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Cultivating excellence in palliative care education and training: a network and thematic deep dive into CODE-YAA@PC-EDU initiatives

[Short title: CODE-YAA@PC-EDU initiatives]

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Abstract

Background: In this study, we employed a collaborative and participatory approach, underpinned by pragmatic methodology, to explore and elucidate the interconnections within the research network of the COllaboratively DEveloped culturallY Appropriate and inclusive Assessment tool for Palliative Care EDUcation the European Cooperation in Science and Technology Action. We demonstrate how the analysis of the publicly available data, as well as the joint publication history of the core group members of this action can accelerate understanding of collaborative dynamics, patterns of collaboration and knowledge exchange within the group.

Methods: We used VOSviewer software to systematically map joint publication and further leveraged InfraNodus software to visualize and analyze the thematic content of our project proposal.

Results: The social network analysis revealed pivotal connections, fostering a robust research ecosystem that needs to expand geographically, scientifically, and linguistically. The application of InfraNodus software informs our pursuit of culturally appropriate quality assessment tools for palliative care education, which are poorly developed and understood so far.

Conclusions: The crux of our research lies in gaining a deeper understanding of the relationships between researchers. This insight is pivotal to enhancing the effectiveness and inclusivity of our work in developing culturally appropriate assessment tools for palliative care education as well as monitoring the global impact of this European Union funded project.

Keywords: collaborative dynamics, social network analysis, palliative care education and training, culturally appropriate assessment tools, impact analysis

Introduction

In the Fall of 2022, a group of palliative care education advocates and researchers came together to develop a project proposal that draws attention to palliative care education and the need for its further development in Europe. We submitted the proposal to the European Cooperation in Science and Technology (COST), a research and innovation network funding organization that helps connect researchers in emerging and promising research areas for building and strengthening research networks. COST funding is designed to launch initiatives for capacity building across Europe, simultaneously enabling researchers and innovators to develop their ideas across scientific and technological fields, sharing them with like-minded people. COST Actions are bottom-up, four-year networks that promote research, innovation, and careers [1]. We successfully obtained funding from this prestigious and competitive program. The Collaboratively DEveloped culturallY Appropriate and inclusive Assessment tool for Palliative Care EDUcation (CODE-YAA@PC-EDU) project officially began on 1 November 2023 [2]. This international collaboration is set up for the upcoming four years (2023–2027), The core group was assembled, drawing upon existing connections within the palliative care community, leveraging Action Chairs' network as a seasoned expert in the field. Through online meetings and email exchanges, a process unfolded to establish the group's foundation. Goals were explicitly set, underlining our commitment to action. This approach ensured that the project targets were derived collaboratively, reflecting the collective vision and expertise of the team. The CODE-YAA@PC-EDU project is expected to develop a framework to help improve education and training in palliative care, highlighting the importance of cooperation and collaboration in this chronically underfunded and often underestimated area of care education.

Global perspectives on palliative care education

Educational recommendations and quality assessment criteria validated by high-level non-governmental organizations, governments or professional bodies are critical to advancing palliative care education. The model proposed by the World Health Organization (WHO) highlights six essential components needed for optimal palliative care provision for people experiencing serious health related suffering [3]. One of these is the education and training of all healthcare professionals and volunteers who provide palliative care. According to the WHO, the

quality indicators for palliative care education are the proportion of formal education in: (1) undergraduate medical studies, (2) undergraduate nursing studies, and (3) specialization in palliative care for medical doctors. The latter seriously undermines the role and contribution of the wider professional team as total patient care relies heavily on nursing, and other health and social care professionals in the delivery of palliative care services [4]. To meet the values and address the needs of people with serious illnesses and their caregivers, countries need greater interprofessional and interdisciplinary resources than those currently identified solely for clinical medicine.

COST Actions differ from other European funding schemes by putting the focus on the funding of the development of a network and building capacity for future endeavors in the chosen field. The impact of the network is a critical change agent. So far, in palliative care, there exists a qualitative model for knowledge transfer and evaluation of the research knowledge, which can be applied to research focused projects. The validation of this model, called Evidence-based Model for Transfer and Exchange of Research Knowledge (EMTReK), is ongoing [5, 6]. Due to the nature of the COST Action it may be difficult to measure the project's real impact, as the results may come with numerous contextual, conditional, and cultural leakages that are difficult to control or monitor. Furthermore, the benefits of a collaborative international and interprofessional network can be difficult to predict and measure. The project may lead to enhanced collaborative research opportunities in palliative care, increase diversity and significance of projects, and foster a sense of community and belonging [7, 8]. We suggest that measuring impact of a network may need specific methods, namely: network analyses. The purpose of this article is to introduce the CODE-YAA@PC-EDU core group members and their research profiles in relation to the preliminary aims of the project. As Core Group members of this action, we considered the early deep dive into CODE-YAA@PC-EDU initiatives relevant to better identify and understand our baseline standpoint to further build on our strengths and address the gaps and challenges.

Methods

This is a collaborative participatory pragmatic methods study. Participatory studies prioritize the value of experiential knowledge for tackling problems caused by unequal social systems, and for envisioning and implementing alternatives [9], as inherent to this CODE-

YAA@PC-EDU project. This participatory approach was deemed to be the most suitable to investigate, explore, and answer the aims of this study. A combination of two techniques were integrated and is presented as follows.

Firstly, we applied Social Network Analysis (SAN) to visualize and analyze the network impact to reveal the relations and patterns within the core group based on core group members' publication history. SAN has become a valuable tool in academic research, offering a more comprehensive view of academic performance [10]. The method's effectiveness in revealing hidden patterns and understanding information flow has been emphasized, with its adaptability to various fields and levels of analysis [11]. Social Network Analysis has been particularly useful in higher education research, providing unique insights into the connectivity patterns of individuals, institutions, and governments [12]. The final refined search of scientific publications by the core group members was conducted on 20 January 2024 *via* Scopus database [13]. Scopus is a comprehensive abstract and citation database of peer-reviewed literature, including scientific journals, books, and conference proceedings, spanning various disciplines. We used the Scopus website to extract summaries of disciplines and affiliations (countries) of the researches. Thus, we analyzed and visualized the connection between the core group members (see Results, Participants) based on joint publications using the VOSviewer software [14, 15]. Thus, in this analysis the core group members are represented as nodes connected to each other based on joint publications.

Secondly, we used the InfraNodus software to analyze the basic text of our grant application [16]. The InfraNodus analyses any text as a network and enables identification of the main concepts and topics, and reveals the relations between the ideas [17]. Texts are visualized as networks of interconnected nodes, where each node represents a word and the connections between them represent their co-occurrences within the text. This visualization helps in identifying the main topics, the relationships between them, and the structural gaps or blind spots within the discourse. The analysis let us identify the discourse's structure through network modularity, distribution of influence, and narrative variability. Based on this representation, we can detect clusters of words or themes that belong together, identify the most influential elements, and reveal the gaps in a discourse.

Ethical considerations

All data retrieved about the core group members and integrated in both the social network analysis and the InfraNodus software is publicly available. Therefore, this study did not require formal ethics approval from an ethics review board. In addition, all core group members gave their written informed consent to use this data retrieved from the internet after being informed about the aims of the study and the data collection procedure. They were free to comment on the final draft of this article that was sent to all core group members to obtain their consent to use their names, data, and findings in the article.

Results

Participants

The core group consists of Action Chair Piret Paal (anthropologist, Austria/Estonia), Action Vice-Chair Sandra Martins Pereira (nurse and bioethicist Portugal), six Working Group Leads: Stephen Mason (psychologist, United Kingdom), Philip Larkin (nurse, Switzerland/Ireland), Gil Goldzweig (psychologist, Israel), Pablo Hernández-Marrero (nurse and health services researcher, Portugal), Minna Hökkä (nurse, Finland), Guillaume Economos (physician, France), and Grant Awarding Coordinator Leszek Pawłowski (lawyer, Poland).

The publications and co-authorships of the core group members

The search in Scopus database indicated that, overall, the core group members have published 404 documents cited 5409 times. The United Kingdom leads by publications by country, followed by Ireland and Israel. This is based on the account of all authors' countries of origin (Figure 1).

By disciplines, approximately half of the scientific publications come from medicine (n = 294, 49.4%), followed by nursing (n = 121, 20.3%), social sciences (n = 53, 8.9%) and psychology (n = 48, 8.1%). In this search, the allocation of the discipline was based on journals' declarations. We can observe that the core group collaborates within Europe (mostly West), and a very low collaboration with the United States, and interestingly some collaboration with Singapore. The further analysis indicates that participants from Poland and France are not linked to the core group via publications (Figure 2).

The social networks generated by the VOSviewer demonstrate that the Action Chair has long-term collaborations with most of the core group members, which have resulted in publications in journals listed in Scopus database. There are also strong independent relations between the core group members, which is an indication of a strong social network (Figure 3).

The themes and nodes in the basic description of the CODE-YAA@PC-EDU project

In the analysis nodes (concepts) that appear in the same context more often are aligned into clusters on a two-dimensional plane, community detection algorithm is used to cluster the nodes into topical groups. This enabled the identification of important concepts, topics, and pathways for meaning circulation, revealing the deep structure of the text. In the CODE-YAA@PC-EDU project description the top ten themes are:

- ethical decision-making,
- high-quality education,
- health integration,
- European innovation,
- harm reduction,
- EU research funding,
- access promotion,
- sustainable delivery,
- joint coordination, and
- group driven excellence.

In Figure 4 different colors and their shades indicate the nodes that relate to specific themes.

Discussion

This study explored, measured, and described the intricate web of collaborative efforts within the CODE-YAA@PC-EDU COST Action [18]. Our findings illuminate critical aspects of

palliative care education and network dynamics, such as collaborative synergy, network impact, and global relevance. Based on the network and thematic deep dive into CODE-YAA@PC-EDU initiatives, we argue that there is the need for more linguistic, geographical, and scientific variety in research and advocacy in terms of international and interdisciplinary collaborations [19, 20] In terms of sustainability, investing in young researchers interested in palliative care education, research, and service development is a paramount. The Cost Action Chair together with the core group needs to promote interactions across the group to increase the social networks, specially focusing on collaborations with Easter-European, emerging scholars, and focusing on scientific outputs that are widely disseminated in national languages.

Per definition, cultural appropriateness and interdisciplinary approach are a core element of palliative care [21]. In health research, there is a strong focus on medical, pharmacological, and, to some extent, nursing research. The role of behavioral and cultural insights is to ensure that the health service makes sense to the community regarding local social, cultural, and economic realities [22]. We need to strengthen the network and build the capacity for introspection and understanding complex webs of causalities that affect human health behaviors regarding palliative care. CODE-YAA@PC-EDU project embraces the interdisciplinarity and hopes to create culturally and ethically appropriate approaches to palliative care education and training, including developing quality indicators for palliative care education that would resonate with local possibilities and service users' needs [23–25].

The social network analysis demonstrates that the core group is well interlinked via scientific publications in medicine, social sciences, psychology, and nursing. In terms of improvements, it is important to widen the network geographically. The Scopus databased algorithm calculates the country by all authors' country of origin. The results indicates the geographical dominance of the United Kingdom. This also means that people prefer collaboration with English speaking researchers, whereas Europeans prefer the United Kingdom to the United States. This certainly affects how palliative care is presented and understood in Europe. The geographical expansion is a strength, which helps to focus on one of the COST Action premises on the inclusiveness of target countries to understand and discuss the country-specific needs of palliative care. The inclusion of countries that are not usually involved in international advocacy and research is seen as a central task, equal to understanding cultural components in the introduction of new care pathways or curricula, which are frequently overlooked in clinical

education research. Appropriate national palliative care terminology is needed for service development, implementation and even uptake among the service users [26].

The CODE-YAA@PC-EDU project will help to pave the way to international publication to present the problems that service developers face locally. The overall dominance of publications written in English and originating from the United Kingdom, indicates that the palliative care language and terminology need to be checked and revised and adapted in national and cultural contexts. CODE-YAA@PC-EDU project will be responsible for collaboration and group consensus to manage linguistic diversity. A glossary of key terms will be developed in English and adapted to host languages through content validation. This will generate data and discussions on linguistic challenges in palliative care and will help to elaborate the critical question of cultural appropriateness of palliative care educational models and training.

To increase the sustainability of these efforts the inclusion of young scholars is of particular importance. Building a network of people interested in investing in palliative care education and training can be a powerful tool to invest in new leaders, and force sustainability and professionalism in palliative care training and education. Many people who work in palliative care are celebrated as champions or pioneers in their field, yet the continuum of health and social care professionals, who can continue with their clinical, research and teaching tasks once retired, is scarce [4]. CODE-YAA@PC-EDU project is investing in young scholars. However, among the core group members; we currently have only one scholar under 40 years of age, which indicate that we need to focus on building the legacy. This pathway will be supported by ethically conducted research, virtual coaching, one to one mentoring, short-term exchange opportunities, congress grants, and topical summer schools.

The overall dissemination agenda of this COST Action will be based on the theory of multiple streams, which states that policies move forward when three streams — ‘the problem’, ‘the potential solution’ and ‘political and public opinion’ — come together to enforce policy change [27]. To achieve a social impact network connectivity, its design and performance are seen as significant in societal and human activity [28]. To excel in its goals, vision and mission, we structured the CODE-YAA@PC-EDU COST Action around six intertwined Working Groups (WGs):

- WG1. Gold Standard Working Group;

- WG2. Culture, Language and Diversity Working Group;
- WG3. Research Coordination, Methods & Impact Analysis Working Group;
- WG4. Capacity Building, Leadership and Ethics Working Group;
- WG5. Global Policy and Advocacy Working Group; and
- WG6. Communication and Dissemination (see Figure 5)

The CODE-YAA@PC-EDU COST Action will set quality indicators to establish a gold standard for high-quality education and training in palliative care. Furthermore, CODE-YAA@PC-EDU will coordinate joint efforts to seek ways to improve palliative care education and training to accelerate knowledge transfer of ethically sound practices that will reduce the societal and economic burden and harmful experiences caused by people experiencing unnecessary health-related suffering. Key to this COST Action is the development of a culturally and ethically appropriate inclusive evidence-based self-assessment tool — the CODE-YAA. This is an online resource for anyone wishing either to develop initial education and training in palliative care or to assess gaps to strengthen their existing education and training in palliative care. The CODE-YAA self-assessment tool can be used by a range of stakeholders, including governments, clinicians, educators, researchers, policymakers and health services users. Open dialogue and discussion will be encouraged by asking stakeholders to consider: (i) where they are now in relation to palliative care education and training, (ii) where they want to be in the future, and (iii) what actions they need to take to achieve this. We raise these questions across a range of issues: palliative care provision, initial education and training of health and social care professionals, access to programs, curricula (general, theory, and practice), academic faculty, resources, clinical learning, and regulation of education. The CODE-YAA tool will also include a response section to summarize the discussions and a section with links to useful resources.

Limitations to this study

We used the Scopus database for our analysis, which certainly has its limitations. Yet, Scopus is widely used also across scientific fields to identify researcher's impact in the research community, which makes it more attractive as solely medical databases.

Conclusions

The CODE-YAA@PC-EDU project thrives on vision, commitment and collaboration. By analyzing joint publication histories, we witnessed the power of collective knowledge exchange among core group members. We employed VOSviewer software to map the collaborative landscape and measure the network impact. This analysis revealed pivotal connections, fostering a robust research ecosystem that needs to expand geographically, scientifically, and linguistically. The application of InfraNodus software informs our pursuit of culturally appropriate assessment tools for palliative care education, but the work on quality indicators has just begun. Our work transcends the European borders; as we monitor the impact of this initiative, we contribute to advancing palliative care education worldwide. CODE-YAA@PC-EDU has the potential to address diverse local and national challenges which exist in palliative care education provision, level and at the same time, provide a cohesive and workable response to establishing a sound basis for academic and clinical preparation for practice. In summary, the CODE-YAA@PC-EDU project exemplifies excellence in collaborative research, propelling palliative care education and training forward.

Article information and declarations

Acknowledgments

None.

Data availability statement

All data retrieved about the core group members and integrated in both the social network analysis and the InfraNodus software is publicly available.

Ethics statement

All data retrieved about the core group members and integrated in both the social network analysis and the InfraNodus software is publicly available. Therefore, this study did not require formal ethics approval from an ethics review board. In addition, all core group members gave their written informed consent to use this data retrieved from the internet after being informed about the aims of the study and the data collection procedure. They were free to comment on the

final draft of this article that was sent to all core group members to obtain their consent to use their names, data, and findings in the article.

Author contributions

The idea for this study came from GG, who conducted the analysis and provided the evidence for further consultations with all authors. PP and GG drafted the outline of the manuscript. SMP helped with finding the relevant literature. GE designed the Figure 5. All authors were involved in finalizing the paper.

Conflict of interest

Authors have no competing interest to disclose.

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Supplementary material

None.

List of abbreviations

COST — European Cooperation in Science and Technology

CODE-YAA@PC-EDU — Collaboratively DEveloped culturallY Appropriate and inclusive Assessment tool for Palliative Care EDUcation

EMTReK — Evidence-based Model for Transfer and Exchange of Research Knowledge

WHO — World Health Organization

SAN — Social Network Analysis

WG — Working Group

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Figures

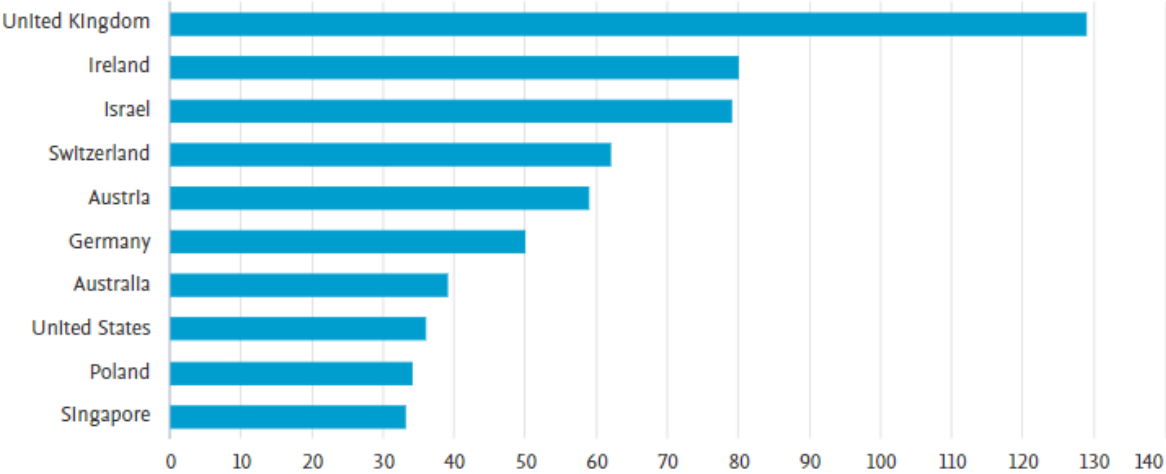


Figure 1. The number of documents by core group members

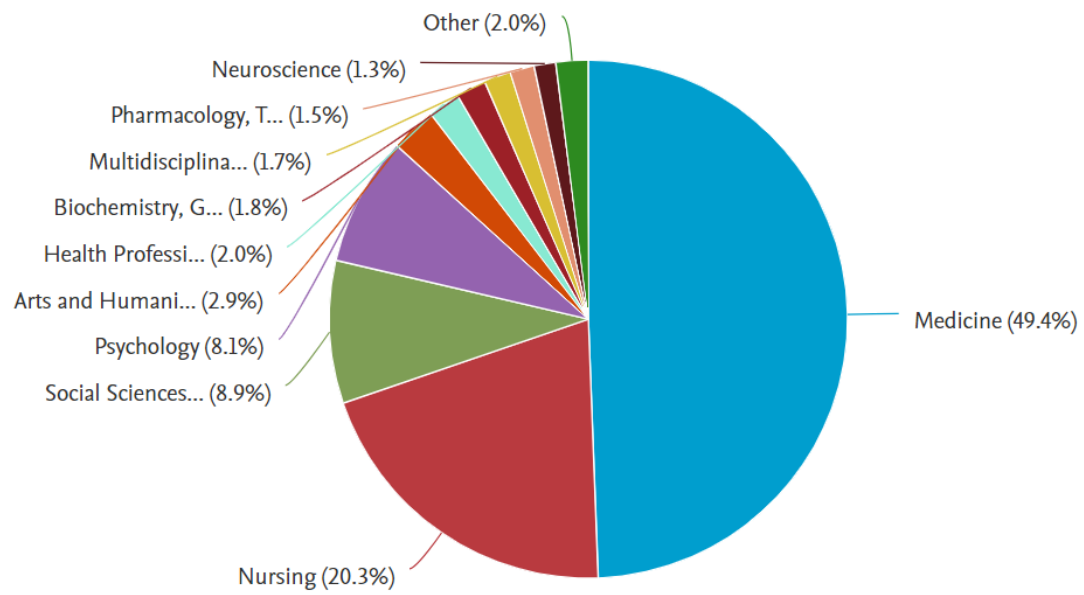


Figure 2. The disciplines of publications by core group members

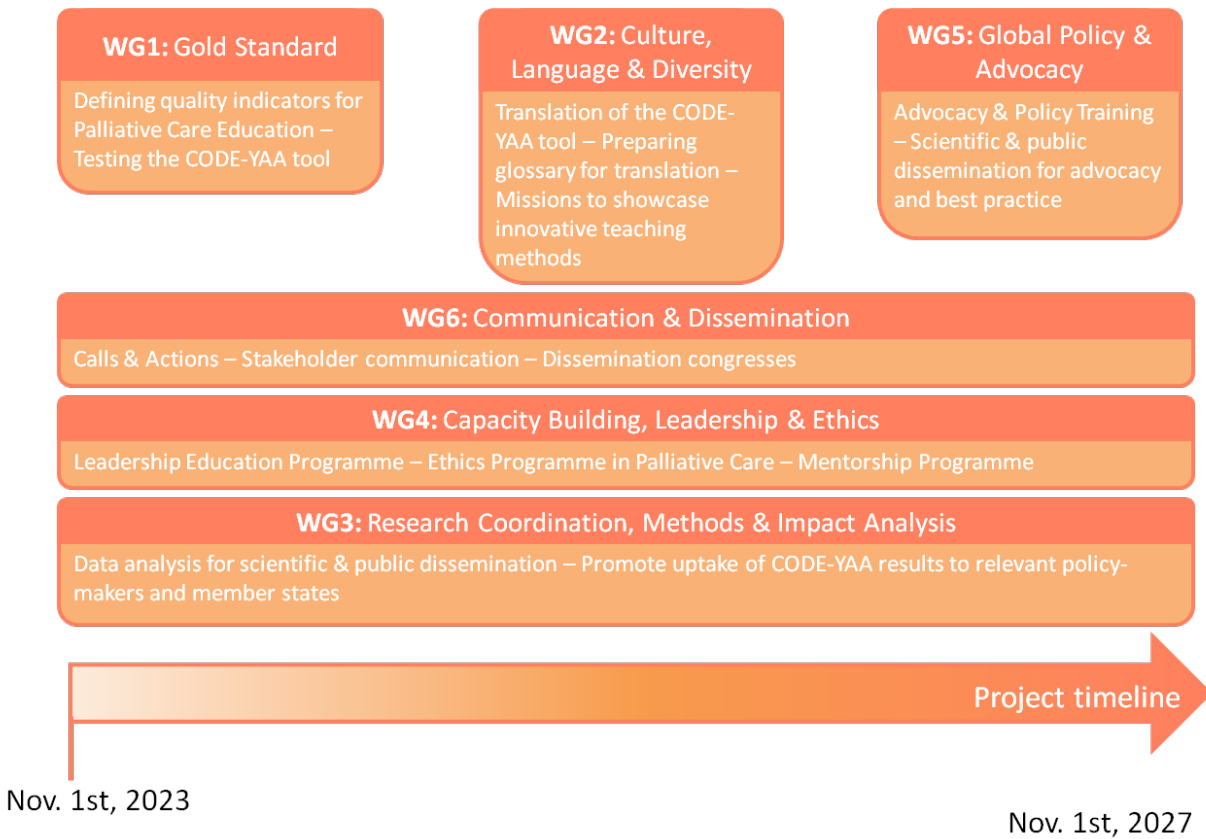


Figure 5. The goals, vision, and mission of the CODE-YAA@PC-EDU COST Action Working Groups