INTERNATIONAL JOURNAL OF COLLEGE OF PALLIATIVE MEDICINE OF SRI LANKA
abhittharetha kalyāṇe

REVIEW ARTICLE

DOI: 10.54448/jcpmsl23102

Compassionate communities and cities in low and middle-income countries: a systematic review protocol to identify transferrable lessons for implementation in the primary care context

Sashiprabha Dulanjalee Nawaratne[1]*, Jeremy Dale[1], John MacArtney[1], Sarah Mitchelle[2], Pauline Rimui[3], Katrin Hirtenlehner[3]

[1] University of Warwick, Unit of Academic Primary Care, Coventry, CV4 7AL, United Kingdom.
[2] University of Leeds, Division of Primary Care, Palliative Care and Public Health, Leeds LS2 9JT, United Kingdom.
[3] University of Warwick, Warwick Medical School, Coventry, CV4 7AL, United Kingdom.

*Corresponding author: Sashiprabha Dulanjalee Nawaratne, MBBS, MSc in Community Medicine, MD in Community Medicine, Visiting Research Fellow. Unit of Academic Primary Care, Division of Health Sciences, University of Warwick, Coventry, CV4 7AL, United Kingdom. Phone: +44 7442097829.
Email: sashiprabha.nawaratne@warwick.ac.uk
sdnawaratne@gmail.com

DOI: https://doi.org/10.54448/jcpmsl23102
Received: 06-04-2023; Revised: 08-06-2023; Accepted: 08-10-2023; Published: 08-14-2023; JCPMSL-id: e23102

Abstract

Introduction: Compassionate Communities are neighbourhood or village level organizations that addresses the holistic concept of health, physical, psychological, spiritual and social well-being. It is estimated that out of the 40 million individuals who require palliative care each year, 78 per cent reside in low- and middle-income countries. **Objective:** Compassionate Communities and Cities are based on a health promotion approach to palliative care, with the goal of supporting individuals in solidarity at the end of life. This systematic review aims to analyse Compassionate Communities and Cities initiatives in low- and middle-income countries to identify transferrable lessons for implementation in the primary care context. **Methods:** A comprehensive, search for studies indexed in Medline, EMBASE, PsycINFO, Web of Science and Scopus databases and grey literature will be conducted using an electronic search strategy. The search strategy will include terms (and synonyms) describing Compassionate Communities and Cities, palliative care and low- and middle-income countries. Article screening will be conducted in two rounds. First, a title and abstract screening will be conducted followed by a full-text screening. Article selection will be conducted by two independent reviewers. Studies or articles fulfilling the inclusion criteria will be evaluated using a data extraction form. Data on objectives, study population, study setting, study characteristics and outcomes will be independently extracted by two reviewers. The reviewers will independently assess the methodological quality of included studies. A narrative synthesis approach will be employed to summarise and explain the extracted data. **Results:** The systemic review will be carried out and documented in accordance with the Preferred Reporting Items for Systematic Reviews and MetaAnalyses. **Conclusions:** This systematic review will summarise the evidence and provide recommendations for the development and the implementation of Compassionate Communities and Cities approach in other low resource settings.

Keywords: Compassionate Communities. Compassionate Cities. Palliative Care. Low-and middleincome countries. Systematic review.

Introduction

Compassionate Communities are based on the World Health Organization concept of 'Healthy Cities' or 'Healthy Communities,' an earlier collection of public health ideals that nominally dates from the 1980s [1]. While it originates in Kerala, India in the 1990s [2], the theoretical framework for Compassionate Communities was drawn-up by Kellehear, who explained how health promotion ideas can be incorporated into palliative care [3]. Compassionate Communities combine health

promotion principles of the Ottawa Charter [4] (building healthy public policy, creating a supportive environment, strengthening community action, developing personal skills, and re-orientation of health services) to provide education, information and policy-making for health, dying, death and bereavement [5]. It is argued that palliative care can gain from health promotion in the same way that public health can benefit from the new awareness of how death and dying are not only palliative care issues, but also public health issues [6].

Compassionate Communities are neighbourhood or village level organizations that addresses the holistic concept of health, physical, psychological, spiritual and social well-being [7]. It highlights the importance of social capital, mutual aid relationships and citizens' ability to actively contribute to the growth of their communities, form social connections and care for one another [1]. Compassionate Cities are densely populated urban organizations [8] with more complex connections offering a wide range of support - educational, psychosocial, and policy-oriented, for people from all walks of life with end-of-life care needs [9]. Both initiatives accepts the 95% rule, which states that 95% of the time a person dying, grieving or caregiving takes place outside of specialised care services, in the community and at home [10]. Considering the need for providing holistic end-of-life care, Compassionate Communities and Cities are viewed as the new norm for restoring community ownership of their own health and establishing respectful and compassionate care [11].

It is estimated that out of the 40 million individuals who require palliative care each year, 78 per cent reside in low- and middle-income countries [12]. Despite being recognized as a fundamental human right, millions of people in need in low and middle-income countries (LMICs) [13] still have limited access to palliative care [2]. By encouraging individuals to advocate for and provide assistance and practical support within their communities, the Compassionate Communities and Cities initiatives has the potential to significantly enhance access to palliative care [14]. This is necessary to full fill the moral and ethical imperative to make palliative care universally available [15]. In this systematic review we aim to analyse Compassionate Communities and Cities initiatives in low- and middle-income countries to identify transferrable lessons for implementation in the primary care context in other low resource settings.

Research Questions

1. What are the common contextual factors found in Compassionate Communities and Cities initiatives in low- and middle-income countries?
2. What are the different roles primary care has in Compassionate Communities and Cities initiatives in low- and middle-income countries and how do they compare?
3. What contextual factors and health promotion principles have been identified as affecting the outcomes of people who are supported by primary care at the end of life in low and middle-income countries?

Methods

Design

This systematic review will be conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [16]. Due to the nature of the research questions a narrative review approach will be used. The review protocol of the study was registered with PROSPERO (ID: CRD42023408640).

Review Inclusion Criteria

The PICOS criteria (Population, Intervention, Comparison, Outcome, Studies) was used to facilitate more focused search of literature.

- **Population:** For the purpose of the review, we will consider studies in the general population, in "low and middle income countries" as defined by the World Bank [13] involving health and social care services, voluntary associations and public institutions within a given geographical area that comprise a compassionate community and city initiatives.
- **Intervention:** A Compassionate Community or City initiative. For this review, Compassionate Communities initiatives are defined as community initiatives committed to improving the quality of life, of those living with serious illnesses together with their families throughout caregiving and bereavement, through empowering, advocacy, skill development and providing support within their communities. A Compassionate City is defined as a permanent and densely settled place with administratively defined boundaries with complex and interlocking social sectors committed to improving the quality of life, of those living with serious illnesses together with their families through developing social policies and actions.
- **Comparison:** Usual care or no comparator.
- **Outcomes:** This review will consider the impact on patients, caregivers and the wider community as a result of the initiative. Impact on patients, caregivers and community is

defined as the degree to which patients, caregivers or community health outcomes were affected (either positively or negatively).

- **Studies:** This review will consider quantitative, qualitative and mixed-method studies, published in the English language.

Information Sources

To find relevant research on Compassionate Communities and Cities published in low- and middle-income countries, a systematic search of significant health, medical, and social care databases such as Embase, Web of Knowledge, PsycINFO, MEDLINE and Scopus will be conducted. Cross-referencing bibliographies will be conducted to identify potential studies that are not considered through the database search. In addition, institutional repositories, and grey literature such as conference proceedings, local government reports, policy statements, survey reports, newsletters, and manuals will also be searched.

Search Strategy

The articles and documents will be searched using keywords ("Compassionate Communities " OR "compassionate community" OR "compassionate cities" OR "compassionate city" OR "neighbourhood network" OR "community participation" OR "community engagement") AND ("Palliative Care" OR "End-of Life Care" OR "Terminal Care") with terms for Low and middle-income countries ("LMICs" OR "[by name of the country]") and database-specific subject headings, where appropriate. There will be no restriction on the publication date. Articles or other types of documents will be excluded that are incomplete or in the process of being written, papers that do not provide information relevant to the search item, or publications written in languages other than English.

Article Screening and Selection

The titles and abstracts of studies collected using the search strategy and those obtained from other sources will be examined independently by two reviewers. The reference management software Endnote version 20.4.1 will be used to facilitate the process. All selected articles will be imported into the web-based application Rayyan [17] after which all duplicates will be checked and removed. The two reviewers will independently analyse the eligibility of articles by retrieving the full text to identify those that fit the inclusion criteria. Any differences between the two reviewers on the eligibility of specific studies will be resolved by discussion with a third reviewer. Article selection will follow the PRISMA flow diagram.

Data Extraction

Two reviewers will extract data independently from papers included in the review using a data extraction table maintained using Microsoft Excel. Extracted data will include: Author(s) and year of publication, aims/objectives, study setting, study population, coverage, stakeholders, modes of funding, details on the implementation (health promotion strategies, challenges etc.), outcomes of implementation and the involvement of primary care. Any differences between the two reviewers will be resolved by discussion with a third reviewer.

Critical Appraisal

Two reviewers examined the methodological quality of the included studies independently. Any disagreements that arise between the reviewers will be resolved through discussion with a third reviewer. To assess the quality of papers, the Mixed Methods Appraisal Tool (MMAT): version 2018 [18] will be used. The MMAT permits to appraise the methodological quality of qualitative research, randomized controlled trials, non-randomized, studies, quantitative descriptive studies, and mixed methods studies. The quality assessment will not result in the exclusion of articles but will be used to inform the reader about the quality of the evidence.

Data Synthesis

Given the expected diversity of data and outcomes, we will be analyzing the data using narrative synthesis method [19]. We do not anticipate having sufficient information to conduct a quantitative metaanalysis. Therefore, the findings will be narratively presented and categorized according to the research questions. Tables will be used to present the quality evaluation and to compare data across different studies.

Discussion

The concept of Compassionate Communities and Cities uses a population health theory of practice in which citizens are mobilized alongside health and social care supports to holistically meet the palliative and end-of-life care needs of individuals. This review will provide a comprehensive understanding of the contributory and supportive factors of Compassionate Communities and Cities initiatives in Low- and Middle-income countries. Literature reveals that most people who require palliative care in low- and middle-income countries, face barriers in accessing such services and primary care is often the first point of contact for most healthcare needs in the community [2]. As public health and primary care often complement each other in improving population

health [20], this review will shed insight on to the different roles of primary care within the initiatives and its contribution as a partner organization improving end of life care needs in the community. Compassionate Communities and Cities applies the health promotion strategies to promote community health [5]. Thus, this review will help to understand how the different health promotion concepts along with other contributing factors influence the patient, community, or service-related outcomes with the support of primary care.

It is believed the findings of this review will not only contribute to the global evidence demonstrating the effects of Compassionate Communities and Cities but also make recommendations to enhance the implementation of such initiatives within the primary healthcare context in similar lowresource settings.

Acknowledgement
Warwick Medical School, University of Warwick, Coventry, United Kingdom.

Ethics approval
Not applicable.

Informed consent
Not applicable.

Funding
Not applicable.

Data sharing statement
No additional data are available.

Conflict of interest
The authors declare no conflict of interest.

Similarity check
It was applied by Ithenticate[@].

References

1. Kellehear A. Compassionate communities: end-of-life care as everyone's responsibility. QJM: An International Journal of Medicine. 2013 Dec 1;106(12):1071-5. doi: 10.1093/qjmed/hct200
2. Kumar SK. Kerala, India: A Regional Community-Based Palliative Care Model. J Pain Symptom Manage. 2007;33(5):623–7. doi: 10.1016/j.jpainsymman.2007.02.005
3. Kellehear A. Health-promoting palliative care: Developing a social model for practice. Mortality. 1999;4(1):75–82. doi: 10.1080/713685967
4. World Health Organization. Ottawa Charter for health promotion, 1986. World Health Organization. Regional Office for Europe; 1986.
5. Dumont K, Marcoux I, Warren É, Alem F, Alvar B, Ballu G, Bostock A, Cohen SR, Daneault S, Dubé V, Houle J. How compassionate communities are implemented and evaluated in practice: a scoping review. BMC Palliative Care. 2022 Jul 20;21(1):131. doi: 10.1186/S12904-022-01021-3
6. Abel J, Kellehear A. Public health palliative care: Reframing death, dying, loss and caregiving. Palliative medicine. 2022 May;36(5):768-9. doi: 10.1177/02692163221096606
7. Howard M, Pfaff K, Sattler D, et al. Achieving holistic, quality-of-life focused care: description of a Compassion Care Community initiative in Canada. Health Promot Int. 2022; 37(3). doi: 10.1093/heapro/daac067
8. Kellehear A. Compassionate Cities: Public Health and End of Life Care. New York: Routledge; 2012. 55 p.
9. Kellehear A. Compassionate cities: global significance and meaning for palliative care. Progress in Palliative care. 2020 Mar 3;28(2):115-9. doi: 10.1080/09699260.2019.1701835
10. Kellehear A. The social nature of dying and the social model of health. Oxford Textbook of Public Health Palliative Care. Oxford University Press. 2022 Mar 31:22-9.
11. Marino L. Time for a shift in power: A people-driven approach to integrated community care.
12. International Journal of Integrated Care. 2021;21(S1):130. doi: https://doi.org/10.5334/ijic.ICIC20536 12. World Health Organization. Palliative care. 2020. https://www.who.int/news-room/factsheets/detail/palliative-care. [Accessed 30th June 2023]
13. World Bank. World Bank Country and Lending Groups – World Bank Data Help Desk 2022.https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country - andlending-groups. [Accessed 30th June 2023]
14. Breen LJ, Macdonald ME. Grief literacy: A call to action for compassionate communities. Death Stud. 2020;46(2):425–33. doi: https://doi.org/10.1080/07481187.2020.173978

0
15. Brennan F. Palliative care as an international human right. Journal of pain and symptom management. 2007 May 1;33(5):494-9. doi: https://doi.org/10.1016/j.jpainsymman.2007.02.022
16. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Annals of internal medicine. 2009;151(4):264-9. doi: 10.1136/bmj.b2535
17. Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan—a web and mobile app for systematic reviews. Systematic reviews. 2016 Dec;5:1-0. doi: 10.1186/s13643-016-0384-4
18. Hong QN, Pluye P, Fàbregues S, et al. Mixed Methods Appraisal Tool (MMAT) version 2018: User guide. 2018.
19. Popay J, Roberts H, Sowden A, et al. Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme version. Vol. 1. Institute for Health Research, Lancaster University; 2006. p. b92.
20. Levesque JF, Breton M, Senn N, Levesque P, Bergeron P, Roy DA. The interaction of public health and primary care: functional roles and organizational models that bridge individual and population perspectives. Public Health Reviews. 2013 Jun;35(1):1-27. doi: 10.1007/BF03391699.