Specialist palliative care classification: typology development

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ABSTRACT

Objectives The heterogeneity of specialist palliative care services requires a classification to enable a clear description and comparison. In Germany, specialist palliative care is provided by palliative care units, palliative care advisory teams in hospitals and palliative home care teams. The differentiation between the three care settings can serve as a first level of classification. However, due to profound variations in regulatory structures and financing systems, services within each setting are heterogeneous and characteristics remain unclear, which impedes quality management. Further characteristics of specialist palliative care models need to be considered to allow for differentiation. Thus, services should be described on a polyhierarchical basis, such as a typology, representing relevant characteristics. We aimed at the development of a comprehensive classification to facilitate the description and differentiation of specialist palliative care models.

Methods Qualitative study including the development of a literature based, preliminary list of structural and processual characteristics, expert interviews and focus groups. Eleven interviews from May to June 2020 and two focus groups, with seven and nine participants each, in January 2021.

Results Several structure and process characteristics were identified as suitable features for the specification of specialist palliative care in Germany. A classification in form of a typology including relevant characteristics has been developed.

Conclusions The advanced typology refines the existing level of differentiation within specialist palliative care services in Germany and paves the way for an improved understanding of services. This deeper insight into structure and process characteristics of specialist palliative care is necessary internationally.

BACKGROUND

Specialist palliative care (SPC) is an increasingly important part of healthcare[1–7] and includes a variety of community as well as inpatient services. In Germany, SPC is provided by palliative care units, palliative care advisory teams in hospitals and palliative home care teams. This differentiation can serve as a first level of classification. However, due to profound variations in regulatory structures and financing systems, services within each setting are heterogeneous, and characteristics remain unclear and are not reported consistently. Previous international studies have identified the obstacles resulting from the resource scarcity in healthcare potentiated with the knowledge gap of differences between models

Key messages

What was already known?
► Specialist palliative care services are heterogeneous, and differences are unclear.
► The differentiation between palliative care units, palliative care advisory teams in hospitals and palliative home care teams can serve as a first level of classification in Germany. For a thorough understanding of services this differentiation is insufficient, which impedes quality management.

What are the new findings?
► We provide a refined, comprehensive classification for the differentiation of specialist palliative care models in Germany. The developed typology provides a basic structure for future adaptation to other countries' palliative care models.
► By defining the terms taxonomy and typology, we raise awareness of different approaches to classification and reveal potentials.

What is their significance?
► The deeper insight into specialist palliative care models will contribute to an improved comprehension of services enabling national and cross-national benchmarking.
► A clear understanding of palliative care services will pave the way for further international research.

of palliative care.[7–9] To adequately address these issues, differences need to be described to classify palliative care models.

Theoretical approaches to classification vary widely, and many lack in-depth definitions.[10–13] Classification forms frequently used in healthcare are typologies and taxonomies, often mistakenly used as synonyms.[10] Taxonomies configure items based on empirically measurable dimensions or physical entities and are common practice in natural sciences such as biology.[14] A typology, in contrast, is a conceptually developed classification scheme, which is applied to the description of more abstract subjects and rather used in, for example, social sciences.[10 14 15] Typologies are qualitatively constructed multidimensional classifications building on characteristics particularly relevant for a clear, value-free and comprehensive differentiation.[14] Therefore, a typological setup is adequate to qualitatively classify SPC or any healthcare models/services.[16]

Controlling certain characteristics is indispensable to make outcomes comparable and inform cross-national projects and research. A clear characterisation of services also promotes a deeper understanding of financing and resource utilisation. Ultimately, a comprehensive description of services can facilitate comparisons and research about which components of SPC increase (cost)-effectiveness.[17]

Core criteria that may be used to define and distinguish different SPC models have been identified for the UK.[17] However, even though the results may serve as a basis for similar research, they cannot automatically be transferred to other countries' healthcare systems. Furthermore, listing characteristics without displaying possible types of the single items seems insufficient for an extensive description of differences and variations between services, whereas a multilayer classification can provide such a comprehensive structure.[10 14 15] We, therefore, aim to develop a typology to facilitate the description and differentiation of SPC.

METHODS
Study design
This qualitative study was embedded in the national research project COMPANION that aims to develop a casemix classification for adult palliative care patients in Germany. We employed a sequential approach including three stages: (1) development of a literature-based preliminary list of structure and process characteristics, (2) expert interviews for the identification of relevant structure and process characteristics for differentiation and (3) focus groups to discuss and verify the resulting typology building on identified characteristics.

The Consolidated Criteria For Reporting Qualitative Research guidelines[18] were followed to ensure high scientific standard.

Participants, setting and data collection
Stage 1: development of preliminary list
A preliminary list of structure and process characteristics was developed based on the research group's earlier work[19] as well as a selection of characteristics provided by the German 'Guide for Hospice and Palliative Care'.[20] The latter is a web-based data platform set up and run by the German Association for Palliative Medicine for voluntary registration of services (see https://www.wegweiser-hospiz-palliativmedizin.de). The list was additionally underpinned with international literature.[9 17]

Stage 2: expert interviews
Semistructured expert interviews were conducted by JW between May and July 2020. Participants were purposively selected. Criteria for inclusion were: (1) engagement in professional associations and/or other political commitment related to palliative care, (2) at least 4 years of respective work experience and (3) overarching expertise regarding structures and processes in at least one SPC setting. Variation regarding age, gender and professional background was considered. Recruitment was based on suggestions by the research team and the German Association for Palliative Medicine.

Experts were approached via email by a member of the research team (CB).

A topic guide for the interviews was developed following a four-step process[21] and pilot tested (see online supplemental appendix 1). In the interviews, participants were first invited to openly discuss suitable characteristics for a differentiation of SPC services in Germany. Subsequently, they were asked to elaborate on the suitability of the characteristics derived in stage 1, and to modify or complete the list as needed.

Stage 3: focus groups
Following the analysis of expert interviews, focus groups with representatives from the different care sectors (inpatient and community care) were conducted in January 2021 as end-to-end encrypted web conferences. Participant selection, recruitment and approach were realised as in stage 2. The focus groups followed a semistructured topic guide for the purpose of discussing and appraising the preliminary findings from stage 2 and reaching consensus on the typology (see online supplemental appendix 2). Both focus groups were moderated by two members of the research team (JW and FH).

Confidentiality
Written informed consent was obtained from all participants. All interviews and focus groups were audiorecorded, transcribed verbatim and completely anonymised to ensure confidentiality.

Analysis
Stage 1
The listed structure and process characteristics were evaluated and revised by the research team with regard

to the research question and the transferability of characteristics to palliative care in Germany.

Stages 2 and 3

Interview transcripts and field notes from the expert interviews were analysed (by JW and FH) using content-analytical techniques.[22][23] Codes were generated through a discursive process of analysis, including inductive and deductive coding. Deductive codes derived from the preliminary list of characteristics and predefined the coding frame, while inductive codes emerged from the material and enhanced the results of analysis. Findings were regularly discussed within the multiprofessional research team to enhance the confirmability and dependability[24] of the results. A provisional typology emerged as a central interim result, which informed the subsequent focus groups.[25] The software MAXQDA facilitated data management.[25]

Need for adaptation of the preliminary typology was identified and agreed on in the focus groups. Transcripts of the focus groups were analysed thematically[26] (by JW) to revise the typology and to identify potential discrepancies and dissent. Findings were discussed with the research team and verified in terms of suitability for the intended use. A detailed presentation of the final results was sent to the participants for comments or clarification of any misconceptions.

RESULTS
Stage 1

Initially, 55 characteristics were extracted from the identified sources to build a preliminary typology.[17][19][20][27] Nine characteristics were excluded because they were unsuitable for the research question or not applicable to the German healthcare system (see online supplemental appendix 3). The remaining 46 characteristics were included in the interviews in stage 2.

Stage 2

Semistructured interviews were conducted with eleven experts with an average experience in palliative care of 14 years and lasted approximately 45 min. Table 1 gives further sample characteristics.

Overall, the experts assessed the suggested differentiation of structure and process characteristics as reasonable to illustrate the heterogeneity of SPC services and pointed out relatedness. The interviews revealed that 28/46 suggested characteristics were not relevant for a differentiation of any of the three settings and were therefore removed from the list (see table 2). Reasons stated were (1) limited informative value for differentiation in form of a typology (7 characteristics), (2) being generally unsuitable for a differentiation of palliative care services in Germany (15 characteristics) and (3) being hard to operationalise typologically (6 characteristics). Moreover, it was argued to merge or split certain characteristics. The remaining 18 characteristics were deemed suitable for at least one of the SPC settings and were thus adjusted and/or sustained.

Table 2 includes information about which characteristics from the preliminary list were removed completely and why, removed for certain settings due to irrelevance, sustained or adjusted in the process of analysis based on the experts' suggestions.

Based on the results, a preliminary typology emerged representing all characteristics that had proved to be suitable for the differentiation of services. Some of those characteristics applied for all SPC settings, for example, 'number of professional groups', while others were relevant only for one or two settings, for example, 'certification' only for palliative care units. Furthermore, even for characteristics relevant across all settings, the possible types had to be adjusted setting-specifically. For instance, 'patients per year' may range from <150 to >300 for palliative care units; whereas numbers above 500 patients are possible for palliative home care teams and over 1000 for some advisory teams.[20] Consequently, certain characteristics were matched to the respective setting, resulting in one specific version of typology for each of the three SPC settings.

Furthermore, it became evident that services might even vary without differences in structures and

Table 1 Sample characteristics of expert interviews

Characteristics	Participants n=11
Professional background	
Physician	7
Nursing	2
Other profession	2
Sex	
Female	4
Male	7
Age, range in years	**31–62**
31–47	4
48–55	3
>55	4
Palliative care experience in years	
4–10	4
11–20	3
>20	4
Care setting of expertise	
Palliative care unit	5
Palliative care advisory team	6
Palliative home care team	7
Interview setting	
Face-to-face at workplace	3
Video call	8
Interview length, range in minutes	**28–86**
<40	5
≥40	6

Table 2 Process of development of list of characteristics during stage 2

| | Preliminary list of characteristics | Setting of care | | |
		Palliative care unit	Palliative care advisory team	Specialist palliative home care
Structure characteristics	Technical equipment	Removed completely (3*)		
	Facilities	Removed	Sustained	Removed
	No of full-time employees	Sustained	Sustained	Sustained
	No of volunteers	Removed completely (2*)		
	No of disciplines delivering the care	Sustained	Sustained	Sustained
	Education/training of external professionals	Removed completely (1*)		
	Employees with special skills or qualifications	Removed completely (3)		
	Presence of employees with migrant background	Removed completely (1)		
	Autonomy of unit	Combined and adjusted	Combined and adjusted	Combined and adjusted
	Subordinate structure			
	Certification of service	Sustained	Removed	Removed
	Clinical lead of service	Removed completely (3)		
	Size of service	Sustained	Adjusted	Adjusted
	Waiting list	Removed completely (2)		
	Membership in network	Removed completely (1)		
	Participation in palliative care and hospice registry	Adjusted	Adjusted	Adjusted
	No of cooperations	Removed completely (2)		
	Structure of cooperation	Removed completely (2)		
	Type of cooperation	Removed completely (2)		
	Funding	Removed	Removed	Adjusted
	Financing system	Sustained	Sustained	Sustained
	Additional funding	Removed completely (1)		
	Impact of funding on referral	Removed completely (2)		
	Primary diagnoses of patients	Removed completely (3)		
	No of patients per year	Sustained	Sustained	Sustained
	No of patients with migrant background	Removed completely (1)		
Process characteristics	Referral times	Removed	Removed	Sustained
	Access to care	Removed completely (2)		
	Referral route	Removed completely (2)		
	Mode of care	Removed completely (2)		
	Area of services	Merged and sustained	Merged and sustained	Merged and sustained
	Type of interventions			
	Out-of-hours availability of professional groups	Removed completely (2)		
	Decision making	Removed completely (2)		
	Culture-sensitive care	Removed completely (2)		
	Care type	Removed completely (3)		
	Communication ways	Removed	Adjusted	Adjusted
	Communication languages	Removed completely (3)		
	24/7 availability	Removed completely (2)		
	Out-of-hours mode	Removed completely (2)		
	Usage of satisfaction surveys	Removed completely (1)		
	Documentation and quality management	Split and sustained	Split and sustained	Split and sustained
	Outcome measurement	Removed completely (2)		
	Availability of standard discharge criteria	Removed completely (1)		
	Bereavement care	Merged and adjusted	Removed	Removed
	Complex grief assessment		Removed	Removed

*Explanatory note: Reasons stated were (1) limited informative value for differentiation when queried in form of a typology (7 characteristics), (2) being generally unsuitable for a differentiation of palliative care services in Germany (15 characteristics) and (3) being hard to operationalise typologically (6 characteristics).

Table 3 Characteristics of focus groups

Characteristics	Group A	Group B
Focus group length in minutes	99	110
Participants, total	7	9
Sex		
Female	2	2
Male	5	7
Professional background		
Physician	7	6
Other	0	3
Previous participation in expert interview		
Yes	4	3
No	3	6

processes, which was explained with variations in self-perception of different services.

> There seem to be differences, even in cases where structures and processes are the same. That teams march to a different drum, work differently, possibly also produce different quality of results. And that is what I mean by CULTURE. It has a lot to do with self-image, it has to do with the socialization of the players, and it also has to do with interaction with other partners, for example. (Physician in interview on palliative home care setting, 1_005, #00:02:05.9–003:04.8#)

As being hard to operationalise, the characteristic self-perception/culture seemed unsuitable for a typology and was disregarded in the further analysis.

Stage 3: focus groups
Two focus groups were conducted, lasting 90 and 110 min each. Group A with seven experts focused on the inpatient setting, while the home care setting was discussed by ten experts in group B. Table 3 provides sample characteristics of the focus groups.

Overall, the preliminarily developed typology with its particular characteristics for each SPC setting was considered suitable for the study objective. Required changes applied to aspects of terminology and the characteristics' possible forms. Three themes were discussed in detail, indicating required adjustments: 'professional groups' and 'range of care provision' for all settings and, for palliative care units, the addition of the characteristic 'palliative care certification'. Moreover, two missing characteristics were identified for all settings: 'Employees with palliative care qualification' and 'clinical supervision'. Besides that, an overarching theme ('neutrality of the typology') was identified.

Minor adjustments regarding terminology
Revision and modification of terminology and characteristics' possible forms were suggested, for example, for the term 'financing system' and few other, which were adopted accordingly.

Restructuring of 'professional groups'
The need for content-related restructuring of characteristics was discussed for the structure characteristic 'professional groups'. Since physicians and nurses represent a mandatory minimum in multidisciplinary SPC teams, the experts did not see any need to specifically display these professions in the options section.

The exact professional groups to be included were suggested in line with the German Diagnoses-Related Groups financing regulations and added in a supplementary footnote later.

> "I would name the professions that are also named in the Operation and Procedure Code financing system. It simply says social work, psychology, physiotherapy, occupational therapy, art therapy, pastoral care and relaxation procedures. (Physician_A-03, #00:49:26–8#)

Possible types of 'range of care provision'
The possible forms of 'range of care provision' appeared inappropriate in the preliminarily developed typology, thus requiring slight modifications.

> I think the division, as it is*, is very technically triggered. You should revise the aspects within this WHOLE symptom management, psychosocial support, and so on (…) what is displayed here are all quite exceptional things. (…) It's not something, I would say, typical and suitable to distinguish services. (Physician_A-04, #00:26:21–8#)
> *Explanatory note: The previously displayed version was a distinction between 'symptom control and psychosocial support only' and 'additional invasive procedures, e.g. invasive ventilation, chemotherapy'.

Analysis and subsequent discussion of the findings within the research team revealed that the purpose of interventions (eg, prolonging life or symptom management only) needs consideration besides the focus on disease-specific interventions, which led to an adaption of the characteristic's forms.

Adjustment of 'palliative care certification' as a characteristic
Following discussions in the focus groups, the originally proposed characteristic 'certification' required adjustment as it included certifications not specifically related to palliative care as, for example, comprehensive cancer centre. To allow for differentiation of palliative care services, only specific palliative care related certifications should be included, which was changed in the typology accordingly.

> So, first of all, BASIC certification, I think there are hardly any units left that are not somehow certified in some way. That's almost standard by now, so to say. (…) But what IS a separator indeed, and the issue of quality plays a big role there, a specifically palliative care certification, simply dichotomously enquired. (Physician_A-03, #01:00:43–2#)

Additional characteristics for differentiation of palliative care services

Two further characteristics were identified in the focus groups and subsequently added to the typology:

Added characteristic 'Employees with palliative care qualification (%)'

The number of team members holding a professional palliative care qualification was deemed relevant for the quality of care and thus a differentiation of services.

> The team members' qualification is decisive for the quality of care, not only referring to the clinical lead but all doctors, nurses and therapists: (Physician_A-06, #00:09:55–2#)
> There is an advanced palliative care training for all relevant professional groups, so I suggest using this as a criterion for qualification. (…) And then indicate percentage ranges like below 50 %, 50% to 75 % and over 75 % or so. (Physician_A-04, #00:10:45–6# - #00:13:55–1#)

Therefore, the characteristic 'employees with palliative care qualification' was added.

Added characteristic 'Clinical supervision'

As another missing, yet relevant aspect to differentiate services, participants discussed the provision of clinical supervision for the team as indicator for high quality of care.

> That is relevant, whether they have access to clinical supervision or not. And whether it is provided by an internal or external supervisor. (Physician_A-04, #01:16:44–6#)

Based on the discussion, the characteristic 'clinical supervision' was added to the typology following the focus groups.

Overarching aspect: neutrality of the typology

During the discourse of both focus groups, it was challenging to employ the typology without any implicit valuation. Neutrality is however an inherent, essential feature of typologies.

> We somewhat tend to put what we think is GOOD in there. (Physician_A-03, #01:19:26-6#)
> The questions we're discussing here are partly connected with considerable dogmatism and to some extent politically tense. (…) There are underlying vibes in the discourse because we are concerned about the loss of our stakes. (Physician_B-05, #00:34:03–8#)

Whenever needed, participants were reminded of the purpose of the typology to ensure the value-free discussion of required adjustments.

Ultimately, the process of analysis and adaptation resulted in a final typology for SPC services in Germany (figures 1–3).

DISCUSSION

In this study, we have developed a refined classification of SPC, which for the first time allows
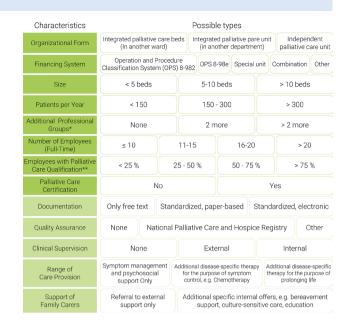

Figure 1 Typology for palliative care units. *Professional groups in addition to physicians and nursing staff: Social work, Psychology, Physiotherapy, Occupational therapy, Art therapy, Music therapy, Pastoral care **Reference: employees (total), not full-time equivalent

for a comprehensive description and categorisation of services on a conceptual, polyhierarchical basis. Increasing economisation and rising quality requirements in the health sector require services to be presentable in-depth and unambiguously. Along with previously developed characteristics from palliative care contexts in other countries, this improved understanding of characteristics
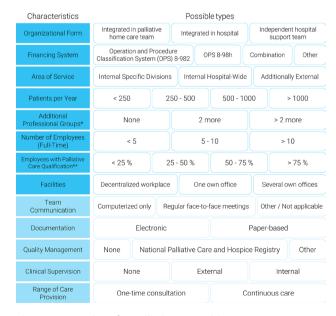

Figure 2 Typology for palliative care advisory teams. *Professional groups in addition to physicians and nursing staff: Social work, Psychology, Physiotherapy, Occupational therapy, Art therapy, Music therapy, Pastoral care **Reference: employees (total), not full-time equivalent
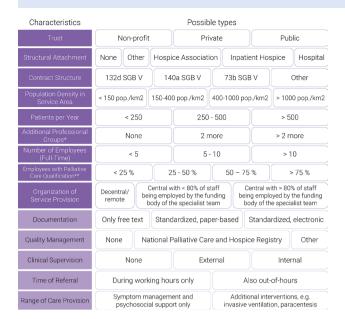
Characteristics	Possible types				
Trust	Non-profit		Private		Public
Structural Attachment	None	Other	Hospice Association	Inpatient Hospice	Hospital
Contract Structure	132d SGB V	140a SGB V		73b SGB V	Other
Population Density in Service Area	< 150 pop./km2	150-400 pop./km2		400-1000 pop./km2	> 1000 pop./km2
Patients per Year	< 250		250 - 500		> 500
Additional Professional Groups*	None		2 more		> 2 more
Number of Employees (Full-Time)	< 5		5 - 10		> 10
Employees with Palliative Care Qualification**	< 25 %	25 - 50 %		50 – 75 %	> 75 %
Organization of Service Provision	Decentral/remote	Central with < 80% of staff being employed by the funding body of the specialist team		Central with > 80% of staff being employed by the funding body of the specialist team	
Documentation	Only free text	Standardized, paper-based		Standardized, electronic	
Quality Management	None	National Palliative Care and Hospice Registry			Other
Clinical Supervision	None		External		Internal
Time of Referral	During working hours only			Also out-of-hours	
Range of Care Provision	Symptom management and psychosocial support only			Additional interventions, e.g. invasive ventilation, paracentesis	

Figure 3 Typology for palliative home care teams.
*Professional groups in addition to physicians and nursing staff: Social work, Psychology, Physiotherapy, Occupational therapy, Art therapy, Music therapy, Pastoral care **Reference: employees (total), not full-time equivalent

also facilitates international contextualisation. Enhancing the systematic comparison of processes through benchmarks will prospectively allow for measurement of quality and efficiency and facilitate quality development. This is a fundamental first step towards the benchmarking of SPC in one country against other countries' norms.[1 28]

The few earlier studies that aimed to develop conceptual classifications to describe SPC[13 17] neither considered the essential features of certain classifications, nor stated a clear rationale for their choice, for example, why a taxonomy was suitable for the research question.[13] With our paper, we seek to bridge this gap. The developed typology serves as a tool for the description and discrimination of services and thereby promotes the understanding of similarities and differences. Including earlier findings from other countries,[13 17] we recognised some similarities in characteristics like number of patients or number of employees. At the same time, we revealed the need for healthcare-system-specific evaluations of structure and process characteristics when describing palliative care models. We newly identified two characteristics to differentiate SPC services, namely 'clinical supervision' and 'employees with palliative care qualification', which are likely relevant not only within the German health system, but also internationally. This calls for prospective international research focusing on the very nature and configuration of SPC in other countries.

Against the background of the basic, polyhierarchical nature of typologies,[16] it must be emphasised

that the displayed order of characteristics does not refer to their importance. Rather, all included characteristics can possibly vary between different services, hence allow for a descriptive characterisation when considered together. In our study, the challenge of neutrality was especially reflected in the description of home care services due to extremely varying standards and conditions across the federal states.

Our overarching theme 'neutrality' demonstrates what Napier *et al*[29] describe as the absence of 'wholly neutral, objective bodies of knowledge' (p. 1626) in health-related research, questioning the apparent epistemological dichotomy of 'scientific objectivity' versus 'lifeworld subjectivity'.[29]

Our study underpins that previously described characteristics,[30 31] like self-perception or attitude of teams, may vary across different SPC services. These aspects are hardly operationalisable in a typological classification and thus were waived in this study. However, it will be worthwhile to explore the theme in future studies, as the concept of culture includes diverse values, beliefs and customs in healthcare teams, institutions and organisations.[29 31]

Strengths and limitations

A notable strength of this study is the applied sequential approach that ensured a successive development of evidence based and comprehensive results rooted in experts' knowledge and real-world conditions of palliative care models. Moreover, we applied a qualitative methodology which, by its theoretical freedom and flexibility, allowed for a rich, detailed account of data.[26]

Similar to previous studies,[17] a main limitation is that this study is specific for the German healthcare system. However, the results may contribute to prospective developments of classifications, and particularly represent a starting point for typologies as an innovative form of illustration of palliative care landscapes in other countries. Based on our results, the presented characteristics were the most significant regarding our study goal to develop a typology for the German context as a take-off point for further (international) classifications of palliative care. Certainly, it will be interesting and important to revise the typology in international contexts in the future. Further, the restriction to physician participants in focus group A introduces a potential bias as other professions may have had different perceptions. By discussing the results within the multiprofessional research team, we sought to reduce the risk of a unilateral perspective.

CONCLUSION

The advanced typology refines the existing level of differentiation within SPC services in Germany and paves the way for an improved understanding and

benchmarking of services internationally. In terms of quality development, this deeper insight into structure and process characteristics of SPC is necessary across all healthcare systems. Conceptual classifications like typologies represent an innovative approach to the understanding and comparison of models of palliative care and can hence contribute to quality development in palliative care.

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