



The expression of ‘policy’ in palliative care: A critical review

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ABSTRACT

The importance of ‘policy’ within palliative care has steadily increased over the past 25 years. Whilst this has been welcomed within the palliative care field and seen as a route to greater recognition, we focus here on a more critical perspective that challenge the effectiveness of a ‘policy turn’ in palliative care. Applying Bacchi’s ‘What’s the Problem Represented to Be?’ (WPR) framework to data from a systematic search, we address the research question, “in what ways has ‘policy’ been articulated in palliative care literature?”. The paper describes the construction of ‘the problem’ context and reflects critically on the robustness and pragmatic utility of such representations. In particular, we identify five elements as prominent and problematic: (1) a lack of empirical evidence that connects policy to practice; (2) the dominance of ‘Global North’ approaches; (3) the use of a policy narrative based on ‘catastrophe’ in justifying the need for palliative care; (4) the use of idealistic and aspirational ‘calls to action’; and (5) a disengaged and antagonistic orientation to existing health systems. We conclude by suggesting that the efficacy of palliative care policy could be enhanced via greater emphases on ‘Global South’ perspectives, ‘assets-based’ approaches and attention to pragmatic implementation.

1. Introduction

Over the past 25 years, the prominence of ‘policy’ has grown within palliative care [1]. In the United Kingdom (UK), Findlay [2] suggests that 1995’s Calman-Hine Report (a cancer services framework in England & Wales) formed the origins of this. The following decades saw further exemplars: Sepúlveda et al. [3] noted a need for activists to advocate for palliative care *policy* development; Stjernswärd et al. [4] saw appropriate *policies* as an overarching feature of their ‘Public Health Model’ for palliative care; the World Health Assembly (WHA) resolution on palliative care of 2014 [5] urged member states to develop, strengthen and implement relevant *policies*; and in 2018, A Lancet Commission [6] highlighted the need for national and global *policy* making. Such expressions appeared to address a void, Clark [7] suggesting that, “before...2000 there was little systematic understanding of how palliative care was developing”. Interest in this policy ground continues to grow, predominantly in relation to primary ‘source’ palliative care policy documentation [8] and in a variety of contexts: specialisms like cancer, dementia and heart failure [9–11]; organisations like hospices, pharmacies and hospitals [12–14] and geographies, such as, Ireland [15] and Uganda [16].

Yet, despite this sense that policy is crucial to enhanced palliative care, little tangible evidence exists to show this ‘policy turn’ is actually championing care [17] and fostering grounded developments [18].

Various exhortations, declarations and resolutions that feature the need for palliative care policies have therefore raised critical questions among some commentators [17,19,20]; about the extent to which high-level policy interventions can escalate the speed and volume of palliative care development [19] and concerns about the slow progress of changes in service delivery directly attributable to policy [19]. Indeed, in their review of the ‘policy’ element of the 2017 global survey of palliative care, Clelland et al. [21] suggest that there is no apparent linear process linking policy to interventions. Moreover, much of this commentary has tended towards what Browne et al. [22] term a ‘mainstream’ orientation – rational and objectivist approaches, inclined to offer-up functional, affirmative and optimistic perspectives.

The work we report here builds on these concerns and shows how, despite the escalating and largely upbeat approach to policy within palliative care, there has been little effort to map or interrogate the character of such expression across the whole field [23]. Likewise, we suggest that this ‘mainstream’ approach has tended to be relatively pragmatic and superficial [15], lacking a sufficiently critical orientation [24]. In these circumstances, we build on and extend various critical insights that do exist in this domain, and which are mainly to be found in work undertaken within the Glasgow End of Life Studies Group [17,19,21,25–28]. With the research question, “in what ways has ‘policy’ been articulated in palliative care literature?”, we adopt in Browne et al.’s [22] terms, an ‘interpretative’ approach to palliative care policy

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narratives within publications identified in a systematic literature search, and in which a range of premises underlying ‘policy’ is considered critically. This is complemented by the use of a narrative form of policy analysis [29] that identifies various dominant and alternative ‘policy’ characterisations.

We start by describing the steps used to search the literature and to extract and analyse data. We then portray and discuss the nature of these expressions within three layered domains and in relation to a series of policy-specific theoretical perspectives. We conclude by suggesting ways to enhance the role of policy in fostering palliative care.

2. Methodology

An extended account of methodology is described: Supplementary material II.

2.1. Phase 1: search strategy

Three databases were identified as appropriate: CINAHL, ProQuest and Scopus. Using Medical Subject Heading (MeSH) terms, search strings were deployed, composed of: ‘Palliative Care’, ‘Palliative Therapy’, and ‘Palliative Medicine’ associated with ‘Policy’, ‘Public Policy’, ‘Health Policy’ and ‘Public Health Policy’.

2.2. Phase 2: data sorting

We adopted the inclusion criteria of publications in English from original papers published in academic journals starting in 1995 (on the basis that this date marked the commencement of significant palliative care ‘policy’ activity) through to July 2021. We excluded non-English papers, primary policy documents, and ‘gray’ literature. A double-blind review process was undertaken by two members of the project team (AB and SW) using the following screening question: Does the output display substantive attention to the relationship between palliative care and policy? Papers were then classed as either ‘pass’, ‘fail’ or ‘possible’ and a consensus reached on these between AB and SW. The ‘possible’ papers were then moderated by a third member of the team (DC). Details of these papers are given in Supplementary data I.

Initial raw search	ProQuest n=104	Scopus n=77	CINAHL n=69
Raw total=224 (26 duplicates removed)			
Full total = 198			
Review 1 (AB&SW)	Pass = 72		
	Fail = 102		
	Maybe = 11		
Review 2 (DC)	10/11 accepted		
	Final corpus = 81		

2.3. Phase 3: data extraction

Within our ‘interpretive’ approach, Braun and Clark’s [174] thematic analysis framework was used, wherein papers were read and outline notes made by SW to gain broad familiarisation and identify initial themes. Drawing on Bacchi’s 2009 framework [30] (“What’s the Problem Represented to Be?”), a series of analytical categories was then created: what is the geographical context?; what is the basis of the problematisation for palliative care policy; what specific ‘objects of policy interest’ are suggested; what is the technical nature of ‘policy’?; how is the need for palliative care policy constructed?; what is the source of policy intelligence?; and what outcomes are suggested? Data were extracted, coded and subsequently analysed from each of the identified papers using these analytical dimensions as informed by Talib and Fitzgerald’s [31] notion of ‘layered’ problematisations.

3. Results and discussion

3.1. Geographical context

Our first interest was to map and categorise the geographical locations of the reported work. Expressions related to varied jurisdictions; some global [32], some regional, like ‘Central and Eastern Europe’ [33] and ‘Latin America’ [34], whilst others focussed on individual nation states such as, Canada [35], South Africa [36] and Norway [37]. In wider terms, this distribution can be seen in relation to the six regions of the WHO (with an additional ‘global’ category).

Palliative care policy discussion was particularly evident in ‘Europe’ and the ‘Americas’ and within these, a further concentration was evident, since publications from the UK (particularly relating to England) were predominant in the Europe category, whilst those from the ‘Americas’ were almost exclusively from the USA. The ‘Western Pacific’ category was made up mostly of examples from Australia.

The preponderance of policy discussion was therefore located in ‘Global North’ countries. Moreover, these publications were based primarily on WHO logics. Of the 81 papers identified, 60 made a specific reference to some aspect of WHO policy. Those that did not, tended to be either older (pre-2000), relate ‘Global South’ domains or to have a USA or Canada jurisdiction, with reference to foundations sourced from their specific North American context. Three WHO-related items were particularly evident: Sepúlveda et al’s. [3] advocacy for “palliative care as a global public health problem”; Stjernswärd et al’s. [4] four-fold public health-based strategy of ‘policy’, ‘drug availability’, ‘education’ (and significantly to later discussion, their subsequent addition of ‘implementation’); and then, the WHA Resolution on Palliative Care’s [5] highlighting of the significance of political support. The authority of this ground is suggested in the assertion of Callaway et al. [38] that it provides a de facto “roadmap” and in the work of Bosnjak et al. [39], who use the principles as a “checklist”. In this sense, these elements are suggestive of what Sum [40] calls a “hegemonic policy ‘knowledge brand’”, in which policy assumptions are passively taken as ‘givens’.

3.1.1. Reflection

In contrast to the adoption of an unquestioning acceptance of this approach, and beyond the specifics of palliative care, a series of critical themes is also evident. As far back as 1994, Robertson and Minkler [41] saw the WHO as a constructed ‘social movement’ and Weisz and Vignola-Gagne [42] suggested that the WHO’s traditional expertise and approach - essentially focused on acute episodic pathogenic outbreaks using a centralised ‘text-book’ policy approach - was unsuited to the complexity of the chronic non-communicable diseases that form many contemporary concerns.

Using ‘interpretive frames’ in domains like mental health and public health, Jakubec [43], Ridde et al. [44] and Titchkosky and Aubrecht [45] have highlighted the partial and often partisan nature of WHO policy formulation, concluding that it is far from irrefutable. In particular, they suggest that solutions have tended to be shaped by Western oriented ‘underdevelopment’ and ‘modernization’ theory [43], favouring ‘statist’ and ‘professional’ approaches at the expense of pluralistic contributions from a variety of stakeholders, particularly those from a ‘civic’ base [46]. Furthermore, some detect a drift in WHO values from being explicitly ‘political’ (for example, 1978’s Alma-Ata Declaration call for an equitable global political health system) to one that foregrounds relatively functional and apolitical Western concepts such as ‘empowerment’ and ‘collaboration’, thereby “detracting from the need for longer-term social, economic, and political change” [47].

These observations are highly relevant to that part of the palliative care policy literature in which specific critical lines are evident. Beyond any hegemonic status, Clark [7] has critiqued both the conceptual rigour and pragmatic value of the WHO ‘public health model’ of palliative care, questioning whether it is, “fully adequate to tackle the barriers to development” and sees the four ‘foundation measures’ (‘policy’, ‘drug

availability', 'education', 'implementation') as, offering an "inadequate model for action and change". Likewise, and in contrast to the simplicity and uniformity often offered by WHO guidance, Lindqvist et al. [48] see palliative care as a 'wicked' policy topic, with "changing, contradictory requirements and complex interdependencies" and "not readily fixed with discrete solutions". So, in contrast to the essentialising nature of WHO guidance, the potential heterogeneity and complexity of palliative care are highlighted in terms of both practice and underpinning values. For example, in relation to the former, Abel et al. [49] differentiate between 'specialist', 'generalist', 'community' and 'civic' forms of palliative care. In terms of the latter, Vijay et al. [26] identify varied "logics" - between 'professional' and 'community' caregiving, 'centralized' and 'decentralized' governance and 'generalist' and 'specialist' approaches. Finally, in the context of the 'Western' orientation suggested by much of the WHO narrative, some also forward a 'post-colonial' critique [27], wherein 'Global North'-centric approaches to death and dying and the 'common future' for palliative care are variously, 'depoliticised' [50], 'homogenised' [27] and 'normalised' [26] at the expense of pluralistic 'decolonised' care and a variety of what Schill and Caxaj [51] call "culturally safe approaches".

We now move on to the substance of the policy narrative and in keeping with Talib and Fitzgerald's [31] notion of the 'interrelated' nature of policy texts that exert a 'cumulative effect', we identify a series of potential problematisations underpinning claims about a need for palliative care policy. These exist at three levels: universal (global context), intermediate (existing health systems) and grounded (palliative care itself). We use this framework to describe the emergent analytical themes.

3.2. Universal problematisation

Here, powerful nominals "demographic shift" and "changes in the future demographics of dying" [52] were most apparent. The concept of "aging populations" was often cited [9]; as was the suggestion of an accelerating rate of change, for example: "the population is...aging faster" [53]; "demographic situations are changing rapidly" [54]. This foundational narrative was complemented by the identification of an associated shift from acute to non-communicable [55] and chronic conditions [56], as well as significant levels of "co-morbidity" [57]. These positions fed through to the perception of "rapidly" ageing countries [54] and "a growing proportion of all deaths" amongst older people [58].

3.2.1. Reflection

The profound and externalised nature of these problematisations is distinctive, particularly the allusions to weighty demographic dynamics. Bacchi [59] recognises this expression of particularly "deep-seated" presuppositions in policy narratives and Terweil [60] associates these with the possibility of them acting to amplify the significance of positions. In relation to the notion of 'narrative linkages' where one element is, "made meaningful through the particular ways it is linked to others" [61], a particularly powerful source of legitimacy is visible in the sequencing of the growing numbers of older people in society, the proportion of this population with complex long term health needs, and thus growing numbers consequently needing palliative care.

For many, such apparent objectivity may seem both transparent and inevitable; for example, Massad et al. [62] contend that, "to intervene.... one must predict". Whilst there is an acceptance that demographic and epidemiological prediction is technically difficult [63] and conceptually thorny, Lobstein [64] stating, "the past is not a good guide to the future", one element of the 'escalation' narrative appears indisputable - that populations are aging [63]. However, in our 'interpretative' context, Stone [65] makes critical observations on the constructed nature of such data, particularly the inclusion and exclusion of 'what counts' in any policy deliberation. She proposes two features pertinent to the current discussion: '*wrongful exclusion*' and '*wrongful inclusion*'.

'Wrongful exclusion' relates to the apparently unequivocal 'escalations' we describe above, with the possibility that evidence which challenges this orthodoxy can be omitted from policy narratives. Such elements are evident - broadly, population growth is slowing markedly [63] and the incidence of dementia (particularly in Europe and the US) [66], ischemic heart disease [67], stroke [68] and some cancers in some particular 'Global North' countries [69] is declining. The 'aging population structure' pre-supposition can also be tempered by the recognition of further narrative exclusions, perspectives that variously assert that: 'chronological' age does not necessarily correlate with 'biological' age [70]; that other metrics offer a more valid assessment of 'healthy aging' [71]; that healthy life expectancy is generally rising [72]; and that ratio indicators of population old age dependency are invalid measures of the burden of an ageing population [73].

More generally, Massad [62] suggests that such predictions can be based on two contrasting premises: "forecasting", that seeks to predict what will happen based on simple extrapolation; and "projections", as attempts to "describe what would happen, *given certain hypotheses*" [62]. Here, in addition to the selection of confirmatory datasets (and the exclusions of others), the tendency to 'forecast' and amplify via crude extrapolations is prominent [9]. These tensions were reflected in the literature we identified and seem to move into the territory of 'wrongful inclusion', particularly in a 'Global North' context. The foregrounding narratives in many of these papers tended to use unequivocal 'forecasts' rather than tempered 'predictions' and rarely alluded to the unpredictability of projections and the emergence of ameliorating variables.

This issue is prominent in the wider literature; for example, in relation to the amplified nature of demographic shifts in ageing, Spijker and MacInnes [74] suggest that existing measures, such as the 'old age dependency ratio' are poor at articulating the 'burden' of an ageing population - so, we should not assume that in itself, population ageing will challenge care systems. In their terms, we have, "a timebomb that isn't" [74]. Yetsenga [75] also identifies prospective 'adjustments' that are already changing global demography and as such, will alleviate future care pressures. These include alterations in population level and demographic structures, as well as transformations in employment patterns and technological innovations. Jones and Greene [76] apply this approach specifically to dementia, noting that various factors are making "the burden of disease....malleable" and that "optimism about dementia is more justified than ever".

This tendency, particularly in 'Global North' contexts to magnify the scale of problems has been recognised by Jones and Green [76] as, 'public health catastrophism', observing that, "epidemiological observations are rarely read as independent...researchers recruit them into larger narratives of catastrophe" [76]. Crisis policy framing is thus linked to Beck's [77] notion of 'emancipatory catastrophism' which suggests that change comes from the creation and perception of a crisis. This notion of catastrophe was visible in our corpus; for example, in relation to inadequate opioid accessibility being seen by Bosnjak, [39] as a "public health catastrophe" and Sleeman et al's. [8] belief that, "failure to provide palliative care....will be catastrophic".

This stance aligns itself with what White [78] calls 'tragic emplotment' narratives, consisting of three elements. First, there is an acceptance of 'threat' - what Stone [65] sees as the indicator "that something 'needs to be done'" as embodied in the above 'set up' narrative. Second, a 'mechanistic argument' follows, consisting of 'rational' perspectives such as "evidence-based, cost-effective interventions" that are contained within the palliative care offering [79]. Finally, a reputational 'saviour' narrative that highlights the 'rightness' of new approaches - for example, in the notion of a "palliative turn" [80] as a reorientation in care perspectives. In a wider context, Glynnos and Howarth [81] call this a 'fantasmatic', policy logic, where the only solution to dystopian 'horrific' narratives (demographic and epidemiological catastrophes) is via utopian 'beatific' actions.

3.3. Intermediate problematisation

Talib and Fitzgerald [31] see the next problematisation domain as reflected in more substantive policy narratives, forming a transitional link between the universal and the specific. Here, the wide-ranging themes described above are complemented by more grounded problematisations within *current* healthcare systems to different relative degrees in Global ‘North’ and ‘South’ contexts. These themes were sometimes expressed affirmatively, as offering “opportunities” [82] – for example, in the possibility of meeting increasingly “complex needs” at the end of life [15]. However, in our corpus, this ground was more frequently associated with negative wording around the consequences of these universal problematisations – mainly in relation to ‘burdens’ and their detrimental impacts on healthcare systems as they are currently configured [79]. These included “financial” [54], “economic” [9] and “service demand” [80] burdens and were again sometimes couched in amplified terms; for example, “greatly increasing” care demands [80], “enormous” service pressures [83] and an “exponential growth” of service costs at death [52].

The very basis of the existing healthcare system in both Global ‘North’ and ‘South’ contexts was at times itself problematised as being variously, “fragmented” [84], “patchy” [85] and made up of “silos” [86]. These issues were additionally expressed in relation to more operational “gaps” [79], “deficits” [87] and “barriers” [33] that tended to focus on features like low organisational capacity [88], low numbers in the specialist workforce [87], shortages in specialist beds and equipment [9] and poor assessment, referral and communication processes [89]. Various human-resource related shortfalls were also expressed – like deficits in palliative care education provision [79], an insufficiently skilled workforce [86] and knowledge and skills deficits [57].

Building on these functional issues, deeper “systems-level” antagonisms [90] were also suggested, expressed variously as: the existence of a problematic “dominant biomedical paradigm” [80]; a “bias toward curative care” [36]; health service cultures where death is still a taboo [54]; hostile professional attitudes toward older people [80]; “legal and regulatory constraints” [80]; and “knowledge deficits and misunderstandings about PC” [79]. These narratives tended to be resolved by seeing palliative care as an “urgent policy and practice imperative” [55] and more policy formulation [80]; increased funding [15]; more trained palliative care professionals [91]; and expanded palliative care [83].

3.3.1. Reflection

This ground is noteworthy in three ways: its tendency to frame existing healthcare systems in broadly problematic terms; the existence of specific ‘crises’; and the urgency of a need for change. The various ‘burdens’ provide the ‘transitional link’ that Talib and Fitzgerald [31] theorise – from the external and universal to care specifics. The perceived ‘deficits’ within this context provide further potential traction to re-negotiate the relationship between current healthcare and the innovation suggested in palliative care policy discourse. Many of these features can be seen in relation to a ‘narrative policy framework’ [92] that suggests policy actors seek to employ discursive strategies to construct and/or exploit potential failings in existing policy and in turn, foreground their own contribution. This often takes the form of a ‘heroic’ narrative acting against ‘villains’ [65]. Here, the critical orientations to both the technicalities of existing healthcare delivery and the philosophical basis of any biomedical paradigm reflects this tendency, creating the need for a ‘palliative turn’ [80] – an example of what Linklater [93] calls a ‘grand policy narrative’ solution.

This negative orientation can also be seen as a form of ‘deficit framing’ – what Hedegaard-Sørensen et al. [94] see as a “conscious, deliberate action....to neutralize a barrier”. This ‘gap-based’ orientation appears to imply that change can best occur via the identification and ‘fixing’ of deficits – a position explicitly reflected in our literature as, for

example, “these barriers signify areas of needed policy development” [95] and “defining barriers to implementation, *and then* developing strategies to overcome them” [96]. Whilst “repairing weakness” [97] can be part of approaches to policy change, drawing on the influences of ‘positive’ psychology [98], ‘asset’ [99] and ‘strength-based’ [100] approaches, some [101] have critiqued this orientation, suggested that promoting the strengths of proposed actions is a more engaging, constructive and effective way of nurturing policy change than “fixing weaknesses” [97].

The ‘urgency’ discursive device is also recognised as a means of establishing the gravity of an issue and the need for a “response to avoid a looming crisis” [102]. The coupling of ‘deficits’ and ‘urgency’ provides what Bacchi [59] terms an “antecedent presupposition” that underpins the representation of ‘problems’; for example, from an item identified here, “there is no greater *urgency* facing American society than relieving the *crisis* that surrounds dying and care for the dying in our country” [103]. The introduction of the ‘crisis’ presupposition here further associates scale and rate of change with this deeper and weightier concept; for example, De Lima and Pastrana [53] class “palliative care issues” as a “public health crisis”. In parallel with the amplified demographic and epidemiological variables above, Hay [104] suggests that the aim of such efforts is to make, “the nature of the submerged threat.... immediately obvious (hegemonic)”.

3.4. Grounded problematisation

Finally, in their three-part schema, Talib and Fitzgerald [31] recognise the importance of a “plurality of micro-practices” – in our context, within palliative care itself. Within our corpus, this ground sometimes existed as a primary focus or concern [15]. But there were also many examples where it had a secondary status within ‘parent’ policies. These included: care delivery such as ‘cancer care’ [105], ‘hospice care’ [106], ‘critical care’ [57]; ‘dementia care’ [107], and ‘pain management’ [108]; defined groups, such as people with ‘chronic disease’ [58], ‘advanced chronic conditions’ [109] and ‘heart failure’ [11]; contexts such as hospitals [14], hospices [106] and ‘resource limited settings’ [110]; and professional groupings like pharmacists [13] and nurses [95].

Beyond broad exhortations, a variety of empirical ‘objects of interest’ are suggested. In substantive terms and particularly in the context those advanced chronic conditions [58] in hospitals and hospices [46] and as an emergent need in the ‘Global South’ [19], expressions of ‘treatment’ and ‘pain management’ were the most prominent features [58], accompanied with the desire to enhance ‘medicine availability’ [53]. This ground was also informed by a series of ‘process’ features: enhancing PC capability through training and education [15]; fostering integration and partnerships [110]; being ‘patient-centred’ by meeting ‘need’ more effectively [112]; and nurturing a more robust approach to evaluation and ‘evidence-based’ practice [79]. Outside this ground, an emphasis on wider ‘health promotion’ [129], ‘community development’ [130] and ‘compassionate communities’ [131] was also evident.

The papers often codified this diversity in relation to various indicators. For example: the prominence of policy [21]; degrees of integration [112]; funding allocated to PC [33]; the extent of specialist services [20]; levels of access to medicines [9]; workforce ‘capacity’ [87]; and the extent of training and education [53]. These were expressed as either stand-alone variables or more systematically [35] as a *suite* of actions [113] and composites presented in various forms – ‘atlases’ [114], ‘mapping’ exercises [115] or ‘league tables’ [116]. Beyond these pragmatic orientations, two contrasting ‘policy logics’ were visible in the form of ethically-based practice values [117]. At one end, the narrative was crafted around principled norms such as ‘holism’ [35], ‘compassion’ [105], ‘human rights’ [118], ‘poverty reduction’ [119], ‘equity’ [109], ‘justice’ [120] and ‘needs’ [112]. In contrast, an approach based on a narrower form of policy ‘rationality’ [120] was evident, expressed as notions like “evidence-based” [53] and

“cost-effective” palliative care [56], using economic principles to, “optimize resource allocation” [121].

The tone of much of this narrative tended towards the normative, aspirational and exhortative, with examples of wordings such as ‘should’ (“countries *should* have appropriate policies” [9]; “palliative care services *should* be integrated into service delivery” [110]); ‘must’ (“services *must* be...comprehensive...*must* respond to all physical, spiritual, and social requirements” [120]; “palliative care *must* be integrated into patient care” [122]; “end of life care...*must* entail community engagement” [107]) and ‘need’ (“there is a fundamental *need* to raise the profile of palliative care” [123]; “the *need* to foster recognition that active disease management and palliation are complementary” [58]).

Few papers reported on actual activity beyond these exhortations – that is, they tended to see policy implementation as a subsequent afterthought to its creation; Beck [36] for example suggests, “successful implementation is *the next necessary step* (italics added)”. These papers rarely engaged with discussion that explored grounded activity and realistic implementation. Only 14 papers in the corpus actually did this *in situ* [11,13,20,23,34,36,48,82,87,105,106,109,111,112]. Some openly recognised this as problematic, for example: Gaertner et al. [122] talk of the ‘challenge’ of implementation; Chattoo and Atkin [11] contend that reviews of implementation “suggest gaps interspersed with patchy progress”; Beck [36] concludes that “the transition from policy to practice...faces formidable obstacles”; May et al. [15] suggest that Irish policy has “struggled to achieve full implementation and key recommendations remain unfulfilled” and more widely, Alikhani et al. [9] suggest, “most countries...still have a long way to reach the desired level in providing...palliative care”. In keeping with this tone, calls for more attention to be paid to implementation were made, highlighting the need for support [53] and the suggestion of various hypothetical ‘pre-requisites’ [124].

3.4.1. Reflection

The heterogeneity within the palliative care policy domain was striking. This should perhaps not be considered surprising. Definitionally, the inclusion of a spectrum of potentially divergent values and practices in the discipline is well established, resulting in a “lack of consensus on a definition” [125] and consequently, a “segmented discipline” [126]. This variability feeds through to practice, with diversity in target groups, service structures and tasks [34] and is ultimately expressed in relation to ‘specialist’, ‘generalist’, ‘community’ and ‘civic’ contexts [49].

In the policy setting, this ground becomes more than an arcane definitional deliberation, rather it assumes material significance. Sin [127] suggests that in this context, concepts can be reified and idealised as constructed and enacted ‘policy objects’; in a political context this refers to what policy ‘becomes when transposed into practice’ [127]. In this sense, it would perhaps be better to refer to palliative care policies in the plural (Lang and Rayner [128] term this a “policy cacophony”), where content comes from disparate worlds above – from the specific functional details of clinical issues such as treating advanced chronic disease [58] and fostering access to opioids [33], through to broader concerns of various types of policy capacity, such as palliative care funding, training and research [15] and wider health promotion [129], community development [130] and ‘compassionate communities’ [131].

Given the variability of these objects, any enactment is potentially complex. Some try to sidestep this issue by seeing palliative care as a ‘complex adaptive system’ [132], comprising individual, professional and social ‘subsystems’ [133]. Such diversity is sometimes accommodated within a consensual pragmatism where policy ambiguity allows, “multiple interpretations” to be matched to “the environmental conditions and motivations of the interpreter” [134]. The relevant examples here often suggested this desire for policy coherence – either implicitly as the nominal unitary concept, ‘palliative care’ [95] or explicitly, where there is a need for “international consensus on the meaning and target

population of PC” [84]. The WHO roots of much palliative care policy we describe above are significant to this tendency. They are in keeping with the wider recognition of WHO public health policy seeking consensus [135] within what Awofeso [47] calls an “umbrella...total public health” approach. Some have critiqued this consensus; Ridde et al. [44] for example noting the ‘polysemic’ nature of many WHO concepts and Tesh [136] suggesting that the WHO “hides its politics” by concealing significant practical, ideological and conceptual tensions.

In this context, narratives rarely alluded to the possibility that some domains are more prominent than others – for example, that attention to palliative clinical care services significantly exceeds that of community approaches [137], or that these domains draw on divergent professional/community, centralized/decentralized and generalist/specialist paradigms [26]. Only four of the papers alluded to any such tensions. Both Seymour and Cassel [84] and May et al. [15] explored the optimal balance of emphasis in relation to ‘downstream’ on the immediate dying phase or ‘upstream’ on wider phases of serious illness (and the relationship between ‘specialists’ in PC and ‘generalist’ providers). Robinson et al. [14] also alluded to the debate about what form palliative care services should take in relation to “the balance between acute and community based services”. Finally, Morrissey et al. [80] recognised that palliative care exists in *both* medical and social domains.

These issues were also reflected in the ground that sought to quantify the status of these palliative care components – in relation to both individual service-oriented ‘indicators’ [138] and the composites embodied in atlases, maps and league tables [114]. Stone [65] notes the significance of ‘numbers’ in how we ‘encode’ policy issues and returning to her notion of ‘wrongful inclusion’, the validity and therefore the intrinsic standing of the data that is included in palliative care policy discourse is open to critique – both technically and in relation to the robustness of the comparisons that inevitably follow.

The inclusion and pertinence of the indicators contained within these instruments have been questioned, often reflexively by those conducting such work. Clark et al. [19] for example acknowledge that, “rigorously tested indicators of palliative care access and development do not yet exist”. A series of technical concerns is also evident, for example: potential under or over reporting based biases arising from self-reported data submitted by palliative care specialists or government sources [28]; the possibility that general country level reporting may conceal within-country variation [21]; and the problem of indicators focussing on specialist palliative care delivery rather than provision in mainstream and primary care and wider communities [138].

This issue is suggestive of a wider set of concerns around a singular validity for such indicators, Arias et al. [138] contending, “there is no consensus determining which set of national-level indicators best assess countries’ development globally”. Those that are included are also considered to reflect and foreground ‘Global North’-centric orientations and priorities in palliative care (mainly professional and formalised forms of care), at the expense of other possible models – particularly the community-oriented models often seen in the Global South [27].

Whilst some, particularly through a ‘pain relief’ frame, see palliative care in the ‘Global South’ as “parlous” [175], the particular socio-economic and social conditions in these domains have led to features that are considered both progressive in policy terms and often absent in the ‘Global North’. For example: drawing on a particular communitarian socio-political environment, the Neighbourhood Network in Palliative Care (NNPC) in Kerala, India has adopted a ‘public health’ approach [176] that addresses the range of social, spiritual and emotional needs at the end of life [177]; similarly, in Dhaka, Bangladesh, a community-based orientation coupled with a pragmatic desire to take services to those in greatest need led to the formation of the Agargaon and Korail slums palliative care project [178]; driven by a desire to be “contextually appropriate” and addressing barriers associated with population density, poverty and geographical diversity, palliative care services in Kolkata have been delivered using a ‘home-based’ model

[179]; and in a desire to make services regionally and culturally sensitive, the KwaZulu Natal HIV/AIDS outreach programme in Durban deployed a ‘volunteer’ at the heart of service provision [180]. These values of social communitarianism, localism and pragmatism can be considered to have acted to attenuate the medical hegemony and ‘top down’ policy-driven approach that tends to be associated with WHO approaches [181]. Encouragingly, Vijay and Monin [182] see these grassroots, ‘civic’ orientations as being more “poised” than others to support *more agile and speedier* innovation.

Furthermore, the source of the intelligence that informed these positions was highly varied. Often, positions were derived from implicit un-sourced foundations [20]. Others drew upon insights from named ‘expert’ sources from within palliative care: reviews of academic literature [33]; existing policy material [111]; policy ‘audit’ [58]; and stakeholder consensus-forming exercises [88].

Such critiques again move the discussion on, from the technical to the political; Woitha et al. [1] for example question the value of such mechanisms, “conceptually, culturally, politically, and morally” and Vijay et al. [26] see indicators in an evaluative context with political consequences. Invoking the ‘regressive’ aspect of Goodhart’s law [139] where proxy indicators are distorted as imperfect correlates of the breadth of potential interventions and ultimate goals, ‘Global North’-centric measures can be seen as privileged and by their adoption become implicitly established as ‘norms’ that have currency in future decision making and resource allocation. These expressions therefore potentially become self-perpetuating [27]. This tendency sees the domains of such atlases, maps and league tables as a “gold standard” that others need to “measure up” to and as an ideal that needs simply to be “rolled out” from the ‘Global North’ to the ‘Global South’ [19].

This normative ‘could/should’ narrative also has broader significance. A simple hubris was apparent in our corpus - the broad belief that with a ‘worthy idea’ and support from expert sources via exhortative proclamations, implementation will inevitably occur. These rudimentary assumptions can be considered problematic in three ways. First, the likelihood of implementation where policy simply rests on normative ideals is questionable. Hills and McQueen [140] note that, “charters, goal statements, mission statements, constitutions...often represent the loftiest and often unobtainable goals of the creators...[whose] expectations far exceed the abilities of mere mortals”. Second, this tendency to resort to normative exhortations has implications for the potential of grounded policy implementation, some suggesting that policy enactment has been a theoretical, secondary and marginal afterthought to creation, inhibiting approaches that might envisage actual implementation or genuinely engage with a range of relevant policy stakeholders [141]. This tendency minimises the significance of what May [142] terms, ‘agentic contributions’ and ‘capability’, and that policy implementation is integral to formation and needs to be a “planned conscious political act”. Third, the basis of implementation engagement appears problematic, with little apparent reference in the papers reviewed to other health professionals and clinicians or the semantic and practice-based tensions that can exist in this context [143]; for example the view that “a peaceful death is ‘not recognised as a legitimate goal’ for intensivists” [57].

The practical crux of this latter issue rests in the recognition of there being ‘poor communication’ between palliative care and the wider medical profession [52], compounded by the tendency for the interaction to focus on ‘deficits’ within ‘mainstream’ health services. Whilst this approach appears to have become one implicit *modus operandi* within palliative care, the evidence tends to suggest that it fosters defensiveness and thus poor implementation [94] and that successful implementation tends to arise from positive and constructive engagement with the wider policy field [144] and “engaging in coalitions and networks to establish trust” [145].

4. Conclusions

This paper is the first to adopt a critical ‘interpretative’ approach to palliative care policy narratives within the peer-reviewed literature. In doing so, we acknowledge some potential limitations. We recognise that the search review was relatively pragmatic (accessing only three databases) and that we did not include any primary policy documents. We also accept the possibility of ‘publication bias’ – a tendency for this literature to be populated by high-level ‘voices’ that are most likely to make broad proclamations and least likely to report on-the-ground implementation and/or examples that might falsify the positions we suggest. In this sense, it could be the case that there *are* some instances *in situ* and in the gray literature that might falsify our inferences. For example, there could be local examples of effective implementation based on constructive relationships in practice. Finally, within the boundaries of the paper’s aims, we have only been able to allude in broad terms to particular empirical concerns in various clinical specialisms, organisational settings and geographies. Two responses are possible. First, as foundational influences on practice, these high-level policy ‘voices’ are in themselves of interest and furthermore, the existence of isolated and localised examples of effective policy expression would not alone be sufficient to refute the problematic features of these higher-level perspectives. Second, there is scope to undertake a more specific and detailed review that would map how palliative care is being empirically framed within specialisms, settings and locales.

In summary, the work exists within a wider debate that sees the mechanism of ‘policy’ as existing somewhere between a comfortable panacea or an ineffective and distracting pretence. As an ‘instrument of change’ [146], ‘policy’ is often seen as particularly effective [147], placed at the pinnacle of intervention ‘impact pyramids’ [148]. Yet despite this conviction, critique often surrounds it: first, in relation to its very essence [149], notions of definitional “vagueness” [150] and ‘ambiguity’ [151]; and second, in the context of the profoundly challenging circumstances [152] and overly optimistic expectations [153], acknowledged by the existence of policy ‘failures’ [154], ‘fiascos’ and wider crises of “legitimacy” [155]. Whilst there appear to be some within palliative care who, at least aspirationally, subscribe to the possibility that ‘policy offers an ideal ‘panacea’, our work here suggests that the existence of policy ‘pretence’ is a real possibility with consequently a series of critical possibilities.

Fundamentally, it is empirically difficult to point to much robust evidence that explicitly connects policy instruments to practice outcomes. Furthermore, the tacit approach to policy making that we have highlighted - founded on the construction of ‘Global North’ centric, amplified catastrophes and the associated creation of idealistic policy ‘wish lists’ that place palliative care at the centre of solutions - is potentially problematic. Whilst many may feel that the ‘catastrophising’ narrative that underpins legitimacy has the capability to elicit change, some insights would suggest the contrary. The ubiquity of such a narrative tactic across a host of other policy areas also tends to reduce the possibility of any particular crisis being seen as *uniquely* problematic [156]. Moreover, the absence of any immediate or visible ‘effect’ can weaken motivation [157] and excessive claims of ‘crisis’ potentially leads to helplessness rather than action [158].

To this we add the further tendency to engage with prevailing health policy on a ‘deficit’ basis – highlighting shortcomings that palliative care might ameliorate. Again, whilst some may feel that emphasising weaknesses in current care models will offer potential leverage, insights from service re-orientation literature [159] would suggest that this antagonistic approach can be problematic, tending to elicit defensive organisational responses [160]. This relational issue is compounded by the propensity for policy progress to be advanced by detached macro-level normative proclamations, with little evidence of grounded engagement with either the politics or implementation pragmatics of local health care provision [161]. It is an approach made even more problematic by the uncomfortable acceptance that palliative care could have

Table 1
Global Distribution of reported work.

Africa	3
Americas	19
Eastern Mediterranean	3
Europe	28
South-East Asia	1
Western Pacific	6
Global	24

a relatively minor status in the wider policy world and may indeed be the recipient of a degree of principled and practical antagonism [143].

In response, a range of theoretically informed approaches are beginning to emerge. First, the need to accommodate perspectives from the ‘Global South’ in policy is increasingly recognised [26,27]. Second, in moving away from negatively-oriented policy catastrophising, ‘assets-based’ approaches to policymaking are gaining a higher profile; Arefi [101], Rosa et al. [162] and Sudbury-Riley and Hunter-Jones [163] have recently offered a series of resources to foster more constructive engagement between various palliative care stakeholders within a “service ecosystem” [163]. Third, McConnell et al. [164] and Demiris et al. [165] tackle head-on the tendency towards policy idealism and the ‘implementation problem’ in palliative care by drawing on a series of pragmatic theoretical resources within a grounded “whole systems approach” to implementation [164].

In broader terms, the existence of such an ‘implementation gap’ can be considered a dislocation between macro, meso and micro policy levels [166]. The very existence of what Clark et al., [19] term, “high-level policy interventions” is indicative of a belief in the value of ‘macro’/‘top down’ activity [167]. However, Clark et al. [19] also note that the ‘micro’/‘bottom up’ reality is often defined by, “motivated individuals and nongovernmental organizations, often with limited financial, political, and policy influence” and they conclude by questioning the ability of distant ‘macro’ influences to do anything to address this.

Here, the potential of various ‘third generation’ implementation approaches [168] is significant to palliative care. These include: using the ‘meso’ policy space as a ‘passage point’ between ‘macro’ and ‘micro’ domains [169]; fostering significant civic action via processes of ‘policy advocacy’ [118]; ensuring that implementation ‘capacity’ is present [170]; deploying ‘implementation intermediaries’ that, “work in between policy-makers...and service providers...to facilitate effective implementation...through specific implementation strategies” [171]; and being conscious of ‘policy entrepreneurship’ [145] and the basis of the ‘currency’ of palliative care [172].

Clearly, the emergence of ‘policy’ as a formal change mechanism in palliative care development is, at least in theory, a significant development within health systems governance. We have shown however that whilst it might be a *necessary* condition, in itself, it will probably not be *sufficient* to bring about significant and sustainable change. If there is to be substantive and sustained palliative care service development as has happened in other health care fields [173], ‘policy’ might better be seen as *one* element in a complex mix that also includes a range of other ingredients, particularly higher levels of participation from health service providers and wider civic society.

Table 1.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.healthpol.2022.06.010.

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