SMER
SOCIETY OF MEDICAL
EDUCATION & RESEARCH

Society of Medical Education & Research

2025, Volume 5, Page No: 175-186
ISSN: 3108-5059

Asian Journal of Ethics in Health and Medicine

Co-creating CURA: A Clinical Ethics Support Tool for Palliative Care

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Abstract

Clinical ethics support (CES) instruments are widely regarded as valuable tools; however, users frequently encounter barriers to their routine use. Involving end users and other stakeholders in the development of CES instruments may help address these challenges. This study outlines the creation of CURA, a user-friendly, four-step ethics support tool designed for nurses and nurse assistants in palliative care. A participatory development approach was employed, involving collaboration with stakeholders through a Community of Practice across the study. Potential end users—nurses and nurse assistants in palliative care—tested CURA in multiple pilot sessions, providing feedback that informed successive refinements of the instrument. The development process was divided into three phases. Phase one, Identifying Needs, concentrated on understanding the preferences and requirements of stakeholders and end users, analyzing existing CES instruments, and identifying gaps in current tools. Phase two, Development, involved iterative co-creation to design, refine, and adapt the instrument. Phase three, Dissemination, focused on implementation and distribution strategies. CURA emerged as a four-step, low-threshold tool that facilitates structured ethical reflection. The participatory development approach proved effective for designing clinical ethics support instruments. Collaboration with end users and stakeholders allowed for better alignment with their needs, informed strategies for improving feasibility, and helped overcome limitations observed in existing CES tools.

Keywords: CURA, Clinical ethics support (CES), Palliative Care, Four-step

Introduction

In recent years, there has been increasing recognition of the importance of involving stakeholders in health care research, including in the development of practical instruments [1–4]. Participatory development entails close collaboration between researchers, end users, and stakeholders throughout the entire research process [5]. Engaging stakeholders can empower end users [6, 7], ensure that instruments meet their needs [8], enhance contextual relevance [8], facilitate early identification of potential issues and solutions [9], and support successful implementation [5], ultimately improving healthcare delivery [4]. This study examines how a participatory approach can inform the creation of clinical ethics support (CES) tools, specifically describing the development of CURA, a low-threshold CES instrument for caregivers in palliative care.

Access this article online https://smerpub.com/

Received: 02 February 2025; **Accepted:** 29 May 2025

How to cite this article: Chhim S, Chea V. Co-creating CURA: A Clinical Ethics Support Tool for Palliative Care. Asian J Ethics Health Med. 2025;5:175-86. https://doi.org/10.51847/59jc1Bjb91

Palliative care presents unique and significant ethical challenges [10, 11], often leading to moral distress, burnout, and high staff turnover [12, 13]. Supporting caregivers in navigating these challenges is crucial for delivering high-quality care and fostering moral resilience, defined as the ability to maintain or restore personal integrity in response to moral distress or setbacks [14].

To effectively assist caregivers with daily moral dilemmas, CES instruments must align with their needs and be tailored to their work contexts, including its constraints and conditions [15, 16]. Existing CES tools, however, face barriers to routine use. They are often time-intensive, require facilitation by highly trained ethicists, and can be complex, which limits accessibility for caregivers with varying educational backgrounds [15, 16].

Through a participatory approach, CURA was developed to address these limitations, creating a CES tool specifically designed to support nurses and nurse assistants in palliative care. The Methods section details the research design, the Results section describes CURA's development process, and the Discussion reflects on both the process and the broader implications of participatory development for CES instruments.

This study was conducted as part of a nationally funded program by the Dutch government aimed at enhancing palliative care quality in the Netherlands. In addition to this article on CURA's development, previous publications have addressed its content [17], as well as its feasibility and initial perceived outcomes [16].

Materials and Methods

Research design

This study was guided by a participatory development approach, which originates from action research aimed at addressing challenges within specific communities or contexts [18]. Participatory design emphasizes that creating practical and effective tools requires active involvement from relevant stakeholders, particularly those who will ultimately use the instrument [19].

We structured the study around three main phases. Phase one: Identifying Needs involved exploring the preferences and requirements of nurses and nurse assistants in relation to ethical support, informed by literature and initial stakeholder input. Phase two: Development centered on iterative co-creation, during which the instrument was drafted, refined, and adapted based on ongoing feedback. Phase three: Dissemination focused on planning strategies for implementing the finalized tool across diverse healthcare environments.

Data were collected through two complementary approaches: (1) interactive sessions with a Community of Practice (CoP) and (2) pilot testing of preliminary instrument versions in educational and clinical settings. Collection methods included audio recordings, observational field notes by researchers, and structured questionnaires.

Community of practice

Consistent with the participatory approach, we engaged a Community of Practice—a group of individuals united by a shared goal, who learn collaboratively through regular interaction [20]. By exchanging experiences, advice, and practical insights, the CoP contributed to the creation of new practices. Unlike informal networks, the CoP is defined by its collective objective—in this case, co-developing a clinical ethics support instrument for palliative care.

The CoP included 26 participants selected through purposeful sampling, encompassing nurses, other caregivers, nurse educators and trainers, implementation specialists, managers, palliative care experts, patient organization representatives, nursing students, and volunteers. **Table 1** provides details on participant roles and session involvement. Four main sessions served as reference points throughout the study, each lasting approximately three hours and conducted in person at six-month intervals prior to the COVID-19 pandemic.

Table 1. Members of the community of practice

Member	1st CoP Session	2nd CoP Session	3rd CoP Session	4th CoP Session
Specialized palliative care nurse	✓	–	✓	✓
Quality manager, ambulatory care organization	✓	✓	✓	–
Palliative care policy officer, large care organization	✓	✓	✓	✓
Coordinators of volunteers in ambulatory palliative care (2 persons)	✓	✓	–	✓
Patient organization representatives (2 persons)	✓	✓	✓	✓
Advisor, training center of large care organization	✓	–	–	–
Palliative care consultant	✓	–	–	–
Managing director, Hospice	✓	✓	–	–
Lecturer, nursing at applied university	✓	✓	✓	–

Student, bioethics	✓	✓	✓	✓
Vocational training teacher, nursing	–	✓	–	–
Vocational training teacher, ethics	–	–	–	✓
Graphic designer	–	–	✓	–
Manager, training center	–	✓	–	–
Trainer, nurses hematology/oncology & palliative care advisor	–	✓	✓	✓
Palliative care nurse	–	–	✓	–
Senior advisor, palliative care cancer expertise center	–	✓	✓	✓
Trainer, training center in healthcare institution	–	✓	–	–
Teachers, advanced nursing course (2 persons)	–	✓	–	✓
ICU nurses (2 persons)	–	–	–	✓
Medical students (4 persons)	–	–	–	✓

During the CoP sessions, we facilitated structured dialogues that allowed participants to share perspectives both with each other and with the research team. Participants provided feedback on each draft of the instrument, and interim findings from the study were presented and discussed. The design of the study itself was also a topic of discussion, including strategies to enhance the participatory nature of the process. Researchers took detailed notes on the discussions, feedback, and collective conclusions, which were compiled into reports and circulated to all CoP members. Participants were invited to review these reports and provide comments, serving as a form of member checking and also engaging those who were unable to attend in person.

Prior to each session, participants received the agenda and relevant materials. Between sessions, three newsletters were sent to keep all members informed about study progress.

Pilots

Alongside the iterative testing conducted within CoP sessions, we carried out several pilot studies in which nurses and nurse assistants applied and evaluated the instrument in practice. All participants were actively involved in palliative care, but came from a variety of settings, including academic hospitals, home care services, and nursing homes. **Table 2** provides an overview of the pilot participants.

Table 2. Overview of pilot studies

Pilot	Setting	Participants	Instrument Version
1	Community of Practice	10 stakeholders (see Table 1)	Version 1
2	Continuing Education Training Institute	Approximately 15 registered nurses in oncology	Version 2
3a	Continuing Education Training Institute	Over 150 registered nurses and licensed nurse practitioners across multiple classes	Version 3
3b	Vocational Training Institute	Around 20 licensed nurse practitioners in training	Version 3
4	Healthcare Organization (home care and nursing home services)	15 participants including certified nurse assistants, licensed nurse practitioners, and registered nurses	Version 3

The first pilot study involved a cohort of oncology nurses enrolled in a continuing education program, who applied the instrument in their own clinical settings and shared their observations and feedback during class sessions.

In the second pilot, participants were nurses engaged in a continuing education program working across multiple palliative care environments. After receiving an introduction to the instrument from the research team, they implemented it in their daily practice and provided evaluations and questionnaire responses (the findings from these questionnaires are reported elsewhere [16]).

The third pilot was conducted at a separate nursing education institute with trainees pursuing part-time vocational programs to become Licensed Nurse Practitioners. They tested the instrument in their workplaces, completed questionnaires, and participated in a structured group discussion to provide feedback, which was captured in detailed field notes by the researchers.

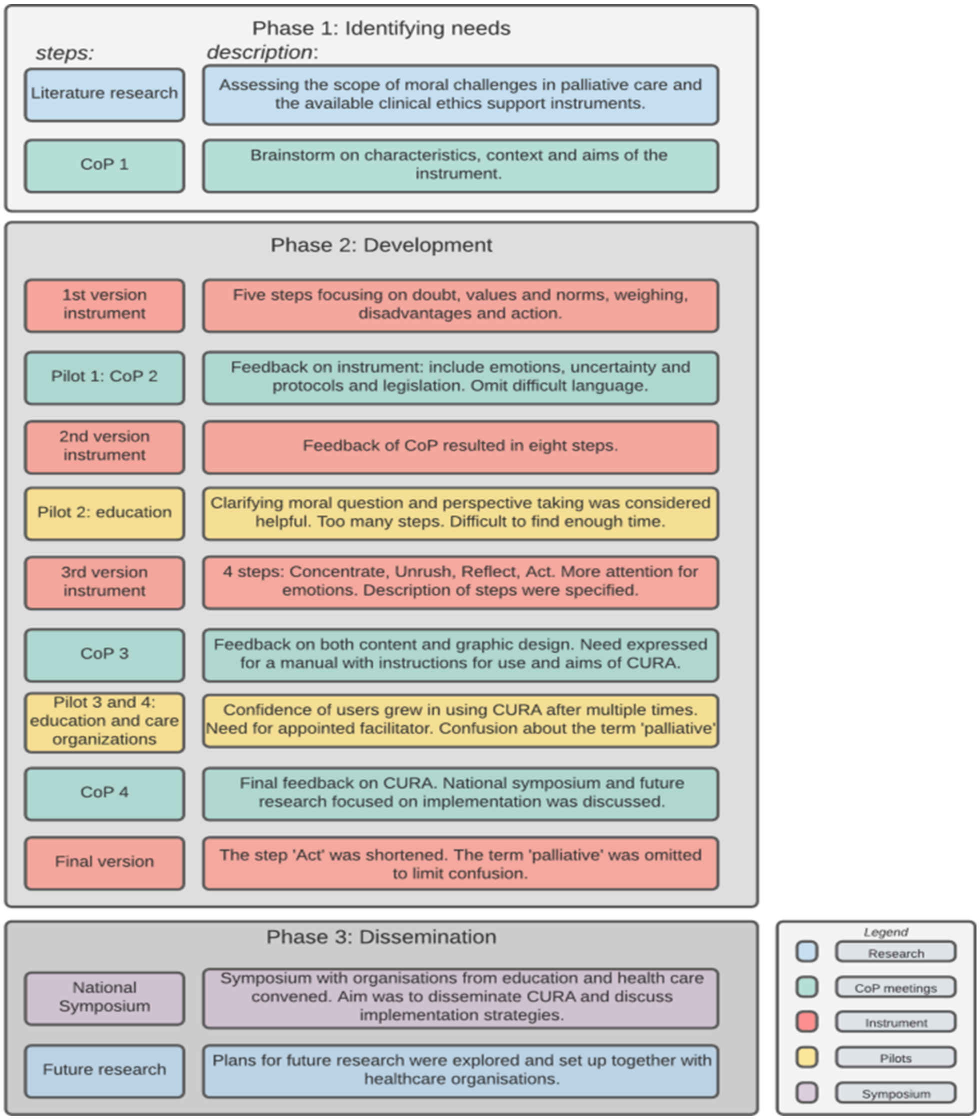
The fourth pilot took place within a large healthcare organization. Two distinct groups were established: one consisting of home care nurses and nurse assistants (n = 7) and the other comprising staff from various nursing homes (n = 8). These groups met monthly for a total of six sessions. In the initial sessions, the instrument was introduced and researchers guided the reflection process. In the later sessions, participants independently applied the instrument to examine ethical challenges encountered in practice. One of the researchers (MvS) attended all sessions to observe and document the discussions for research purposes.

Ethical considerations

All participants were informed of the study's scientific objectives and provided verbal or written consent. Nurses-in-training were explicitly told that participation, including completing questionnaires or giving feedback, was voluntary and would not influence their course assessments. Institutional approval was obtained from the management of the educational programs. In the fourth pilot, healthcare staff provided written consent for researcher observation and note-taking for research purposes.

Results and Discussion

The development of CURA progressed through three main stages: Identifying Needs, Development, and Dissemination. **Figure 1** illustrates the overall process, detailing the activities and steps undertaken within each phase.



Phase 1: Identifying needs

steps:	description:
Literature research	Assessing the scope of moral challenges in palliative care and the available clinical ethics support instruments.
CoP 1	Brainstorm on characteristics, context and aims of the instrument.

Phase 2: Development

1st version instrument	Five steps focusing on doubt, values and norms, weighing, disadvantages and action.
Pilot 1: CoP 2	Feedback on instrument: include emotions, uncertainty and protocols and legislation. Omit difficult language.
2nd version instrument	Feedback of CoP resulted in eight steps.
Pilot 2: education	Clarifying moral question and perspective taking was considered helpful. Too many steps. Difficult to find enough time.
3rd version instrument	4 steps: Concentrate, Unrush, Reflect, Act. More attention for emotions. Description of steps were specified.
CoP 3	Feedback on both content and graphic design. Need expressed for a manual with instructions for use and aims of CURA.
Pilot 3 and 4: education and care organizations	Confidence of users grew in using CURA after multiple times. Need for appointed facilitator. Confusion about the term 'palliative'
CoP 4	Final feedback on CURA. National symposium and future research focused on implementation was discussed.
Final version	The step 'Act' was shortened. The term 'palliative' was omitted to limit confusion.

Phase 3: Dissemination

National Symposium	Symposium with organisations from education and health care convened. Aim was to disseminate CURA and discuss implementation strategies.
Future research	Plans for future research were explored and set up together with healthcare organisations.

Figure 1. Summary of the development process

Phase 1: identifying needs

The first stage concentrated on understanding the perspectives and requirements of potential end users. To do this, the research team reviewed existing literature to examine three main areas: (1) the ethical challenges commonly faced by nurses and nurse assistants in palliative care, (2) the strengths, limitations, and gaps of current clinical ethics support tools, and (3) considerations for designing a participatory research approach. Insights from this review served as a starting point for discussion during the initial CoP session.

First CoP session

During the inaugural CoP meeting, which included ten participants, the study aims were introduced, focusing on developing an accessible, low-threshold ethics support tool for palliative care, alongside an explanation of the participatory development process. Participants affirmed the importance of having a straightforward tool to address day-to-day ethical dilemmas and recognized the high levels of moral distress previously reported among palliative care staff.

While acknowledging the value of structured ethical reflection, participants noted that existing sessions are often skipped due to time constraints. They also emphasized that many current tools are overly complex and typically require a trained facilitator or ethicist to guide their use.

The group then explored what the new instrument should look like, considering its essential features, practical application, and overall objectives. Through discussion, they reached agreement on the instrument's key characteristics, the settings in which it should be used, and its intended purpose. The results of this first CoP session are detailed in **Table 3.**

Table 3. Outcomes of the first CoP session: criteria for the instrument

Aspect	Agreed Criteria
Key Features	Simple and easy to understand; visually appealing with a clear and recognizable name; requires minimal or no formal training; emphasizes the patient's values; aligns with existing guidelines and protocols; time-efficient; suitable for both individual and group use
Intended Context	Designed for both educational and clinical environments; versatile across all palliative care settings, including hospice, hospital, home care, and nursing homes; accessible to nurses and nurse assistants of all educational backgrounds; practical for everyday use; avoids additional administrative burden; readily available
Primary Objectives	Enhance awareness and sensitivity to ethical challenges; support caregivers in managing difficult situations and coping with moral distress; enable caregivers to follow guidelines appropriately or make justified deviations when necessary

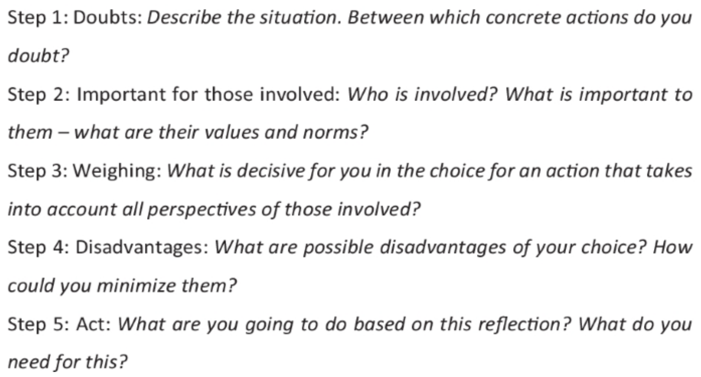
Phase 2: development

After clarifying stakeholder needs and establishing the criteria for the instrument, the development phase began. The instrument was created through an iterative, cyclical co-creation process, in which stakeholders participated in successive rounds of designing, piloting, and evaluating the evolving concept.

Initial draft of the instrument

The first draft of the instrument was prepared ahead of the second CoP session **(Figure 2)**, guided by the criteria identified in the initial CoP meeting. Development also drew on previous experience with creating tailored ethics support tools [15, 21] and with Moral Case Deliberation (MCD). MCD is a structured approach to clinical ethics support that enables healthcare professionals to systematically reflect on real ethical challenges. Its key principles include: (1) using personal experience as the starting point for reflection, (2) clearly defining the moral dilemma, (3) examining multiple ethical perspectives by considering the values and norms of all stakeholders, and (4) determining an informed and justified course of action. Dialogue plays a central role in MCD, as it promotes moral learning among participants.

Integrating these principles with the feedback from the first CoP session led to a preliminary instrument structured around five sequential steps.



Step 1: Doubts: *Describe the situation. Between which concrete actions do you doubt?*

Step 2: Important for those involved: *Who is involved? What is important to them – what are their values and norms?*

Step 3: Weighing: *What is decisive for you in the choice for an action that takes into account all perspectives of those involved?*

Step 4: Disadvantages: *What are possible disadvantages of your choice? How could you minimize them?*

Step 5: Act: *What are you going to do based on this reflection? What do you need for this?*

Figure 2. First version of instrument

Second CoP session

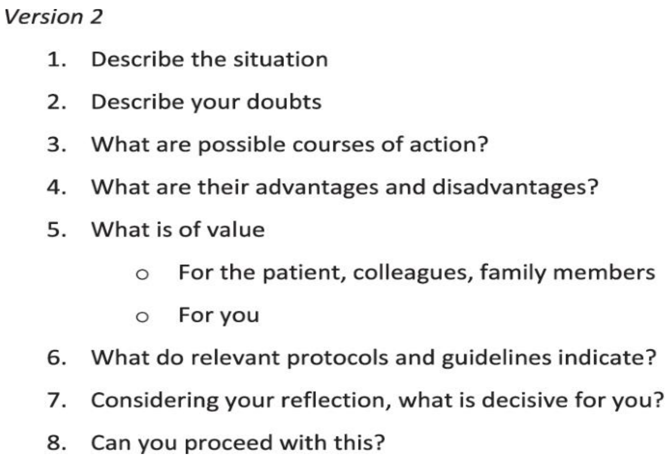
During the second CoP meeting, the initial draft of the instrument was presented, and participants were invited to provide feedback. They also engaged in small-group exercises, applying the tool to either professional or personal cases that involved ethical challenges. Several key suggestions emerged from this session.

Participants recommended adding an initial step in which the situation is clearly described. They also noted the need for a step capturing the user's immediate reactions, including emotions and bodily responses. Reflection prompts should explicitly encourage users to consider their personal values, while the patient's perspective should be more prominently represented. Additionally, legal requirements, regulations, and protocols should be explicitly integrated into the reflection process. Participants emphasized allowing space for uncertainty, acknowledging aspects that remain unknown, and suggested including a final evaluative step to review the reflection process.

Concerns were raised regarding the feasibility of the instrument for nurses with vocational-level training. To address this, Licensed Nurse Practitioners were included in testing to ensure their perspectives were incorporated. Moreover, CoP members involved in education recommended piloting the instrument among nurses enrolled in continuing education programs, and researchers were invited to introduce it during an ethics course in such programs.

Revision to the second version

In response to the CoP feedback, the first draft was revised and developed into a second version of the instrument **(Figure 3).**



Version 2

1. Describe the situation
2. Describe your doubts
3. What are possible courses of action?
4. What are their advantages and disadvantages?
5. What is of value
    - For the patient, colleagues, family members
    - For you
6. What do relevant protocols and guidelines indicate?
7. Considering your reflection, what is decisive for you?
8. Can you proceed with this?

Figure 3. Second Version of the Instrument.

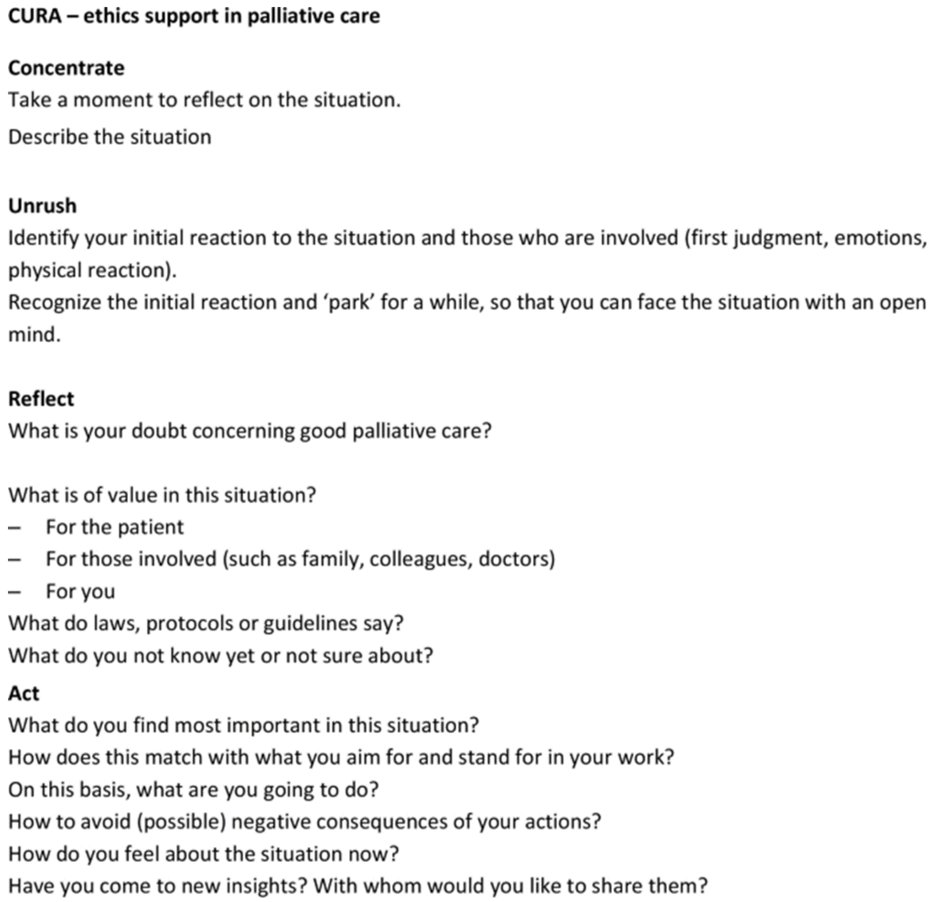
Piloting the second version

Nurses-in-training were first introduced to the instrument and the study, after which they applied it during class exercises and later in their own clinical settings, involving colleagues in the process and providing evaluations.

Feedback highlighted that the instrument was useful for clarifying moral questions or uncertainties, sharing knowledge and perspectives, and seeking advice from peers. In particular, analyzing the case from multiple stakeholder viewpoints (Step 5) was seen as especially helpful. Challenges included finding sufficient time to use the instrument with colleagues during work hours, and Step 8, "Can you proceed with this?", was considered unclear. Additionally, the overall eight-step structure was viewed as too lengthy.

Development of the third version

Based on this feedback, the instrument was streamlined into a third draft **(Figure 4),** reducing the number of main steps to four, each containing several substeps to maintain detail while simplifying use.



CURA – ethics support in palliative care

Concentrate

Take a moment to reflect on the situation.

Describe the situation

Unrush

Identify your initial reaction to the situation and those who are involved (first judgment, emotions, physical reaction).

Recognize the initial reaction and 'park' for a while, so that you can face the situation with an open mind.

Reflect

What is your doubt concerning good palliative care?

What is of value in this situation?

- For the patient
- For those involved (such as family, colleagues, doctors)
- For you

What do laws, protocols or guidelines say?

What do you not know yet or not sure about?

Act

What do you find most important in this situation?

How does this match with what you aim for and stand for in your work?

On this basis, what are you going to do?

How to avoid (possible) negative consequences of your actions?

How do you feel about the situation now?

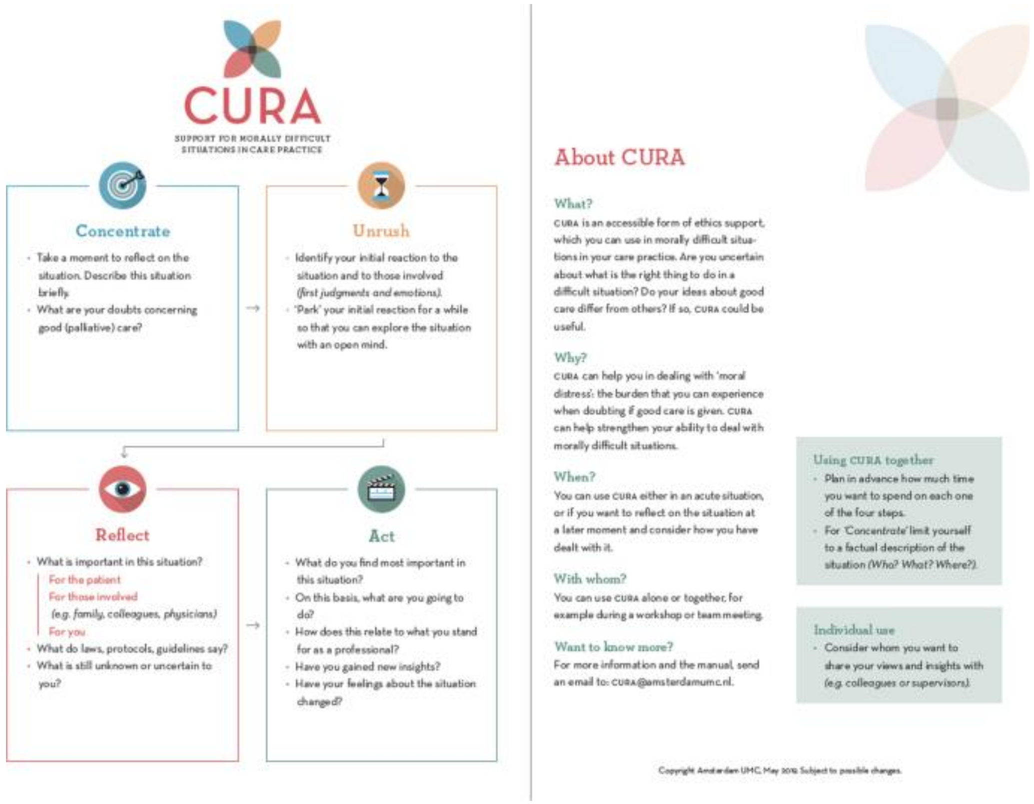
Have you come to new insights? With whom would you like to share them?

Figure 4. Third Version of the Instrument

The revised instrument consists of four main steps. The first step, "Concentrate," directs attention to the situation at hand and encourages caregivers to focus on their specific moral uncertainties. The second step, "Unrush," was newly introduced to provide space for reflecting on emotions, a component highlighted as important by CoP members. The third step, "Reflect," examines the values of everyone involved in the situation and includes a substep prompting users to consider "What do you not yet know or remain uncertain about?". The fourth step, "Act," connects moral judgment with practical actions. A substep here invites users to align their chosen actions with their personal motivations and professional principles, while the previous Step 8 was reworked into substeps asking "How do you feel about the situation now?" and "Have you gained new insights, and with whom would you like to share them?".

These four steps form the acronym CURA, which was selected for multiple reasons described elsewhere [17].

At this stage, a graphic designer was involved to translate the instrument into a visually accessible format. The designer was briefed on key priorities identified by the CoP, including simplicity, an appealing design, and a distinctive, recognizable logo. The layout was intentionally designed to avoid overwhelming users who may be unfamiliar with dense text. The final design is shown in **Figure 5.** The designer also participated in the next CoP session to engage directly with members and incorporate their feedback into the visual presentation.



CURA

SUPPORT FOR MORALLY DIFFICULT SITUATIONS IN CARE PRACTICE

Concentrate

- Take a moment to reflect on the situation. Describe this situation briefly.
- What are your doubts concerning good (palliative) care?

→

Unrush

- Identify your initial reaction to the situation and to those involved *(first judgments and emotions)*.
- 'Park' your initial reaction for a while so that you can explore the situation with an open mind.

Reflect

- What is important in this situation?
  - For the patient
  - For those involved *(e.g. family, colleagues, physicians)*
  - For you
- What do laws, protocols, guidelines say?
- What is still unknown or uncertain to you?

→

Act

- What do you find most important in this situation?
- On this basis, what are you going to do?
- How does this relate to what you stand for as a professional?
- Have you gained new insights?
- Have your feelings about the situation changed?

About CURA

What?
CURA is an accessible form of ethics support, which you can use in morally difficult situations in your care practice. Are you uncertain about what is the right thing to do in a difficult situation? Do your ideas about good care differ from others? If so, CURA could be useful.

Why?
CURA can help you in dealing with 'moral distress': the burden that you can experience when doubting if good care is given. CURA can help strengthen your ability to deal with morally difficult situations.

When?
You can use CURA either in an acute situation, or if you want to reflect on the situation at a later moment and consider how you have dealt with it.

With whom?
You can use CURA alone or together, for example during a workshop or team meeting.

Want to know more?
For more information and the manual, send an email to: CURA@amsterdamumc.nl.

Using CURA together

- Plan in advance how much time you want to spend on each one of the four steps.
- For 'Concentrate' limit yourself to a factual description of the situation *(Who? What? Where?)*.

Individual use

- Consider whom you want to share your views and insights with *(e.g. colleagues or supervisors)*.

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Figure 5. Final Version of CURA

Third CoP session

During the third CoP session, attended by 11 members, the third draft of the instrument was presented and tested in small-group exercises. Participants provided feedback on both content and visual design. The name CURA was considered appealing and easily recognizable. Members agreed that the instrument could be used relatively quickly (approximately 30 minutes) and was generally straightforward to apply. The step "Reflect" was identified as the most challenging, though participants noted that this difficulty was inherent to the reflection process rather than a flaw in the step's wording. They recommended providing concise instructions and brief information on the purpose of CURA and guidance on when to use it, enabling users to work independently without a trained facilitator. Based on these recommendations, a first version of the user manual was drafted.

Piloting the third version

Educational setting

The third iteration of CURA was tested in vocational training for Licensed Nurse Practitioners and in a continuing education program for practicing nurses. In both settings, participants balanced part-time education with clinical work. After an introduction to CURA, nurses-in-training practiced using the instrument in small supervised groups and later applied it in their own work environments with colleagues. Feedback from students indicated that while the instrument was generally easy to use, time constraints made collaborative use challenging. They also expressed confusion over the term "palliative", questioning whether CURA was intended solely for palliative care cases.

Practical setting

CURA was also tested with nurses and nurse assistants in a large healthcare organization, providing insights into its use over a longer period than in the student trials. Users reported growing confidence in applying CURA, including leading reflective sessions as facilitators. One nurse assistant described feeling empowered to discuss dilemmas with physicians after first exploring the issues with colleagues using CURA. Several participants began using CURA independently to address moral issues within their teams, reporting that it provided a sense of support and validation:

"The [CURA meeting] was very helpful. I felt supported, and it reassured me that my difficulty in accepting the situation was understandable. Colleagues could see my perspective, which strengthened me in dealing with it."

Observations by the researcher (MvS) highlighted some recurring issues. Participants often conflated palliative care with terminal care, raising uncertainty about whether cases qualified as palliative care. Additionally, it became clear that appointing a facilitator is crucial to maintain focus during the reflection process, prevent steps from taking too long, and ensure the reflection progresses effectively. These points were subsequently integrated into the user manual.

Finally, the researcher observed a notable improvement in reflective skills among participants, particularly nurse assistants with limited prior ethics education. Initially, they struggled to consider the patient's perspective and to differentiate their own priorities from the patient's. With repeated use of CURA, their ability to reflect from multiple viewpoints improved considerably.

Fourth CoP session

During the fourth CoP meeting, pilot study results were shared with members, and a final round of feedback on CURA was conducted, addressing both content and design to refine and finalize the instrument. The step "Act" was considered overly lengthy, leading to the removal of some questions, such as "How can potential negative consequences of your actions be avoided?" and "With whom would you like to share your new insights?". To reduce confusion around the term palliative care, the instrument's tagline was revised. Participants recommended producing a laminated, pocket-sized card, a poster for common areas, and an easily accessible online handout, as well as integrating the method into existing apps and websites. The user manual was also reviewed and discussed during this session.

Implementation and dissemination strategies were key topics of discussion. Although CURA is designed for independent and individual use without extensive instruction, participants suggested training certain staff as CURA ambassadors to facilitate reflective sessions and support quality implementation within their organizations. These ambassadors could serve as catalysts for wider adoption.

The idea of a national CURA symposium was also proposed and agreed upon. The symposium would target users from both healthcare and educational settings, emphasizing practical applicability. Its program was designed to reflect the co-creative research process and highlight the productive interactions between teaching, research, and practice.

Phase 3: dissemination

The final phase concentrated on planning dissemination and laying the groundwork for future implementation research, in collaboration with stakeholders. The development study concluded with a national symposium, which attracted a diverse audience from healthcare institutions and educational programs. Workshops and presentations were delivered by both researchers and CoP members, reflecting the participatory nature of the study. The symposium's goals were to share the results, introduce participants to CURA, and build a support network for a forthcoming national implementation study.

CoP members emphasized the importance of considering future implementation research, to ensure the long-term sustainability of CURA. Planning strategies for broader adoption and ongoing evaluation was viewed as a critical component of the development process.

In this section, we reflect on the development of CURA and the insights gained from employing a participatory approach to designing clinical ethics support (CES) instruments, concluding with directions for future research.

The goals of participatory development align closely with our approach to clinical ethics support, which is grounded in philosophical pragmatism and hermeneutic ethics [21, 22]. Both frameworks emphasize collaborative learning processes that take the lived experiences and contextual knowledge of participants as the starting point and reference [6, 15]. Rather than predetermining what constitutes a "good outcome," these outcomes emerge through joint engagement with stakeholders [5].

Participatory development proved valuable for several reasons. First, its emergent and flexible nature [5, 7] allows researchers to integrate stakeholder suggestions and take advantage of opportunities as they arise, thereby improving the instrument while engaging more participants and generating broader benefits [5, 22]. For example, our CoP members proposed piloting CURA within a continuing education program for nurses, involving these nurses as co-researchers and thereby expanding stakeholder engagement [22, 23].

Second, collaborating closely with stakeholders during development helps bridge the research-practice gap, the divide between knowledge production by researchers and its practical application by healthcare professionals [2, 3]. By involving end users from the outset, CURA was designed to meet the specific needs of nurses and nurse assistants in palliative care, addressing limitations observed with existing CES tools, such as excessive complexity or the requirement of trained facilitators [15, 21]. During the pilot testing, we observed that not all healthcare professionals were familiar with terms like "dilemma," "value," or "norm," which led us to deliberately avoid jargon and ensure accessibility across all professional levels.

Third, stakeholder involvement fosters a sense of ownership, momentum, and relational networks, which are critical for successful implementation.

Despite these advantages, there has been limited reporting on how CES instruments are developed. While some studies from our group describe CES tools [15, 21], they often provide little detail on the development process itself. By documenting the method and process behind CURA, we aim to demonstrate the value of participatory development for tailoring CES instruments to user needs and contexts and to provide an example of how this approach can be applied. Explicitly describing decision-making processes in CES development is crucial to maintain sensitivity and alignment with the inherently transparent, deliberative, and critical nature of ethics support, as highlighted by Schildmann *et al*. [24].

Feedback from CoP participants highlighted their appreciation for being involved in the process. They reported feeling taken seriously and noted that their input had been actively incorporated into subsequent iterations of the instrument [25].

Nevertheless, challenges were encountered. One such challenge was ensuring adequate stakeholder representation within the CoP. After the first two sessions, we recognized a lack of bedside nurses and invited them to subsequent sessions, which helped us better understand and address the needs of frontline staff. For instance, bedside nurses recommended producing laminated pocket-sized cards and posters for common areas, which were subsequently developed.

Another challenge involved achieving genuinely consensus-based conclusions, as multiple perspectives, ideas, and judgments had to be balanced [26]. Questions around power dynamics, such as whose voices were most prominent, required ongoing reflection. To address this, researchers actively sought feedback after each session and adjusted subsequent sessions accordingly. For example, participants requested more dialogue-focused activities rather than discussion-heavy formats. We responded by increasing small-group interactions, which encouraged quieter voices to be heard and fostered more equitable engagement.

Ongoing reflection on the researchers' own positionality was essential, as final decisions ultimately rested with them [5]. We maintained a logbook of all stakeholder input on both content and process and engaged continuously with CoP members to explain and discuss our decisions [7], allowing adjustments to the process or stakeholder composition when necessary.

A follow-up study is currently underway to examine the implementation of CURA across various palliative care settings, including hospices, hospitals, care homes, and home care services. This research also evaluates the effectiveness of CURA in enhancing moral competence and moral resilience when used consistently within an organization [17].

Although CURA was specifically designed for nurses and nurse assistants in palliative care [17], interest has emerged from other healthcare professionals and domains. Further research is needed to determine its suitability in other contexts and whether adaptations are required for broader application.

Conclusion

Using a participatory development approach, we created CURA, a low-threshold clinical ethics support instrument tailored for palliative care. Collaborating closely with end users and other stakeholders enabled us to align the instrument with their needs, refine its design, and address limitations observed in existing ethics support tools.

The development unfolded in three phases: (1) Identifying Needs, which involved assessing the range of moral challenges, existing ethics support, and user requirements; (2) Development, during which the instrument was iteratively co-created with stakeholders; and (3) Dissemination, focusing on strategies for future implementation and wider adoption of CURA.

Throughout the process, the Community of Practice (CoP) played a central role by offering a platform for exchanging diverse perspectives and knowledge, while also fostering momentum and support for implementation.

Ongoing and future studies will examine how CURA can be integrated across different palliative care settings and will evaluate its impact on healthcare professionals' moral competence and moral resilience.

Acknowledgments: The authors would like to thank the members of the CoP and all nurses, nurses-in-training and nurse assistants that participated in the study.

Conflict of Interest: None

Financial Support: This study is conducted in the context of a large national programme aimed at improving palliative care in The Netherlands. Itwas funded by ZonMW 'Pal-liantie. Meer dan Zorg.', Grant Number: 844001315.

Ethics Statement: Ethical approval was granted by Institutional Review board (IRB) of Amsterdam UMC, location VUmc. This study was considered not subject to the Medical Research Involving Human Subject Act (non-WMO). All participants were given written and/or verbal information about the study. An information letter describing the purpose of the study and the voluntary nature of participation was given to all healthcare professionals and nurses-in-training contributing to the pilots of this study.

References

1. Donetto S, Pierri P, Tsianakas V, Robert G. Experience-based co-design and healthcare improvement: realizing participatory design in the public sector. Des J. 2015;18(2):227-48.
2. Langley J, Wolstenholme D, Cooke J. Collective making as knowledge mobilisation: the contribution of participatory design in the co-creation of knowledge in healthcare. BMC Health Serv Res. 2018;18:585.
3. Rycroft-Malone J, Burton CR, Bucknall T, Graham ID, Hutchinson AM, Stacey D. Collaboration and co-production of knowledge in healthcare: opportunities and challenges. Int J Health Policy Manag. 2016;5:221-3.
4. Boaz A, Hanney S, Jones T, Soper B. Does the engagement of clinicians and organisations in research improve healthcare performance: a three-stage review. BMJ Open. 2015;5:e009415.
5. Goodyear-Smith F, Jackson C, Greenhalgh T. Co-design and implementation research: challenges and solutions for ethics committees. BMC Med Ethics. 2015;16(1):1-5.
6. Steen M. Virtues in participatory design: cooperation, curiosity, creativity, empowerment and reflexivity. Sci Eng Ethics. 2013;19(3):945-62.
7. Abma TA, Cook T, Rämgård A, Kleba E. Social impact of participatory health research: collaborative non-linear processes of knowledge mobilization. Educ Action Res. 2017;25(4):489-505.
8. Noergaard B, Sandvei M, Rottmann N, Johannessen H, Wiil U, Schmidt T, Pedersen SS. Development of a web-based health care intervention for patients with heart disease: lessons learned from a participatory design study. JMIR Res Protoc. 2017;6(5):e75.
9. Dearden A, Rizvi H. Participatory design and participatory development: a comparative review. In: Proceedings of the Participatory Design Conference (PDC'08); 2008; Bloomington, Indiana, USA. p. 1-4.
10. Schofield G, Dittborn M, Huxtable R, Bennett MJ, Dewhurst F, Earle CG. Real-world ethics in palliative care: a systematic review of the ethical challenges reported by specialist palliative care practitioners in their clinical practice. Palliat Med. 2021;35(2):315-334.
11. Maffoni M, Argentero P, Giorgi I, Hynes J, Giardini A. Healthcare professionals' moral distress in adult palliative care: a systematic review. BMJ Support Palliat Care. 2019;9(3):245-54.
12. Frey R, Robinson J, Wong C, Gott M. Burnout, compassion fatigue and psychological capital: findings from a survey of nurses delivering palliative care. Appl Nurs Res. 2018;43:1-9.
13. Kamal AH, Bull JH, Wolf SP, Swetz KM, Shanafelt TD, Ast K, Kavalieratos D, Sinclair CT. Prevalence and predictors of burnout among hospice and palliative care clinicians in the US. J Pain Symptom Manag. 2020;59(5):6-13.
14. Rushton CH, Caldwell M, Kurtz M. Moral distress: a catalyst in building moral resilience. Am J Nurs. 2016;116(7):40-9.
15. Hartman LA, Metselaar S, Molewijk AC, Widdershoven GAM. Developing an ethics support tool for dealing with dilemmas around client

autonomy based on moral case deliberations. BMC Med Ethics. 2018;19(1):1-11.

16. van Schaik MV, Pasman HR, Widdershoven GAM, Hartman LA. CURA: an ethics support instrument for nurses in palliative care: feasibility and first perceived outcomes. HEC Forum. 2021;33:1-21.
17. Metselaar S, van Schaik MV, Widdershoven GAM, Hartman LA. CURA: a clinical ethics support instrument for caregivers in palliative care. Nurs Ethics. 2022.
18. Patton MQ. Qualitative research and evaluation methods: integrating theory and practice. 4th ed. Thousand Oaks: Sage Publications; 2014.
19. Clemensen J, Rothmann MJ, Smith AC. Participatory design methods in telemedicine research. J Telemed Telecare. 2017;23(9):780-5.
20. Wenger E. Communities of practice: a brief introduction. Scholars Bank; 2011.
21. Hartman LA, Metselaar S, Widdershoven GAM. Developing a moral compass tool based on moral case deliberations: a pragmatic hermeneutic approach to clinical ethics. Bioethics. 2019;33(9):1012-21.
22. Ramaswamy V, Gouillart F. Building the co-creative enterprise. Harv Bus Rev. 2010;88(10):100-9.
23. de Jong G, Meijer E, Schout G. Involving undergraduate nursing students in participatory health research: implications from the Netherlands. J Prof Nurs. 2018;34(6):507-13.
24. Schildmann J, Molewijk B, Benaroyo L. Evaluation of clinical ethics support services and its normativity. J Med Ethics. 2013;39(11):681-5.
25. de Van Staveren J. Verbinding tussen onderzoek en praktijk: een evaluatieonderzoek naar de succesfactoren bij de ontwikkeling van CURA, een instrument ter ondersteuning bij morele dilemma’s. Ned Vlaams Tijdschr Palliat Zorg. 2021;17(2):75-80.
26. Lachapelle P. A sense of ownership in community development: understanding the potential for participation in community planning efforts. Community Dev. 2008;39(2):52-9.