Briefing Paper: Public Health Approaches to Palliative Care

NOVEMBER 2017

1. Introduction and Purpose of Paper

All Ireland Institute of Hospice and Palliative Care (AIIHPC)[1] is a collaborative of hospices, health and social care organisations and universities on the island of Ireland. As a leading organisation with national and international influence driving excellence in palliative care, AIIHPC advances education, research and practice to improve the palliative care experience of people with life-limiting conditions and their families.

Through its involvement with the Regional Palliative Care Programme in Northern Ireland[2] – Palliative Care in Partnership – and the National Clinical Programme for Palliative Care in the Republic of Ireland[3], AIIHPC supports the delivery of high quality palliative care. This paper has been produced as a result of a request from the Palliative Care in Partnership Programme and as part of the Public Health Agency's support for AIIHPC. The paper is offered to all of AIIHPC's partners, the wider palliative care sector and all those interested in this topic.

A range of activities are supported by AIIHPC to contribute to the palliative care policy agenda across both jurisdictions on the island of Ireland, informed by service user experiences. These activities include comment on policy developments and regular, ongoing contact with key policy influencers across the community and voluntary sectors and in agencies and government departments[4].

In recent years, there has been increasing interest in what is generally referred to as a public health approach to palliative care. This interest across palliative care internationally has been shared on the island of Ireland. There are many elements of what is being done to improve the experience of palliative care on the island of Ireland which fit under the umbrella of a public health approach. However, it is not always clear what is meant when reference is made to a public health approach to palliative care.

The purpose of this paper is to contribute to a better understanding of what the paper refers to as public health approaches (plural) to palliative care.

This paper is offered as a resource to enable further discussion on how public health approaches to palliative care can be developed to support people living with a life-limiting illness to maintain their quality of life.

As public health approaches must respond to the needs and cultures of the societies in which they are being implemented, by their very nature they will always be undergoing development and change.

2. Palliative Care

The starting point in palliative care is always the person. The goal of palliative care is to improve the quality of life for both the person living with an illness that is life-limiting and for those who matter most to them. While not denying the reality of death, palliative care offers a positive approach which holds space for living life to the full to the very last days of life[5].

By focusing on the person's physical, emotional, social and spiritual needs, and involving friends and family, palliative care can help to maintain quality of life. This care can be provided at home, in a nursing home, in hospital or in a hospice.

Palliative care often involves a range of health care professionals (alongside family carers), from the GP and community nursing at the generalist level, to support for those needing more specialist treatment in hospice, hospital, or at home. Palliative care maximises the quality of life for the person at the centre of care and those important to them and it continues that care into bereavement.

3. Palliative Care Need

The need for palliative care is growing, and a range of responses are being generated to address this need. This paper aims to provide an insight into public health approaches to palliative care. While emphasis may differ between understandings of these approaches, exponents of the various approaches share a desire to address the needs of the population.

Significant unmet palliative care need is acknowledged, as well as a desire for the benefits of palliative care to be experienced beyond the population living with cancers. A desire for equity of access to care is expressed for such groups as the older population living with multiple illnesses/conditions, those in nursing and care homes, people in remote areas, people with disabilities, those in prison and homeless people[6,7].

Alongside this aim to broaden access to care is a view that this will only be achieved by healthcare professionals and the community working together and by building up social support networks.

By 2050, it is estimated that more than a quarter of the population of the European region will be aged 65 and older. The greatest percentage increase will be among people aged 85 years and older[8]. The scale of need for palliative care, particularly for the growing population of older adults, suggests that it requires a multifaceted approach.

4. The Public Health Approaches to Palliative Care

In recent years, there has been rising interest in public health approaches to palliative care and they have gradually gained momentum within health practice and policy, and among those who are part of and responsible for palliative care services[9,10].

It is important to be aware of the range of terminology used within this discourse. References include: the public health approach to palliative care, new public health approaches, the public health model for palliative care, health promoting palliative care, compassionate cities, compassionate communities, community development[6,7,9-13].

Referring to public health approaches is not to suggest that there are separate and distinct approaches, but reflects that there are elements emphasised in one approach over another. It is important to be aware that every application of the approach needs to take account of the local circumstances in which it is being implemented[6,7,13].

Although it might appear contradictory to consider health promotion and end-of-life care together, it is now widely acknowledged that health and wellbeing can be improved in the context of a life-limiting illness, both for the individual and for those around them. There is general consensus that public health palliative care approaches can complement and go beyond the scope of formal service models of palliative care[9,10].

However, there is not widespread clarity about how public health approaches can be undertaken in practice[9,14].

4.1 Which Public Health Approach to Palliative Care?

Starting from the premise that there is a lack of clarity around the 'merged model' of public health and palliative care, a recent study was undertaken to describe the theoretical features of the public health approach to palliative care[14].

Three different paradigms were identified within the current empirical research:

- World Health Organization (WHO) Approach
- Health Promotion Approach
- Population-based Approach

It is suggested that viewing these three paradigms as distinct and separate may not be helpful, and the study authors acknowledge that the three approaches share significant common ground.

Nonetheless, a consideration of the three paradigms is a useful tool for understanding the development of public health approaches to palliative care, and the varying emphasis of these approaches.

The Ottawa Charter (1986) emanated from the World Health Organization's First International Conference on Health Promotion, held in the Canadian capital, in November 1986. The charter heralded what is known as the new public health, or health promotion. This was a movement away from a narrow bio-medical model towards a broader conceptualization of well-being that acknowledges the influence of the person and their social context[6,10,14,15].

It is suggested that linking palliative care to public health first occurred within the WHO, and in particular in the work of one time WHO cancer unit chief, Jan Stjernsward[14,22].

4.1a World Health Organization (WHO) Approach

Stjernsward states that the WHO pioneered a public health strategy to integrate palliative care into existing health systems in 1990. This strategy included advice and guidelines to governments on priorities and how to implement national palliative care programmes and national cancer control programmes where palliative care will be one of the four key components (pillars) of comprehensive cancer care. These four pillars are: 1) appropriate policies; 2) adequate drug availability; 3) education of health care workers and the public; and 4) implementation of palliative care services at all levels throughout the society[6].

Based on experience with this model and the process to implement it, an enhanced Public Health Model (the Model) emerged[6]:
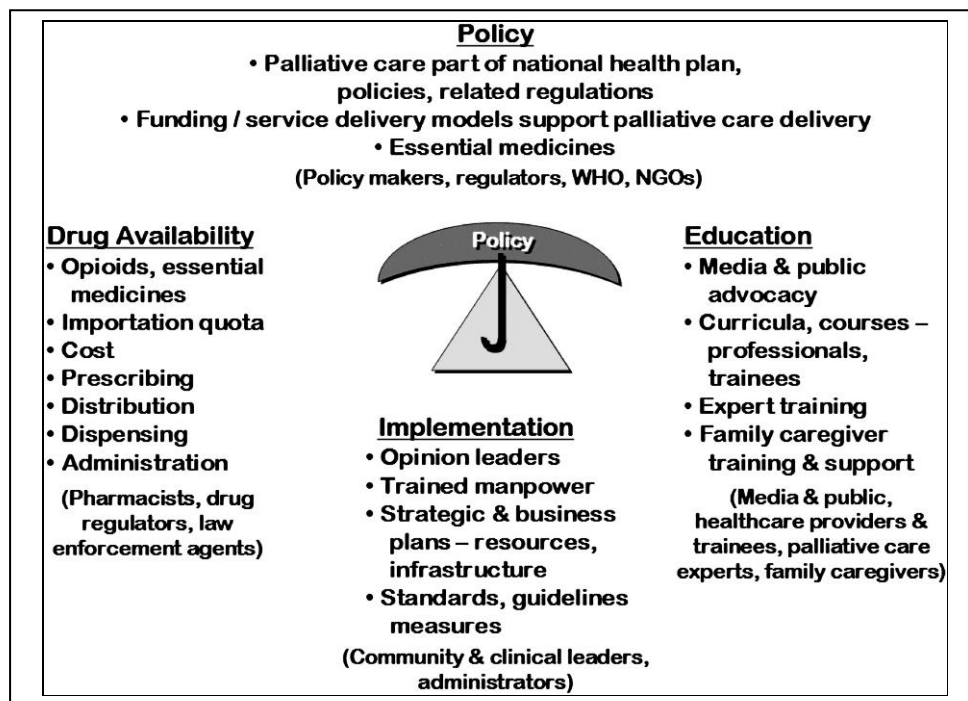
World Health Organization Model

This model is always implemented within the context of the culture, disease demographics, socioeconomics, and the health care system of the country.

It is important to bear in mind that the WHO model is to have application on a global scale, therefore there will be elements which will be at different stages of development in the geographical context in which they are being implemented.

Stjernsward's vision is to integrate palliative care into all levels of society from the community level upward and from the palliative care expert in the health care system downward.

In a resolution adopted at the World Health Assembly in 2014, the WHO sets out what it identified as the policies which needed to be formulated and implemented for strengthening palliative care[16]. These policies are in line with the WHO model[6] as set out in 2007 and appear to place an emphasis on interventions in health systems and focus on medicines and the role of healthcare professionals. The resolution does refer to fostering partnerships between governments and civil society, including patients' organizations, to support, as appropriate, the provision of services for patients requiring palliative care[16].

4.1b Health Promotion Approach

The public health model developed by sociologist Allan Kellehear aligns the principles of palliative care with those of health promotion as outlined in the Ottawa Charter[14].

Kellehear is closely associated with the Public Health and Palliative Care International Association[17] which defines a public health approach to palliative care as, one that views the community as an equal partner in providing quality health care at the end of life.

Just as health, according to the WHO, is 'everyone's responsibility' so too is death, dying, loss and caring. While this definition acknowledges the social aspect of the WHO's take on health, it makes no overt reference to the WHO's public health strategy for palliative care[14].

The principles of health promoting palliative care developed from the mid-1990s can be found, as indicated by Kellehear, in the compassionate city charter and this charter has been derived from the WHO concept of 'healthy cities'[7,12].

Compassionate Communities

Compassionate cities represent a similar approach to public health as healthy cities but with an orientation towards death, dying, loss and caring. By developing compassion - the capacity to share and support in another person's suffering - compassionate communities organise around death, dying, loss and caring and create appropriate responses to those experiences in the form of institutional policies and community practices[18].

In line with a community development approach, the Compassionate City Charter gives guidance on where implementation should be focussed, but it does not specify how implementation should take place – it is fashioned to suit the needs of the local community.

The work requires engaging with communities consistently to develop trusting relationships built over time. It encourages local government and administrations to play an active role as change agents in the policy development of organisations such as schools, workplaces, commercial districts, and churches/temples[7,13].

A compassionate city is a community that recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility[7].

Community Assets

Compassionate communities can be built anywhere that there are people. A central issue in this public health approach to end-of-life care is how community assets and capacity can be mobilised effectively to enable the dying to be supported by the people who are closest to them[7].

The bottom up approaches in public health, which Kellehear, along with specialist palliative care medical consultant Julian Abel, identify as health promotion and community development, have provided alternatives to direct services provision by exploiting the social assets (local social, financial, practical supports) of a community.

For them, a co-operative approach of professionals and communities working together not only is a practical way of solving what appears to be unaffordable financial demands, it is preferable in terms of quality and continuity of care experience for all concerned[7].

Julian Abel illustrated the model he envisages (Slide 1) and the potential for the model's impact (Slide 2) in a presentation to the Annual Marie Curie Research Conference in October 2017 at the Royal Society of Medicine in London[19]:
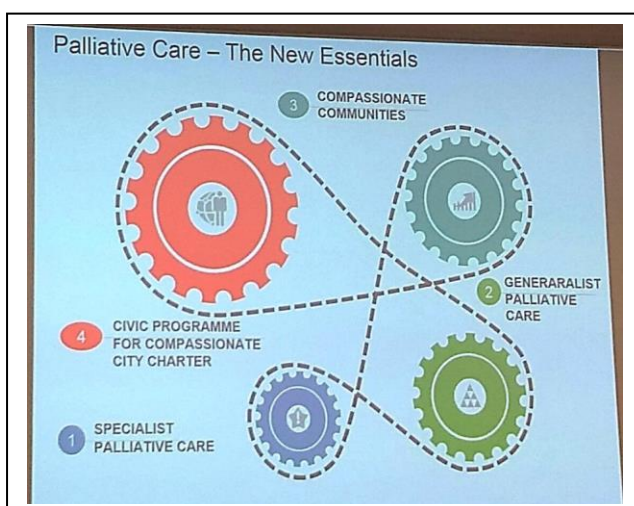
Slide 1
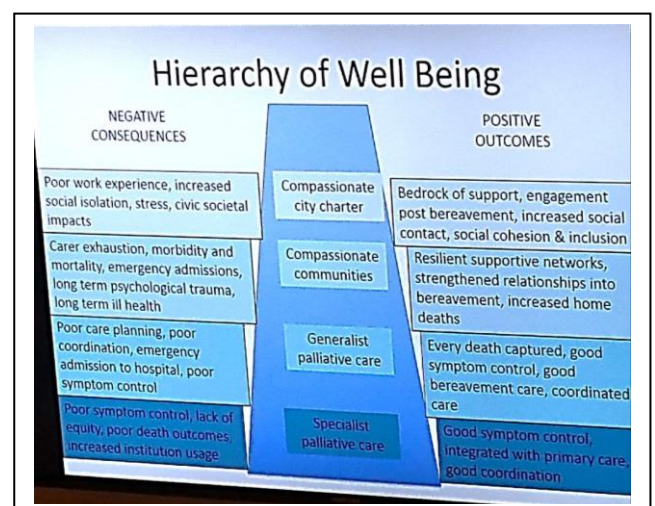
Slide 2

Health Promotion Approach in Practice

The health-promoting approach to end-of-life care first outlined by Kellehear now encompasses a large-scale, international effort to incorporate the principles of health promotion into end-of-life care[10].

It is described as a series of social efforts by communities, governments, state institutions and social or medical care organisations that aim to improve health and wellbeing in the face of life-limiting illness.

Examples exist throughout the world of the application of health-promoting principles to end-of-life care. These incorporate a range of processes, determined by local need[7,10]. They include:

- mobilisation of community resources, either through naturally occurring social networks or externally facilitated ones – using community development principles

- development of supportive communities of volunteers, for example befriending schemes, to support for the carer in daily tasks, a listening ear, or direct support to the person with an illness (lifts, spending time with someone or giving a carer respite)

- attempts to influence society's perception of and reaction to death and dying, such as through work with schools, businesses, or professionals or offer seed grants to communities to develop work themselves

- creation of supportive policies within institutions – compassionate policies, volunteers from within the institution to provide support to colleagues

- awareness, education and training of community members directly in topics such as writing a will and advance care planning or efforts to explore society's perception of the issues through local or national conversation

- Policy examples exist where lobbying from local services and communities has led to policy reform and the emergence of dementia-friendly communities is an example of how the environment may be manipulated to improve experiences of those living with life-limiting illnesses.

See Appendix A for further Examples of Public Health Approaches to Palliative Care (predominantly health promotion approach) and Useful Resources.

4.1c Population-based Approach

Within the current empirical research, the third paradigm of a population-based approach in the public health approaches to palliative care was identified[14]. Of the studies considered, three did not fit comfortably into either of the first two themes and a focus on population

data was available in all three of these studies[14]. One was a population-based survey (of schools of public health in the USA), a second expressly advocated a population-based approach (a Canadian survey on public preferences for final days of life), and the third was a pilot survey (of a public health model for bereavement in Australia) that recommended the results be tested in a larger population-based study.

This population-based approach often relied on the science of epidemiology for evidence. Epidemiology is the study of how often diseases occur in different groups of people (populations) and why. Epidemiological information is used to plan and evaluate strategies to prevent illness and as a guide to the management of patients who are already living with an illness or illnesses[20].

Further to the third approach identified in the study[14], an emphasis on identifying needs within different groups of people (populations) is discernible from a number of key leaders in palliative care. In advocating public health methods, their approach is a broad one, encompassing identification of need, interventions at health care professionals and community levels, and incorporating data and monitoring systems to achieve good end of life care for all[21,22].

4.2 Common Ground between Approaches

The health promotion approach (as described in 4.1b) is the dominant articulation of a public health approach to palliative care in the literature reviewed for the study cited[14].

While the World Health Organization approach appears concerned with integrating palliative care into health systems, at country level predominantly, studies linked to a health promotion approach talk much about social empowerment and are seemingly focussed at a community level.

While this does show different emphases, it cannot be said that these two themes are mutually exclusive, because arguably the goals of one would support the goals of the other being achieved[14]. One study (from Northern Ireland) fitted into both themes of the WHO and the health promotion approaches[14,23].

Community empowerment and mobilization would certainly improve reach, as has been demonstrated elsewhere, and it must be acknowledged that social participation and community ownership is unambiguously upheld in the WHO Public Health Model for Palliative Care. For public health strategies to be effective, they must be incorporated by governments into all levels of their health care systems and owned by the community[6].

The third approach - a population-based approach - and the use of epidemiology may be employed and upheld by proponents of all three paradigms[14].

That these three themes share significant common ground can add to the confusion. Researchers are advised to make clear which public health approach to palliative care they are drawing on when considering this topic[14].

5. Measuring Impact

While there has been rising interest in public health approaches to palliative care and they have gradually gained momentum within health practice and policy, it is acknowledged that this has not been matched by a rise in evidence showing their effectiveness or supporting their use[9,10].

A systematic review led by Libby Sallnow, a palliative medicine doctor and doctoral researcher, offers some new clarity about the potential impact of the application of health promoting principles to end of life care.

Looking at studies from across the globe, the positive impact on family carers, ranging from decreased fatigue to increased confidence is a strong theme; similarly, the impact on volunteers or community members who offer care and support, whose experience can be transformative. Sallnow also finds evidence of 'harder' outcomes – home death rates and rates of involvement of palliative care services are higher when a caring network involves friends as well as immediate family[10].

More recently, Sallnow has been presenting on a study of a community-led intervention in London which highlighted the role of social networks in promoting well-being at the end of life[24].

Participants in this compassionate neighbours initiative described becoming socially connected and linked this connection to increased wellbeing. Volunteers viewed themselves and those they visited as peers, despite differences in age or diagnosis. A key facilitative process was the development of a relationship based on mutuality rather than passivity and dependence.

Another example of a recent, smaller scale project in Canada, under the compassionate community approach to early palliative care, suggests its positive potential to address the important needs of this population[25]. This programme is currently being implemented and evaluated in diverse rural and urban communities across Canada. Kellehear also cites examples of health promotion approaches which have had a positive impact on the communities where they were delivered[12].

Sallnow argues that health promoting principles applied to palliative care can deliver on addressing social isolation, carer support, personal and community capacity and well-being, and that it is possible to measure and capture the impact. She suggests this should be an integral component of this work going forward[10].

6. Considerations for Practice

Palliative care has a role to play in promoting health and wellbeing. Serious illness, death, dying, loss and grief are universal experiences.

The need for palliative care is growing, and public health approaches to palliative care do offer potential to meet this increasing need.

In supporting the development of public health approaches, the following prompts for consideration are offered:

- What is the need which is being addressed?
- Who is involved? What skills do we need to harness?
- Is there clarity on the public health approach which is being referred to?
- What is the balance between 'top down' and 'bottom up' involvement?
- Will the community 'own' it?
- Will the model be multi-faceted?
- Will the model be flexible to allow for adaptation to address the needs in each community?
- What assets are there already in communities (not limited to geographical communities)?
- What is needed to mobilise other assets to develop public health approaches to palliative care?
- Are separate/new developments necessary?
- Is there already support which can be linked into or influenced, for example, initiatives addressing isolation/loneliness?
- Is the approach taking account of local society/history/culture/identities?
- Is the initiative supporting the development of relationships based on mutuality rather than passivity and dependence?
- Is there thinking beyond health care as the provision of services?
- Is there involvement of communities not normally involved?
- What can be learned from what is already being done well in communities in relation to death, dying, loss and caring? Why is this considered good?
- Will projects make a positive difference and how will you know?

It is hoped this paper will be a resource to enable further discussion on how public health approaches to palliative care can be developed in various communities and societies so that people living with a life-limiting illness can be supported to maintain their quality of life to the very last days of life.

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http://www.phpci.info/

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http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf

19. The Annual Marie Curie/Royal Society of Medicine Research Conference: People who care: relationships at the end of life
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APPENDIX A: Examples of Public Health Approaches to Palliative Care (predominantly health promotion approach) and Useful Resources

Compassionate Communities (UK)
http://www.compassionatecommunities.org.uk/

Compassionate Communities Network (Australia & International)
http://www.compassionatecommunities.net.au/

Compassionate Neighbours in East London (St Joseph's Hospice, London)
https://www.stjh.org.uk/neighbours

Compassionate Neighbours (South East London, St Christopher's Hospice)
http://www.stchristophers.org.uk/compassionateneighbours/

Death Café
http://deathcafe.com/

Dying Matters
http://www.dyingmatters.org/overview/about-us

Forum on End of Life in Ireland
http://hospicefoundation.ie/programmes/public-awareness/forum-on-end-of-life/

Foyle Hospice, Compassionate Communities 'Reach Out' project
https://foylehospice.com/services/compassionate_communities

Good Life, Good Death, Good Grief
https://www.goodlifedeathgrief.org.uk/

Limerick Compassionate Communities Project Evaluation Report
http://www.lenus.ie/hse/handle/10147/621066

Limerick Good Neighbour Partnership
https://www.inspirestudy.ie/publications

Marie Curie Helper Service
https://www.mariecurie.org.uk/help/helper-volunteers

Murray Hall Community Trust And National Council for Palliative Care. Dying Matters Coalition: An Overview of Compassionate Communities in England. July 2013
http://www.compassionatecommunities.org.uk/files/PDF/CC_Report_Final_July_2013-2.pdf

Palliative Care Week
http://www.thepalliativehub.com/public-awareness

Palliative Hub
http://www.thepalliativehub.com/

Plan Ahead: Advance Care Planning Video Competition
http://www.thepalliativehub.com/plan-ahead-advance-care-planning-video-competition

Public Health Approaches to End of Life Care - A Toolkit (Middlesex University, London; Public Health England; National Council for Palliative Care)
http://www.ncpc.org.uk/sites/default/files/Public_Health_Approaches_To_End_of_Life_Care_Toolkit_WEB.pdf

Severn Hospice Compassionate Communities
https://www.severnhospice.org.uk/for-patients/care-at-home/co-co/

Think Ahead – Planning for Death and Dying
http://hospicefoundation.ie/programmes/public-awareness/think-ahead/

Your life and your choices: plan ahead Northern Ireland
https://be.macmillan.org.uk/be/p-21065-your-life-and-your-choices-plan-ahead-northern-ireland.aspx

Other useful links

European Association for Palliative Care: Reference Group on Public Health and Palliative Care
http://www.eapcnet.eu/Themes/Resources/Organisation/PublicHealth.aspx

Report of the National Advisory Committee on Palliative Care (2001)
http://www.professionalpalliativehub.com/sites/default/files/nacpc.pdf

Palliative Care Services: Three Year Development Framework (2017-2019), HSE Primary Care Division
http://www.hse.ie/eng/services/publications/Clinical-Strategy-and-Programmes/palliative-care-services-development-framework.pdf

Living Matters: Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland (2010)
http://www.professionalpalliativehub.com/resource-centre/living-mattersdying-matters-palliative-and-end-life-care-strategy-adults-northern

Review of the Implementation of the Palliative and End of Life Care Strategy NI RQIA (2016)
http://www.professionalpalliativehub.com/resource-centre/review-implementation-palliative-and-end-life-care-strategy-ni-rqia

Palliative and end of life care in Scotland: The rationale for a public health approach.
https://www.scotphn.net/projects/palliative-and-end-of-life-care-pelc/palliative-and-end-of-life-care-pelc-2/

Palliative Care is a Public Health Issue: A White Paper commissioned by the British Columbia Centre for Palliative Care
http://www.bc-cpc.ca/cpc/palliative-care-is-a-public-health-issue/

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18