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Area-Based Compassionate Communities: A systematic integrative review of existing initiatives worldwide

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Area-Based Compassionate Communities: a systematic integrative review of existing initiatives worldwide.

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Background: Area-Based compassionate community initiatives are community public health interventions which focus on the role of the community in palliative care provision. They apply a set of actions based on the Ottawa Charter for Health Promotion which aims to increase people's control over their health.

Aim: To review and compare area-based compassionate community initiatives with respect to their contextual characteristics, development processes and evaluations.

Design: A systematic integrative with narrative synthesis. Registered in Prospero: CRD42020173406.

Data sources: Five databases (Pubmed, Web of Science, PsycInfo, Embase and Scopus) were consulted, consisting of publications from 1999 onwards. This was supplemented with grey literature and author-provided documentation.

Results: Twenty articles were drawn from the peer reviewed search, three from grey literature and two from author-provided documentation. Notwithstanding the substantial variation in what is reported, all area-based compassionate community initiatives focus on multiple action areas of the Ottawa Charter for Health Promotion. Variability in their contextual and developmental characteristics is high. Only a minority of initiatives have been evaluated and although conclusions are generally positive, what is evaluated often does not match their aims. Attaining support from policy makers can help in obtaining funding early in the project. Strengthening people's social networks was a recurring community engagement strategy.

Conclusions: While the concept of area-based compassionate community initiatives is gaining momentum as a new paradigm for the creation of palliative care capacity across society, only a handful of initiatives have been described. The lack of formal evaluations of their proclaimed health benefits indicates a pressing need for rigorous research about ongoing and future initiatives.

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Key statements

What is already known about the topic?

- Compassionate communities and cities are one example of the application of a public health perspective to palliative care. Papers describing individual compassionate communities or cities show that they are being developed in different parts of the world.

- Only one systematic review has previously been performed on compassionate communities or cities and concluded that there is very little evidence about their development and that assessment models are lacking.

What this paper adds

- This review provides a clear overview of similarities and differences between Area-Based Compassionate Community initiatives with regard to their contextual characteristics, development process, whether they have been evaluated and what the reported results of any evaluation are.

- Only a handful of Area-Based Compassionate Community initiatives have been described in the last decade, only a minority underwent some form of evaluation and reported results of these evaluations are generally very limited.

- Because of the scarce description of existing initiatives in the literature, it remains unclear which elements are essential for success and which, if any, model yields the best results.

Implications for practice, theory or policy

- The lack of formal evaluations of the claimed health benefits of Area-Based Compassionate Community initiatives indicates a pressing need for rigorous research about ongoing and future initiatives to assess whether these benefits are realised.

- Every city or region has its individual priorities and needs related to the end of life and could therefore benefit from the expansion or initiation of their palliative care delivery together with the active participation of the community.

- Training healthcare workers in the adequate provision of palliative care together with a stimulated community that acknowledges its own potential could unburden local healthcare systems.

- Educating and informing the public on its own potential in palliative care can have far-reaching impacts that are not yet well known, such as decreased carer burden and decreased emergency hospital admissions.

Background

There is increasing recognition that the challenges of health and wellbeing around serious illness, dying and bereavement go substantially beyond the scope of professional healthcare services.[1–3] The more protracted part of care in serious illness at the end of life and subsequent bereavement involves periods of time spent not with professionals but with family, friends, co-workers and other social connections. Therefore it has been suggested that promoting the health and wellbeing of people with serious illnesses, their carers, relatives, friends and neighbours, entails a civic response in co-existence with health service responses. These efforts, organised by society to optimise the circumstances of the dying and all those involved through collective or social actions, have by some been coined a 'public health approach to palliative care'.[1,3–5]

Allan Kellehear, a sociologist, published Health Promoting Palliative care in 1999 which adapted the Ottawa Charter principles to palliative care and which laid the foundations for the concepts of compassionate communities and cities.[3,6] Put forward as one possible model of a civic response to palliative care, compassionate communities and cities are social ecology approaches, based on principles of participation, empowerment, inclusion, respect and dignity, which consider serious illness, dying, caregiving and grief as everyone's business.[6] Our focus is on compassionate communities around serious illness, death, dying and loss that target geographic areas delineated by physical or administrative boundaries at the scale of municipalities or larger and are multi-sectoral, inclusive and participatory in nature. Their development is often characterised by the involvement of various stakeholders, including the local government, health and wellbeing organisations, workplaces, schools, churches and neighbourhoods who collaborate to work out actions aimed at prevention, harm reduction and early intervention around serious illness, death, dying, loss and caregiving.[7] The actions can include awareness-raising, education, policy development and creation of new or strengthening of existing social networks in co-creation. These initiatives have sometimes been referred to as compassionate cities but the concept of compassionate communities is equally used and a clear conceptual demarcation between both is lacking. To avoid the existing conceptual confusion, we choose to use the descriptive term "Area-Based Compassionate Communities". The set of actions or activities are based on the five action areas of the Ottawa Charter for Health Promotion: (1) building healthy public policy

60 around serious illness, death, dying, loss and caregiving, (2) creating supportive environments, (3)

61 strengthening community action, (4) developing personal skills through education and information and

62 (5) re-orienting of healthcare services toward these changes.[8]

63   While the concepts of compassionate communities and cities seem to be gaining momentum

64 as a new paradigm for the creation of palliative care capacity across society in various countries, there

65 is little systematic knowledge about their characteristics, how they were developed, whether the process

66 and impact of the existing initiatives have been formally evaluated and what the results are of these

67 evaluations.[4,9] Studying these topics is important since it provides future developers with invaluable

68 information on what characteristics are important, what development processes lead to success and

69 what results can be expected when developing a compassionate community or city. We argue that that

70 knowledge is important to add an evidence base to the growing enthusiasm for compassionate

71 communities and cities by, for instance, indicating what can be learned from previous initiatives or where

72 more evidence is needed.

73   A review by Sallnow et al. (2016) included different examples of new public health approaches

74 to palliative care and concluded that involving communities can result in decreased fatigue and social

75 isolation for those caring for people at the end of life and an increase in the size of caring networks, and

76 that it can influence place of death and the involvement of palliative care services.[4] A recent literature

77 review by Librada et al. (2020) on compassionate communities and cities concluded that there is very

78 little evidence about their development and that assessment models are lacking because no models

79 have been thoroughly evaluated.[10] The authors chose not to apply specific definitions for

80 compassionate communities or cities and thereby included initiatives with a less specific focus. The

81 published review provides hardly any insight into contextual characteristics, the different elements of

82 the process development, the main domains of activity in terms of the action areas of the Ottawa Charter

83 or on results from the evaluations of the programmes. Nevertheless, insight into these aspects seems

84 essential if a review is to motivate and inform further development and evaluation of compassionate

85 community and city programmes. In order to encompass all compassionate community and city

86 initiatives that cover a demarcated area we will use the term "Area-Based Compassionate

87 Communities". We aimed to conduct a systematic integrative review to address the following research

88 questions:

89

90   1.   What are the contextual characteristics (i.e. geographical demarcation, number of inhabitants,

91   funding) of Area-Based Compassionate Communities?

92   2.   What is reported regarding the development processes of Area-Based Compassionate

93   Communities?

94   3.   How have Area-Based Compassionate Communities been evaluated and what are the reported

95   results of this evaluation?

Methods

Protocol registration, review design, reporting guidelines

We performed a systematic integrative review which permits the processing of diverse types of data sources, in this case peer reviewed articles and grey literature (i.e. websites of included initiatives, documents and a book) to build a holistic understanding of a specific phenomenon: Area-Based Compassionate Communities. Furthermore, this type of review allows for the inclusion of theoretical literature (i.e. framework presenting or opinion articles).[11] We followed the six steps of the integrative review process as proposed by de Souza et al. (2010): Souza et al. (2010): (1) formulate purpose and/or review question(s), (2) systematically search and select literature, (4) analysis and synthesis, (5) discussion and conclusion, (6) dissemination of findings. We explain further why we did not perform step (3) quality appraisal.[12] Due to the complexity of combining diverse study designs in a review, we decided to apply a rigorous methodology typical of systematic reviews to a heterogeneity of studies. This review can be regarded as a systematic integrative review because we make use of different data sources and apply a synthesis which is drawn up in a table and narratively described.[11] This review has been registered in Prospero (CRD42020173406). We used Prisma guidelines for reporting of results as advised by Toronto and Remington (2020).[11]

Search methodology

We produced a list of synonyms for the most commonly used terms for *Area-Based Compassionate Communities.* We did this to make sure no articles would be missed. 'Kellehear' was added as a search term because many, though not all, articles on compassionate communities and cities are based upon the compassionate city model as described by Kellehear and thereby refer to the author in their text. The applied search string was consulted on with a librarian, tested in Pubmed and translated to the other databases. A search in all databases was performed October 6, 2021. We made an overview of findings per database in tables in Microsoft Excel.

Pubmed applied search string:

123 ((("compassionate communities"[Title/Abstract] OR "compassionate community"[Title/Abstract] OR

124 "compassionate cities"[Title/Abstract] OR "caring communities"[Title/Abstract] OR "caring

125 community"[Title/Abstract] OR "new public health approach"[Title/Abstract] OR "public health palliative

126 care"[Title/Abstract] OR "community participation"[Title/Abstract] OR "community

127 engagement"[Title/Abstract] OR "health promoting palliative care"[Title/Abstract]) AND (palliative* OR

128 hospice* OR terminal* OR "end-of-life" OR bereave*)) OR Kellehear) AND ("1999/01/01"[PDat] :

129 "3000/12/31"[PDat])

130

Information sources

132   The information sources consulted are described by referring to the search methods used to

133 obtain the used articles. We first performed a search of the peer reviewed literature by consulting the

134 following databases until October 6th 2021: Pubmed, Web of Science, PsycInfo, Embase and Scopus.

135 To find more information in peer reviewed literature we then used a snowball method by hand searching

136 the reference lists of the publications found.[13] Finally, we performed a grey literature search to find more

137 information on the Area-Based Compassionate Communities covered by screening their websites and

138 by emailing the corresponding author of every included article (July 2020) and asking them to provide

139 additional information on the compassionate community or city described in the article. If after two

140 weeks no response was obtained, they were contacted again together with the second author. If this

141 did not result in a response, no further steps were taken.

142

Eligibility criteria

144   We included the article if the described initiative:

145 (A) related to a geographically defined community and comprised a city/municipality or a group of

146   cities/municipalities, and

147 (B) was constructed in or after 1999, the date of publication of the book Health Promoting Palliative

148 Care by Allan Kellehear that introduced the principles, and

149 (C) applied at least one of the five action areas of the Ottawa Charter for Health Promotion[3,8], and

150 (D) focussed on themes related to serious illnesses, dying, death and/or bereavement, and

151 (E) was covered in an article published in English.

153 We excluded articles that described an Area-Based Compassionate Community that was (A) limited to

154 the functioning of a single service-led initiative or (B) aimed at specific subgroups as opposed to the

155 whole population and (C) if it could not be established, based on the published information, whether the

156 described project was in fact an Area-Based Compassionate Community.

157

Study selection process

159 All obtained articles were downloaded from each respective database and then uploaded into

160 Rayyan QCRI, a systematic review application tool which allows for the automatic removal of

161 duplicates.[14] The included articles were imported into Zotero reference manager, together with all other

162 references used in this review. The process of study selection is visualised in a Prisma flow chart *(Figure*

163 *1).* Once the articles were imported into Rayyan QCRI, all duplicate articles were removed. Then they

164 were screened on title and abstract using the in- and exclusion criteria first, after which a full text

165 analysis was performed on all included articles. This process was performed independently for all

166 articles by two authors (BQ and LDEE). If disagreements about the inclusion of an article arose, we

167 attempted to reach an agreement. If no agreement was reached, a third researcher (TS) made the final

168 decision. Reasons for the exclusion of articles were documented.

169

Data collection process

171 A data extraction form in the format of the tables in this review was developed prior to data

172 collection and its applicability was tested on one study. The first author extracted data from the articles

173 to answer the research questions on:

174 (1) contextual characteristics: country, geographical demarcation, number of inhabitants, initiator,

175 funding, reason for initiation, start date and continuation of the Area-Based Compassionate

176 Communities;

177 (2) characteristics of the development process: aim of the Area-Based Compassionate Communities,

178 development process mentioned, building public policies, creating supportive environments, developing

179 of personal skills, strengthening community action and reorienting healthcare services;

180 (3) characteristics of the evaluation of the Area-Based Compassionate Communities: whether the

181 initiative was evaluated or not, what was evaluated and reported results.

182

183   The data was directly entered into the data extraction form in order to give a clear overview of

184 the answers for each research question. We were as elaborate as possible in order not to miss any

185 information and with the idea of retaining what is most important later in the process. The tables shown

186 in this review are therefore a collection of the most relevant findings from the data extraction. The data

187 extraction was repeated by a second researcher (LDEE) for 20% of the included articles. Discrepancies

188 were discussed and if no agreement was obtained, they were discussed with a third researcher (TS) to

189 make the final decision. Once this was done, all extracted data in the tables were imported into NVIVO,

190 a qualitative data analysis programme which allows performance of a thematic analysis on the data.

191 We started by reading through all the data and constructing initial codes inductively. Next, similarities

192 and differences between the initial codes were sought and grouped together and common codes were

193 formed where possible and inserted into the tables.

194

195 # Results

196 **Study selection**

197   The peer reviewed search resulted in 1464 articles. Out of these, 556 duplicates were removed.

198 This resulted in 908 articles of which 113 met the eligibility criteria and were included for full text

199 screening. Ninety-two articles were excluded and 21 were included. There was an initial disagreement

200 about 24 articles between BQ and LDEE; after discussion 20 disagreements were resolved. The four

201 remaining disagreements were discussed with a third reviewer (TS) to reach a final decision (all were

202 excluded). The most common reasons for exclusion were that the article focused on a single service

203 initiative, was a conference abstract or the Area-Based Compassionate Communities aimed at

204 subgroups (e.g. people with dementia, people in the LGBT community). The 21 included articles discuss

205 a total of 22 individual Area-Based Compassionate Communities. By screening the references of the

206 included articles, we included two additional articles on already-included Area-Based Compassionate

207 Communities. The grey literature search resulted in an additional three articles, all on already-included

208   initiatives. Fourteen authors were contacted for additional documentation of whom eight replied. For

209   one article, we could not identify any authors' contact details.[15] This process resulted in a total of 26

210   included articles on 22 Area-Based Compassionate Communities *(Table 1)*. A short summary of results

211   is shown in the Prisma flow chart *(Figure 1)*. We did not perform a critical appraisal of the included

212   articles for the following reasons: (A) only a minority of the included articles has some empirical

213   evidence and since evidence was only a partial focus of this review, all were included and equally

214   analysed, (B) we included articles based on their relevance to the research questions, not their critical

215   appraisal scores and (C) information was sometimes extracted from parts of the article such as the

216   result or introduction section, a critical appraisal about the article as a whole was less relevant.

217

218   ## Context

219   Fourteen of the 22 included Area-Based Compassionate Communities were located in high

220   income countries.[16–27] The other eight were located in upper middle-income[15,18,28] or lower middle-

221   income countries.[29] Of the included initiatives, eleven are in Europe,[17–24] six in South America,[18,28] two

222   in Oceania (Australia),[25,26] one in Asia (India),[29] one in North America (Canada)[27] and one in Africa

223   (South Africa) *(Figure 2)*.[15] Fifteen of the Area-Based Compassionate Communities can be regarded

224   as an individual town or city,[15,17–19,21,25,28] six as a larger administrative demarcated area such as a

225   country or state[20,22–24,27,29] and one as a group of towns or cities.[26] The number of citizens living in the

226   Area-Based Compassionate Communities varied between 3,000-100,000,[17–19,21,24,26,28,30] 100,000-

227   500,000[18,25,27] and >500,000.[15,18,20,22,23,29]

228   Reasons mentioned for developing an Area-Based Compassionate Community programme

229   were diverse but often fell under one or both of the following two major categories: 1) gaps in current

230   healthcare system (e.g. the need for an integrated healthcare system,[17,18,22,27,30] limited

231   resources,[18,25,27] general mentioning of gaps,[18,27] people's complex care needs,[17,21,25,27] having a

232   limited populational palliative care coverage[15,20,28–31] and to unburden the healthcare system[25–27]) or 2)

233   societal challenges (e.g. to strengthen community action,[7,18,19,23,26,27,29,32,33] having an ageing

234   population,[18,25–27,34,35] to normalise palliative care in society[7,20,23] and to address loneliness).[24,32] With

235   the exception of three Area-Based Compassionate Communities,[15,25,29] all were created in or after

236   2011 *(Table 2)*.

237

Aims and ambitions

239   Most Area-Based Compassionate Communities had multiple aims (*Table 3)*. The overarching

240 aims (explicated or inferred) were to improve public health in all the included initiatives, to achieve

241 better end-of-life care at population level in most cities[17–20,22–24,26–29,36] which was sometimes

242 attempted by increasing access to palliative care,[17–19,26–30] to change cultural attitudes,[17–19,23,24,26,37] to

243 build community capacity[19,20,23,25,26,29,38] or to educate the population on the end of life (e.g. by

244 informing people on legal, medical or financial issues associated with the end of life).[22,23,37] Another

245 aim was to promote community action by providing end-of-life care by the community[17,18,20,22,24,26,29,38]

246 and the development of a volunteer programme.[18,25,29,31,39] Other mentioned aims were to create an

247 integrated healthcare system[7,17–21,28] or to change policies.[23,40]

248

Development process

250 **Inputs**

251   For some of the Area-Based Compassionate Communities, information was provided about

252 their development process[7,17–19,21,22,24,25,36,41] albeit never extensively. The development of the Area-

253 Based Compassionate Communities was initiated by three main groups *(Table 2)*: healthcare oriented

254 governmental and/or non-governmental organisations,[7,15,18,19,21–25,27,29–32,35,36,41] academic

255 researchers[7,15,17,19–21,26,34,38,40] or policy makers.[18,19,41] Funding for Area-Based Compassionate

256 Communities came from five major sources, where different sources for funding are sometimes

257 combined: crowd,[15,17,18,22,24,26,29,31,39] non-profit organisation,[18,19,23] government,[17,21,23,25–29,35,39]

258 healthcare institution[21,22,24] or research.[17,20] All Area-Based Compassionate Communities involved

259 other organisations in their development where sometimes these organisations were healthcare

260 institutions.[17–19,21–23,25,28–30,33,41] Other external partners were policy makers[17–20,23–29,31,35] and all Area-

261 Based Compassionate Communities, with the exception of two initiatives from *Todos Contigo,*[18]

262 explicitly mentioned the involvement of lay people. In some cases volunteers were involved in the

263 project.[15,17,18,21–27,29,31,35,39,41] At the time of data collection, four of the initiatives had terminated, all

264 because they were initiated as part of a pilot project which had ended.[19,21,22,25] For one initiative, we

265 could not determine whether it was still ongoing or not.[15]

266

Outputs

268   The development activities could be classified according to the five action areas of the Ottawa

269 Charter for Health Promotion *(Table 3)*. In terms of the action area *'building healthy public policies'*,

270 Area-Based Compassionate Communities mentioned the public endorsement of the project by policy

271 makers (e.g. mayor presents the project)[17–19,23,25,28,29,41,42] and policy adaptations.[18,23,25,27–29,41,42] For

272 the action area *creating supportive environments*, some Area-Based Compassionate Communities

273 organised activities to strengthen a person's social networks (e.g. training family members in basic

274 personal care),[18,19,21,23,25,26,28,29,32,34,41,43,44] to create an integrated healthcare system (e.g. making an

275 overview of existing healthcare providers and signposting patients to designated services),[15,21–24,27]

276 and to influence people's social determinants of health (e.g. interventions to improve patients'

277 financial problems)[21,23,29,45] and to focus on underserved groups (e.g. events with

278 prisoners).[20,22,23,34,40,46] The action area *developing personal skills* was realised by activities to engage

279 the community around end-of-life related themes which was mentioned for all Area-Based

280 Compassionate Communities (e.g. palliative care information seminar or talking café where people

281 could be signposted to designated services), or by centralising resources (i.e. by increasing access to

282 resources and information people gain more control over the choices they make).[19,21,23–25] The action

283 area *strengthening community action* is achieved by giving ownership to the community (e.g. local

284 initiatives organised by the community so that the Area-Based Compassionate Community becomes

285 self-sustainable).[15,19–26,29,31,36,39] Other strategies mentioned were supporting the community to

286 undertake action[15,17,19,23–26,28,29,31,32,39,41] or connecting organisations.[18,20,21,23,25–27,32,35,37,39,47] The last

287 action area, *reorienting healthcare services*, was sometimes accomplished by training healthcare

288 workers[18–20,22–25,29–31,35] or by applying preventive instead of reactive measures (e.g. healthcare

289 workers stimulating people to make use of their social networks instead of fully relying on professional

290 services).[18,20,21,25,26,46] For the Soweto and the WECCC initiatives, nothing was mentioned with regard

291 to this action area.[15,27]

292

Evaluation and outcomes

293

294   For ten of the 22 Area-Based Compassionate Communities, some form of evaluation was

295   mentioned *(Table 4)*. Sometimes the initiative was evaluated using a combination of quantitative and

296   qualitative methods (Vic, GLGDGG, Hume and The Hills),[17,23,25,26] such as the realist evaluation of

297   The Hills using mixed methods,[42] or using quantitative methods only (TC Sevilla, Frome, NNPC, and

298   WECCC)[21,27,29,43,49] such as the retrospective cohort study of unplanned hospital admission data used

299   to evaluate Frome.[21] Two Area-Based Compassionate Communities (Döbra and Inverclyde) were

300   evaluated using qualitative methods only.[24,34] For some cases, the project's outcomes were

301   evaluated.[18,21,24,25,27,29] For seven Area-Based Compassionate Communities, the generated outputs

302   (i.e. activities) within the Area-Based Compassionate Community[17,21,23–25,31,34] and/or the process of

303   development were evaluated.[17,24,25] For only two (Inverclyde and Hume), the outcomes of the initiative

304   as well as the process of development were evaluated.[24,25] For another two Area-Based

305   Compassionate Communities, the studies reported on whether their aims were actually achieved.[21,25]

306   For The Hills and WECCC, no results from the evaluation were reported.[26,27] Sometimes reported

307   results were not specific or without adequate explanation, such as "the compassionate city has many

308   strengths in areas which will lead to a positive social return on investment",[50] or "some areas (media,

309   schools) are not reached by the project",[17] or one case where an increase in social media activity was

310   reported while at the same time arguing for more social media activity.[51] Examples of what has been

311   evaluated can be seen in *Table 5.*

Discussion

Main findings

This systematic integrative review identified 22 Area-Based Compassionate Communities initiatives and found considerable variability in their contextual and developmental characteristics and a lack of information on their evaluations. Area-Based Compassionate Communities are located in all continents, but most are in Europe and South America. There were differences, among others, in geographical demarcation, number of inhabitants targeted, sources of funding and in the specific social actions that they developed. However, all Area-Based Compassionate Communities were initiated to address similar gaps in the healthcare system or challenges in society and all aimed to improve public health. All Area-Based Compassionate Communities focused on multiple action areas of the Ottawa Charter. Some form of evaluation was reported for only a few initiatives and studies rarely evaluated on whether the original aims were actually met.

Commonalities and differences

Our study shows that there is substantial variability in the contextual characteristics of Area-Based Compassionate Communities, but that they also share some important similarities. Although we found Area-Based Compassionate Communities existing all around the world, they were generally developed in the last decade, and are thus a very recent form of social innovation in healthcare and palliative care. The main reason for initiating an Area-Based Compassionate Community was to address existing gaps in the healthcare system or societal challenges such as challenges related to an ageing population. They also all aimed to improve public health and more specifically to achieve better population end-of-life care. This is not surprising since healthcare systems around the world are facing similar challenges in the provision of palliative care to their populations.[52–55] Literature and studies have demonstrated that health provision through community engagement together with professional healthcare services can be successful in alleviating stressed healthcare systems.[1,2,4,56–58] The majority of Area-Based Compassionate Communities were initiated by healthcare oriented governmental or non-governmental organisations (e.g. palliative care service, hospital, local health and wellbeing service), which is not surprising because of the movement's focus on palliative care. All

1   Area-Based Compassionate Communities focused on multiple pillars of the Ottawa Charter and

2   although similarities were found (e.g. involvement of schools, local organisations, the media,

3   politicians), the specificities of local actions differed greatly between initiatives. Given the variability in

4   the characteristics of Area-Based Compassionate Communities and the movement's relatively

5   embryonic existence, it is unclear which specific characteristics pave the way to successful Area-

6   Based Compassionate Communities.

7   For most, but not all, Area-Based Compassionate Communities, some information about the

8   development process was provided, but never extensively. However, a commonality in the

9   development process seems to be that the initiators seek support for the project from policy makers

10   who publicly endorse the project and whose influence can be used to allocate funding. Furthermore,

11   attaining political support is likely to facilitate the creation of networks i.e. political, professional, social

12   or cultural, which would otherwise be more difficult to establish. This finding does not come as a

13   surprise as many of the aims formulated by Area-Based Compassionate Communities (e.g. better

14   end-of-life care for the population, the creation of an integrated healthcare system) imply the need for

15   political support, something community development projects can hardly do without.[59,60] The fact that

16   most Area-Based Compassionate Communities have been initiated only in the last decade may also

17   explain why we found the involvement of policy makers to be a recurrent element: the first years of

18   development are generally characterised by searching for support and funding, establishing a leading

19   coalition for the project and defining its long-term aims.

20   We found strengthening social networks to be a recurring community engagement strategy in

21   multiple Area-Based Compassionate Communities. Studies have shown that having adequate social

22   networks is strongly related to an increase in quality of life, that the use of these networks may have

23   more positive outcomes than the use of professional services,[61] and that having adequate social

24   networks may lead to a reduction in health service costs.[62] Since Kellehear (2005) highlighted that the

25   potential for improved health provision should be sought in the community, it is not surprising to see

26   Area-Based Compassionate Community developers putting this into practice.[6] The current COVID-19

27   pandemic challenges activating and expanding such social networks due to many countries applying

28   social restrictions. Finding a balance between adhering to local pandemic regulations, which often

limit social contacts, while at the same time broadening these networks is a difficult task but examples

in literature exist (e.g. remote befriending using technology).[63–65]

Thorough evaluations are lacking

This review shows that there is a lack of scientific evaluation of Area-Based Compassionate Communities. Only a minority of existing Area-Based Compassionate Communities have been formally evaluated, possibly because initiators may not always have an interest in research but focus mainly on the process of development of the initiative. For those that have undergone some form of evaluation, the conclusions about their impacts have mainly been positive, but the domains and outcomes evaluated often did not match the original individual aims. Evaluators often seem to opt for an evaluation of the short-term effects of specific social actions rather than the long-term impacts of the Area-Based Compassionate Communities as a whole. It may also be that the aims of the initiative were not formulated specifically enough, which complicates the evaluation of whether desired outcomes have been achieved. Furthermore, the methodological background provided on how evaluations were performed is insufficient. The absence of rigorous evaluation methods for these types of new public health interventions further hampers evaluation studies and the assessment of the success of the individual initiative. Our findings confirm the gaps that exist in proving the efficiency of specific community engagement programmes in realising better health outcomes or behaviours.[10,56,58]

Regarding future evaluations, we argue that there is a strong need for transparent process and outcome evaluations in order to better understand which elements are crucial in the development of Area-Based Compassionate Communities in order to realise better health outcomes or behaviours and to demonstrate whether they achieve the impacts to which they aspire. We would promote the use of mixed-method study designs in compassionate city/community evaluations in which a survey is used in combination with qualitative data collection techniques to capture societal and/or cultural changes over a period of time. Interviews, observations and focus groups may be useful for future process evaluations but researchers should consider non-traditional qualitative data collection techniques (e.g. photovoice or the Most Significant Change technique) which may provide rich and diverse data on such a complex intervention.[66,67] The researchers of this review are currently working

on a research protocol for the evaluation of an Area-Based Compassionate Community which they aim to publish in the future.

Implications of findings for policy and practice

Although progress in end-of-life care provision differs greatly between and within countries and regions, we have shown that every initiative stemmed from individual priorities and needs and could therefore benefit from the expansion or initiation of palliative care delivery. This conclusion, together with the finding that some actions in Area-Based Compassionate Communities were positively evaluated, can motivate policy makers to invest in Area-Based Compassionate Communities. Emphasis should be put on training healthcare workers in the adequate provision of palliative care who then operate together with an informed community which acknowledges its own potential to decrease the burden on local healthcare systems.

Strengths and limitations

This review was the first to compare Area-Based Compassionate Communities in terms of their characteristics, development and evaluation. By applying a combination of peer reviewed studies, grey literature and the snowball method we were able to provide in-depth information about the initiatives. However, this review also has some limitations. No projects and publications on Area-Based Compassionate Communities were found in low-income countries, where palliative and other healthcare services are often un- or under-developed and health inequality is high.[68–70] This finding however may also be attributed to language and publication biases.[71] This review was limited to publications in English while many more Area-Based Compassionate Communities may exist of which no information has ever been published in peer reviewed journals in English. Furthermore, several authors of included articles could not be contacted, making it likely that we missed some of the existing grey literature. Although we applied a systematic methodology, the presence of data collection bias as well as interpretation bias can not be ignored.

A recently published review by Librada et al. (2020) also described a number of Area-Based Compassionate Communities but had a clear focus on their implementation models. Our review, through its use of an operational definition of an Area-Based Compassionate Community, is more

complete and more specifically focused on Area-Based Compassionate Communities and their

characteristics.[10] Because we made use of grey literature we were able to add additional information

which proved useful especially in finding examples focusing on the pillars of the Ottawa Charter.

Lastly, we provided in-depth information on the evaluations by looking at what is evaluated in specific

Area-Based Compassionate Communities.

What this review adds/conclusion

While the concept of Area-Based Compassionate Communities is gaining momentum as a

new paradigm for the creation of palliative care capacity across society, this review showed that only

a handful of initiatives have been described in the last decade and only a minority underwent some

form of evaluation. Because of the scarce description of existing initiatives in the literature, it remains

unclear which elements are essential to success and which, if any, model yields the best results. The

lack of formal evaluations of the proclaimed health benefits of Area-Based Compassionate

Communities indicates a pressing need for rigorous research about ongoing and future initiatives to

assess whether these benefits are realised. These evaluations can be used to inform and convince

various actors and organisations to support the development of Area-Based Compassionate

Communities.

Declarations

Authorship

All authors contributed to the concept of this article, the study design and the analysis and

interpretation of the data. BQ, LDEE and TS performed study selection. BQ and LDEE performed

data extraction. BQ and TS drafted this article with the other authors revised and eventually approved

the final version.

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4   **Conflict of interest**

5   The authors declare that there is no conflict of interest.
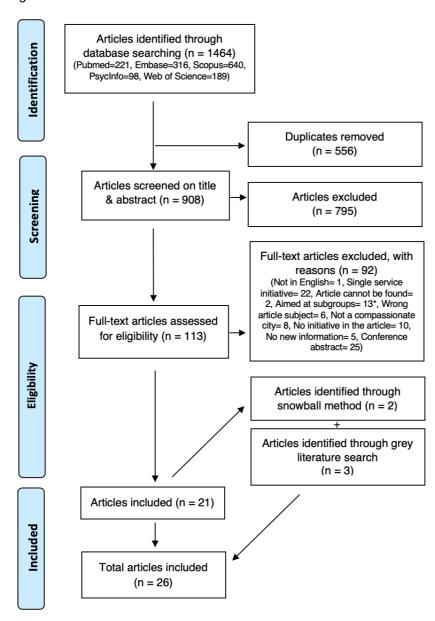
6

7   **Ethics and consent**

8   Not applicable.

9

10   **Data management sharing**

11   The datasets used and/or analysed during the current study are available from the corresponding

12   author on reasonable request.
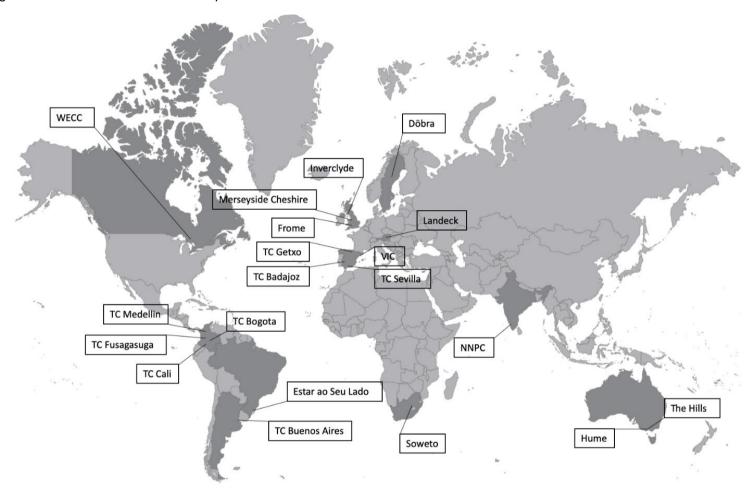
1   Figures

2   *Figure 1: Prisma flow chart of article selection.*

3

4   **e.g. persons with dementia, people in the LGBT community*

1   *Figure 2: Location of Area-Based Compassionate Communities**

2

3   **Figure made through a freely available online software tool*

Tables

Table 1: List of included articles.

Initiative	Articles
Vic	1. Compassionate communities: design and preliminary results of the experience of Vic (Barcelona, Spain) caring city.[17]
TC Sevilla	2. All with You: a new method for developing compassionate communities—experiences in Spain and Latin-America.[18] 3. Development and Management of Networks of Care at the End of Life (the REDCUIDA Intervention): Protocol for a Nonrandomized Controlled Trial.[43]
TC Badajoz	2. All with You: a new method for developing compassionate communities—experiences in Spain and Latin-America.[18]
TC Getxo	
TC Pamplona	
Landeck	4. Caring communities as collective learning process: findings and lessons learned from a participatory research project in Austria.[19] 5. 'Ingredients' of a supportive web of caring relationships at the end of life: findings from a community research project in Austria.[44]
Döbra	6. Going public: reflections on developing the DöBra research program for health-promoting palliative care in Sweden.[20] 7. Navigating power dynamics in engaging communities in end-of-life issues – Lessons learned from developing community-based intergenerational arts initiatives about death and loss.[37] 8. Developing and using a structured, conversation-based intervention for clarifying values and preferences for end-of-life in the advance care planning-naïve Swedish context: Action research within the DöBra research program.[46] 9. Death, loss and community—Perspectives from children, their parents and older adults on intergenerational community-based arts initiatives in Sweden.[34]
Frome	10. Reducing emergency hospital admissions: a population health complex intervention of an enhanced model of primary care and compassionate communities.[21]
Merseyside and Cheshire	11. End-of-life conversations and care: an asset-based model for community engagement.[22]
GLGDGG	12. Health-promoting palliative care: a Scottish perspective.[35] 13. Scotland's public health palliative care alliance.[23] 14. To Absent Friends, a people's festival of storytelling and remembrance.[32]
Inverclyde	15. Compassionate communities and collective memory: a conceptual framework to address the epidemic of loneliness.[24]
Hume	16. From concept to care: Enabling community care through a health promoting palliative care approach.[25] 17. Bereavement care for the non-bereaved: A health promotion challenge.[47]
The Hills	18. Healthy End of Life Project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia.[42] 19. Choice depends on options: A public health framework incorporating the social determinants of dying to create options at end of life.[26]
NNPC	20. Home-based palliative care in Kerala, India: the Neighbourhood Network in Palliative Care.[29] 21. Kerala, India: A Regional Community-Based Palliative Care Model.[31] 22. Neighborhood network in palliative care.[39]
TC Medellin	2. All with You: a new method for developing compassionate communities—experiences in Spain and Latin-America.[18]
TC Cali	
TC Fusagasuga	
TC Bogota	
TC Buenos Aires	
Estar ao Seu Lado	23. Palliative care for all? How can Brazil develop a palliative care service founded on principles of equity and access for all?[28] 24. Brazil: time for palliative care in the community![30]
WECCC	25. Unpacking 'the cloud': a framework for implementing public health approaches to palliative care.[27]
Soweto	26. The Soweto care givers network: Facilitating community participation in palliative care in South Africa.[15]

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Table 2: Contextual characteristics of the Area-Based Compassionate Communities.

Characteristic			Vic	TC Sevilla	TC Badajoz	TC Getxo	TC Pamplona	Landeck	Döbra	Frome	Merseyside Cheshire	GLGDGG	Inverclyde	Hume	The Hills	NNPC	TC Medellin	TC Cali	TC Fusagasuga	TC Bogota	TC Buenos Aires	Estar ao Seu Lado	WECCC	Soweto	Total
Country			Spain	Spain	Spain	Spain	Spain	Austria	Sweden	England	England	Scotland	Scotland	Australia	Australia	India	Colombia	Colombia	Colombia	Colombia	Argentina	Brazil	Canada	South Africa	
Geographical demarcation		Town or city	X	X	X	X	X	X		X				X			X	X	X	X	X	X		X	15 68%
		Larger administrative demarcated area							X		X	X	X		X								X		6 27%
		Group of towns or cities														X									1 5%
Number of inhabitants		3,000-100,000	X			X		X		X			X		X							X			7 32%
		100,000-500,000			X		X							X					X	X			X		6 27%
		>500,000		X					X		X	X				X	X	X			X			X	9 41%
Used inputs	Initiator	Healthcare oriented organisations (both governmental and non-governmental)		X		X	X	X		X	X	X	X	X		X	X	X	X	X	X	X	X	X	18 82%
		Academic researchers	X					X	X	X					X									X	6 27%
		Policy makers			X		X																		2 9%
	Funding	Crowd	X	X	X	X	X			X			X			X	X	X	X	X	X			X	14 64%
		Non-profit organisation		X	X	X	X	X					X				X	X	X	X	X				11 50%
		Government	X							X	X	X	X	X								X	X		8

Reason for initiation																									n / %
																									36%
		Healthcare institution								X	X		X													3 *14%*
		Research	X						X																	2 *9%*
	Involving external partners	Organi-sations	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	22 *100%*
		Lay people	X	X	X			X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	20 *91%*
		Volunteers	X	X			X			X	X	X	X	X	X	X	X	X			X	X		X	X	16 *73%*
		Policy makers	X	X	X	X		X	X			X	X	X	X	X				X			X	X	14 *64%*
		Healthcare institutions	X		X		X	X		X	X	X		X		X							X		10 *45%*
	Gaps in current health-care system	The need for an integrated healthcare system	X	X	X	X	X					X						X	X	X	X	X	X		12 *59%*
		Limited resources		X	X	X	X						X			X	X	X	X	X		X		11 *50%*
		General gaps		X	X	X	X									X	X	X	X	X		X		10 *45%*
		People's complex care needs	X							X			X										X		4 *18%*
		Having a limited populational palliative care coverage							X							X						X		X	4 *18%*
		Unburden the healthcare system												X	X								X		3 *14%*
	Societal chall-enges	Strengthen community action		X	X	X	X	X				X			X	X	X	X	X	X	X		X		15 *68%*
		Having an ageing population		X	X	X	X		X			X		X	X		X	X	X	X	X		X		14 *64%*
		Normalise palliative						X	X			X													3 *14%*

		2016	2015	2015	2017	2017	2013	2013	2014	2011	2011	2017	2003	2018	2001	2015	2015	2016	2017	2016	2014	2014	2001	
	care in society																							
	Address loneliness										X	X												2 *9%*
	To lower unplanned hospital admissions								X															1 *5%*
Start date		2016	2015	2015	2017	2017	2013	2013	2014	2011	2011	2017	2003	2018	2001	2015	2015	2016	2017	2016	2014	2014	2001	
Continuation of the compa-ssionate city	Ongoing	X	X	X	X	X		X			X	X		X	X	X	X	X	X	X	X	X		17 *77%*
	Ended (because of ending of the Area-Based Compassionate Community pilot project)						X		X	X			X											4 *18%*

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Table 3: Characteristics of the development processes of the Area-Based Compassionate Communities.

Initiative / Characteristic	Vic	TC Sevilla	TC Badajoz	TC Getxo	TC Pamplona	Landeck	Dóbra	Frome	Merseyside Cheshire	GLGDGG	Inverclyde	Hume	The Hills	NNPC	TC Medellin	TC Cali	TC Fusagasuga	TC Bogota	TC Buenos Aires	Estar ao seu Lado	WECCC	Soweto	Total
Aim of the Area-Based Compassionate Community — To improve public health	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	22 *100%*
Better population end-of-life care — General mentioning	X	X	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X	X	X	X		20 *91%*
Better population end-of-life care — Increase access to palliative care	X		X	X		X	X					X								X	X		8 *36%*
Better population end-of-life care — Reduce avoidable suffering							X																1 *5%*
To change cultural attitudes	X	X				X	X				X	X		X									8 *36%*
To build community capacity — General mentioning						X	X				X	X	X	X									6 *27%*
To build community capacity — Population end-of-life education						X			X	X													3 *14%*
To promote community action — End-of-life care provided by the community	X	X					X		X		X		X	X									7 *32%*
To promote community action — Volunteer programme												X		X	X								3 *14%*
To create an integrated healthcare system	X	X				X	X	X												X			6 *27%*
To change policies							X			X													2 *9%*
Development process mentioned — Something mentioned	X	X	X	X	X	X		X	X		X	X			X	X	X	X	X				15 *68%*
Nothing mentioned							X			X			X	X						X	X	X	7 *32%*
Extensively mentioned																							0
Outputs categorised according to the Ottawa Charter for Health Promotion action areas																							
Building healthy public policies — Public endorsement of the project by policy makers	X	X		X		X			X		X	X	X							X			9 *41%*
Policy adaptations									X		X	X	X			X				X	X		7 *23%*

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	n / %
	Nothing mentioned						X			X	X							X	X		X	X	X	8 / *36%*
Creating supportive environ-ments	To strengthen social networks		X			X	X	X	X		X		X	X	X	X	X				X	X		13 / *59%*
	To create an integrated healthcare system							X	X	X	X											X	X	6 / *27%*
	To influence people's social determinants of health							X		X			X									X		4 / *18%*
	To focus on underserved groups						X		X	X														3 / *14%*
Developing personal skills	By engaging the community	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	22 / *100%*
	By centralising resources						X		X	X	X	X												5 / *23%*
Streng-thening community action	By supporting the community to undertake action	X				X	X			X	X	X	X	X	X	X	X					X	X	13 / *59%*
	By giving ownership to the community				X		X	X	X	X	X	X	X	X	X								X	11 / *50%*
	By connecting organisations			X			X	X		X			X				X					X		7 / *32%*
	Nothing mentioned			X	X	X											X							4 / *18%*
Re-orienting healthcare services	By training healthcare workers		X	X	X		X	X		X	X	X	X		X	X	X	X	X	X	X			16 / *73%*
	By applying preventive instead of reactive actions		X				X	X				X	X											5 / *23%*
	Nothing mentioned																					X	X	2 / *9%*

¹The aims mentioned for the Todos Contigo movement were interpreted as common aims for every individual Area-Based Compassionate Community that is part of this movement.

1

Table 4: Characteristics of the evaluation of the Area-Based Compassionate Communities.

Characteristic			Vic	TC Sevilla	TC Badajoz	TC Getxo	TC Pamplona	Landeck	Döbra	Frome	Merseyside Cheshire	GLGDGG	Inverclyde	Hume	The Hills	NNPC	TC Medellin	TC Cali	TC Fusagasuga	TC Bogota	TC Buenos Aires	Estar ao seu Lado	WECCC	Soweto	Total
Evaluated?	Yes	Quantitative	X	X						X		X		X	X	X							X		7 32%
		Qualitative	X						X			X	X	X	X										6 27%
	Not mentioned				X	X	X	X			X						X	X	X	X	X	X		X	12 55%
What was evaluated?	Project outcomes			X						X		X	X			X							X		5 23%
	Generated outputs		X						X	X		X	X	X		X									7 32%
	Process of development		X									X	X												3 14%
If evaluated, are any results reported?	Yes		X	X					X	X		X	X	X		X									8 36%
	No														X								X		2 9%

1

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Table 5: Evaluated Area-Based Compassionate Communities and their reported results.

Initiative	Reported results
Vic	The project's first year of implementation was evaluated (including one output): -High participation by organisations, diverse activities developed by organisations. -Some areas are not activated (media, schools, trade unions,…) by the project. -Some organisations don't develop internal activities (variety in participation grade). -Multicultural visions need to be taken into consideration. -Plan for sustainability is needed. -Trainings scored positively by attendants. A semi-structured survey was distributed and 51 responses were obtained: The topics were considered relevant (3.67/4), the exposition was clear (3.75/4), the training was dynamic and participative (3.24/4), and time and dates were evaluated (3.51/4).
TC Sevilla	The project has planned an outcome evaluation but only preliminary results are reported:[18,43,49] -An increase in care and support networks of citizens participating in the project (from one person to an average of ten people involved in care). -A decrease in the emotional and physical overload of the main caregiver thanks to the creation of care and support networks, and improvement in the satisfaction of family members regarding the care provided in the programme. -An improvement in the quality of life, especially in the areas of anxiety, loneliness and depression in citizens. -It is possible to cover up to 70% of the total identified needs, reduce the loneliness of the beneficiaries of the process, decrease the overload of the caregivers involved in the care network, improve the quality of life of the beneficiaries (especially regarding pain, anxiety, and depression), and increase the degree of family satisfaction, by contributing together to the care of these people in this final stage of life.
Döbra	The project evaluated participants' and parents' reflections on intergenerational workshops:[34] -Participants motivations to participate in Studio Döbra -Participants' experiences of participating -Ways in which participation affected children, older adults and parents The results from this evaluation were divided into three themes with main reported findings: Findings indicate that participants acted as individuals with agency in connecting across generations and in creating spaces for engaging with End of Life-topics, not only in Studio DöBra but also in their social networks. Participants reflected on a changing sense of community through new intergenerational connections and social activities, and expressed a desire to maintain these. However, participants indicated sustainability challenges related to lacking agency in maintaining these spaces and sense of intergenerational community, as they rely on support from community organisations.
Frome	The project performed an outcome evaluation:[21] -Before the project, a not statistically significant trend showed an increase in unplanned hospital admissions in the intervention city and in its surrounding area over a five-quarter period, after the project, an increase in the number of unplanned hospital admissions in the area of the intervention city was recorded (+28.5%) while at the same time the intervention city recorded a significant decrease in unplanned hospital admissions (-14%). -Comparing data from 2013-2014 with data from 2016-2017, the intervention city recorded a reduction of 20.8% in cost for unplanned hospital admissions. The project focused on some generated outputs:[72] -Through *The Warwick-Edinburgh Mental Well-being scale* (a tool for monitoring mental well-being at a population level) it was assessed that 81% of the citizens making use of the service to strengthen their social networks had measurable improvements of their wellbeing. Through a patient feedback form distributed to citizens reached by the health connectors, it was assessed that 94% felt more able to manage their health and 95.6% said that they felt more able to access support in the community. -Through *The Patient Activation Measure* (an assessment tool of an individual's self-management competency) it was assessed that citizens making use of the service to strengthen their social networks on average increased on their knowledge, skill, and confidence for managing one's health and healthcare.
GLGDGG	The project focused on the outputs from different editions of an end-of-life themed festival:[32,51,73,74] -Increase in website use and social media activity. -All respondents to an online survey after the festival felt their activity promoted openness about death, dying and bereavement. -A large majority of event organisers felt they were helping people to find ways of dealing with their own experience of death, dying and bereavement and helping individuals or communities to support people through difficult times. -Fewer events were seen as helping NHS/social care/volunteers or helping people to make practical preparations although there were some events.

	-Most participants return to take part in subsequent years. -Feedback on experiences of the festival was overwhelmingly positive. -Community came through strongly when people were asked what aspects of the festival they found valuable. 62% said that "being part of a community" was one of the things they valued about the festival. In fact, there were a number of aspects of the festival that were rated valuable by a majority of the respondents. These included hearing the experiences of others (63%), having events to get involved with (53%), finding new ways to remember people (51%) and helping others (50%). 49% appreciated having a dedicated time to remember someone. Fewer people valued the festival as a way to meet others who'd experienced loss (19%) or to access bereavement resources (11%). Data obtained through an online survey. -Events that were best attended or particularly well-received were, in general, conceived and organised by one or two enthusiastic individuals, for a community of which they were part. The project also focused on some parts of the process of realising the end-of-life themed festival: -Though there is plenty of creativity and enthusiasm about participating in To Absent Friends, a barrier to participation can be money. In the current financial climate of extremely limited resources, providing just a small amount of money can provide the support an organisation needs to undertake something amazing within their local community. -People appreciate and use ideas and resources produced by the Scottish Partnership for Palliative Care and they acted as a catalyst for participation in the festival. -Dedicated staff time is valuable. Extra staff has increased social media activity and secured more publicity. -Local ownership is the key ingredient for success.
Inverclyde	The project expresses the desire to focus on outcomes:[75] -Reporting has affirmed the countless contributions of local people but has not attempted to attribute direct impact or estimate cost effectiveness. -The data gathered through the evaluation process to date highlights that it has many strengths in areas which will lead to a positive social return on investment (no further information provided). -Hospitalisation data (e.g. readmission to hospital within 28 days, delayed discharge) show a positive trend for Inverclyde, but proving causality is not (yet) possible. -The project reports increased skills and confidence in people, increased volunteering, greater satisfaction with quality of life in the neighbourhood amongst project helpers and those receiving acts of kindness and compassion (citizens). Some outputs are evaluated: -A programme to generate improved wellbeing was developed where participants had to self-assess their wellbeing. A pilot project with a group of carers where participants reported improved wellbeing scores, new friendships and feeling more confident. -Generally positive feedback on the self-assessment of wellbeing in pilot projects in different settings. The project mentions key aspects of their applied leadership (development process): -The type of leadership used: leadership that enhances the intrinsic motivation of people and reinforces their fundamental altruism. It helps promote a culture of learning where risk taking is accepted within safe boundaries, and where there's an acceptance that not all innovation will be successful. Diametrically opposite to cultures of blame and fear and bullying. -The functioning of the board (people who develop compassionate Inverclyde): Representation of volunteers is key; strong and decisive chairmanship which enables healthy debate and shared decision-making; establishing sub groups to execute made decisions, etc.
Hume	The project mentions some evaluated outputs:[76] -Practical skills for working with end-of-life issues were developed for many of the community members. -Sustainability of the community capacity in community members participating in the project has yet to be demonstrated long term; but the reflective thinking, equitable participation and shared knowledge emerging through the local projects are themselves marks of a sustainable community. -Many activities have developed skills in community members that contribute substantially to their local community's capacity to care for those in their midst living with loss and grief, or life-threatening illness. The project mentions some evaluated outcomes:[76,77] -Palliative care volunteer services in the Hume Region provided 14.8% of all patient contacts and 19.5% of all direct client contacts which is higher than the state average. -The leading team had been most effective in its task of promoting and supporting community development activities that have increased understanding and knowledge of dying, loss and grief in general, and palliative care in particular, across the region (not mentioned how this was evaluated). -Understanding of end-of-life issues in general and palliative care in particular was enhanced for community members who might otherwise not have come into contact with these resources. The project mentions lessons learned from their development process:[76] -Palliative care volunteer training can be delivered in local areas by local health professionals if a supportive structure is provided.

	-It takes time, effort and skill to effectively lead, manage and coordinate a palliative care volunteer service at the local, sub-regional and regional level and this should be financially recognised. -Education and training information on a public health approach to palliative care needs to be presented to health professionals and staff in an accessible way. -Community based projects sometimes asked for seed funding that otherwise would not have been readily accessible at the local level. Access to other traditional funding sources could then be supported by the identified needs and partnerships formed from this starting point. -Projects seeking smaller funding amounts were achievable for the applicant and community partnerships. The larger the project the more time consuming and unwieldy it became to manage. -The simplification of funding guidelines enabled community groups to be motivated to engage in an activity as they achieved the criteria with a minimum of red-tape. -The Big 7 Checklist was a significant and simple tool used to mentor and guide the development of health promoting palliative care activities, educate around a public health approach and promote a diversity of partnerships between community groups and the local specialist palliative care service and palliative care volunteer service. -How the objectives of the project are achieved is described in detail through 10 different strategies.
The Hills	Nothing mentioned.
NNPC	The projects mentions one evaluated output:[31] -The project expands into 'non-traditional' areas in palliative care (e.g., palliative care for patients with non-malignant conditions, including chronic psychiatric disorders). The project mentions one evaluated outcome:[31,39] -In Malappuram (district in Kerala), coverage of palliative and long-term care rose to 70% in 2 years' time. Within less than five years, the NNPC initiatives have resulted in the establishment of 68 community-based palliative care initiatives in northern and mid-Kerala, covering a population of more than twelve million; an estimated coverage of more than 70% in palliative care and long-term care in the region compared to a national average of around 1%. -Wayanad, Kozhikode and Thrissur (districts in Kerala) show the same steep upward trend in coverage.
WECCC	Nothing mentioned.

1

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