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Do palliative care research priorities match those for its care? A journals content analysis 2021–22

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Background: Most international definitions of palliative care in the worlds of policy and practice emphasize the 'holistic' dimensions of end-of-life experience and its care.
Aim: To discover whether the definitions of palliative care are reflected in the field's research priorities.
Design and Setting: A content analysis of two research journals, one British and the other American, is described to provide a simple indicative answer to this question. The abstracts of 609 research papers drawn from these two journals between the years 2021–22 were examined thematically.
Results: The categories of physical alone, physical, and psychological, and psychological alone, when combined accounted for 69% of all research reports. The broader social aspects of care, outside of communication and advance care planning, were largely unaddressed. The social domain accounted for 29%, but 78% of this figure was about advance care planning and communication. Likewise, the role of spirituality, present in most of the definitions, was under researched and under reported. Even within this context, the results were disappointing. Spiritual care accounted for only 2% of reports.
Conclusion: Examination of research publications of two major palliative care research journals showed a significant overemphasis on symptom management and health service delivery assessments. This significant dearth of investigation in the major areas of social and spiritual domains is a call to action for researchers, grant making bodies, researchers, ethics committees, and journal editorial teams.

Keywords: Holistic care, Research bias, Multi-disciplinarity, Public health

Introduction

In 1964 Cicely Saunders introduced a radical revisioning of the idea of pain alleviation at the end of life as 'total pain' management. By 'total pain' Saunders included, not only the need to address physical symptoms, but also mental distress, social problems, and even spiritual anguish[1,2] This inclusive 'whole person' idea of how pain arises and is mitigated has been a foundational idea of modern palliative care ever since that time. The interrelationships of physical and psychological predicament with their social and spiritual origins and influences have since been acknowledged and stressed by all major public health organizations and policies beyond the field of palliative care itself.[3–5] In this way, Saunders was not only a pioneer of modern hospice but also one of the leaders of the modern health promotion movement. But has this clinical commitment to a holistic understanding of human health, even at the end of life, drawn parallel commitment and dedication from its own researchers?

The aim of this paper is to explore the question of the coverage and proportional emphases to the commitment that palliative care as not simply physical care but also psychological, social, and spiritual care. We conducted a content analysis of two recently published, research-focused, palliative medicine journals to collect some of the first indications of their assumptions of what constitutes holism in palliative care research. Do the research priorities in palliative care also support this holistic practice vision? Do our current research directions indicate support or departure from current policy and practice vision? If there is a departure, how serious is the rift, and what reasons might account for a trajectory in research so different in a field where both policies and practices have long enjoyed agreement.

We first summarize some of the key definitions of contemporary palliative care and describe the common themes that unite them, and more

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specifically unite them around Saunders's original vision of attending to total pain at the end of life. We then outline our method of content analysis, describe the results, and discuss the implications of these results finally asking, is there a need to reimagine palliative care research going forward into the future?

What does palliative care say is important about its own definitions of 'care'?

Whenever discussing the field of palliative care, the issue of definitions needs to be explored. There have been multiple definitions as the field formed, became specialized and developed. The terms palliative care; generalist palliative care; specialist palliative care, and even hospice are often used interchangeably, and this adds confusion and barriers to access into a field that is already not greatly understood).[6,7] Out of scope of this discussion on definitions is the term 'end of life care'. However, this additional term, often used to describe a late 'stage' within a person's journey through their illness is also often used interchangeably with palliative care.

Whilst the most-used definition internationally is that provided by the World Health Organization (WHO), there are others used by organizations and groups operating in the field. Table 1 provides some of the commonly used definitions.

The WHO and International Association for Hospice and Palliative Care (IAHPC) definitions are the most comprehensive because they specifically mention early identification (and prevention) which the others do not. Both WHO and Hospice UK's definitions specifically mention adults and children. WHO use the term 'life-threatening' illness whereas Hospice UK use 'terminal' and 'cannot be cured' as a way of defining the term they then use as 'life-limiting'. The NHS use both 'terminal' and 'life-limiting' in a similar way. The Association for Palliative Medicine used 'progressive', 'advanced', disease.

Table 1 Palliative care definitions

World Health Organisation	'Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual' This has an expanded description … '*Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.*[8]'
International Association for Hospice and Palliative Care	*PC is the active holistic care of individuals across all ages … health-related suffering is serious when it cannot be relieved without medical intervention and when it compromises physical, social, spiritual, and/or emotional functioning … .negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress … .and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers … .includes, prevention, early identification, comprehensive assessment, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress, and social needs.*[9]
Hospice UK	'*Hospice care aims to improve the quality of life and wellbeing of adults, children and young people who have a terminal illness or a long-term condition that cannot be cured, also known as life-limiting. It is free for patients, their carers and family members. Hospice care can be provided at any stage of a person's condition, not just at the end of their lives. It can include symptom management, and social, practical, emotional, and spiritual support. It helps people live as fully and as well as they can to the end of their lives, however long that may be. This type of care is also known as palliative care, and can also be provided in other places, such as in a hospital, at home, or in a community setting*[10]'
National Health Service (UK)	*If you have an illness that cannot be cured, palliative care makes you as comfortable as possible by managing your pain and other distressing symptoms. It also involves psychological, social, and spiritual support for you and your family or carers. This is called a holistic approach, because it deals with you as a 'whole' person, not just your illness or symptoms.*[11]
American Academy of Hospice and Palliative Medicine Palliativedoctors.org	*In the USA, palliative care is often referred to as symptom management accompanying curative treatments. Hospice is palliative care for the last year to six months of life. This can be provided in homes, hospitals, long-term care facilities, and other sites. This care is provided by healthcare teams and addresses 'more than physical needs, but also provide(s) emotional, spiritual, and practical support'*[12]
(UK) Association for Palliative Medicine	Specialist Palliative Care definition *Palliative care is active, total care of patients whose disease is not responsive to curative treatment; the control of pain and other symptoms, and of psychological, social and spiritual problems is paramount; the goal is to achieve the best possible quality of life for patients and their families; priorities focus on meeting every individual's goals, to deliver individualized, holistic care*[13]

WHO, Hospice UK, NHS, and the Association for Palliative Medicine mention families as part of the definition. The WHO extended definition specifically mentions bereavement support.

Whatever variations are reviewed, all the definitions have one central theme in common: palliative care is described as a scope of care that includes psychosocial, social, spiritual, emotional, and practical support in addition to physical care (symptom control). The Saunders's 1964 legacy of 'total pain' remains well evidenced in the contemporary formulations of multidisciplinary approaches and definitions of care at the end of life. Notwithstanding national differences about 'staging' in the dying process, or the accompaniment or not of curative treatments within different definitions of palliative and hospice care, there is overall agreement about the broad interprofessional and intersectoral contribution of that care.

The key definitions used for palliative care, whilst having some differences, are nevertheless similar because they continue to describe a field of practice that has breadth in supporting the whole person and their family, regardless of their type of 'life-threatening' disease, and with aspirations toward quality of life. Each of these definitional priorities of care, these multidimensional practices, draw on physical (i.e. aspects of the bodily experience), psychological (i.e. aspects of behavioral, emotional, or cognitive experience), social (i.e. aspects of identity, culture, and community experience), and spiritual (i.e. aspects of religious/spiritual meaning-making, support, and ritual experience), domains of the 'whole person' and their 'family'. Our main question then is: are these domains and priorities of experience mirrored in the current research directions of this field? To collect elementary indicators that would help us form a preliminary assessment of this question, we conducted a content analysis of the contributions from two major palliative medicine journals – one from the UK and one from the USA.

Content analysis method

We chose one prominent US palliative care journal (*American Journal of Hospice and Palliative Medicine*) and a prominent UK palliative care journal (*Palliative Medicine*) to analyze. These journals were chosen for two reasons. First, both journals display significant impact factor ratings. The British journal *Palliative Medicine* describes an annual impact factor of 4.4 in August 2023 while the *American Journal of Hospice and Palliative Medicine* describes an impact factor of 1.9. Secondly, both journals describe their interest as reflecting a 'multidisciplinary approach that is the hallmark of effective palliative care' (Palliative Medicine) whilst the other describes their 40-year history as 'highlighting the interdisciplinary team approach' to care (*American Journal of Hospice and Palliative Medicine*) All abstracts were reviewed from these two journals over a period of almost two years (PM: 1/21-9/22, AJHPM: 1/21-11/22). A total of 609 article abstracts were analyzed, with 259 of them drawn from *Palliative Medicine* and 350 drawn from the *American Journal of Hospice and Palliative Care*. When necessary, the full text of the articles was reviewed to gather the information needed to properly conduct the content analysis.

We separated the articles thematically into commonly used, frequently authored-described categories of medical care: physical, combined physical/psychological, and psychological. Our thematic analysis was guided by an 'open coding' method, generating specific categories that are guided by the language of the authors as well as the aims of the study.[14,15] From these cluster of initial categories, we further characterized these categories into the more abstract themes of dimensionality and epistemology. In other words, we characterized the earlier inductively-derived themes deductively into the broader themes of care – physical, psychological, social, and so on. This back-and-forth movement from inductive-descriptive to deductive-ascriptive is designed to uncover authors 'tacit assumptions' and 'pervasive logic'.[15] Initial codes were randomly cross-checked for reliability by other colleagues within the team. The raw data is described in Table 2.

Other categories, also commonly used in palliative care research and practice, were added as these slowly emerged from the initial physical and psychological pattern of themes: social, spiritual, and an additional category – 'multi'. The raw data for these groups is described in Table 3. The 'multi' category was created for articles that combined multiple theoretical and methodological areas: physical/social, psychological/social/spiritual, and mixed methods research.

From these thematically derived categories of care, we further identified and categorized the research population, research focus, and research methods, again, as author-described within the papers. These subcategories are also described within each table. The 'multi' category under research population was used when multiple populations were targeted by the authors of the research, i.e. patient/team, patient/family, etc. (e.g. The most important components of out-of-hours community care for patients at the end of life: A Delphi study of healthcare professionals' and patient and family carer's perspectives, *Palliative Medicine*, 9/22 36:8) The 'other' category in research focus was used when the focus was on a measurement tool or social policy rather than a specific population

Table 2 Categories of care

Key: TOTAL (Palliative Medicine/American Journal of Hospice and Palliative Care)

RESEARCH POP.	RESEARCH FOCUS	RESEARCH METHOD
	CATEGORY OF CARE: Physical = **123** (51/72)	
Patients = **101** (36/65)	Advance Care Planning = **0**	Cohort Study = **8** (6/2)
Caregivers/Family = **0**	Caregiver Experiences = **0**	Trial = **3** (1/2)
Medical Team = **14** (9/5)	Communication = **0**	Questionnaire = **2** (-/2)
Community = **0**	Community Experiences = **0**	Survey = **10** (4/6)
Multi:	Education/Training = **0**	Interviews = **4** (3/1)
Patients/Team = **1** (1/-)	Health Services Research = **58** (23/35)	Focus Groups = **1** (1/-)
Patients/Family = **2** (2/-)	Symptom Management = **62** (26/36)	Review – scoping = **2** (2/-)
Family/Team = **0**	Team Experiences = **1** (1/-)	Review – systematic = **21** (13/8)
Patients/Family/Team = **3** (3/-)	Other = **2** (1/1)	Existing Sources = **49** (10/39)
Other = **2** (-/2)		Multi = **5** (3/2)
Included subpop focus = 2 (-/2)		Other = **18** (8/10)
CATEGORY OF CARE: Physical/Psychological = **157** (68/89)		
RESEARCH POP.	RESEARCH FOCUS	RESEARCH METHOD
Patients = **83** (24/59)	Advance Care Planning = **0**	Cohort Study = **9** (7/2)
Caregivers/Family = **6** (5/1)	Caregiver Experiences = **1** (1/-)	Trial = **10** (6/4)
Medical Team = **30** (18/12)	Communication = **0**	Questionnaire = **6** (3/3)
Community = **1** (1/-)	Community Experiences = **1** (1/-)	Survey = **18** (10/8)
Multi:	Education/Training = **7** (3/4)	Interviews = **17** (11/6)
Patients/Team = **2** (1/1)	Health Services Research = **116** (50/66)	Focus Groups = **2** (0/2)
Patients/Family = **16** (9/7)	Symptom Management = **28** (11/17)	Review – scoping = **6** (2/4)
Family/Team = **4** (1/3)	Team Experiences = **1** (1/-)	Review – systematic = **27** (17/10)
Patients/Family/Team = **9** (8/1)	Other = **3** (1/2)	Existing Sources = **35** (5/30)
Other = **6** (1/5)		Multi = **9** (6/3)
Included subpop focus = 12 (4/8)		Other = **18** (1/17)
CATEGORY OF CARE: Psychological = **113** (55/58)		
RESEARCH POP.	RESEARCH FOCUS	RESEARCH METHOD
Patients = **21** (8/13)	Advance Care Planning = **0**	Cohort Study = **0**
Caregivers/Family = **43** (29/14)	Caregiver Experiences = **25** (13/12)	Trial = **7** (3/4)
Medical Team = **35** (13/22)	Communication = **0**	Questionnaire = **5** (5/-)
Community = **6** (1/5)	Community Experiences = **1** (-/1)	Survey = **27** (7/20)
Multi:	Education/Training = **4** (-/4)	Interviews = **29** (17/12)
Patients/Team = **0**	Health Services Research = **45** (25/20)	Focus Groups = **2** (-/2)
Patients/Family = **5** (3/2)	Symptom Management = **12** (8/4)	Review – scoping = **1** (1/-)
Family/Team = **1** (1/-)	Team Experiences = **23** (9/14)	Review – systematic = **14** (10/4)
Patients/Family/Team = **2** (-/2)	Other = **3** (-/3)	Existing Sources = **4** (3/1)
Other = **0**		Multi = **8** (4/4)
Included subpop focus = 4 (1/3)		Other = **16** (5/11)

group (e.g. Adaptation and psychometric evaluation of the parenting concerns questionnaire – advanced disease. *American Journal of Hospice and Palliative Care*, 8/22, 39:8). Finally, the 'multi' category in Research Methods was used when mixed-methods were employed, (e.g. in Evaluation of a WeChat-based Dyadic Life Review program for people with advanced cancer and family caregivers: A mixed-method feasibility study, *Palliative Medicine*, 3/22, 36:3) and 'other' was used for less commonly used methods like a retrospective analysis, etc. (e.g. Health professionals perspectives of the role of palliative care during covid-19: Content analysis of articles and blogs posted on twitter, *American Journal of Hospice and Palliative Care*, 4/22, 39:4).

Research populations that included a sub-population focus were noted. Sub-population foci referred to traditionally underserved/marginalized groups – prisoners, people living with HIV individuals, indigenous peoples, homeless, as well as country- and religious-specific groups. Different age groups studied were not sub-categorized.

Editorials and letters to the editor were excluded, but essays (minimal in number overall) were included. The research method 'existing sources' refers to medical records reviewed retrospectively. Results are presented in the tables (2 through 4) below. Overall totals appear in bold, with (Palliative Medicine/American Journal of Hospice and Palliative Care) following. The final table (Table 4) summarizes *the key trends* in percentage terms for the whole content analysis. The key trends which directly address the central question of this paper are four in number. These are (1) trends in the categories of care receiving the most to the least attention from researchers; (2) overall research topic emphases; (3) the dominant

Table 3 Emergent categories of care

<table>
<tr><td colspan="3">CATEGORY OF CARE: Social = 168 (62/106)</td></tr>
<tr><td>RESEARCH POP.</td><td>RESEARCH FOCUS</td><td>RESEARCH METHOD</td></tr>
<tr><td>Patients = 59 (13/46)
Caregivers/Family = 15 (8/7)
Medical Team = 49 (19/30)
Community = 12 (4/8)
Multi:
Patients/Team = 6 (-/6)
Patients/Family = 19 (12/7)
Family/Team = 3 (3/-)
Patients/Family/Team = 5 (3/2)
Other = 0
Included subpop focus = 24 (6/18)</td><td>Advance Care Planning = 58 (20/38)
Caregiver Experiences = 1 (-/1)
Communication = 73 (23/50)
Community Experiences = 8 (7/1)
Education/Training = 7 (1/6)
Health Services Research = 17 (9/8)
Symptom Management = 0
Team Experiences = 2 (1/1)
Other = 2 (1/1)</td><td>Cohort Study = 0 (-/-)
Trial = 8 (2/6)
Questionnaire = 10 (2/8)
Survey = 32 (5/27)
Interviews = 36 (23/13)
Focus Groups = 4 (3/1)
Review – scoping = 3 (1/2)
Review – systematic = 16 (11/5)
Existing Sources = 18 (5/13)
Multi = 13 (7/6)
Other = 28 (3/25)</td></tr>
<tr><td colspan="3">CATEGORY OF CARE: Spiritual = 11 (2/9)</td></tr>
<tr><td>RESEARCH POP.</td><td>RESEARCH FOCUS</td><td>RESEARCH METHOD</td></tr>
<tr><td>Patients = 7 (1/6)
Caregivers/Family = 0
Medical Team = 3 (1/2)
Community = 0
Multi:
Patients/Team = 1 (-/1)
Patients/Family = 0
Family/Team = 0
Patients/Family/Team = 0
Other = 0
Included subpop focus = 2 (1/1)</td><td>Advance Care Planning = 0
Caregiver Experiences = 0
Communication = 0
Community Experiences = 0
Education/Training = 0
Health Services Research = 8 (1/7)
Symptom Management = 1 (1/-)
Team Experiences = 1 (-/1)
Other: 1 (-/1)</td><td>Cohort Study = 1 (1/-)
Trial = 1 (-/1)
Questionnaire = 0
Survey = 5 (1/4)
Interviews = 0
Focus Groups = 1 (-/1)
Review – scoping = 0
Review – systematic = 0
Existing Sources = 2 (-/2)
Multi = 0
Other = 1 (-/1)</td></tr>
<tr><td colspan="3">CATEGORY OF CARE: MULTI: 37 (21/16)</td></tr>
<tr><td colspan="3">Physical/Social = 1 (-/1); Physical/Psychological/Spiritual = 3 (-/3); Physical/Psychological/Social/Spiritual = 1 (1/-); Psychosocial = 11 (8/3); Psychological/Social = 2 (2/-); Psychological/Spiritual = 14 (6/8); Psychological/Social/Spiritual = 4 (4/-); Psychological/Psychosocial/Spiritual = 1 (-/1)</td></tr>
<tr><td>RESEARCH POP.</td><td>RESEARCH FOCUS</td><td>RESEARCH METHOD</td></tr>
<tr><td>Patients = 17 (8/9)
Caregivers/Family = 4 (2/2)
Medical Team = 9 (7/2)
Community = 4 (2/2)
Multi = 3
Patients/Team = 1 (1/-)
Patients/Family = 0
Family/Team = 1 (1/-)
Patients/Family/Team = 1 (-/1)
Other = 0
Included subpop focus = 5 (3/2)</td><td>Advance Care Planning = 0
Caregiver Experiences = 1 (-/1)
Communication = 1 (-/1)
Community Experiences = 2 (1/1)
Education/Training = 4 (3/1)
Health Services Research = 15 (9/6)
Symptom Management = 11 (7/4)
Team Experiences = 1 (-/1)
Other = 2 (1/1)</td><td>Cohort Study = 0
Trial = 2 (1/1)
Questionnaire = 1 (-/1)
Survey = 1 (1/-)
Interviews = 10 (5/5)
Focus groups = 2 (2/-)
Review – scoping = 1 (1/-)
Review – systematic = 8 (6/2)
Existing Sources = 2 (1/1)
Multi = 5 (3/2)
Other = 5 (1/4)</td></tr>
</table>

Table 4 Summary (%)

Category of Care	Physical	Physical & Psychological	Psychological	Social	Spiritual	Totals
% Research Topic Emphases	21.5% Symptom Mgt & Health Serv Research 97.5%	27.5% Symptom Mgt & Health Serv Research 92%	20% Symptom Mgt & Health Serv Research 50% Caregivers & PC Team 42%	29% ACP & Communication 78% Community experiences 4.7%	2% Health Services Research 8/11 (73%)	*N* = 572
Dominant Research Method	Trials, Cohort studies, surveys, psychometrics, records examination = 47% Interviews or focus groups = 17%					
Population	Unspecified patients, caregivers/family, and clinical teams = 92% Underserved populations (migrants, people of color, prisoners, homeless, LGBTQ+, intellectual/developmental disabilities) = 8%					

research methods employed, and (4) the key populations of interest.

Results: the research trends

37 out of the total of 609 studies (6%) were eclectic studies that incorporated multidisciplinary dimensions within their research and mixed methods in their research designs and these reflect *prima facie* a commitment to the broader multidisciplinary orientation of the field. Most papers – 94% of the articles – reflected a singular themed perspective on care, and so it is to these single themed approaches to which most of our analysis will be concerned because they constitute the majority and dominant form of research approach taken by the field. The most dominant focus of research among these remaining 572 articles reviewed was the singular concern for physical (21.5%), combined concern for physical and psychological (27.5%), or solely psychological study of palliative care (20%) (See Table 2). These research interests combined describe over 2/3rds (69%) of all articles reviewed. On the other hand, social research accounted for 29% of all articles. Only 2% of all articles were devoted to the study of the spiritual dimension of dying, caregiving, or grief and loss.

Of all the physical care research conducted by the 572 articles reviewed, 97.5% of that research was focused on symptom management and health services research. Of all the combined physical/psychological research conducted, 92% were also focused on symptom management and health services research. Of all the psychological research conducted, 50% were focused on symptom management and health services research (evaluations, trials, or implementations aspects of types of services provided by professionals or institutions) but 42% was focused on caregiver and palliative care team experiences. There was one piece of research from a psychological perspective interested in community experiences (representing less than 1% of all interest from this viewpoint of care).

Of all the social research conducted by the 572 articles, 78% were devoted to advanced care planning or communication research while only 4.7% explored *community experiences*. In terms of overall priorities this 4.7% represents 1.3% of the overall research interest in community support or experiences among all the palliative care articles reviewed. It is also noteworthy to observe that within the social care research profile the research *population* of dominant interest was not communities (7%) but rather patients, families, and medical teams (93%).

Of all the spiritual care research noted by this review (2% of all articles), most of this work (8 out of 11 studies) was interpreted in service delivery terms, establishing the effectiveness or otherwise of this type of service. There was no evidence of interest in the community and its relationship to spiritual meaning-making or support. No study employed interviewing within this group, all studies instead preferring to approach their interest in spiritual research with a survey, focus group, or existing sources and even a trial (1) and cohort study (1). Aside from a focus group study, the uses of conversation and dialogue characteristic of interviews or pastoral care was not evidenced in these 11 studies. All these studies were interested in patients in their relationships to their healthcare teams as study populations and not in family/caregivers or the community.

The most popular research method employed across all studies was the use of trials, cohort studies, questionnaires, surveys, or study of medical records, or in other words, quantitative studies (47%). Only 17% employed interviews or focus groups across all research approaches. Of all populations studied only 8% were from sub-populations representing international or marginalized populations. Over 90% of the populations studied were unspecified patients, families, and clinical teams from the UK and USA. Specific studies of migrants, people of color, prisoners, homeless, LGBTQ+, or intellectually or developmentally disabled people comprised all of 8% of the total journal contributions.

In summary, the headline results from this content analysis are: first, the main priority of palliative care researchers publishing in these journals are physical and psychological care issues. Secondly, spiritual care issues – support, experiences, and professional services – receive the least attention from all writers and researchers in this review. Thirdly, although social care matters received less than a third of academic interest, most of this research was devoted to clinical matters of advance care plans and communication issues. If the content analysis of these two journals is anything to go by, less than 2% of social care research examines the support role and experiences of everyday communities. This is less attention than even spiritual care receives from palliative care academic research.

Fourthly, interest in marginal and underserved communities – from migrants to homeless populations – remain marginal and underserved from our research community. Unlike other departures of concern from international policies in palliative care, the actual lack of field innovations for underserved populations is equally supported by a complementary uninterest from the research sector. Finally, palliative care research as revealed by this content analysis, demonstrates an aversion to direct conversations with the recipients of palliative care, preferring instead the less personal methods such as questionnaires, psychometric scales, or trials. Qualitative methods are far less popular in palliative care. While some may argue this is less intrusive when researching dying patients, the same cannot always be said of families and communities involved in caregiving and those living with grief and loss.

Table 4 highlights these findings in percentages:

To check if there were any significant differences between the sample of UK articles (259) and the US articles (350) cross tabs were performed. No statistical differences were revealed in terms of research focus ($P < .05$). There were slightly more social care articles in the US than the UK (6.4%) and slightly higher psychological approaches in articles from the UK then the US (4.6%). The UK had slightly higher interest in mixed methods and eclectic care approaches than the US (3.6%). All other differences were less than 2%. To reiterate, despite the differences in national sample sizes there were no significant transatlantic differences in research focus or care themes.

Discussion

From the perspective of public health palliative care, existing definitions of palliative care practice remain limited, focusing more on service delivery and less on the importance of relationships and that death, dying, loss and caregiving as everyone's responsibility.[16] These problems are naturally reflected in the narrow confines of existing research emphasis. However, before tackling this potentially larger problem, the authors were keen to find out if existing research reporting in two major palliative care research journals met with several of the current definitions of palliative care. The existing definitions of palliative care include improving the quality of life for patients and families facing problems associated with life-threatening illness and the relief of suffering whether this be physical, psychosocial, social, or spiritual (WHO, IAHPC); helping people to live as fully and as well as possible (Hospice UK); and the active and total care of patients and their families (Association for Palliative Medicine). The research publications examined in this study leave a significant shortfall in matching the ambitions of these definitions. The primary focus for most research proved to be symptom management and health service research.

The categories of physical alone, physical, and psychological, and psychological alone, when combined accounted for 69% of all research reports. The broader social aspects of care, outside of communication and advance care planning, were largely unaddressed. The social domain accounted for 29%, but 78% of this figure was about advance care planning and communication. Likewise, the role of spirituality, present in most of the definitions, was under researched and under reported. Even within this context, the results were disappointing. Spiritual care accounted for only 2% of reports. In 2004 Hermsen and ten Have conducted a review of all articles on pastoral care, spirituality, and religion in palliative care journals between 1984 and 2001 and found that these types of articles represented less than 2% of all articles.[17] It is noteworthy to observe that some 20 years later, the current review found the same percentage of (un)interest in this form of care despite commonplace palliative care rhetoric to the contrary.

Several of the palliative care definitions refer to quality of life and living well. Lack of publications about this area is perhaps the greatest omission of all. Assumptions are made that addressing needs and symptoms, whether these be physical, social, psychological, or spiritual, will result in a good quality of life and living well right up until the end. These assumptions are seldom made outside of the field of palliative care, where living well is defined in the context of the multiple domains of social ecological models.[18] Papers about living well, what this means and whether it is achieved or not, for the person with the illness and those around them, were absent. This same deficit has been observed in palliative care research as a whole.[19,20]

That such a chasm has become obvious is one thing, understanding why and how it has developed is another, especially given that both policy and practice have long enjoyed a shared vision of holistic interdisciplinarity. However, perhaps the issue runs deeper than this. Recently, there has been an identified trend that describes academic research as becoming less disruptive. Whilst the volume of literature being produced continues to grow exponentially it is not shifting the trajectory of thinking.[21] This may go some way in explaining why the papers we have identified fail to break from a narrative that is orientated towards longstanding biomedical frameworks.

Palliative care policy and practice has done much to promote greater attention to psychological, social, and spiritual care, bringing care of the dying into sharper focus for healthcare internationally. Whilst this has afforded a platform for a fuller public discussion of dying, this is not reflected in current palliative care research priorities. In the world of palliative care research, the focus remains heavily on health services and medical challenges that prioritize physical, psychological, and institutional issues.

How then do we embrace, even promote, a body of work that challenges these old medical and institutional emphases and bridge the gaps in social and spiritual research? Research relevant to palliative care is not just the remit of palliative medicine and clinical practice. Indeed, there are multiple other disciplines that contribute valuable and crucial knowledge to this field. Whilst recent decades of palliative care knowledge generation have genuinely helped shed light in some areas, it has cast a serious, corresponding shadow on others. Embracing knowledge that reflects our interdisciplinary policy priorities, including the complex sources and divisions with our communities, may help dissipate the current shadows that under-research the social and spiritual dimensions of end-of-life experience and care. Part of this involves the redistribution of research funding to embrace and welcome disciplines and methods that are currently excluded by the current over-emphasis on clinical and institutional perspectives.

Limitations

We argue that examining the research foci and trends in two of the world's leading palliative care journals over the last two years provides a credible if elementary indicator of recent trends in the research community. These two journals advertise themselves as advocates of research that mirror the multidisciplinary nature of palliative care priorities. They also exhibit among the highest impact of the journals within their field. However, there are other palliative care journals, some of which specialize in social research (e.g. *Journal of Social Work in End-of-Life and Palliative Care*, *Palliative Care & Social Practice*). In this way, examining generalist journals may provide only a minimal estimate of the social care research done in this field. The same may also be argued in the case of spiritual and pastoral care research in palliative care (see for examples, *Journal of Healthcare Chaplaincy, Health and Social Care Chaplaincy*). There are also 'death studies' journals that may be favored by palliative care researchers more interested in researching and writing about support, experience, and meaning making (e.g. *OMEGA, Mortality*).

Furthermore, the chosen journals here are also ones that highlight the profession of medicine in their titles, and this too may promote a self-selection of submissions that favor physical care, quantitative research designs, and an emphasis on symptom management. In this way, although the current data does suggest important trends, it does so within these publishing market limitations. Nevertheless, since medicine is a major healthcare leader, and a role model for research within the field of palliative care, the data and trends for these journals send important professional messages to the rest of the field and funding agencies) about what priorities should be and may remain important. For this reason alone, trends from these sources will continue to be important to describe, discuss, and debate.

Conclusion: reimagining palliative care research

Evidence is an important facet of the delivery of healthcare, both in the context of understanding whether clinical interventions and service delivery have positive outcomes and for providing a basis for commissioning of palliative care services.[22] Coherence of evidence of effectiveness in the multiple domains of existing palliative care definitions is a reasonable starting point for further investigation. Examination of research publications of two major palliative care research journals showed a significant overemphasis on symptom management and health service delivery assessments. This significant dearth of investigation in the major areas of social and spiritual domains is a call to action for researchers, from grant making bodies, to researchers, ethics committees, and to journal editorial teams.

The broader context drawn from a public health approach to palliative care, the recognition of the positive aspects of death, dying, loss and caregiving, and of the societal impact of whole population participation as described in the compassionate city charter[23] are further challenges for palliative care researchers. For whole-person-care policy in palliative care to become whole-person-care research priority in palliative care, greater research imagination, collaboration, and funding redistribution will be needed. Furthermore, the recipients of care are the beneficiaries of research knowledge. To ensure this benefit is useful and meaningful, setting the research question, designing protocols and review of results should be a participatory process, involving those who have experienced death, dying, loss and care giving. The matching of interdisciplinary policy vision with interdisciplinary research vision is crucial if we are to succeed in supporting our professionals and communities with the needed research that is relevant to the work of both. It is also an essential that the policy and practice vision, and the research enterprise for the field, travel together and strengthen each other in a joint purpose for what is best in palliative care for patients, families, and their communities.

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