Review Article

Compassionate communities interventions: a scoping review

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Background: The compassionate communities (CC) movement is an emergent health promotion approach to palliative care that views illness, dying, death, and loss as universal experiences, and challenges the notion that disease precludes one from health care attention and interest. It seeks to normalise these phenomena and reorientate care to communities by activating naturally occurring networks and mobilising community resources. A surge of interventions aligned with the ethos of CC has been observed over the last decade. This scoping review seeks to synthesise what is currently known about the design, efficacy, and impact of CC interventions.

Methods: Cochrane, PubMed, Scopus, and Web of Science were systematically searched. Hand searching was performed on three key journals, reference lists and citation lists of included articles, and relevant review articles. Two levels of analysis were conducted. First, a numerical presentation of the characteristics of CC interventions. Second, a thematically orientated narrative analysis of intervention efficacy.

Results: A total of 1,882 records were screened; 62 papers were included. Most were implemented by palliative care organisations in Europe, North America, and Australia. Included studies were mapped against Clark *et al.*'s taxonomy of end-of-life interventions: educational (n=17); service (n=20); clinical (n=3); cultural (n=4); and multi-dimensional (n=18) interventions are discussed. While preliminary findings are positive, claims of efficacy are limited due to methodological paucity in the field.

Conclusions: We argue that the field would benefit from more transparent and theoretically driven CC interventions in order to explicate the mechanism(s) for successful intervention implementation.

Keywords: Compassionate communities (CC); scoping review; intervention; palliative care

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Introduction

The compassionate communities (CC) movement is a public health approach to palliative care (PHAPC) that has developed against the backdrop of growing medicalisation and the perception of death as a failure or threat to public health policy (1). The CC movement advocates for death, dying, loss, and caregiving to be reclaimed as phenomena fundamental to the human condition, and to overturn the current compartmentalisation of the medical model which has taken death out of people's homes and the community (1). Influenced by the World Health Organisation's Ottawa Charter [1986] (2) which

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embraced a "holistic definition of health as an empowered lifestyle which is more than the mere absence of illness" (3), Kellehear argued that "by inadvertently omitting the idea of living with dying from health promotion discourse, it has contributed to an old medical idea that the prospect of death disqualifies one from legitimate health care attention and interest". He envisaged a complementary relationship between health promotion, palliative care, and community which seeks to "enhance a sense of control and support for those living with a life-threatening illness" through shared responsibility. In so doing, the CC movement has pivoted away from contemporary discourse, policy, and practice that reduces palliative care to the medical concerns in the weeks and days before death. Instead, it has embraced a broader conceptualisation of palliative care that includes meeting the needs of those living with chronic and life-limiting illness, caregivers, and the bereaved (4) through the combined efforts of professional specialists, the experiential expertise of social networks, and the voluntary sector (5).

Kellehear (6) has gone on to develop the Compassionate City Charter which serves to invite cultural and social sectors into palliative care and was designed to be employed over significant geo-political areas, such as cities or towns. As such, the charter requires commitment from local government or community leaders and partnerships with local services (such as palliative care, bereavement support, care for older persons) to enact change. Thus, it typically operates as a top-down approach to behavioural and social change where "a community development strategy is usually employed alongside but after the initial decisions are taken by the leadership" (7). The charter therefore speaks to policy and programme development across a range of integral institutions (such as schools, workplaces, and prisons), community and religious groups, and hospices and care homes that are often developed and implemented in tandem. On the other hand, CC are not bound, but are often guided, by the charter to inform incremental local action which serve to showcase the social value of specific actions within their respective communities (6). Kellehear anticipated and welcomed this kind of incremental social action, arguing pragmatically that such an approach affords organisations latitude to develop relatively low-risk policies and programmes that serve their communities whilst simultaneously contributing to a growing body of evidence evaluating the efficacy and impact of CC interventions. Indeed, many communities, cities, and countries have responded to Kellehear's call to develop more CC and cities; what this looks like in practice is the focus of this scoping review.

Highlight box

Key findings

- 62 sources reporting a compassionate communities (CC) (Kellehear, 2005) intervention were identified.
- Findings indicate there is a public appetite to attend educational and cultural events informed by the CC movement which can elicit change in attitudes and behaviour.
- 'Community Champion' interventions can positively influence the quality, if not the trajectory of end-of-life experiences.
- Cultivating effective organizational partnerships remains an ongoing challenge.

What is known and what is new?

- Early systematic reviews (Librada Flores *et al.*, 2020; Sallnow *et al.*, 2016) demonstrated a growing interest in developing CC interventions, but few interventions had been published.
- Subsequent reviews (see, Collins *et al.*, 2021; D'Eer *et al.*, 2022; Quintiens *et al.*, 2022) provide preliminary evidence for specific intervention functions.
- This scoping review consolidates what is currently known about the characteristics and efficacy of CC interventions.

What is the implication, and what should change now?

- We argue for more transparent and theoretically driven CC interventions to explicate the mechanism(s) for successful intervention implementation.

But first, throughout this article the term 'intervention' is used to describe the projects, programmes, initiatives, and services identified. Cognisant that for many, 'intervention' has become synonymous with the randomised controlled trial we pause briefly to clarify the definition used in this paper. The holistic nature of palliative care (8), and the commitment of CC to identify, design, and deliver initiatives using participatory and emancipatory practices (1), warranted a broad and inclusive definition of 'intervention'. The definition proffered by Clark *et al.* (9), which positions intervention as "organised responses to end of life issues" was embraced as it provided legitimacy to the multitude of aims, designs, and methods employed in the field that merit attention. Whilst simultaneously excluding empirical research concerned with naturally occurring networks (i.e., research exploring how end of life is currently experienced without external intervention) which fell outside the remit of this review having been captured in previous reviews (10,11).

Indeed, a number of researchers in the field have produced reviews that demonstrate the advancements in the field over time and further our understanding of how CC are conceptualised and operationalised through intervention. Early systematic reviews in the field (10,11) highlighted there was a growing interest in, and discussions around developing CC and presented tentative evidence for their effectiveness. However, given that the field was in its infancy when the searches of these reviews were performed, they yielded very few interventions and therefore also incorporated conceptual papers (11) and empirical research investigating the characteristics of naturally occurring networks of support which did not include any form of external intervention (10) thereby limiting their ability to respond to their research questions. Other reviews have focused on CC interventions concerned with civic engagement (12); area-based programmes (13); and health system outcomes (14) respectively which have enriched our understanding of the field. For example, Quintiens *et al.* (13) present a robust investigation which identified the key similarities and differences between area-based CC with regards to their contextual and developmental characteristics and called for more rigorous research to gauge intervention efficacy. While Collins *et al.*'s (14) search permitted the inclusion of any public health care intervention that measured an aspect of end-of-life experiences or care they focused their paper on five studies that specifically measured a health system outcome. Perhaps unsurprisingly then, the authors conclude that the empirical data in the field is limited and predominantly in the conceptual stage of implementation. On the other hand, D'Eer *et al.*'s (12) review yielded 34 interventions which when taken together indicated that civic engagement within the context of life-limiting illness, death and loss can elicit positive impact(s), caveated by the recommendation that more research is required to unpack the mechanisms for efficacy.

The valuable insights afforded by these reviews notwithstanding, it is contended that this review provides unique contributions in four significant ways. First, this review was born out of the first author's doctoral research which was concerned with the lived experiences of people participating in a bereavement-focused CC intervention within extra care housing. While the research aligned with the PHAPC, there exists considerable definitional ambiguity and multiple paradigms within this broader framework (15). In response, this review was motivated by a narrower focus on interventions aligned specifically with Kellehear's CC movement as an exemplar of the PHAPC. Second, in previous reviews (10,11) there was a tension between the research questions, systematic review methodology, and the heterogeneity of studies in the field. It is argued that the scoping review methodology employed in this review is a useful way of mapping fields of study that may otherwise be difficult to visualise, and is particularly suited to responding to broader topics where a range of designs is anticipated (16). Third, this review sought to present the landscape of interventions undertaken in the field of CC rather than focus on individual intervention functions [see (12-14)]. Fourth, health and social care systems have faced unprecedented challenges supporting the bereaved and those at the end of life during the Covid-19 pandemic and are looking to movements such as CC to direct future support efforts (17,18). This is therefore an opportune time to collate and synthesise what is currently known about the characteristics and efficacy of CC interventions. We present this article in accordance with the PRISMA-ScR reporting checklist (19) (available at https://apm.amegroups.com/article/view/10.21037/apm-22-867/rc).

Methods

This review was conducted by the first author (CR) who followed the six-phase scoping review framework outlined in Arksey and O'Malley's (16) original paper, supplemented by the recommendations and insights that have contributed to the refinement and enhancement of scoping review methodology since its publication (20-23). The integration of these sources, adapted from The Joanna Briggs Institute Manual for Evidence Synthesis (24) guided this review (The integrated Scoping Review Framework endorsed by the Joanna Briggs Institute: https://jbi-global-wiki.refined.site/space/MANUAL/4687752/11.1.3+The+scoping+review+framework). There is no published protocol for this scoping review.

Stage one: identifying the research question

This review aims to address two key questions: (I) What is known from the existing literature about the design of CC interventions (e.g., the population, setting, scale, methods); and (II) What are the core components of CC interventions, and which are most effective and therefore valuable to include in future interventions?

Stages two and three: identification and selection of studies

Electronic databases

The first author searched for English language publications in the following electronic bibliographic databases: Cochrane, PubMed, Scopus, and Web of Science. Grey literature was searched from ProQuest Dissertations and Theses. The search term "*compassionate community/communities*" within the fields of "*article title*, *abstract*, *keywords*" was executed on all databases. No limits (e.g., date of publication, document type) were applied to the search.

Inclusion criteria

The 'Participants, Concept, Context' framework (22) served to operationalise the active components of the research questions in the search strategy. The '*concept*' of "compassionate communities" was the primary indicator driving inclusion in this review, specifically, interventions that had been informed by, or inform the CC movement. Papers which framed CC as a public health approach to end-of-life care (including death, dying, bereavement, or palliative care) concerned with community responsibility and building partnerships between the community and services, and reported an intervention aligned with this approach, were included. In an effort to map the landscape of interventions in the field, no limits were imposed regarding the core component(s) of the intervention (e.g., education, volunteer mobilisation, area-based interventions), nor was it a requirement for the intervention to have been developed in consultation with the Compassionate Cities Charter (6). Neither '*participants*' nor '*context*' per se determined inclusion for this review. However, those data were gathered to describe the characteristics of CC interventions.

The types of evidence sources permitted for inclusion included primary research articles, review studies (e.g., systematic, scoping, narrative reviews), evaluation reports, and book chapters. Documents were included irrespective of design (e.g., randomised controlled trial, before and after studies, prospective and retrospective cohort studies, cross-sectional studies) or methods employed to evaluate the intervention (e.g., quantitative, qualitative, or mixed methods).

Exclusion criteria

Papers were excluded based on the following: (I) reference to "*compassionate communities*" in a context outside of the area of interest; (II) full text not available (including presentation, conference, or meeting abstracts); and (III) not available in English.

Hand-searching

Three journals (*Annals of Palliative Medicine*, *BMC Palliative Care*, and *Progress in Palliative Care*) were identified as key because of the volume of included studies published in them and were screened. Citation chaining of the included studies was also performed.

Quality assessment

Not performing a formal quality appraisal of the evidence included in a scoping review has been identified as one of its defining (16,22,25), and most contentious (26) features. Nevertheless, it is argued that eschewing prescriptive and restrictive notions of evidence hierarchies and quality concerns liberates the scoping review, permitting the inclusion and dissemination of evidence from a range of different methods and study designs (16). While individual paper quality assessments were not performed as part of this review, Yardley's (27) four principles of good quality research, '*sensitivity to context*', '*commitment and rigour*', '*transparency and coherence*', and '*impact*', were used to inform more generic critical evaluations of the state of the evidence overall.

Stage four: data charting

A summary of each of the included papers recorded: the author(s), year of publication, country of study, organisation(s) implementing the intervention; study setting; study population(s); core component(s) of intervention; intervention comparator (if any); duration of intervention; method(s) of data collection; method(s) of data analysis; sample size and demographic details; and key findings. In alignment with the iterative sensibility of the scoping review methodology (16), we later added level of community involvement (e.g., community engagement, community development, community consultation etc.) to the data charting form.

Stage five: collating, summarising, and reporting the results

As recommended by Arskey and O'Malley (16), two levels of analysis were performed. First, to establish the nature of the evidence base, a basic numerical analysis of the key features of included studies (e.g., country of study, setting, population) was performed with a view to identify trends, and potentially isolate gaps in the literature. The second, a thematically orientated (organised by intervention type) narrative synthesis of the findings identified the efficacy and value of CC interventions.

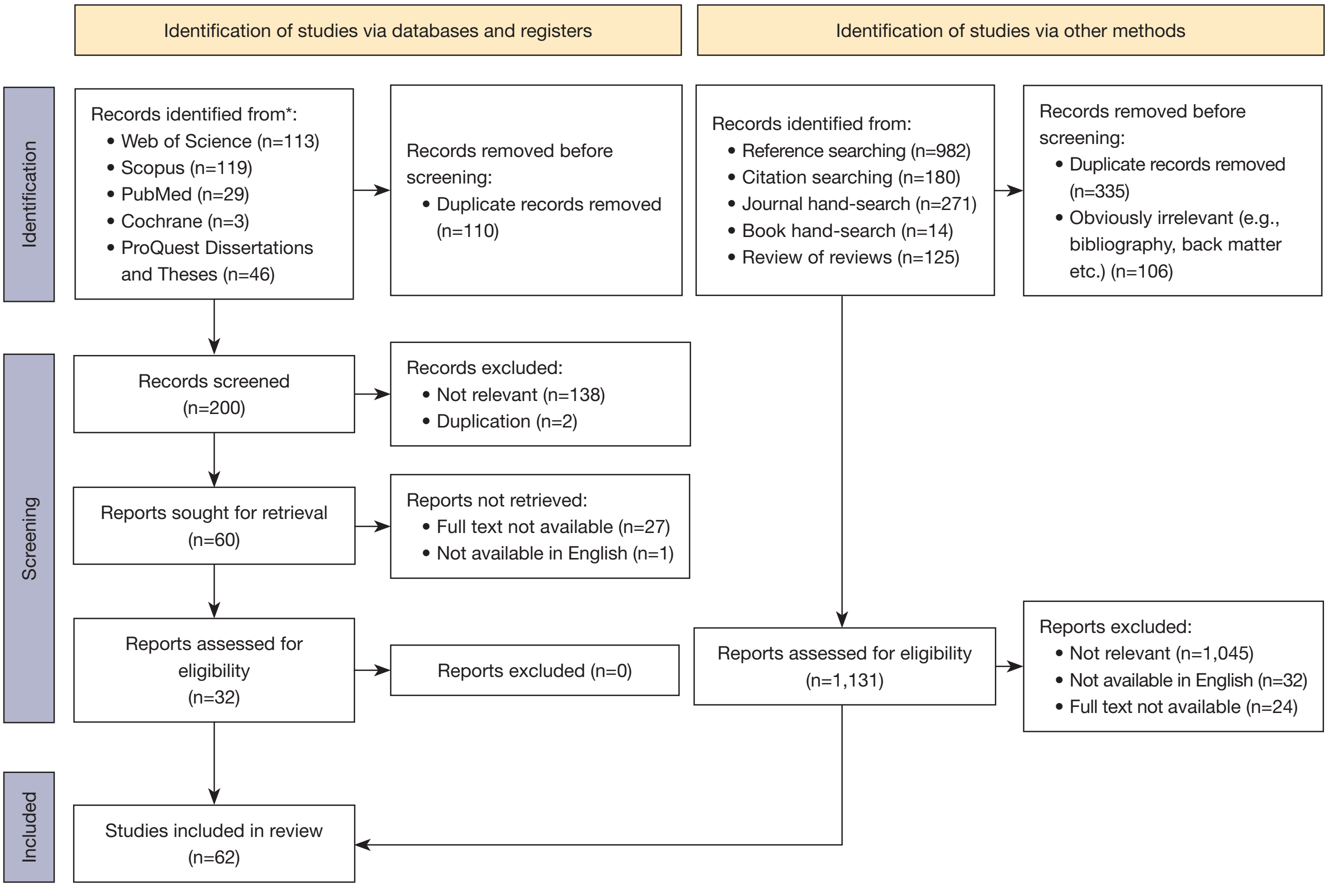

Figure 1 PRISMA flowchart of the search and screening process.

Stage six (optional): consultation exercise

Time and resource constraints prohibited consultation with stakeholders.

Results

The search, last performed in May 2022, yielded 310 titles and abstracts (see 'Identification of studies via databases and registers', *Figure 1*); duplicates (n=110) were immediately removed leaving 200 records. Through screening, 168 records were excluded as: irrelevant (n=138); full text unavailable (n=27); duplication (n=2); and not available in English (n=1). Consequently, 32 records were retained for inclusion. As summarised in *Figure 1* ('Identification of studies via other methods), a further 1,572 records were identified through a combination of reference (n=982) and citation searching (n=180) of the 32 records retained for inclusion, journal hand searching (n=271), reviewing the studies included in review papers (n=125), and reviewing Kellehear's book (28) (n=14) which had been identified through our original search strategy. Of these, 335 were duplicate records and 106 were obviously irrelevant (e.g., bibliography, back matter etc.) and were immediately removed, leaving 1,131 records. Screening excluded 1,101 records as: irrelevant (n=1,045), full text not available (n=24), and not available in English (n=32). Consequently, 30 additional records were retained for inclusion bringing the total to 62 included studies.

Key characteristics of CC interventions

A total of 62 empirical studies were included in this review (see Table S1); it is noted that some CC interventions yielded multiple studies. For example, the Healthy End-of-Life Project (29,30); End-of-Life Social Action Study (31,32); All With You (33,34); Caring Community in Living and Dying (Landeck) Project (35-37); Cheshire Living Well

Dying Well (38,39); End-of-Life Care in First Nations Communities (40,41); Good Neighbour Partnership (42,43); Heidi's Have a Go Project (44,45); Last Aid Courses (46-49); Nav-CARE (50-53); and the Pallium Project (54,55).

Since 2013 there has been a rapid rise in publications about CC interventions, particularly in Europe (n=33), specifically in the United Kingdom (31,32,38,39,56-66); Austria (35-37,67); Spain (34,68-70); Ireland (42,43,71); Sweden (72,73); Germany (46); Poland (74); Portugal (75); and across (European) country comparisons (47,48). A large proportion of studies were conducted in Canada (n=12) (29,40,41,50-55,76-78), and Australia (n=9) (30,44,45,79-84), but also in Taiwan (n=1) (85), India (n=1) (86), Hong Kong (n=1) (87), Mexico (n=1) (88), and through cross continent collaboration (n=4) (33,49,89,90).

The vast majority (n=28) of the included interventions were designed and implemented by palliative care teams/organisations based in the UK (31,32,38,57-59,62-64); Europe (34,39,42,46,49,70,71,74); Canada (50-53,55,76); Australia (44,45,79,84,89); or through multi-agency (often including palliative care) collaboration (n=21) (29,33,35,36,43,54,60,65-69,73,77,78,82,83,85-88). Single interventions were implemented by primary care (56); a children's charity (72); community group (61); and a dementia care centre (81). Nine studies (30,37,40,41,47,48,75,80,90) did not specify who had deigned and/or implemented the intervention.

The level of community involvement in the intervention differed across studies. The majority of interventions were designed, delivered, and evaluated at an organisational level and partnered with community organisations to support interventions in their communities (n=16) (33,35,36,37,39,42,54,55,59,60,67,68,70,73,82,85); involved community members in a consultancy capacity to provide feedback on the programme (n=8) (38,46,47,48,49,62,71,80); or recruited them as community volunteers (n=16) (31,32,34,43,50-53,56,57,65,66,76,77,79,87). Interventions were also developed in response to needs identified from within the community (n=11) (29,30,40,41,58,61,63,64,69,74,86); activities were co-constructed (n=6) (44,45,75,78,81,89); or emerged from communities themselves (n=3) (83,88,90); and in two studies community involvement was not an explicit goal (72,84). The language used to describe community involvement was applied inconsistently across studies.

The population under study predominantly fell under one of three categories: residents or organisations within a particular community or region (n=23) (29,33,35-42,46,55,60,61,63,68-71,75,83,85,87); specific patient groups including people identified to be at the end of life, living with advanced chronic illness, or else identified as vulnerable (31,32,43-45,50-53,56,58,74,76,77,79,80,86), the informal caregivers/family members of someone at the end of life (57), both patient and informal caregiver (34,65), people living with dementia (67,81), and the bereaved (64,66,72,78,88); and the general public (n=9) (47-49,59,62,82,84,89,90). The three remaining studies (30,54,73) did not state the study population.

The majority (n=46) of included studies stated no intervention comparators, however, more robustly designed interventions including pre- and post- intervention comparisons (n=9) (38,52,56,58,62,71,81,84,87), and (non-) randomised controlled studies (n=7) (31,32,34,43,65,76,79) were included.

To generate data the included studies employed mixed methods (n=21) (31,40,41,42,43,44,45,46,47,48,49,52,54,62,65,68,70,74,75,79,81); qualitative method(s) (n=21) (29,30,35,36,37,50,51,53,63,64,66,67,69,72,77,78,80,82,83,86,90); and quantitative method(s) (n=12) (32,34,38,55,56,58,71,76,84,87,88,89). Of these, a small number of included studies (n=5) (31,32,34,76,87) employed psychometric scales to evaluate intervention efficacy. However, most had not yet completed data collection prohibiting direct comparison. Finally, a sizeable number of the included studies do not name their methods for data collection (n=8) (33,39,57,59,60,61,73,85) and/or data analysis (n =23) (30,33,35,36,39,42,54,56,57,58,59,60,61,62,64,67,68,69,73,74,76,81,85).

What do evaluation findings contribute to our understanding of the efficacy and value of CC interventions?

In order to present the findings of the included studies in a cohesive narrative they were mapped onto the taxonomy of interventions at the end of life developed by Clark *et al.* (9) (see Table S2) based on the overarching aim(s) and the core components of the intervention. Clark *et al.* themselves acknowledge that these categories are not to be viewed as discrete or exhaustive but rather intend them to serve as a "road map" to organise, strengthen, and deepen our understanding of end-of-life interventions. In summary, the included studies were identified as educational (n=17); service (n=20); clinical (n=3); cultural (n=4); and multi-dimensional (n=18). The subsequent sections will expand on the implementation, findings, and learnings of each of these categories, respectively. See Table S1 for a summary of the main findings of the included studies.

Educational interventions

Seventeen education-based interventions were included. The majority aimed to provide information and raise awareness about end-of-life care (38,46,47,48,49,55,60,62, 63,75,84), and to provide attendees with skills and tools to encourage further conversations (and other actions) about death, dying, loss, and care (38,47,48,49,55,62). A smaller number of studies had more specific aims: to support and empower couples to navigate the changes and challenges of dementia (81); to provide workshop discussions for pharmacists to better understand the needs of people with dementia and their carer (67); to scale-up learning and development in rural, remote, and other resource-constrained settings (54); to assess the educational needs of First Nation communities in Canada (40); and to provide psychoeducation on topics related to grief and loss in combination with discussion-focused sessions (72,88). The majority were one-off educational events that could be completed within a couple of hours (38,46,47,48,49), a single day (55,67,75), or a flexible delivery over the course of a few days or sessions (55,62,72,81,84); five were delivered online (47,49,55,62,84), the others were delivered in-person. Half of the included studies report on small-scale pilot study/studies (60,62,63,67,72,75) with the remainder (38,46,47,48,49,54,55,88) reporting on ongoing educational events.

Findings from cross-sectional studies (46,47,48,49,55,62) evaluated course content favourably, and the majority (99–100%) of respondents recommended the course to others (48,49). While educational interventions have shown to be effective at ‘continuing the conversation’ (84) they have had limited success in encouraging participants to ‘take action’, such as making a will (38), with only two participants having done so at follow-up. Overall, attendees welcomed the opportunity to discuss their experiences of death, dying, and loss and to connect with others through shared experience (38,72,75,81).

Most studies reported on the evaluation of developed and implemented programmes, however, Paul *et al.* (63) and Prince *et al.* (40) focused on the educational needs of specific communities, primary school children and First Nations communities, respectively. Both emphasised the importance of holistic but tailored educational initiatives that connect with, and serve, all members of the community and health care systems. Implementation and evaluation of these initiatives was forthcoming at the time of publication.

Evidence from the included interventions suggest educational interventions effectively provide attendees with an opportunity to gain information and provide space to discuss topics pertaining to illness, dying, and bereavement. However, given that evaluation of the included studies [excepting (38,72)] took place on the day of the intervention, the impact of these interventions beyond the classroom is unknown. Furthermore, it is suggested that the included studies were influenced by participation bias; with attendees being disproportionately retired, educated women from the least deprived areas (38,84) who were demonstrably ‘death-positive’ prior to the intervention (38,81,84). It is unfortunate that studies drawing from broader populations, such as Martins Pereira *et al.* (75) and Plunger (67) provided limited insight of the perspectives, attitudes, and experiences of attendees despite employing potentially data-rich methods such as semi-structured interviews, focus groups, and participatory observation. In future education-based interventions, a more concerted effort is required to recruit participants beyond healthcare professionals and those with a vested interest in death, dying, and bereavement.

Cultural interventions

In an effort to facilitate a death-positive discourse among the general public, a small number of included studies (n=4) focused on cultural events, namely Café Conversations (71), Death Cafés (90), Twitter discussions (89), and combining arts-based activities with “weaving conversations” to cultivate a community garden (83). In one study, the #PallANZ hashtag was used to create a safe space for discussion and information provision during the Covid-19 pandemic (89). Analysis of these Twitter discussions elicited conversations between 25 participants and generated almost 750,000 impressions, with a second discussion a month later generating greater engagement indicative of ongoing, and perhaps growing, engagement.

Furthermore, using the Death Café model McLoughlin *et al.* (71) reported significant post-intervention improvements in understanding the importance of talking about the topics under consideration, although respondents’ perceived difficulty talking about death, dying, loss, and care did not reach significance. Richards *et al.* (90) had a wider orientation, conducting an international exploration of Death Café organisers’ experiences which challenged UK-centric findings. For example, globally, organisers and attendees were more diverse than had previously been reported. Nevertheless, they contend that both organisers and attendees were predominantly women, and in the case of organisers, the majority were healthcare, mental health, or death industry professions. Notwithstanding geographical, cultural, political, and religious differences, participants spoke of the prevalence of death avoidance and the outsourcing of death to professionals within their respective countries. Against this backdrop, participants were emphatic that people needed a 'safe space' to talk about death and believed this was "a good thing in and of itself". Marsh *et al.* (83) likewise reported that 'death talk' was seldom permitted as part of the everyday and so participating in the community garden was a "cathartic emotional experience" as it provided a much-needed opportunity to deliberately discuss death and dying. Moreover, while some organisers suggested that conversations could extend to other spheres, such as making practical plans or carrying on the conversation with their loved ones, others cautioned against the over-emphasis on tangible evaluative outcomes as this ran counter to the central ethos of the Death Café movement (90).

In summary, findings suggest there is a growing counter-cultural appetite to engage in death-positive discourse (71,83,89,90), and that cultural events can elicit significant changes in attitudes (71) and encourage continued action in other aspects of life (90). Given the paucity of research focused on end-of-life cultural interventions conclusions are tentative, more research in this field would be welcome.

Service interventions

Within the context of CC, service interventions (n=20) adopted a broadly equivalent approach; community volunteers were trained and matched with vulnerable older people (and/or their carer) with the aim of providing ongoing support and advice, and mobilising community networks to provide appropriate support (31,32,34,43,50-53,56-58,65,66,76,77,79,87). While these were often implemented by palliative care organisations, or allied professionals, there was an emphasis on redirecting care away from clinicians and into the capable hands of the community. Notable exceptions developed services to rehabilitate prisoners through hospice volunteerism (74); provide online bereavement support for people during the Covid-19 pandemic (78); and provide peer-led bereavement support group for carers of someone at the end of life (64). Five of the included interventions (31,34,43,76,79). had not yet concluded, therefore these papers report no findings.

Findings indicate that being supported by a volunteer reduced total visits to GP practice, total phone calls to family doctor, total accident and emergency (A&E or emergency room) admissions, total unplanned hospital admission, and total calls to/visits by out-of-hours palliative care services (56,58); with an increase only in planned hospital visits (58). However, randomised controlled studies that compared 'volunteer intervention' to 'usual care' on a battery of measures, including quality of life, loneliness, social support, and coping strategies reported no statistically significant differences between comparator groups at any time points (32,65). Although the authors cautiously assert there was a positive trend in favour of the intervention group. Given that the effect size of these interventions was small, both suffered from being insufficiently powered.

Qualitative research with clients has reported high levels of satisfaction. Benefits included increased confidence asking for help, having access to someone knowledgeable, provision of resources, and knowing there was back up when needed (51), particularly when clients had previously felt "invisible" (77). Clients also shared humorous and uplifting anecdotes with the volunteer; such experiences "altered the qualitative nature of their experience, even if it did not change the medical trajectory" (52). Additionally, stakeholders argued that writing personal health goals "empowered [clients] to improve their social connections and personal wellbeing through intentional connections to community activities" (77). The authors claim clients echoed these benefits but provided no direct excerpts from clients to support this. Volunteer experience however was marked by ambivalence, with volunteers asserting their lives had been equally enriched through the programme, yet role ambiguity challenged their ability to gauge their performance and contribution (52). This was ameliorated somewhat over time as volunteers refined their understanding of the role to include the significance of emotional as well as instrumental support.

Furthermore, three of the included studies focused on supporting people bereaved by, or during the Covid-19 pandemic (50,66,78). Bruce *et al.* (50) and West *et al.* (66) both emphasised the unique challenges endured by bereaved people during the Covid-19 pandemic, including being denied the opportunity to be with their loved one at the end of their life (50); the loss of the usual rhythms of life (50), and the absence of forward momentum (66); the acute pain of grieving alone (66), and thwarted efforts to hold remembrance events for their loved one(s) (66). For those at the end of life, forced isolation led to sadness and regret as opportunities to connect with others was lost (50). Nevertheless, participants identified affordances nurtured through pandemic grief, such as developing new activities and hobbies (50); dwelling more deeply in life (50); the re-collectivising of bereavement through collective mourning and memorialisation (50,66); and welcome respite from "mandatory happiness" (66).

Moreover, a number of the included studies reflected on their experience implementing the intervention which offer critical insights for future programmes and research. First, the single best predictor of successful implementation was having trusted community leaders (58) with the right characteristics, beliefs, and attitudes to take ownership of and carry forward the intervention (51). However, organisational capacity, disruption, and resistance of the respective partners often undermined the efforts of community leaders and volunteers and threatened programme success and sustainability (51). Specifically, authors reflected on the unanticipated challenge of instilling the ideals and practice of community-volunteer end-of-life services within clinical teams (57), which led to a disappointing number of professional referrals that inhibited the recruitment of clients to the respective studies (51,65). Walshe *et al.* (65) for example, hypothesised clinics may not be the most suitable recruitment location for non-clinical interventions and argued that alternative recruitment strategies, such as social and traditional media advertising, could be utilised in the future as it is more "congruent with the mutuality of a peer mentor intervention". Abel and Townsend (57) likewise acknowledged a tension operating within a risk-averse corporate understanding of volunteering and the principles of community participation and engagement which, perhaps unduly, influenced intervention implementation. Furthermore, they pointed out that referrals often occurred late in the patient's illness which limited the possibilities for emotional support and network development and therefore the efficacy of the intervention.

Clinical interventions

A small number of the included studies delivered clinical interventions (n=3), in many ways these were similar to 'services' but were more overtly orientated within, and delivered by, professional or clinical teams. For example, Aoun *et al.* (80) described a pilot study testing the acceptability of an adapted version of the Carer Support Needs Assessment Tool (CSNAT)—which seeks to identify unmet carer needs—to be administered in a paediatric context. Through qualitative interviews, parents commended the comprehensiveness of the CSNAT in that it "highlighted issues that might otherwise have been forgotten, especially in a stressful situation" and provided validation of their needs. Furthermore, parents reported it had improved communication with clinical teams, and empowered them to seek additional sources of support in response to their needs.

The other two included studies (44,45) report on the programme "Heidi's Have a Go" which facilitated palliative care patients to "have a go" at something they had longed to do. It is a model of care that features no predetermined programme activities, rather, it is a collaborative approach that responds to the unique wishes of each individual and their family. Activities included, but are not limited to, learning how to make cheese (the eponymous Heidi's elected activity), cuddling a koala, and shooting a gun. These two papers report on qualitative semi-structured interviews with staff and volunteers engaged with the programme. Participants reflected the informality of the programme "created a personalised space within the clinical world where humanity was shared" (44) which in turn provided welcome respite from the typically medicalised focus of care (45) and redistributed the balance of power in care relationships that "empowers a sense of control for patients who may have relinquished a lot of choice to those guiding their care and treatment". Furthermore, activities had the power to "nurture intimate moments" (45) within families that "witnessed and supported an experience of emotional processing, nurturing the foundation of a deeper, connected relationship between this family and staff".

Multi-dimensional interventions

There were 18 interventions that are perhaps better understood as Compassionate Cities. They describe multi-phase protocols and, in some cases, preliminary findings, that apply the Compassionate Cities Charter (6) into practice in their respective city or region (29,30,33,35,36,37,39,41,42,59,61,68,69,70,73,82,85,86). Their aims were ambitious, striving to shift cultural attitudes to normalise death, dying, and bereavement, and to enrich society by bridging community, social, spiritual, psychological, and medical resources for (amongst others) those with advanced illness, caregivers, and the bereaved. Consequently, these interventions were multi-faceted, multi-phased, multi-agency initiatives that embraced a multi-dimensional approach by incorporating three or more intervention categories from Clark *et al.*'s (9) taxonomy.

While the complexity of these interventions is acknowledged, there are nevertheless taxonomical trends observed across the included studies, which include a combination of: *'research'* into the current needs of the communities under study (30,36,39,61,68,69,73), or surveying pertinent literature and theory to inform policy and practice (30,33,42); '*education*' through the development and dissemination of pertinent resources and information activities (30,33,35,36,39,42,59,61,68,69,82,85); driving changes in '*policy*' (33,35,42,59,82); '*services*' such as community volunteer programmes to supplement and mobilise existing support networks for people at the end of life or bereaved people (30,33,36,39,42,68,69,82,85); '*cultural*' events, such as art exhibitions, Death Cafés, and remembrance festivals (35,42,59,61,68,69,73,82,85); and '*advocacy*' efforts including, community and organisational outreach, engagement, and partnership (29,33,35,36,39, 42,59,61,68,69,82,85,86). A small proportion of included studies focused on the development of palliative care to communities that had previously had little to no access and/or provision (41,86). These studies employed equivalent implementation techniques, but focused on establishing palliative care systems, cultivating trust between healthcare professionals and community members, and attending to issues pertaining to cultural competency and security.

While overall there is a paucity of methodological and analytical detail related to evaluation strategies, the preliminary findings indicate that positive outcomes had been achieved. The level of community and organisational engagement with events and training, and commitment to establishing and maintaining partnerships demonstrates an appetite to engage with a Compassionate Cities approach to death, dying, and bereavement (33,39,42,61,68,69,85,86). Hasson *et al.* (69) for example have reached over 7,400 people through workshops, conferences, Death Cafés, and training courses over a four-year period. There is also evidence (38) that public education sessions can produce change in perceptions about death and dying. In particular, attendees reported recognition of the individual and social aspects of death and dying in addition to the medical, although others have reported discussion to be too difficult and painful (61).

Furthermore, a small number of studies reflected upon the learning and challenges they have experienced implementing CC interventions. These include but are not limited to: social norms around offering and accepting help which may be unhelpful and potentially undermine community capacity (30,61); a lack of public knowledge about palliative care (33); healthcare professionals and/or organisations struggling with the concept of public health end-of-life care and consequently resisting CC programmes (39,59,82); social norms, politics, and local culture and religions relating to death and dying (41,85,86); limited funding opportunities and poorly linked resources creating significant barriers to sustainability (33,39,61); and the breadth of the CC agenda and concerns over efficacy (59,61,70,82). Reflecting on their experience, Wegleitner and Schuchter (35) eschew the conceptualisation of CC as something that can be 'implemented' using standardised techniques and measurements. Instead, they propose CC to be "a type of framing, mutual care philosophy, which has to be translated into concrete, localised practices in collaboration with the community".

Discussion

The magnification of the experiences and support needs of the bereaved and those at the end of life during the Covid-19 pandemic is likely to have amplified (17,18) an already growing interest in and development of CC interventions (1). This review sought to map the core characteristics of CC interventions and synthesise what is currently known about their efficacy and value. Given the heterogeneity of fields in their infancy, a scoping review methodology was employed as it permitted greater latitude for inclusion than traditional systematic review procedures (16).

By mapping out the core characteristics of the field this review has identified distinct trends, as well as notable absences within the current literature. Most notably, the vast majority (n=39) of the included studies were designed and implemented by and within palliative care organisations. Given the CC movement is rooted in palliative care practices and traditions, it follows that this emerging field of work would initially be driven by palliative care priorities and/or settings. However, several of the included studies discuss the challenges inherent in developing community-centred programmes within medically orientated environments (51,57,65). Specifically, authors noted that a lack of public knowledge about palliative care (33); tensions operating within risk averse institutions (57); and healthcare professionals' resistance to the de-professionalisation of palliative care (39,59,82) limited the efficacy of intervention implementation.

The professional and medical dominance in palliative care was identified by Kellehear (1) to be the single greatest challenge to any public health approach, warning that, "anger and pique is the usual reaction towards new ideas by those who are the guardians of the old ones". Unfortunately, while Kellehear aptly identified these potentially significant cultural and organisational barriers to the implementation of CC interventions, he offers few strategies or solutions to overcome them. It is then imperative that future publications in the field continue to reflect upon, and where possible, share their experiences and strategies to overcome, or mitigate these obstacles, as well as developing community-led initiatives outside of palliative care.

As Kellehear anticipated (6), this review identified interventions that implemented the Compassionate Cities Charter (n=17) in addition to interventions with a narrower focus (educational (n=17); service (n=20); clinical (n=3); cultural (n=4)). Irrespective of intervention function, the vast majority of interventions articulated a commitment to community development to "enable as much resource as possible to exist within the community, without always involving health and social care services" (56), often through participatory action research approaches (29,30,35,36,37,40,41,64,78,83). That being said, most of the interventions were designed to "extend or transcend current service offerings" (1) through formal direct services as opposed to bottom-up grassroots initiatives. Drawing upon Kellehear's (1) four implementation models, we argue that while the "healthy cities model" employed by multi-dimensional interventions and the "community development model" adopted by service and educational interventions are certainly legitimate approaches, we welcome and encourage future programmes to use the "community activist model" in an effort to move beyond organisationally orientated services.

The second aim of this review was to synthesise the most efficacious intervention functions to cultivate CC. Preliminary findings indicate there is public appetite to attend cultural and educational events (38,39,42,46,47,48,49,55,60,61,62,68,71,72,75,84,88), and that attendance can precipitate further conversation and action (38,61,72). Additionally, there is accumulating evidence that being supported by a community volunteer can contribute to reduced emergency hospital admissions of those identified at risk (56,58), as well as positively influence quality of life, social connectedness and cohesion, and illness experience for those at the end of life (44,45,51,52,64,83) and during bereavement (50,66,78). However, the two randomised controlled trials included in the review (32,65) reported no statistically significant benefits to receiving volunteer support than 'usual care'. At this stage, the mechanisms contributing to the observed effects of CC interventions remains unclear, in part because interventions appear to be "based on implicit common-sense models of behaviour" with "no formal analysis of either the target behaviour or the theoretically predicted mechanisms for action" (91). Further to this, interventions were largely cross-sectional meaning there was no mechanism to assess whether the intended behaviour change has occurred. Consequently, the most efficacious approach(es) for implementing CC remains elusive, and more theoretically driven research is needed to be able to identify the most efficacious components for change.

There were limitations to the literature included in the review. Methodological detail was missing in a sizeable proportion (n=22) of the included studies. It is acknowledged that the inclusion of varied sources of evidence (such as book chapters where there is potentially less emphasis placed on describing intervention protocols and methods rigorously) is likely to have contributed to this. It may also be expected that interventions initiated by communities are conducted without reference to theoretical or methodological background and so these features cannot be reported, at least in the ways we have come to expect in scientific journals. Nevertheless, Yardley's (27) '*transparency*' criterion speaks to the expectation that research (of any kind) is reported thoroughly. It is a fundamental requirement in research to describe what work has been done and how, and this has not been met in a sizeable proportion of the included interventions. Consequently, the trustworthiness of their claims is significantly undermined, a critique echoed in other reviews (10,11).

In addition, there are limitations in the conduct of the review. First, limited resources precluded engagement with the (optional) consultation exercise advocated within the scoping review methodology (16,20,21), and restricted eligibility to literature written in English. Second, while the search terms employed ('*compassionate community/communities*') yielded a greater volume of eligible studies than other reviews that employed more comprehensive search terms (11) it is possible that some literature was missed. Third, although this review was conducted systematically and meticulously, it is acknowledged that reviews conducted by a single researcher are open to criticism (21,92).

Conclusions

In conclusion, this review identified 62 articles that describe CC intervention(s), the majority of which were published within the last five years, indicative of a movement gaining traction. The CC movement seeks to radically reorient how we think about, talk about, and act towards death, dying, and bereavement. Interventions aim to change cultural and societal attitudes about death, dying, and bereavement; to facilitate fruitful partnerships between, and within public, private, and third sectors to better serve individuals at the end of life; and finally, to raise social capital through the mobilisation of community volunteers. Success against such ambitious objectives is perhaps to some extent an impossible standard to meet, and yet, the emergent findings of this review do demonstrate an appetite at both organisational and individual levels for a shift in how we conceptualise, discuss, and support those at the end of life and their families. However, marrying the philosophy of community development to improve the quality of life of people with life limiting illness with the medical dominance within palliative care remains a challenge. Nevertheless, the clinical interventions included in this review demonstrate that these two philosophies can work together to elicit meaningful (80) and memorable (44,45) experiences when facing life limiting illnesses. There is also emerging evidence that interventions informed by the CC movement can elicit change in attitudes and behaviour, as well as improve the quality of life of those living with advanced illness. Finally, the surge in (non)randomised controlled trial protocols published (34,43,76,79) is promising as evidence from robustly designed and evaluated studies will soon be forthcoming. It is imperative going forward that published works demonstrate greater methodological transparency and rigour to engender greater trust in the efficacy and value of their findings.

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Table S1 Main findings of the included studies

Author, Year	Intervention Population	Intervention	Description of Public Involvement in Intervention	Sample Size and Demographics	Main Findings
Educational Interventions					
Abba *et al.*, 2019	Residents and health and social care staff of Cheshire, England.	Part of the Cheshire Living Well Dying Well (CLWDW) programme. 'Awareness-raising' presentations aimed to raise awareness of the benefits of planning for end of life and talking about plans and preferences. Events were 60-90 minutes long. 'How to' workshops aimed to increase participants' confidence and skills to facilitate conversations with loved ones about their end-of-life plans and preferences. Workshops were 150-180 minutes long.	Community not involved with the development or delivery of intervention. It was intended that participants acted as a "seed, spreading ideas within the population" (p. 9).	Attendees (n=676); completed baseline questionnaires (n=498); completed post intervention questionnaires (n=478); and completed follow-up questionnaires (n=141). Responders were predominantly female (76%), aged 45-74 (66%), retired (47%), living with a partner or spouse (60%), and resided in the least deprived quintile in England (49%).	Both educational programmes were well received and rated as highly relevant to respondents. Of those who completed all three parts of the survey, 84% indicated their intention to 'take action' post-intervention, and 64% reported 'taking action' at the 3-month follow-up; the most frequently cited action was engaging in discussion with family and friends. The interventions had limited success in encouraging participants to make a will, with only 2 participants doing so at follow-up.
Aherne & Pereira, 2008	Healthcare professionals and community leaders across Canada.	The Pallium Project used the 3Cs (coordination, collaboration, and communication) approach to support a rapid scaling-up of learning and development interventions.	"Strategically engaging local clinical and service opinion leaders as active collaborators and champions (i.e., co-owners) in goal-directed (i.e., access, quality and capacity) change intervention, using the aforementioned Action Learning and Collaborative Inquiry approaches" (p. 243).	72 learning and development sub-projects, including but not limited to: 40 weekend courses (n=957); 7 1-day continuing education workshops (n=310); 2 cohorts completed Clinical Pastoral Education programme (n=not stated); monthly continued professional development audioconference (3337 instructional contact hours confirmed during first year); and resource development.	Paper synthesises the findings, learning, and recommendations from the 72 sub-projects of the Pallium Project (Phase II).
Bollig, Kristensen & Wolff, 2021	General public.	Last Aid Course comprised of four modules: (1) dying as a normal part of life; (2) planning ahead; (3) relieving suffering; and (4) final goodbyes. Each module lasted 45 minutes; all modules were delivered in a classroom setting over the course of one day.	Community not involved with the development or delivery of intervention. Feedback used to refine course content. Intended that participation would "empower citizens to recognise the need for palliative care and to participate in its provision" (p. 140).	408 courses (n=6014); respondents included in analysis (n=5469). Majority of participants were female (87.9%), with a non-medical profession (90.6%), with a median age of 56 years.	Respondents were positive about the course; 75.8% rated it as "very good", 99% would recommend it to others, and 84.4% reported they had learned new things. Qualitative analysis reported five topics (1) atmosphere and surroundings; (2) the instructors; (3) course content; (4) effects of the course on the participants' feelings of views; and (5) suggestions for improvement.
Bollig, Meyer, Knopf, Schmidt & Bauer, 2021	General public.	Last Aid Course comprised of four modules: (1) dying as a normal part of life; (2) planning ahead; (3) relieving suffering; and (4) final goodbyes. Each module lasted 45 minutes; all modules were delivered online over the course of one day.	Community not involved with the development or delivery of intervention. Feedback used to refine course content. Intended that participants would be empowered to support dying people at home.	15 courses (n=174); respondents included in analysis (n=92). No demographic details provided.	Respondents were positive about the course; 80% rated it as "very good", 100% would recommend it to others, and 98% reported they felt more prepared to encounter death, dying, and grief. Qualitative analysis addressed the pros and cons of conducting the course online.
Bollig *et al.*, 2022	General public.	Last Aid Course comprised of four modules: (1) dying as a normal part of life; (2) planning ahead; (3) relieving suffering; and (4) final goodbyes. Each module lasted 45 minutes; all modules were delivered over the course of one day either online or in a classroom setting.	Community not involved with the development or delivery of intervention. Feedback used to refine course content. Intended that attendance would "empower people to contribute to end-of-life care in the community" (p. 1).	8 courses (n=79); respondents included in quantitative analysis (n=53). Majority of participants were female (90%), with non-medical profession (57%), and a mean age of 60 years. Attended focus group (n=49).	Quantitative findings indicated that the course was well received; 98% rated the course as "good" or "very good" and 96% would recommend the course to others. Qualitative findings identified four themes (1) general opinions and impressions; (2) effects of the course; (3) cultural and national differences; and (4) need for adaptation?
Hagström, 2021	Families affected by parental suicide.	Weekend camps for families bereaved by suicide using psychoeducational techniques. Parents and children separately explored nine themes: (1) information about suicide and suicide bereavement; (2) the family then and now: what happened; (3) what has changed; (4) grief responses and emotions; (5) my grief/others' grief; (6) remembering the deceased parent; (7) what helps and how do I take care of myself; (8) questions I wanted to ask but have not dared; and (9) what is my future.	Community not involved with the development or delivery of intervention.	14 families attended the camp. Of these, 11 families agreed to be interviewed. Majority of parents were mothers (82%); children (6 girls and 5 boys) were aged between 6 and 13.	Results are structured chronologically from narratives about life before to life after the support programme, with meanings and changes highlighted.
Hill *et al.*, 2020	Couples living with dementia.	Programme consisted of six sessions: (1) introductions; (2) affirming our relationship; (3) strength, resilience, and change; (4) nurturing ourselves and our relationship; (5) what have we learnt about navigating change; and (6) celebration. Sessions were conducted in person and lasted 2.5 hours (including break).	"The participants played a major role in developing this program beyond its original conception" (p. 3). The authors drew upon participants' reinterpretation of one of the activities to demonstrate this.	3 couples. No demographic details provided.	All participants felt they gained something from the programme. In particular, participants valued connecting with others and being listened to.
Matthiesen *et al.*, 2014	Community inhabitants.	Employed a four-stage asset-based community (ABCD) development approach. Case study 1 (Cumbria Conversations for Life): aimed to improve awareness about, and increase, advance care conversations through stories, outreach and information, and education. Case study 2 (Merseyside and Cheshire Cancer Network): six communities led their own awareness initiatives.	"The process of facilitated community development follows the following four steps: getting started, coming together, action planning and intervention" (p. 2).	Cumbria: Radio and regional newspapers estimated to have reached 200,000 people. The website received 3645 visitors. 11 workshops (n=93), majority female (79%). Merseyside and Cheshire: the activity undertaken across the region led to the participation of 143 organisations.	Findings present (1) the nature of the assets available in communities, and (2) the common priority areas for action (information, outreach, education, leadership, and sustainability).
Martins Pereira *et al.*, 2018	Teenagers who attend the religious activities of the parish, the catechists and community members	Employed the typical cycle of action research: (1) preparatory phase where teenagers were invited to reflect upon their understanding of palliative care and pose questions; (2) education-intervention phase informed by phase one; and (3) evaluation phase. Delivered over 3 hours in classroom setting.	As part of Action Research cycle education-intervention responded to educational needs of community identified through preparatory phase.	Attended educational session (n=69); completed evaluation (n=67). 69% were teenagers, 12% parents, 16% catechists, and 3% community members.	The session was rated as "very good" by 71% of respondents, and 65% rated the education phase as "very good". Field notes indicated teenagers were open and had a positive attitude towards discussion with high levels of engagement.
Mueller *et al.*, 2021	Non-medical hospital staff (although open to all hospital staff).	Last Aid Course comprised of four modules: (1) dying as a normal part of life; (2) planning ahead; (3) relieving suffering; and (4) final goodbyes. Each module lasted 45 minutes; all modules were delivered over the course of one day in a classroom setting.	Community not involved with the development or delivery of intervention. Feedback used to refine course content.	Course attendees (n=56); survey respondents (n=55). Majority of participants were female (90.9%), non-medical staff (67.3%). The sample was heterogenous with regard to age, profession, and patient contact.	Respondents were motivated to participate in the course to prepare for the emotional and medical aspects in care for the dying, and to gain knowledge in supportive services and facilities. Overall, respondents rated the course highly; 76.4% rated it as "good" or "very good", 99.1% would recommend it to others, and 87.3% reported they had learned something.
Patterson *et al.*, 2022	General public.	End of Life Aid Skills for Everyone (EASE) course consisted of four modules (1) an introduction to death in Scotland; (2) serious illness and frailty; (3) realities of caring and dying; and (4) caring for the carer. Each module lasted 2 hours; course delivered flexibly (e.g., 2 hours per week for 4 weeks, or 2 modules over a morning/afternoon). In response to Covid-19 pandemic, EASE ONLINE introduced. Course delivered 3 hours per week for 4 weeks.	Working group "brought with them experience of and expertise in course development, education, chaplaincy, bereavement support, general practice, and palliative care nursing" (p. 2) which informed course development. Course content was refined following survey with general public and pilot study. Intended that course would "empower communities and not rely heavily on busy (and scarce) palliative care or other healthcare professionals" (p. 4).	Survey responses (n=208); majority (80%) were from people who had supported someone informally at the end of life. Number of focus group participants not stated. No demographic details provided.	Findings from survey informed course content. The EASE course was piloted in two locations. Experiential evaluation found the course was well received. The course was revised in response to feedback to improve the course. Paper indicates that the EASE ONLINE course was well received but does not report the findings from the pre- and post-course questionnaires.
Paul *et al.*, 2019	Primary school children ages 9-12 years, their parents and teachers, and Hospice staff.	Employed an Action Research methodology to develop a five-phase educational intervention: (1) preparation and scoping; (2) exploration; (3) planning and development; (4) pilot developed practice; and (5) evaluate developed practice.	Used an Action Research methodology which "is a developmental process in which participants resolve the issues in question" (p. 3) in order to develop knowledge and practice.	Hospice (n=22); School 1: staff (n=7), children (n=21), parents (n=4); School 2: staff (n=6), children (n=12). No demographic details provided.	Three action areas were identified, (1) raising awareness of hospice care and end-of-life care issues more broadly; (2) education and training; and (3) providing leadership in death education and bereavement. Phases 4 (pilot) and 5 (evaluation) were ongoing at the time of publication.
Pereira *et al.*, 2021	Prior to 2013, the LEAP course was only available to community-based primary care professionals. Since 2014, versions for different settings, services, and specific disease groups have been made available	Learning Essential Approaches to Palliative Care (LEAP) courses (part of Pallium Project) address core palliative care competencies. Course (classroom) consisted of the following modules: (1) self-awareness; (2) taking ownership; (3) decision-making; (4) advance care planning and goals of care; (5) essential conversations; (6) pain; (7) dyspnea; (8) nausea and GI symptoms; (9) psychosocial and spiritual needs; (10) delirium; (11) last days and hour; (12) palliative sedation; and (13) quality improvement. Originally delivered as a 2-day workshop.	"Pallium positions itself as a Knowledge-to-Action broker (…) [that] brings together palliative care subject matter experts from across the country to identify best practices and evidence and synthesise and spread them to health professionals" (p. 2).	From 2015-2019, 1603 courses were delivered. A total of 28,123 learners have participated in LEAP courses from 2014-2019. Nurses make up the largest proportion of learners (55.3%), followed by physicians (14.3%), and paramedics (12.9%). In response to Covid-19 pandemic 103 online courses were delivered to 1979 learners. Additionally, 25 webinars (average 288 registrants) which addressed emergent pandemic-related topics were delivered.	Paper summarises (1) main findings from programme evaluation and impact research (2) success factors and spread accelerators; and (3) challenges and barriers.
Plunger *et al.*, 2015	People living with dementia who access participating community pharmacies.	Three workshops were conducted with key stakeholders to review their needs. In phase two, pharmacies will carry out small-scale projects to increase the wellbeing of people living with dementia	Based on Participatory Health Research approach, "the core elements of the approach are participation, action and reflection" (p. 140. Phase two (in progress) involved implementing small-scale "community outreach" projects.	40 staff (almost exclusively women) in 18 pharmacies actively participate in the project. Focus groups with caregivers of people with dementia (n=9); interviews with caregivers of people with dementia (n=not stated). No demographic details provided.	Pharmacists reflected upon the unique affordances and challenges supporting people living with dementia in the semi-public environment as well as identifying areas of professional development. People living with dementia identified different obstacles to care based on whether they lived in an urban or rural location.
Prince *et al.*, 2019	Community inhabitants.	Paper focuses on community educational strategies of the End-of-Life Care in First Nations Communities (EOLFN) Project. Initiatives unfolded in three phases: (1) assess educational needs in each community; (2) develop recommendations based on the findings; and (3) develop and implement educational resources in response to identified needs.	"Consistent with the PAR [Participatory Action Research] approach, all aspects of the research and palliative care program development were controlled by community members" (p. 4).	Surveys (n=94), respondents were aged between 30 and 60, the majority were female (94%). 62 focus groups and interviews (n=185) with community members, Elders/Knowledge Carriers, and external health care providers.	Findings are organised using the following headers, (1) educational needs of clients and families; (2) educational needs of First Nations community; and (3) education needs of Canada's health care system. Paper also summarises community-led initiatives developed to address the educational needs identified in the community assessments.
Tieman *et al.*, 2018	General public.	Course consisted of four modules: (1) how we engage with death and dying; (2) representations of death; (3) if death is the problem…is medicine the answer; and (4) digital dying. Content was delivered online over six weeks (four modules plus introduction and reflection sessions).	Community not involved with the development or delivery of intervention. It was intended participation would "build community engagement with death and dying" (p. 2).	Enrolled in the Dying2Learn MOOC (n=1156), completed some content or activity (n=895), completed the MOOC evaluation at both time points (n=208). The majority of those enrolled were female (92.1%); aged 40 and over (78.2%); self-identified as a health professional (68%); resided in Australia (94%).	Findings indicated the course was well received; 96.5% reported the course was enjoyable, 94.5% would recommend to others, and 91.2% agreed the course gave them a deeper understanding of death. There was a statistically significant increase in agreement with the statements "death is a normal part of life"; "I am comfortable talking about death/dying"; and "social media provides different perspectives to mainstream media on death/dying" following participation in the Dying2Learn MOOC.
Zuniga-Villanueva *et al.*, 2021	Bereaved inhabitants of city.	Session was divided between (1) psychoeducation covering topics related to loss, grief, and bereavement; and (2) discussion of personal loss. Delivered as weekly 2-hour sessions.	"The grief and bereavement support program emerged from within the community; recently, a local palliative care service has partnered with the program" (p. 10).	New attendees registered (n=827). Majority female (82%), religious (94%), and had experienced one loss (59%). Median age 43.8 years.	Most common reasons for attending the programme were personal experience of loss (69.5%) and wanting to learn about grief (23%). Most frequent type of losses were the death of a partner (30.1%), death of a parent (14.3%), and death of a child (8.4%). There was no statistically significant difference between the types of losses among men and women.
Cultural Interventions					
Marsh *et al.*, 2017	Community inhabitants.	Adopted a Participatory Action Research framework which consisted of: (1) information evening; (2) four "weaving conversations" sessions facilitated by an artist based on the themes of death and new life; and (3) a one-day workshop to develop the garden. Sessions were held over the course of three months.	"Adopted a Participatory Action Research (PAR) framework, a key principle of which is that research participants are active, informed community members who share the end goal of producing "action and knowledge that is directly useful to a group of people"" (p. 112).	Information session (n=23); weaving conversations (n=19); one-day workshop (n=36); interview (n=5); focus group (n=9). No demographic details provided.	Themes identified (1) "Conversations" - the need to talk about death and dying; (2) "Informal caring" - the need to be with others in the time of death and grief to give and receive support; and (3) "Community gardening" - needing toil, tea, and tranquillity.
McLoughlin *et al.*, 2016	Community inhabitants.	The World Café approach was used to organise themed discussions about the importance and challenges thinking and talking about death, dying, loss and care. Discussions were supplemented with presentations and short films. Events were delivered in person and lasted 2 ½ hours.	Framed as "community engagement"; community not involved with the development or delivery of intervention. Course content refined following pilot.	Attended information session (n=74); completed evaluation (n=51). Respondents were predominantly female (84%) with a mean age of 55.6 years.	All respondents would recommend Café Conversations to a friend. Statistically significant post-Café improvements were observed in all key domains, with the exception of participant's' self-rating of difficulty discussing death, dying, and bereavement.
Mills *et al.*, 2020	General public.	Two hour-long Twitter discussions in March and April 2020. Twitter hashtags (e.g., #PallANZ #PalliCovid) were used to engage the public on both community and professional issues pertaining to palliative care.	Community not involved with the development or delivery of intervention but responded to discussion themes. Intended that intervention would "support both professional and community capacity for end-of-life care" (p. 252).	See main findings.	The #PallANZ hashtag enabled interaction between 25 participants, who posted 230 tweets generating close to 750,000 impressions, followed by 55 participants sharing 107 tweets resulting in a further 210,000 impressions over the next 24 hours. A second chat involved 32 participants posting 256 tweets, followed by 67 participants sharing 120 tweets in the subsequent 24 hours.
Richards *et al.*, 2020	General public.	Death Café – 'pop up' events where people meet informally to discuss aspects of death and dying. Official guidelines stipulate that Death Cafés operate (1) on a not-for-profit basis; (2) with no intention of leading participants to any conclusions, product or course of action; (3) as an open, respectful, and confidential space; and (4) that food and refreshments are served.	Death Cafés are framed as opportunities to "engage in death talk" (p. 32) but "should not be used as a method of community consultation or engagement" (p. 5).	Death café organisers (n=49). Majority were women (71%) working in the death industry (n=13), healthcare (n=9), or mental health (n=5). Participants had a mean age of 40-50 years.	Findings organised into the following sections, (1) how international is the Death Café movement? (2) who are the organisers and who are the attendees? (3) international variation in the Death Café form; (4) why organisers think Death Cafés are needed; and (5) the perceived effects, beyond the event itself.
Service Interventions					
Abel *et al.*, 2018	Patients identified using broad criteria, including anyone giving "cause for concern".	The Health Connections Mendip employed the following process: (1) patient identification; (2) goal setting and care planning; (3) enhancement of naturally occurring supportive networks; and (4) linkage to community resource. Delivered from April 2013 to December 2017.	"The aim of community development is to enable as much resource as possible to exist within the community, without always involving health and social care services" (p. e808).	During study period, there were 235,195 unplanned admissions to hospital for patients registered in Somerset and 9885 in Frome. No demographic details provided.	There was a progressive reduction by 7.9 cases per quarter in unplanned hospital admissions across Frome: a decrease of 14%. In comparison, there was a 28.5% increase in admissions per quarter within Somerset. Cost of unplanned admissions in Frome reduced by 20.8% between 2013/14 and 2016/17.
Abel & Townsend, 2015	Carers of hospice patient.	Volunteer Community Champion (VCC) were recruited from Hospice pool of volunteers (i.e., carers group, bereavement support group, befrienders) and received training that included but was not limited to communication, bereavement, end of life, boundary setting. VCCs were matched with carer of hospice patient with the aim to provide emotional support, network development, and bereavement support.	Community Development was used to "start to develop naturally occurring supportive networks" (p. 17).	At the 18-month evaluation: VCCs recruited and trained (n=17); VCCs confident to provide support (n=4); carers supported (n=39). Average caring period was 6.5 months. No demographic details provided.	Paper provides descriptive summary of key outcomes and reflects upon the lessons learned implementing the programme.
Aoun *et al.*, 2020	Adult patients with advanced illness(es)/ palliative care needs.	Volunteer Compassionate Communities Connectors (VCCC) will attend a 2-day training programme delivered by content experts. VCCCs will be matched with vulnerable older adults with the aim of mobilising their network of Caring Helpers (friends, family, and neighbours willing and able to provide instrumental support). VCCCs will visit/telephone the client a minimum of six times over the course of three months.	Intervention framed as a "community-led" (p. 1) "partnership between the community and the palliative care service" (p. 8). Intervention relied on community volunteers, but community members were not involved with intervention design.	Proposed sample size of 10 VCCCs and 30 patients/families.	Not yet available.
Bruce *et al.*, 2021	Community dwelling older adults with advanced chronic illness.	Part of the Nav-CARE (Navigation – Connecting, Accessing, Resourcing, Engaging) programme (see Pesut *et al.*, 2017, 2020). Volunteers are trained and matched to client(s) with the aim to connect them with persons, resources, and services in the community to improve their quality of life. Volunteers visit client(s) every two weeks for 1-2 hours.	Level of public involvement unclear. But frames programme as "working in collaboration with patients, families and communities" (p. 572).	Clients (n=23), majority female (73.9%) living at home (60.9%) with mean age 72.06 years. Volunteers (n=33), majority female (84.4%), with mean age 64.81 years.	Paper reports three themes (1) pandemic emotions; (2) negotiating social interactions; and (3) growing through the Covid-19 pandemic.
Cronin, 2015	Practice population of Stretton Medical Practice identified to be in greatest need.	Compassionate Communities (Co-Co) in Shropshire matched Community Volunteers with older person identified as being at risk of loneliness and/or social isolation. The type of support and frequency of contact is agreed between volunteer and client and is regularly reviewed.	Described as a "locally derived model developed in response to feedback from frail and vulnerable people" (p. 31). "It is not a service provided by an organisation but rather a community development supported by Severn Hospice working in partnership with local medical practices" (p. 33-4, emphasis in original).	Compassionate Community Developments (n=14); Community Volunteers (n=80); clients (n=38). No demographic details provided.	A year after commencement of the programme an audit of outcomes was undertaken. Total visits to practice, total phone calls to family doctor, total A&E admissions, total hospital admission, total calls to/visits by out-of-hours services decreased over the 6-month period following deployment of volunteers. Total planned hospital admissions increased.
Howard *et al.*, 2018	Adults living with disabilities in the catchment area(s).	A community facilitator will coach individuals to identify needs and priorities, and link with resources.	Level of community involvement unclear. States "intervention aimed at reducing social isolation by mobilizing individuals to act on their health and social needs individually, and in collaboration with fellow members of their community".	Proposed sample size of 1000 participants.	Not yet available.
Krakowiak *et al.*, 2018	Patients in hospice setting.	Prisoners are trained, after which they are gradually introduced to join teams in caring for patients in the hospice wards. Volunteers work up to 8 hours a day for no payment. From 2003-2008 project limited to one hospice in Gdansk but has since expanded to other hospices in Poland.	Programme stemmed from community observation. Authors state, "we are exploring further the foundation of our practice experience with community development, policy reform and social and political change" (p. S112).	Survey (n=892); interviews with prisoners (n=14). No demographic details provided.	93% of survey respondents agreed that prisoners should have opportunities to work in places like hospices. The qualitative research identified differences in how prisoner-volunteers relate to the world, to others, and to themselves compared to prisoners who had not volunteered.
Librada Flores *et al.*, 2018	Residents of Saville with an advanced or terminal illness, are receiving palliative care supervision, and identified as having unmet needs.	REDCUIDA (part of the All With You programme) intervention will match a Community Promoter with person living with advanced illness and/or their families to identify unmet needs and mobilise support network(s). The intervention will be delivered in person over seven weeks.	Intervention relied on community volunteers, but community members were not involved with intervention design. Seeks to address unmet patient needs "through mobilisation of the community" (p. 2).	Proposed sample size of 320 patients per group.	Not yet available.
McLoughlin *et al.*, 2015	Community dwelling adults with advanced life-limiting illness in Limerick.	In accordance with MRC Framework for the Evaluation of Complex Interventions the INSPIRE study (part of the Good Neighbour Partnership) will be completed in three phases: (Phase 0) explore relevant theory and evidence to inform intervention development; (Phase 1) identify components of intervention and the underlying mechanisms; and (Phase 2) exploratory delayed randomised controlled trial. Compassionate Community Volunteer (CCV) will be trained and matched with person living with life limiting illness to mobilise community support. Delivered in person over the course of eight weeks.	Described as a "volunteer-led model of social and practical care/support for community dwelling adults living with advanced life-limiting illness" (p. 3). Intervention relied on community volunteers, but community members were not involved with intervention design.	Proposed sample of 10 CVVs and 80 community dwelling adults living with life-limiting illness.	Not yet available.
Pesut *et al.*, 2017	Clients had to be over 55 years of age and have one or more advanced chronic illnesses that could reasonably lead to death within the next year.	Nav-CARE pilot study recruited and trained volunteers who were then matched with a client to identify unmet care needs and mobilise community-based resources and supportive networks. Volunteers visited client according to client preference (typically every 2-3 weeks) over 12 months.	Study followed a "community-based research approach" that included advisory committee (representation from hospice societies and allied professionals) to guide project. Intervention relied on community volunteers whose feedback has been used to refine programme training materials.	Volunteers (n=7); all female, mean age of 60 years. Clients (n=18); majority female (n=10), mean age of 70 years.	Volunteers dedicated 378.4 direct contact hours visiting clients engaged in multiple activities with clients. Including but not limited to, facilitating greater connection with others, signposting to services and resources, and engaging strategies to assist clients to engage more fully in life. Overall, there was high degree of satisfaction particularly in supporting clients over the long term. Clients reported volunteer navigators had transformed their illness experience. Both clients and volunteers expressed some uncertainty over the meaning of 'navigation activities'.
Pesut *et al.*, 2020	People living with advanced illnesses who accessed the participating hospice societies.	Expansion of Nav-CARE programme to eight community-based hospice societies. Volunteers are recruited, trained, and matched with clients to identify unmet care needs, mobilise community-based resources and supportive networks, and support client with desired activities. Volunteers visit clients in person every 2-3 weeks. The planned action cycle was 12 or 18 months, depending on site.	Described as a "volunteer-led navigation intervention" (p. 3). Intervention relied on community volunteers, but community members were not involved with intervention design. Study builds upon findings from pilot studies.	Clients (n=49); family (n=38); volunteers (n=38); stakeholders from healthcare and hospice settings (n=55). No demographic details provided.	Key contextual factors that determined the ease with which Nav-CARE was implemented included (1) the individual skills and characteristics of the volunteer coordinator champion; (2) organisational capacity and connection; (3) the successful recruitment of older persons; (4) the adequacy of volunteer preparation and mentorship.
Pfaff *et al.*, 2021	People with chronic disease, people living in social isolation, older people.	Vulnerable Persons Project (part of Windsor-Essex Compassion Care Community) oversaw staff and volunteers assist clients to identify their own personal needs, goals, and preferred intervention. Intervention varies from in person consultations with fully integrated health and social care supports, to scheduled calls to assess client goal setting and quality of life. Clients are never discharged.	WECCC "is a collective of volunteers and 65 health/social care organisations that partner in identifying and reducing the unmet needs of persons living with complex health and social issues" (p. 2). Intervention relied on community volunteers, but community members were not involved with intervention design.	Focus group with clients (n=5); interview with clients (n=3); stakeholders (n=16). No demographic details provided.	The findings are presented in the following sections: (1) participant characteristics; (2) intervention characteristics; (3) programme processes - taking time, advocacy, and empowerment; and (4) impacts and opportunities for improvement.
Riley *et al.*, 2018	Bereaved people who had accessed Weston HospiceCare.	Peer-led bereavement support for carers of palliative care patient. Meetings happen monthly for two hours; it has no structured therapy sessions.	Aligned with "participatory development" where "the hospice had a role in facilitating this process rather than leading it" (p. 69). Group developed in response to community needs and delivered by Hospice. Facilitation has since been assumed by former carers.	150 bereaved people have attended Buddy Groups. No demographic details provided.	Buddy Groups have been self-sustaining with bereaved participants taking on facilitation and organisation roles. In addition to monthly meetings, the group also go on social outings (e.g., cinema, day trips, coffee mornings). Participants valued having people outside of their family to talk to and to empathise with their experiences.
Ummel *et al.*, 2021	People bereaved by Covid-19 complications or during the Covid-19 pandemic.	Online support group for bereaved people based around: (1) education and training; (2) hospices and nursing homes; (3) media and social media; (4) commemoration; (5) celebrations; (6) artistic practices and storytelling; (7) marginalised populations; and (8) review and evaluate.	"The overall research design was informed by participatory research approach, which emphasises research as a collaborative, practical, emancipatory, critical, and reflective social process between the researchers and participants" (p. 3). Activities were co-constructed with community members.	Community participants (n=35). Majority of participants were married (57,1%), Canadian (86%) women (88.6%) bereaved by parental death (71%). Majority of deaths occurred in hospital (65.7%) caused by Covid-19 (71.4%). Only 17.1% had been able to hold in-person commemorations.	Paper reflects upon the eight areas of activities co-constructed within the intervention (see 'Intervention').
Walshe *et al.*, 2016	Adult patients identified to be in the last year of life and their self-identified informal carer.	End-of-Life Social Action Study (ELSA) protocol. Volunteers will be trained and provide support (befriending, signposting, practical assistance) to people identified to be in their last year of life. Support will be provided 1-3 times per week in person or by telephone. The trial will last 8 or 12 weeks, but support may continue beyond this.	Intervention framed as a "social action volunteer befriending service" (p. 3) for adults in the last year of life. Intervention relied on community volunteers, but community members were not involved with intervention design.	Proposed sample size 350 participants per arm. Qualitative case studies will be completed at eight sites with a proposed sample size of 88-168 participants (including patients, informal carers, volunteers, key managers or coordinators).	Not yet available – see Walshe et al (2016) below.
Walshe *et al.*, 2016	Adult patients identified to be in the last year of life and their self-identified informal carer.	ELSA Study: volunteers trained and provided support (befriending, signposting, practical assistance) to people identified to be in their last year of life. Support was in response to client needs but was typically once a week for 1-3 hours. Intervention duration was eight weeks, although support could continue beyond this.	"The content (coping strategies to maintain wellbeing) and chosen delivery mechanism (via trained peer mentors) are derived from our previous qualitative study" (p. 2). Intervention relied on community volunteers, but community members were not involved with intervention design.	Intervention (n=100); control (n=95). Participants were recruited from all 11 sites (range 3-40 participants per site). Participants mean age was 72, and 60% were female. No significant demographic differences were observed between groups.	No statistically significant difference in effectiveness between volunteer provided support and 'treatment as usual' (control). There was however a pattern of deteriorating levels of quality of life in the control group, a decrease not observed in the intervention group, and which tended to disappear when all received the intervention.
Walshe *et al.*, 2020	Adults living with advanced cancer and their family/informal carer.	Peer mentors attended 2-day training and were matched with patient participants. Support was delivered either in person or by telephone in response to need. Typically volunteers met with clients 1-2 times per week (capped at 2 hours) for up to 12 weeks.	Intervention framed as a "social action volunteer befriending service" (p. 2) for people in the last year of life. Intervention relied on community volunteers, but community members were not involved with intervention design.	Intervention (n=8); control (n=10); peer mentor (n=12). Interviews conducted with clients (n=4); carers (n=2); mentors (n=7). Majority of patients in control (67%) and 50% of patients in intervention group were male, with mean age of 69.6 and 64.8 years respectively. All participants were British and most (75%) were married and living with together with no children. Majority of peer mentors were female (67%), British (91.7%) with an average age of 60.8 years.	Peer mentor recruitment and training met feasibility targets. Patient participants were not recruited to feasibility targets. Outcome data must be treated with extreme caution due to small numbers but indicate the intervention may have a positive effect on quality of life.
Wang *et al.*, 2020	Adults aged 18 years and above willing to complete training and provide 6 months' care in specific communities for end-of-life patients and their families.	The following phases were followed (1) recruitment and motivational screening; (2) training; and (3) evaluation of training effects in building volunteers' confidence providing end-of-life care (EoLC).	"The transformative sustainability-learning framework was adapted to guide the development of the four-step capacity building program" (p. 410) for volunteers in EoLC.	Recruitment enrolment (n=171); eligible participants after motivational screening (n=92); participants who join the training and complete pre-test (n=88); participants who complete training and post-test (n=81); participants who complete 6-month follow-up test (n=56). Majority of course attendees were female (74.7%), nearly 60% were aged 50-69 years, and more than half were retired or unemployed.	Competence in EoLC, awareness of self-care, and death work competence all significantly improved after training and remained intact at 6-month follow-up.
Warner *et al.*, 2021	People living with advanced illness.	Nav-CARE study delivered in eight sites across three Canadian provinces. Volunteers attended a 2-day training course and then matched with older person to provide support and help them navigate community services. The precise frequency and timing of visits was negotiated with the client.	Intervention relied on community volunteers, but community members were not involved with intervention design. Volunteer feedback to inform programme development.	Participants (n=16) included, hospice staff, volunteers, advisory committee members, and community stakeholders. No demographic details are provided.	Five themes are reported, (1) intraorganizational perceptions of Nav-CARE; (2) public and healthcare professionals' perceptions of palliative care; (3) interorganisational partnerships and relationships; (4) community and national-level factors that should have facilitated Nav-CARE implementation; and (5) suggested changes to Nav-CARE.
West *et al.*, 2021	Bereaved people during Covid-19 Pandemic.	Drew upon two established bereavement support programmes as they responded to the Covid-19 pandemic: (1) the Bereavement Supporter Project which provided peer support for bereaved people living within ExtraCare Charitable trust, and (2) Cruse Bereavement Care's national support service.	Bereavement Supporter Project sought "to develop the capacities of communities to support friends, neighbours, and family members through "normal" processes of grief" (p. 4).	8 diarists (3 Cruse Bereavement Volunteers and 5 ExtraCare Resident Supporters). 43 diary entries were submitted. No demographic details provided.	Themes identified (1) when only physical presence will do; (2) talking and remembering on hold; (3) absence of forward momentum; (4) virtual spaces of bereavement support; (5) re-collectivising bereavement; and (6) welcome respite from "mandatory happiness".
Clinical Interventions					
Aoun *et al.*, 2022	Parents of children receiving palliative care	The Carer Support Needs Assessment Tool was adapted for use with parent caregivers. Parents used the tool either independently or in discussion with health professionals to identify their unmet needs and develop an action plan. The tool was completed a second time 2-8 weeks later.	Goal of study was to "obtain feedback [from parents] regarding their experience using the CSNAT (Paediatric)" (p. 321).	28 parents completed the intervention, all of whom were interviewed. The majority were female (93%), were married/de facto married (82%), and aged between 27 and 55 years old.	Five themes were identified (1) caregiving challenges, perceived gaps, and feelings of isolation; (2) practicality and usefulness of the systematic assessment; (3) emotional responses to self-reflection; (4) validation and empowerment; and (5) receiving support responsive to their needs.
Daddow & Stanley, 2021	Patients accessing palliative care.	'Heidi's Have a Go' programme supported patients to pursue unique experiences and 'have a go' at something they have longed to do. There is no predetermined schedule of activities but instead responds to patient requests.	"It is a uniquely patient-led program in a regional locale, providing non-clinical, informal environments with no prescribed schedule nor outcome, positioned within an integrated model of palliative care" (p. 533).	Survey (n=10) and interviews (n=4) with staff/volunteers who had participated in the programme. No demographic details provided.	Staff reported that the programme had helped them understand patient priorities (90%) and needs (70%); 60% noticed changes to patients' physical wellbeing and 70% noticed changes to patients' emotional wellbeing. Three themes are reported (1) privileging the whole person; (2) strengthening networks of care; and (3) shifting the balance of power in care relationships.
Stanley & Daddow, 2022	Patients accessing palliative care.	'Heidi's Have a Go' programme supported patients to pursue unique experiences and 'have a go' at something they have longed to do. There is no predetermined schedule of activities but instead responds to patient requests.	Intervention "features no pre-determined programme activities and responds to individual and family requests as they emerge from conversations with clinical, allied staff and volunteers" (p. 4).	Survey (n=10) and interviews (n=4) with staff/volunteers who had participated in the programme. No demographic details provided.	Three themes are reported (1) providing respite from a medicalised focus; (2) nurturing emotional processing and legacy; and (3) altering perceptions of palliative care.
Multi-dimensional Interventions					
Gómez-Batiste *et al.*, 2018	Residents of Vic, Spain.	The full extent of intended and/or completed activities is unclear. Paper focuses on cultural and educational activities.	"A group of eight organisations composed the "core nucleus" of the project, helped in the design of activities, and met regularly to follow up" (p. S34). The "core nucleus" then partnered with community organisations who committed (to various degrees) to "establish policies and protocols to promote positive attitudes and volunteer proposals in their organisations" (p. S35).	Organisations registered (n=48); attended training course, workshop, or activities (n=1470). No demographic details provided.	The training was well received by the 51 attendees who completed the survey. SWOT analyses informed programme changes for the 2nd year.
Grassau *et al.*, 2021	OSPN coordinating committee.	Study is part of the Healthy End of Life Project (HELP) Ottawa, a community-based participatory action research project to build the community capacities needed to form, maintain, and sustain Compassionate Communities. This paper focuses on community consultation with LGBTQ2S+ people as part of phase one of the project.	HELP is a "community-based participatory action research project" (p. 2). Study was part of an "initial community consultation" that sought to "centre the voices of LGBTQ2S+ people from the outset of this larger project" (p. 3).	Focus group (n=9). Majority were white women who identified as lesbian; mean age 72 years. All participants had attended university and half had a post-graduate degree.	Themes identified (1) many of us are survivors of trauma; (2) 'where can I go that is safe'? Creating our own safety; (3) 'connection is very important': disrupting ageism and stigma; and (4) asking for - and receiving - help.
Grindrod & Rumbold, 2018	Community inhabitants.	Study is part of HELP which seeks to build the community capacities needed to form, maintain, and sustain Compassionate Communities. The enquiry was carried out in three phases: (1) investigated individual and community experiences of providing end of life care; (2) literature review to establish an evidence-based framework for HELP; (3) project implementation and evaluation. At the time of publication phase three was ongoing; paper focuses on phase one.	The Ottawa Charter for health promotion, "a public health standard for shaping and creating health through participatory action" (p. S75) was used as the organising framework for HELP.	Interviews with local leaders (n=8), community development workers (n=6), and carers (n=6) attending community meetings (n=16). No demographic details provided.	Themes identified (1) social norms can be unhelpful; (2) social interactions can undermine community capacity; (3) vulnerability can be engaged constructively; and (4) community culture needs to be collaborative.
Hasson *et al.*, 2022	Inhabitants of city.	The Getxo Zurekin initiative consisted of four iterative, non-linear phases, based on the social innovation spiral concept: (1) listening; (2) co-creation; (3) modelling; and (4) constant evaluation. Paper focuses on phase one.	Project applies "community action model" where co-creation and development of actions rely on the close involvement and constant participation of community members" (p. 8).	Interviews as part of Phase One (listening) (n=80); majority female (58.8%) volunteers (23.5%), aged 16-90 years. Phase Two (co-creation) has led to talks/workshops (n=1442); Death Cafés (n=387); training courses (n=497); conferences (n=5020); telephone support (n=18 families). Phase Three (modelling): the identification of new ideas that would meet community needs were followed by collaborative development. Phase Four: mechanisms in place to continuously monitor activities.	Main ideas identified from interview data included: (1) services cannot reach and attend to the needs of everyone in end-of-life situations; (2) healthcare and educational professionals lack specific training to care and support people at the end of life; (3) stigma around help seeking; and (4) social care structures do not take advantage of people in the community.
Hazelwood & Patterson, 2018	General public.	Good Life, Good Death, Good Grief (GLGDGG) is an alliance that seeks to engage, support, and enhance the assets of communities, organisations, and individuals who have the potential to improve the experience of death, dying, and bereavement in Scotland. GLGDGG has built a portfolio of community-driven initiatives in addition to providing infrastructure, developing resources, and coordinating promotions and events.	"GLGDGG is non-prescriptive in its approach, aiming rather to provide a sounding board to build capacity and inclination of individuals and organisations to undertake the change they think needs to happen in their local area" (p. S101).	As of November 2017, GLGDGG has over 1100 members – 800 individuals and 300 organisations.	Paper explores the key challenges and successes to implementation.
Horsfall *et al.*, 2020	General public.	The GroundSwell Project launched two Compassionate Communities projects (The National Compassionate Communities Forum and the Nepean Blue Mountains Primary Health Network) that have been combined here. The projects employed multiple intervention strategies including current needs assessment, educational workshops and seminars, discussion and support groups, organisational partnerships, cultural events, and volunteers to signpost local end-of-life services.	"Both projects were underpinned by a strong ethos of community development work where building capacity of people to work together and take collective action to address their common needs and interests is central (p. 11, emphasis in original).	18 community leads participated in focus groups, research groups, and research training groups. The majority (94%) were female.	Paper organised into two themes, (1) resistance and struggle; (2) what does it take to do this work? Each theme consists of multiple sub-themes.
Horton *et al.*, 2015	Inhabitants of city.	The Cheshire Living Well Dying Well (CLWDW) programme employed multiple intervention strategies including public health partnerships; resource development; public education; care mobilisation through informal help or formalised volunteering; and workplace initiatives.	"The vision of the programme is driven by an underpinning belief that palliative care services have a role to play in the empowerment of people and that a community development approach releases assets 'into' and 'out' of communities. A drive for knowledge transfer on many levels is key" (p. 66).	CLWDW Champions (n=176); events (n=64); attendees (n=676). No demographic details provided.	Range of bespoke courses and resources have been developed. Community sessions have changed perceptions about death and dying and encouraged 60% of attendees to have conversations about their end of life wishes or made some other change post-session. Challenges identified: (1) organisational change within the NHS (National Health Service) and local governments; (2) leaders feeling overwhelmed; and (3) healthcare professionals struggled with concept of public health end of life and so were resistant to the programme.
Kelley *et al.*, 2018	Community inhabitants.	The Improving End-of-Life Care in First Nations Communities (EOLFN) Project was a six-year participatory action research project which employed a four-phase community development model: (1) having necessary antecedent community conditions; (2) experiencing a catalyst for change; (3) creating a palliative care (PC) team; and (4) growing the PC program.	Using PAR, "each community developed their own PC [palliative care] program into existing health services. Each community created an Advisory Committee that ensured development was consistent with their visions, community capacity and context" (p. 13).	Surveys (n=94); interviews/focus groups with community members (n=82), elders/knowledge carriers (n=68), and external health care providers (n=35). No demographic details provided.	Findings presented in three sections, (1) summarises community needs assessment; (2) outcomes to guide development of PC programs in First Nations communities; and (3) outcomes to guide policy and planning.
Librada Flores *et al.*, 2018	Inhabitants of city.	"All With You" programme was developed in accordance with the Compassionate Communities Charter to meet the needs of people living with advanced illness or are at the end of life. The process was designed in four phases (1) systematic review of literature and methodology; (2) creation of central office and observatory; (3) creation of a living lab and demonstration project to test and check the methodology; and (4) replication within other organisations and cities.	All With You method was "co-developed by members of the team including representatives from the leading community partners and the NHF [New Health Foundation] team" (p. 5). Team identifies community partners to commit to implementing a "compassionate-driven initiative" (p. 5) within their community and support the design, implementation, and evaluation processes.	City Hall, along with 42 organisations representing the corporate, public, and non-profit sectors, have committed to the movement. Awareness programmes have reached 16,077 members of the public; 4040 children; 270 university students; 1420 caregivers; and 95 trained health professionals.	Paper summarises (1) the development of the eight-phase "All With You" Method; (2) preliminary findings and learning from the pilot study in Saville; and (3) the current progress of 9 Compassionate Communities initiatives following "All With You" protocol.
Lindqvist & Tishelman, 2016	Variety of publics.	The Döbra programme seeks to diminish avoidable suffering related to dying, death, and bereavement. The aims are aligned with four facets of the Ottawa Charter: (1) to strengthen community action and develop personal skills; (2) to create supportive environments; (3) to build public policies to support health; and (4) to reorientate health services.	Döbra combines Action Research, experience-based co-design, and knowledge exchange which "all aim to bring together a variety of stakeholders to exchange ideas and expertise, and co-create experience-based evidence through knowledge generation, dissemination, and sharing" (p. 21).	Not stated.	Paper identified some of the Döbra Projects, which includes but is not limited to: the development of the first Advanced Care Planning programme in Sweden; community awareness and competency-building; the Room for Death project; and using photographs and interview quotes to compile 'trigger films' that will be used in workshops to elicit discussion among patients, caregivers, and staff.
Liu *et al.*, 2022	Community inhabitants.	The Compassionate Communities in Taipei project is informed by the Compassionate Communities Charter. Four implementation strategies were employed: (1) humanistic care; (2) social network; (3) holistic care; and (4) the wisdom of life and death.	The project "constructed a public-private framework by connecting government agencies, communities, social welfare institutions, businesses, charitable and religious organisations, and other non-governmental organisations" (p. 176).	'Life Issue Café' events held in 2018 (n=4), attended by older people (n=27) and students (n=60). No demographic details provided. There are now 20 Compassionate Communities across the 12 districts of Taipei city.	Questionnaires from 'Life Issue Café' events found respondents believed it was important to talk about death matters (84.2%/90.9%) but that it was difficult to do so (78.9%/90.9%). Paper identifies the following to be important for developing Compassionate Communities: (1) glocalisation; (2) collaboration, partnership, and integration; (3) communication and public education; and (4) local culture and religion.
McLoughlin, 2013	Inhabitants of cities.	Milford Care Centre's Compassionate Communities Project employed a three-strand framework aligned to the Ottawa Charter: (1) whole population approach through the distribution of information and resources, and development of marketing/PR strategy; (2) engaging and supporting communities through educational programmes, seed grants, public events; and (3) Good Neighbour Scheme.	Informed by Compassionate Cities Charter, specifically the "emphasis on community development into the field of death, dying, loss and care, thus raising the profile of end of life in public health using a life stages approach" (p. 13).	See key findings.	This is a comprehensive interim evaluation report, findings are organised into the following sections: (1) social media, printed media, posters, radio, tv; (2) leaflets, website; (3) programme events; (4) training programmes; (5) grant scheme; and (6) community mentor programme.
Patel, 2015	Community inhabitants.	Compassionate Communities in Sandwell employed multiple implementation strategies including education and raising awareness; community and organisational engagement; supporting individuals and carers to utilise support from their networks; and training Compassionate Communities Champions.	"Murray Hall's community development approach is to encourage and foster solutions to inequalities found in the erosion of solidarity and to nurture agency" (p. 47).	Conference attendees (n=100). No demographic details provided.	Study describes overview of activities, learning, and challenges.
Vanderstichelen *et al.*, 2021	Community inhabitants.	Madrid Charter aims to promote the development of Hospice and Palliative Care volunteering, promote research and best practice, and to develop policy, training, funding, and research. Paper assesses the awareness, reach, and use of the Charter to evaluate its perceived usefulness.	"Charter aims are to promote the development of HPC [Hospice and Palliative Care] volunteering for the benefit of patients, families and the wider hospice palliative care community" (p. 2).	64 responses across 11 countries, majority (53%) were Dutch general managers (45%).	The majority (64%) had heard of the Charter, 44% had signed it, but had not used it (70%). Qualitative analysis identified that participants saw the potential in the Charter as an advocacy tool and to make global connections. But many reported it lacked practical utility.
Vijay *et al.*, 2018	Those with advanced cancer, chronic renal conditions, and the chronically bed-ridden.	Employed three key practices (1) community members are the locus of care-giving, decision making, and fund-raising; (2) palliative care is conceptualised as 'total care' and includes medical, social, and financial support, rehabilitation and bereavement services for patients and families; and (3) integration of community organisations into public health.	Project described as a "community-based palliative care intervention" which "emphasised the bottom-up role of communities in improving their health status and reaching a state of physical, mental and social wellbeing" (p. 3).	Semi-structured interviews (n=22). No demographic details provided.	Paper focuses on three 'moments' that influenced the translation of community-based palliative care practices to Nadia: (1) the translator's enactment of symbolic power; (2) translating member relations; and (3) translating social participation.
Wegleitner & Schuchter, 2018	Inhabitants of region.	Caring Community in Living and Dying (Landeck) project aimed to encourage citizen-orientated approaches in elderly and end of life care in German-speaking countries. Employed four-phase approach: Phases (0) building trust and commitment; (1) survey of local care practices and cultures in elderly- and end-of-life care; (2) awareness and engagement; and (3) implementation of initiatives in various community spheres. Lists a number of interventions that have been conducted during Phase 3 including: public Last Aid Courses; school engagement; developing resources; movie night.	Followed "community-based participatory research process" where "research is understood as a collaborative process that engages researchers and community members in knowledge generation, capacity building and action for social change to improve community well-being as well as to reduce health disparities" (p. 3).	Focus groups with family carers (n=11); hospice volunteers (n=6); coordinators of self-help groups (n=3); home care team (n=4; all women). Focus group with GPs (n=4; 3 male); interview with undertaker (female), and pastor (male). International expert workshop (n=40).	Findings focus on lessons learned (1) the caring community is already there: making it visible and learning from it; (2) caring communities as a collective learning process; (3) making citizen wisdom and knowledge available for the community; (4) reflecting and processing the question of a good life until the end; (5) dealing with care (in)justice; and (6) maintaining the "critical" potential of caring communities.
Wegleitner *et al.*, 2015	Inhabitants of region.	Caring Community in Living and Dying (Landeck) project employed a three-phase approach: (1) survey of local care cultures and traditions in end-of-life care; (2) strengthening local networks and self-help resources; and (3) supporting implementation and sustainability of initiatives and measures for caring networks in living and dying.	Project "began as a research and development concern" within a university context and "follows community-based participatory research and a community development approach" (p. 110).	Not stated.	Themes identified (1) 'Collapse of the world': disturbance of everyday life at every level (practical, social, self-identity and social role), caring experienced as a crisis that requires a fundamental reorientation in life; (2) 'narrowness of caring': burden that requires relief; and (3) 'guilt': particularly difficult issue for family caregivers. Paper also reflects on lessons learned and hopes for the future. Important 'ingredients' of a compassion community also identified.
Wegleitner *et al.*, 2018	Inhabitants of region.	Caring Community in Living and Dying (Landeck) project. This article focuses on phase 1 (of 3) which aimed to better understand local care cultures and traditions in end-of-life care.	Described as "large-scale community-based participatory research" that "aimed to strengthen networks and solidarity in the community, in order to support older and vulnerable people as well as family caregivers" (p. 989).	Focus groups with family carers at different stages of their caring process (n=11; all women); hospice volunteers (n=6; all women); coordinators of self-help groups (n=3; all women); community general practitioner (n=4; one woman); ambulatory nursing care team (n=4; all women). Interviews with a local undertaker and a local Catholic priest.	Analysis identified 'ingredients' of a 'supportive care web', (1) contributing specific competencies; (2) sharing wisdom of life; (3) keeping an eye on each other; (4) sensitively gaining access to house and soul; (5) vicariously organising care; (6) moderating care arrangements; and (7) enabling freedom from care.

Table S2 Taxonomy of Interventions at the end-of-life [reproduced from Clark *et al.* (9)]

Focus	Definition
Policy	Decisions taken or rules adopted by governing authorities to deliver, facilitate, monitor, or regulate end-of-life issues
Advocacy	Expressions or actions on end-of-life issues that aim to influence decisions on the institutional elite and/or promote the interests of specific populations, groups, or individuals in particular contexts
Educational	Development of knowledge, skills, good judgment, and character required for the delivery of appropriate end-of-life care
Ethico-legal	Frameworks included within laws, guidelines or ethical codes that relate to issues at the end of life and which permit, facilitate, or require specific courses of action
Service	Medical, nursing, and other services for the prevention, alleviation, and/or reduction of suffering at the end of life through inpatient, outpatient, home care, or other forms of services
Clinical	Medical, nursing, allied health, and psycho-social procedures at the individual level to relieve symptoms and sufferings associated with advanced illnesses and when death is imminent
Research	Systematic enquiry on end-of-life issues for the purposes of establishing new knowledge and understanding by description, prediction, improvement and/or explanation
Cultural	Initiatives taken to influence patterns of shared knowledge and symbolic meanings in particular communities, through which people perceive, interpret, express, and respond to end-of-life issues
Intangible	Actions to promote the recognition and significance of aspects of human existence that have intrinsic value at the end of life
Self-determined	Actions, decisions, or choices made by individuals to engage in or refrain from something that has implications for them at the end of their life or the life of another
Multi-dimensional	Not included in original taxonomy. These were multi-faceted, multi-phased, multi-agency initiatives that embraced a multi-dimensional approach by incorporating three or more intervention categories from Clarke *et al.*'s taxonomy

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