predictive analysis technique aims to build correlations between data and interpret them based on their occurrence among participants; in addition, preliminary categories and themes were found during these analyses. The FG transcriptions, observers' field notes, and digital conversations were analysed inductively by three independent research experts in palliative care, qualitative analysis, and communication (authors CR, AS, BG). Constant comparisons and discussions of the findings were then undertaken to reach a final agreement.

3. Findings

The results of the co-design are presented below, followed by a summary of the evaluation design.

3.1. Generating Ideas and Possible Solutions

The creative process enabled the generation of many ideas and possible solutions. Considering the specific problem described in Table 1, the design group discussed and prioritised the following design principles:

1 How might we highlight the visibility of palliative care as a human right?

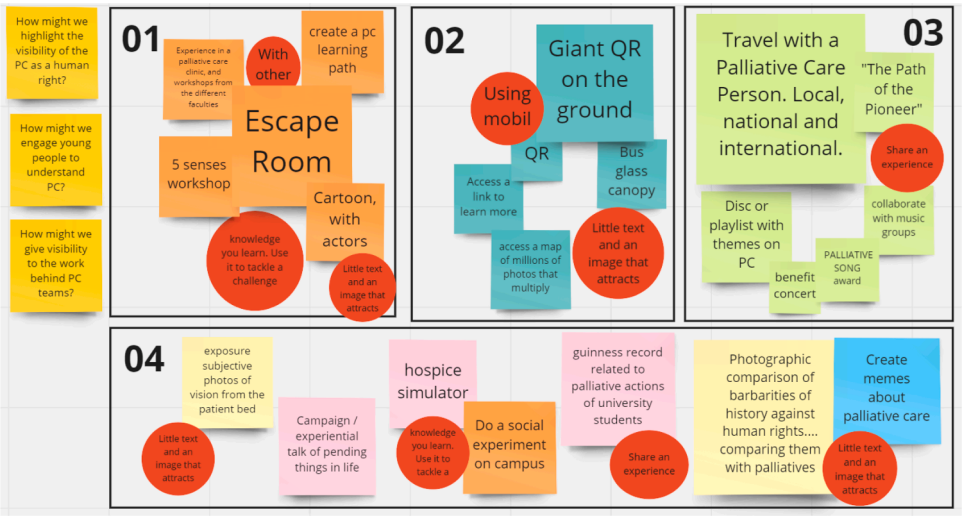

Fig. 1. Group of Ideas for Increasing Palliative Care Awareness.

2 How might we engage young people in learning about palliative care?
3 How might we make the work of palliative care teams more visible?

The design group generated 33 challenges, each heeding the three design principles, using several techniques. One technique was the *How-Might-We…* brainstorming exercise that challenges participants to change their perspective (Curedale, 2019), which helped to generate 20 disruptive solutions for each challenge. A second method, the *Anti-Problem Exercise*, encourages thinking by having participants identify ways to worsen rather than solve issues (Curedale, 2019); this method yielded ten more ideas for each challenge.

3.2. Grouping the generated ideas

In total, 21 ideas were launched from the discussions within the FGs to address the three design principles described above (Section 3.1). These ideas were organised by the participants into four main groups (Fig. 1).

Group 1 – A learning experience: This group of ideas describes the activities mentioned by the participants as solutions capable of providing a learning experience: create an Escape Room; create a PC learning path; promote experience in a PC clinic; hold a 'five senses' workshop; develop cartoons with actors.

Group 2 – A technological experience: Having technological expertise can also increase the visibility of palliative care and engage people in learning about it. Some ideas described were: we can place a giant QR code on the university grounds linked to palliative care information; we can place messages about palliative care on a glass bus canopy; we can build a link to empower access to millions of photos related to palliative care.

Group 3 – A sharing experience: Participants believe that spending time with someone who knows about palliative care can be beneficial. This group of ideas includes the following solutions: travel with a "palliative" person sharing a conversation about the topic (e.g., professional, family, patient) in an activity we can call 'The path of the pioneer'; collaborate with groups of musicians; promote a palliative song award; promote a benefit concert; create a playlist related to "palliative care" themes.

Group 4 – Other ideas: In this group, participants describe other ideas that can promote the visibility of palliative care: expositions with photos from the patients' bed-based viewpoint; campaigns or experiential talks on "pending things in life"; hospice simulator; social experiments on the university campus; Guinness record related to PC-related actions of undergraduate students; photographic comparison of historical human rights abuses and palliative experiences; creation of PC memes.

3.3. Engaging participants using disruptive tools

For interdisciplinary work to accompany the creative design techniques, we used brainstorming and brainwriting together with disruptive tools. This allowed the design group to be actively involved in discussing the design principles, as summarised in Fig. 2:

(a) *Stakeholder mapping*, a visual depiction that explores the relationships and connections between different actors in the PC field (Curedale, 2019; Ingle, 2013).
(b) The *5 Whys* tool, iterative questioning to uncover the underlying causes of a problem (Curedale, 2019; Ingle, 2013).

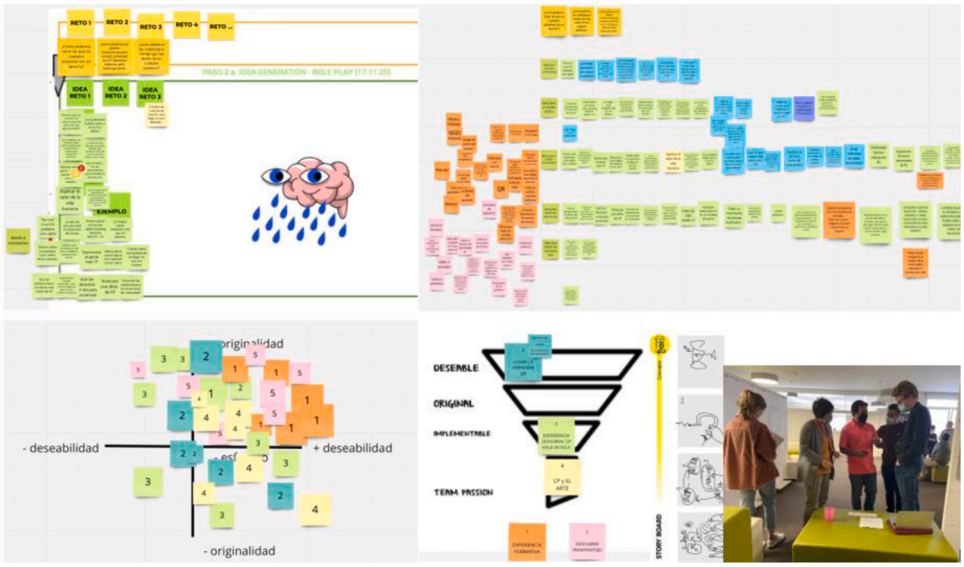

Fig. 2. Visual Results of the Creative Design Techniques for Palliative Care Awareness.

(c) The *Empathy Map*, a visual tool that analyses and describes thoughts, feelings, sensations, relationships, and actions, detecting individual needs in a specific context (Curedale, 2019; Ingle, 2013).
(d) The *Impact and Effort Matrix* (Curedale, 2019; Ingle, 2013), which allowed the design group to think about the resources needed to implement each idea, helping to decide which activity would be feasible in the specific context of the University of Navarra campus.

To refine and validate the choice of activity, the design group also used the (e) *Funnel Model*, a visual prioritisation structure that, through consensus among participants, allowed the final ideas to be filtered by applying four criteria: convenience, originality, degree of implementability, and team passion (Curedale, 2019; Ingle, 2013).

3.4. Identifying an innovative activity – 'escape room on palliative care'

At the end of the creative process, the design group identified a 'Palliative Care Escape Room' as an innovative activity to implement on the university campus. To test the feasibility of this idea, the design group imagined what an 'Escape Room' experience would look like using (f) the Customer Journey Storyboard, a visual representation that illustrates how an activity can be developed and implemented. This strategy allowed them to think about all the activity's pertinent design, structural, and organisational details arranged in terms of hours, days, and resources in a quick, fun, and easy way. The design group described, as an example, the following moments:

> Before the activity (enacted to generate interest among undergraduate students): 'When students arrive at the university, they are confronted with a series of mirrors scattered around campus. The mirrors bear small, intriguing phrases such as "Be aware" or "Look around". Some mirrors show a wheelchair, others an oxygen mask. As students walk through the university campus, they see a tunnel, and near it, they will find a QR code saying "Registry". When they sign up, students will receive information by email simply saying: "This is an Escape Room that you can play together with five friends. All you must do is to do the registry selecting the day and time"'.
>
> The activity: 'The students find a giant tent on the university campus. Inside is an Escape Room with a space that awakens three senses: sight, hearing, and touch (i.e., you can hear the whistle of hospital machines, it is dark, you can touch different materials; you can touch the objects deposited in the different rooms); the space also has a bed and a "patient". The game's goal is to help the patient to have a better day, with the player given a designated amount of time to perform each activity while controlled by a heartbeat sound (e.g., when you hear the heartbeat accelerating, it means that the game time is ending). There are specific actions that the player can perform to gain playing time, such as holding the "patient's" hand, chatting, and empathising. There is a voice-off, and the player must discover codes associated with actions. In the end, there is a twist in the game and the "patient" dies. What the player does not expect is that the "patient's" family then calls the player to thank them for everything they did; in addition, the "patient" sends a post-mortem message to thank the player for "letting him go" and expresses his appreciation for the actions that gave him the quality of life. After the Escape Room, there is an instructive video and talk about palliative care'.

Table 3
Positive and Challenging Aspects of Multi-methodology in Palliative Research.

Positive aspects	Challenging aspects	Gold recommendations
Innovation and creativity	Not mastering all methods, makes researcher nervous	PI must have excellent interpersonal skills, a good command of qualitative research, open-mindedness, curiosity and enthusiasm for innovation
Allows flexibility, adaptability and diversity	Difficult to do via virtual platforms, but not impossible	All participants should have a very well-assigned role, by phase and aims
Very useful for tackling challenging issues	Lack of knowledge on new and creative tools	Observers are indispensable
Interdisciplinarity	Difficult to know when each method begins and ends because they are all participatory	Ensure that all participants can attend all sessions together. If this is not possible, ensure they all have the same information
Enables team building	Different areas, different ways of communicating. Different words can share the same meaning	Promote an active role for participants from the beginning
Participative and inclusive		In the first session, always allow an additional half hour to form a group
Constant reflexivity		If possible, run the innovative groups in person; if not, take double time to prepare it
Promotes motivation to keep doing well		Thoroughly prepare sessions and introduce students to the digital platform before starting FG
Extraneity/Imagination		Promotes discussion of terms and concepts within the group
Development of new support tools		Always have a plan B, and in some cases a plan C
Systematic preparation of materials and procedures		Bring everyone together and put the group to work systematically, every week
Role play among facilitators before doing it with students		

3.5. Bringing innovative ideas to life through rapid prototyping

The last technique used during the creative process was *Rapid Prototyping*, a process of bringing innovative ideas to life through multiple discussions, followed by a systematic process of review and approval (Neeley et al., 2013).

- Rapid prototype 1: A 3-minute animated video explaining the Palliative Care Escape Room story was presented in Miro software. This video was then shown to 15 undergraduate students who gave quick feedback. The video garnered a very positive reception, and the idea was validated by most viewers. However, the viewers noted two weaknesses: the fact that the video talks directly about palliative care, as well as their perception that the ending was overly dramatic.
- Rapid prototype 2: The Escape Room was developed and simulated on a small scale at the entrance hall of the Institute for Culture and Society of University of Navarra. The research team members who did not actively participate in the design group participated in this simulation (seven researchers, two university professors, and two undergraduate students). Their suggestions for improvement were incorporated to return to the ideation phase, including advice to focus more on the message than on the game, to make sure the puzzles are not overly difficult, and to do more work on the storytelling.

3.6. Design validation and evaluation

A sixth FG was performed to validate insights from the creative process. The goal was to reflect on the process learned and recommend aspects for improvement to others who may want to use the same methodology to find ways to empower any specific community to solve their problem of palliative care-related misunderstandings and lack of discussion. This evaluation determined that interdisciplinarity and innovation are two fundamental issues for both this and future projects. Table 3

In the area of interdisciplinarity, the design group reflected on their active involvement in the conception, design, and discussion of palliative care-related social intervention. They displayed a variety of disciplinary backgrounds, and all had different sub-specialisations (journalism, storytelling, service design, project design, project management, qualitative methods, Design Thinking, and psychometrics). The design group defended the use of multi-methodology when such interdisciplinarity is present. Although considered very challenging and costly at the beginning, the research group described the great satisfaction they felt once they saw the effectiveness of such an approach:

> 'At first, it was a challenge due to our different backgrounds and experiences.' (R5)

> 'We have managed to use this method with different students of different grades, experiences, ages and disciplines.' (R4)

> 'The meetings were hard (smiles)... but in the end, it was a challenge for everyone to better approach the next meeting. I think that this tension, although often uncomfortable, was necessary and very satisfying at times.' (R3)

An interdisciplinary approach also implies transdisciplinary effort, which requires many relational competencies. The design group met virtually during the COVID-19 pandemic, which was a challenge, since most participants, even those working at the same university, got to know each other through the computer. It was necessary to learn to work together and maintain motivation, focus, interest, and well-being.

> 'It was a great challenge to meet everyone through a computer, especially when you want to bring curiosity and creativity. But this group has succeeded.' (R4)

> 'This group has achieved the most difficult thing of all, which was to form a group of different people to work weekly on this project for three months. This is not easy to do, even with people within the same company.' (R3)

In terms of innovation, the design group believes that multi-methodology combining PAR, DT, PE-RRI, and multiple techniques and tools is key to finding innovative solutions for complex social issues in palliative care. They also believe that such multi-methodology promotes change, which generates transformation and positive effects.

> 'Palliative care needs something new at the moment because we are not reaching out to society. I believe that the methods used in this study have sparked the creativity needed to address this issue. PC needs solutions to secure visibility.' (R6)

> 'Don't think chair, think "sit". Don't think of home, think "rest". To provoke innovation, you always have to think of an action associated with a need'. (R3)

While many participants felt that the methods were novel, they continually questioned their rigour. This concern was pointed out as good reflexive practice, as it allowed them to stop, think and redefine the procedures together and so ensure that other participatory methodologies complement PAR. This atmosphere of open, respectful, and free discussion allowed the group to learn.

> 'It is a completely new method. When you do it, you understand that it is a system that responds to where we are going through constant reflection, and that is reassuring. If we are dealing with such a difficult subject as how to transform the vision of palliative care in society, we need these.' (R2)

> 'This method has reminded me that I must always go back and ask why? The why justifies the need and allows me to create something innovative and truly sustainable.' (R7)

Within the creative process, it is necessary to be methodical and organised to create 'controlled chaos'. The process benefited from having well-defined roles for each member of the design group, with tasks to help each other and objectives for each session as the study progressed. In addition, having prepared for each FG with virtual tools and games 48 hours after each session helped make the simulation of the next session successful.

> 'The facilitators are doing things, but we are losing perspective. The observers provide important constructive advice. You learn to take it on board and look for solutions.' (R3)

> 'In the end, the method comes into its own. I don't know if there is a pure method, but what we have created is justified by the rigour with which it was conducted.' (R2)

4. Discussion

Lack of knowledge and general misperceptions about palliative care have been identified as considerable barriers. Better education of the young university population, who may involuntarily perpetuate stigmas, can therefore be of great value in improving their potential engagement. Palliative practitioners are key actors in dealing with possible misunderstandings and building a discourse to promote greater and better understanding and to cease perpetuating myths, misunderstandings, and a negative reputation for PC (Reigada et al., 2021a). A palliative care-protective public discourse must accompany this comprehensive and global transmission of palliative care in young university students (O'Connor et al., 2012). However, the inaccurate narratives that adolescents perceive around them, often through their screens, do not help to change their misunderstandings (Liu et al., 2019). For this reason, the teaching strategy to be used must be attractive and innovative if university students are to be engaged in critically evaluating messages about palliative care. At the same time, the strategy should avoid the discomfort that talking about death-related topics may cause the students (Mroz et al., 2022). The methodology focused on should help to bring about a cultural change in PC studies, in which university students are seen as part of the solution, as members that are vital in changing society. For this reason, participation in the debate should be encouraged (Mallon et al., 2021, Reigada et al., 2021b).

This study aimed to find a novel strategy to empower a specific community to solve their problem of misunderstanding and lack of discussion around palliative care in an interdisciplinary and creative way. This is the second study of an action-research project involving undergraduate students. The first study in this series concluded that encouraging people to absorb messages about palliative care requires working on accepting people's vulnerability (Reigada et al., 2021b). Following this initial step, as young people learn about palliative care it is essential to create an environment that empowers their autonomy and sparks their sense of being protagonists. The design group of this study further prioritised finding a solution to the communication and identity problems that affect the understanding of palliative care among youth. In their specific university context, the design group found that generating many ideas, as well as possible solutions using disruptive tools and rapid prototyping, offers an effective strategy to find novel solutions to increase palliative care awareness.

Moving forward required an open and flexible approach to promote solutions and new ways of working and researching (Reigada et al., 2021b; Van Niekerk et al., 2021). An innovative strategy was therefore designed and tested within this specific group. The key ingredients enabling the strategy's effectiveness were interdisciplinarity and creativity applied in a university context. After the experience of this study, in which Design Thinking and systematic procedures were grounded in classical research methodology, we concluded that undergraduate students could design innovative activities to raise awareness among the young on issues related to palliative care. They have taught us that, if we assume an active role, solutions to persistent problems can be found.

We can also say that the approach used in this study is largely novel. Many PAR studies exist, though few use the Design Thinking approach or methodology in palliative care (Kamran & Dal Cin, 2020; Walshe et al., 2021). Architecture, among other disciplines, has described how the combination of PAR and Design Thinking enriches architectural research by bringing out the best of both approaches (quantitative and experimental, and qualitative and participatory) (Katoppo & Sudradjat, 2015). This is the first study in palliative care we know of that combines these two methodologies while using the PE-RRI approach. Palliative care research groups can learn from widely disparate areas, such as arts and humanities or design and management, and fruitfully employ disruptive thinking in their research projects. Indeed, these findings are supported by evidence that art can contribute to acquiring competencies related to person-centred care by improving empathy, among other qualities (Centeno et al., 2017). Our study clearly demonstrated that through constant reflection, good role designation between members, respectful interdisciplinarity, and open-mindedness, this method can be used in palliative care research.

This work presents a starting point for improving existing palliative care impact and awareness-raising strategies across many different settings. At the teaching level, this strategy can be also used to design a wide variety of programs, using gamification to allow a deeper understanding of the care of people with serious illnesses. The methodology described was effective in resolving the two misunderstandings detected in the study group. Firstly, the dialogue between peers supervised by palliative experts, which exposed what palliative care was perceived to mean, and the sharing of concerns among young university students has enriched the experience and helped to clarify concepts. The questions that guided the first part of this study – especially the question "how might we engage young people to understand palliative care?" – have been highly clarifying in our efforts to detect misunderstandings (Zimmerman et al., 2021). This process has contributed to the design of innovative experiential activities in palliative care. Secondly, the incorporation of a one-off immersive experiential activity of palliative care has helped to reinforce elements of its definition that were considered fundamental. Both the content and the location were appropriate for this purpose.

In terms of content, it was key to have the Escape Room evoke the story of a protagonist, close in age and interests to those of the

participant, who shares his own experiences from before his diagnosis until he enters palliative care. The students integrate their own narrative, which reinforces the idea that palliative care helps to maintain the dignity of patients and their families, that it is synonymous with hope, offering a quality of life and relieving pain and other symptoms in accordance with the diagnosis and thanks to a multidisciplinary team.

Regarding the setting, it was vital that the students were able to feel the experiences by entering the spaces in which the "patient" invited them to live, which allowed them to feel what the patient was telling them he felt. This experiential integration has been fundamental in moving the students to feel empathy and compassionate care (Centeno et al., 2016; Miltiades, 2020). Other elements have remained blurred because the students have approached a complex reality from a narrow point of departure that is unable to delimit all the dimensions of palliative care. They did not, for example, know about clinical interventions carried out by professionals. It is, therefore, possible that the students, although they have clarified certain misunderstandings, may have reinforced others, such as the confusion between palliative care and hospice care.

It is, perhaps, time to combine the usual action research methodology with more creative and participatory methodologies, such as citizen science, Design Thinking, and action design research (Becker et al., 2019). Future studies should thus be conducted to evaluate the effectiveness of such multimethod strategies for palliative care awareness in other contexts.

5. Limitations

This study aimed to find a new strategy to empower a specific university community to resolve their misunderstanding of palliative care. Some limitations of the strategy are listed as follows:

Firstly, the main limitation of this study is related to the generalisability of the results. The sample of students chosen is small and composed of highly educated participants from a university that is well positioned in international rankings and who, after an invitation, have decided to participate. There may, therefore, be a bias towards showing more favourable attitudes towards palliative care than other students on campus who did not participate. For this reason, and although it has not been the intention of this study, no generalisations can be made from the results obtained. This paper does, nonetheless, provide good examples of how participants can find innovative solutions to address a complex issue.

Secondly, given that palliative care is a multifaceted concept that is susceptible to other perceptions and interpretations, a specific definition (Radbruch et al., 2020) is used as a starting point. Starting from a concrete definition (Radbruch et al., 2020), we derive from it a specific creative process that can be framed within the specialty/consultative (Miller et al., 2017). The educational domain from which it has been approached, however, has neglected the domain of implementation and policy.

Thirdly, the study is based on a particular cultural paradigm, the Western one, which is suspected of a 'conspiracy of silence' (Miller et al., 2017) around death and everything related to it, such as palliative care. These aspects can therefore be considered differently from other cultures, allowing them to be recognised as contextual and historical variations on representations and attitudes towards death, dying, and social responses to these experiences (Alonso, 2012). In this line, the purpose of this manuscript has been to show how the creative process itself was pursued, to allow it to be used after being adapted to different cultures and contexts.

Fourthly, the target population for this methodological proposal is specific. It is not aimed at the clinical setting, palliative care professionals, or participants with a great deal of knowledge about the field, with the goal being to improve their practical skills. Nor is it aimed at patients and families who use palliative services, although they too may have strong stigmas associated with palliative care even following positive experiences with early PC intervention (Zimmerman et al., 2016). The focus of the study is the public and within it, the population group of university students from different fields who are not currently patients or carers.

Fifthly, there is an intrinsic limitation linked to the methodological experience, which is the impossibility of covering, for the university population, each of the dimensions implied by palliative care in a short time. Among these dimensions, we can point out those referring to the sources of perception of these PCs (focusing on the clarification of values that influence their understanding), the work with initial reactions, or the work on the students' perceptions after having received PCs (not perceiving themselves as probable patients of PCs due to their current state of health). Thus, two parameters have been chosen, while others have been left out, knowing that these may reinforce other stigmas (such as, for example, the perception that to be in CP is not to fight one's own illness) (Shen & Wellman, 2019).

The space for reflection that aims to bring conversations about life and death into the public domain can be a positive experience that works at lessening the misunderstanding around some questions of palliative care knowledge and attitudes in the university population. However, this reflective process described leaves aside many other issues that, from an expert's point of view, could indeed be considered. In any case, the potential of the presented methodology to influence attitudes and improve understanding holds some promise. It helps to strengthen the concept of teaching compassionate care and to focus on quality of life and dignity, which are important aspects of end-of-life care. It can also encourage re-evaluation of end-of-life care. However, without professional accompaniment and follow-up by PC experts, this experience may lead to perpetuating misunderstandings, such as the confusion between hospice care and PC. It seems for this reason essential that this methodology be incorporated as an activity within a university course for non-health students. In this way, the conceptualisation of CP can be approached in a more complete way and the teaching can be enriched with this activity.

Without detracting from all the learning that comes out of the activity and knowing that student experiences both contribute to the acquisition of new knowledge and facilitate citizenship education (Carson & Raguse, 2014), there is an awareness that an activity, while intense, can be a small but important part of learning for university students unaccustomed to delving into health issues.

6. Conclusion

The process of generating solutions to a complex problem is not linear but iterative. This study demonstrates that through the interdisciplinary and creative strategies offered by Design Thinking, a specific community can be engaged in solving persistent problems, such as misunderstandings about palliative care. Taken as a whole, this paper presents an innovative strategy for finding new solutions to raise awareness of palliative care in the university setting, yielding insights which can be tested in many other contexts.

Informed consent

Informed consent was obtained from all individual participants included in the study.

CRediT authorship contribution statement

CR: Conceptualization, Methodology, Formal Analysis, Writing: Original Draft; SH-R: Methodology, Formal Analysis, Writing: Review & Editing; AT: Methodology, Analysis, Tables Design; AA: Methodology, Analysis; AS: Observation, Analyses, Writing: Review & Editing; AC: Observation, Analyses, Writing: Review & Editing; SR: Observation, Analyses, Writing: Review & Editing; BG: Discussion, Writing: Review & Editing; CN: Discussion; CC: Conceptualization, Supervision, Project Administration, Writing: Review & Editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data Availability

No data was used for the research described in the article.

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