



From outcomes to action: the power of compassion

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Purpose of this talk

- To highlight the findings of an international project on core outcomes or potential benefits of compassionate cities
- To compare the findings with the charter of compassionate cities and with the 'Bern declaration'
- To implement the findings in a local environment: what we experienced in Bern during organizing this conference and city festival – a co-creation

Buenos Aires



Medellin



Bern



**Development of a list of
the most important
benefits of preexisting
compassionate
communities**



Project leads: V.Gonzalez, A.Krikorian, V.Tripodoro, S.Eychmüller

Why this project?



Compassionate Communities Evaluation Guide - Pallium Canada

Evaluation Guide

Version year: 2023

STAGES OF DEVELOPMENT FOR COMPASSIONATE COMMUNITIES

Initiative stage	Description
1. Not started	Interested in the concept but haven't started any activities yet.
2. Public awareness	Raising public awareness of the benefits of participating in a compassionate community.
3. Engaging partners	Engaging potential partners and the community to ensure support or commitment.
4. Co-planning	Forming a coordinating group or organization to start up the compassionate communities' initiative.
5. Initial implementation	Implementing activities or programs within its first six months.
6. Early implementation	Implementing activities or programs within its first year.
7. Mid-implementation	Implementing activities or programs within its second year.
8. Mature implementation	Implementing activities or programs within its third year or more.

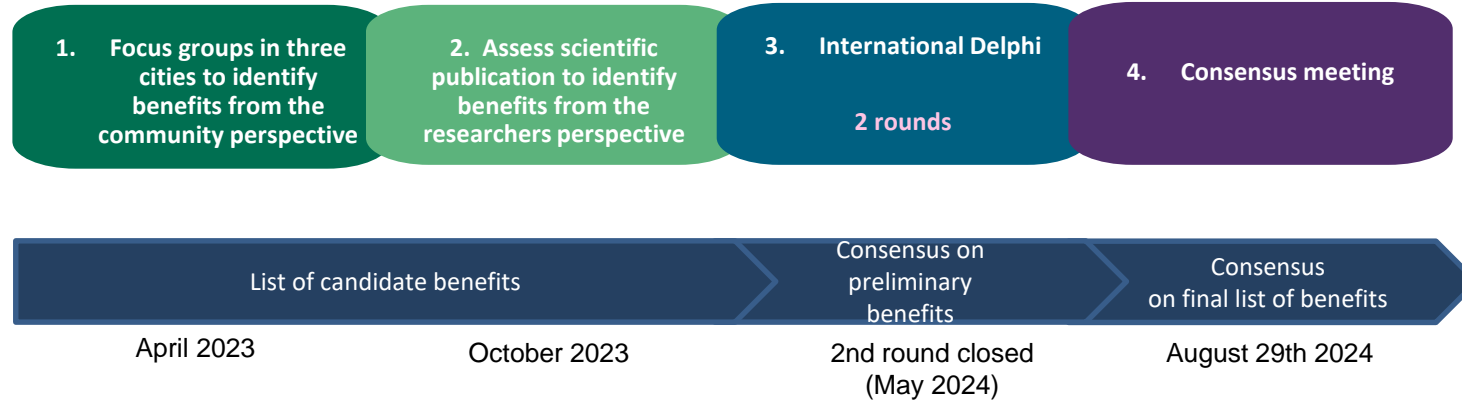
7. Mid-implementation	Outcome evaluation	2 to 3 years after implementation
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Which outcomes or benefits?

For 'mid- implementation communities':

- Which benefits may be generalizable globally in order to push a worldwide understanding and value of community engagement?
- Which benefits relate mostly to local/ regional/ national conditions or prerequisites?
- How to be measured?

What we did



Following the methodology proposed by COMET
www.comet-initiative.org



A workshop during PHPCI 2022 in Bruges



Where the project gathered first feedback



Lesson 1:
use PHPCI -
workshops for
your projects

Results of 2nd
Delphi round

Consensus to
include.
Confirmed?

Hubo consenso
para ser
incluidos. Lo
confirmamos?

No consensus
yet. To be
discussed today

No ha habido
consenso. Los
discutiremos
hoy

Lower scores:
consensus to
exclude?

Puntuación más
baja: consensos
para excluir?

Benefit	Argentina	Switzerland	Colombia	International	Total
Strengthen the institutions belonging to the network and promote alliances between those with similar interests	100	87.5	100	89.89	94.3475
Integrate different disciplines and sectors of society to achieve collaborative work	100	87.5	100	88.89	94.0975
Facilitate the creation and coordination of caregiver and community networks, both locally and across cities	100	87.5	100	87.5	93.75
Make visible, characterize, and prioritize the caregivers and their needs while increasing their confidence to seek help	100	87.5	100	87.5	93.75
Instill a collective responsibility in the society to accompany and support each other, particularly, at the end of life	100	87.5	93.33	87.5	92.0625
Make visible the compassionate community, the information, and the training received so that it reaches more people	100	88.89	100	75	90.9725
Train the general community (children and young people, caregivers, patients, and health care professionals)	100	75	100	88.89	90.9725
Help people to become more familiar with end of life and death through information, conversations, or experiential learning	100	77.78	93.33	87.5	89.6525
Instill in the community the awareness that at some point we may have to take care of someone and be prepared for it	100	75	93.33	87.5	88.9575
Improve the quality of patient care by getting closer to patients, listening to them, respecting their autonomy and preferences	100	87.5	86.67	75	87.2925
Make people reflect on life and the future, including old age, illness and death and to become more accepting of life's uncertainties	87.5	87.5	93.33	75	85.8325
Provide access to centralized information about other institutions and what to do in each case to direct people to the appropriate services	87.5	87.5	86.67	77.78	84.8625
Change (improve) regional and cultural attitudes, including attitudes towards vulnerability, illness, and death	100	71.43	86.67	77.78	83.97
Generate spaces (and give tools) to talk about grief, normalize it and address it from the community so as to reduce its impact	87.5	75	80	87.5	82.5
Decrease loneliness by making people know that they are not alone; that if they need someone, they have support	100	62.5	93.33	75	82.7075
Offer legal and juridical support including knowledge of caregivers' rights	75.5	87.5	93.33	66.67	80.75
Care for and raise awareness about the mental and emotional health of the community, including caregivers and patients	100	62.5	93.33	66.67	80.625
Promote home care, decreasing hospitalizations and visits to emergency departments, ultimately decreasing costs	100	62.5	93.33	66.67	80.625
Contribute to current social and demographic challenges	87.5	66.67	73.33	88.89	79.0975
Generate motivation and commitment for compassionate community care to help secure the continuity of patient care	75	62.5	100	77.78	78.82
Make people feel represented, looked upon, valued, and part of the compassionate community network	87.5	71.43	86.67	62.5	77.025
Promote wider social networks that influence place of death and palliative care services involvement	100	50	80	77.78	76.945
Support caregivers and help them to find respite by providing substitutes or helping them with formalities and administrative tasks	75	57.14	93.33	75	75.1175
Generate personal and societal growth: Transform the society to be more compassionate on a daily basis	75	57.14	93.33	75	75.1175
Generate spaces open to the public for social integration, exchange of experiences, and creation of strong bonds	75	75	93.33	55.56	74.7225
Foster research in the field of Compassionate Communities	100	66.67	86.67	44.44	74.445
Provide people tools to support others regardless of their condition or level of dependency	100	50	80	66.67	74.1675
Seek gender equality in caregiving by encouraging that, in families, not only women take the caregiving role	87.5	44.44	86.67	77.77	74.12
Help to understand when and how to use institutions for the elderly or sick	87.5	50	80	77.78	73.82
Decrease unnecessary hospital use	100	50	73.33	66.67	72.5
Be a bridge between the public and private sector and complement public offerings	87.5	44.44	85.7	66.67	71.0775
Help the community to have open conversations with neighbors and to know that they will support each other in times of need	87.5	50	80	66.67	71.0425
Empower citizens, including underserved and forgotten populations, to recognize and demand what they need from public services	75	33.33	86.67	88.89	70.9725
Impact public policies (including work-related policies) and ensure compliance	62.5	77.78	86.67	55.56	70.6275
Recognize the wisdom of the community and ancestral peoples; learn from it and embrace it	87.5	62.5	66.67	62.5	69.7925
Raise awareness about (early) palliative care	100	62.5	71.43	44.44	69.5925
Identify volunteers (including ex caregivers) of different ages who have time and resources to support care	75	50	86.67	66.67	69.585
Help to relieve pain	100	37.5	73.33	66.67	69.375
Identify those who have needs and offer them solutions adapted to each context	87.5	37.5	86.67	55.56	66.8075
Offer spiritual support	75	37.5	86.67	62.5	65.4175
Support healthcare professionals and fill gaps in current healthcare and economic systems	87.5	50	66.67	55.56	64.9325
Raise awareness of issues related to caregiving, illness, death, and dying through art	62.5	50	80	50	60.625
Foster economic solidarity to lighten the financial burden on others	75	37.5	66.67	55.56	58.6825
Help to find meaning in life	50	62.5	66.67	50	57.2925
Make hospitals a more welcoming place	87.5	25	73.33	37.5	55.8325
Enable access to and redistribution of care supplies	62.5	12.5	66.67	33.33	43.75

Consensus Meeting, August, 29th 2024

The image shows a Zoom meeting grid with 20 participants. The participants are arranged in a 4x5 grid. The names and roles of the participants are as follows:

Row	Column 1	Column 2	Column 3	Column 4	Column 5
1	Vilma Tripodoro, Research	Egloff, Martina (MED)	Christina Beglinger, Caregiver	Steffen Eychmueller	Silvina Montilla, Research
2	Margarita Jorge	Marisa Martin, International Expert	Mariana Abranches Pinto, Compassio, Porto...	Alicia Kikorian, Research	Mariana Soiza, NGO
3	Sebastián Orellana, Research	Elena D'Urbano, HCP	Belen Carballo, HCP	Gustavo de Simone, HCP	Valentina Gonzalez, Research
4	Barbara Petersen, Caregiver	Berena Torres, ONG	[Participant Name Obscured]	Caregiver	Marta Sosa, ONG

At the bottom of the grid, two additional participants are visible: Tatiana Noguera and Antonio Mejia C... (Antonio Mejia Correa, Caregiver).

A large red oval is overlaid on the bottom center of the grid, containing the text: **Lesson 2: Use online communication for consensus**

Ratification of benefits included

1. Strengthen the institutions belonging to the network and promote alliances between those with similar interests
 2. Integrate different disciplines and sectors of society to achieve collaborative work
 3. Facilitate the creation and coordination of caregiver and community networks, both locally and across cities, and identify/support existing initiatives
 4. Make visible, characterize, and prioritize the caregivers and their needs while increasing their confidence by both receiving training and feeling supported in caregiving
 5. Instill a collective responsibility in the society to accompany and support each other, particularly, at the end of life
 6. Make visible the compassionate community, the information, and the training received so that it reaches more people
 7. Train the general community (children and young people, caregivers, patients, and health care professionals) in compassion, caregiving, end of life, death, and bereavement, independent of whether they need these skills at present or may need them in the future
 8. Help people to become more familiar with end of life and death through information, conversations, or experiences
 9. Instill in the community the awareness that at some point we may have to take care of someone and be prepared for when this happens
 10. Improve the quality of patient care by getting closer to patients, listening to them, respecting their autonomy, supporting them, and addressing their needs
 11. Make people reflect on life and the future, including old age, illness and death and to become more accepting of them
 12. Provide access to centralized information about other institutions and what to do in each case to direct people to someone who can solve the need
 13. Change (improve) regional and cultural attitudes, including attitudes towards vulnerability, illness, and death
 14. Generate spaces (and give tools) to talk about grief, normalize it and address it from the community so as not to depend on health professionals
 15. Foster research in Compassionate communities
 16. Empower citizens, including underserved and forgotten populations, to recognize and demand what they need
 17. Recognize the wisdom of the community and ancestral peoples; learn from it and embrace it
 18. Identify volunteers (including ex caregivers) of different ages who have time and resources to support care
-

Triangle of benefits of compassionate cities

A proposed model

Organisation & Access

1,2,3,12,18

**Benefits of
Compassionate
cities**

Awareness & Information

5,6,8,9,11,13,16,17

Education & Support

4,7,10,14,15

Awareness and Information

- 5.** To encourage a collective responsibility in the society to accompany and support each other, particularly, at the end of life
- 6.** To make the compassionate community visible, including the information and training received, so that it reaches more people.
- 8.** To help people to become more familiar with end of life, death and bereavement through information, conversations, or experiences
- 9.** To promote in the community the awareness that at some point we may have to take care of someone and be prepared for when this happens
- 11.** To encourage people reflect on life and the future, including old age, illness and death and to become more accepting of them
- 13.** To change (improve) regional and cultural attitudes, including attitudes towards vulnerability, illness, and death
- 16.** To empower citizens, including underserved and forgotten populations, to recognize and get what they need
- 17.** To recognize the wisdom of the community and ancestral peoples; learn from it and embrace it

Organization & Access

1. To strengthen the institutions belonging to the network and promote alliances between those with similar interests
2. To integrate different disciplines and sectors of society to achieve collaborative work
3. To facilitate the creation and coordination of caregiver and community networks, both locally and across cities, and identify/support existing initiatives
12. To provide access to centralized information about other institutions and what to do in each case to direct people to someone who can solve their need
18. To identify volunteers (including experienced caregivers) of different ages who have time and resources to support care

Education & Support

4. To make visible, characterize, and prioritize the caregivers and their needs while increasing their confidence by both receiving training and feeling supported in caregiving
7. To train the general community (children and young people, caregivers, patients, and health care professionals) in compassion, caregiving, end of life, death, and bereavement, independent of whether they need these skills at present or may need them in the future
10. To improve the quality of patient care by getting closer to patients, listening to them, respecting their autonomy, supporting them, and addressing their needs
14. To generate spaces (and provide tools) to talk about grief, normalize it and address it from the community so as not to depend on health professionals
15. To foster research in Compassionate communities

Consensus as a starting point

- An attempt to define potential benefits
- Providing guidance for various use and needs
- Health care remains an important partner and ideally a change agent (participation, co- education)

A critical voice: **not included** into the final list were "personal and community growth + transforming our societies" and "supporting to find a meaning of life«

«don't we need a more compassionate society? don't we dream of such a transformation? - don't we believe that one strong inner way of finding deep personal healing is to find meaning in our suffering/lives?» (G.d.S)

Essential outcomes – half of the truth....?!

- In the initial focus groups only half of the identified benefits/ outcomes found agreement in ALL three cities
- Role of diversity: societal needs, organization, expectations, CC- development, cultural differences, burdens
- The future?

Lesson 3:
Combine the best
of 2 worlds:
global and local

**Generalizable
benefits of CCs**

**Locally defined
benefits of CCs**

How to proceed? Too much written?

A set of **specific benefits of compassionate cities**
international definitions/ potential benchmarking and local
adaptation and branding

The **charter of compassionate cities**

Defining local/ regional partners and co-creating actions related to
outcomes/ potential benefits

The **Bern declaration**.....

A first step providing strategic guidance – worldwide - in order to
keep the development of CCs running

from strategy to benefits to action

Define goals/ benefits Core & local/ regional



The Bern declaration 2024

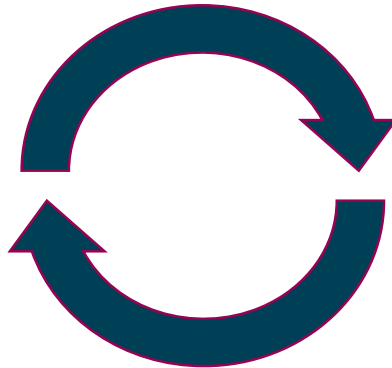
With close to one million of people dependent on care in our country, its many care sites, death and bereavement are large out of sight and often kept within the confines of healthcare institutions. Sorrow, many people unable, unprepared or reluctant to discuss it openly and leading to unresolved and/or preventable suffering. A change in how we care support the culture of life and bereavement is urgently needed.

In this context, **Public Health Palliative Care International** (www.phpci.org) represents, city administrations and all care organisations within Switzerland and also in consent to the following health promotion principle and action for the good of all life and death people:

1. Support citizens to become more familiar with supporting and caring for the seriously ill and bereaved through conversations and experiences that **improve health and death literacy** – the knowledge and skills that people need to navigate this challenging part of our life.
2. Create learning opportunities in **compassion and consciousness** during caregiving, end of life, death and bereavement in the general community.
3. Share stories and experiences of **people dying and grieving in everyday life** from all parts of society through media and in public spaces to provide representation and a realistic understanding of what happens at the end of life and to grief and loss.
4. Actively address loneliness and promote a sense of security, connection and belonging for everyone, raising the need of life by **strengthening relationships through neighbourhood and community networks**, as a central part of serious illness and bereavement support.
5. **Make visible the strengths and needs of informal caregivers** (family and volunteers), increasing their confidence through education and connections, and helping support all in caregiving, acknowledging the disproportionate role women play in caregiving.
6. Work together to craft and extend policies to **enable financial independence** in end-of-life caregivers and those, months and even years, in support and of their and patients care team.
7. **Promote civic participation and practices** for supportive care inside all civic spaces – from workplaces, schools, or faith groups to social clubs, cultural centers, and neighborhoods.

1. Strengthen the institutions belonging to the network and promote alliances between those with similar interests
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3. Facilitate the creation and coordination of caregiver and community networks, both locally and across cities, and identify support existing initiatives
4. Make visible, characterize, and profile the caregivers and their needs while increasing their confidence for both receiving training and being supported in caregiving
5. Seek a collective responsibility in the society to accompany and support each other, particularly, at the end of life
6. Make visible the compassionate community, the information, and the training received to that it reaches more people
7. Train the general community (children and young people, caregivers, patients, and health care professionals) in compassion, caregiving, and of life, death, and bereavement, regardless of whether they need these skills at present or may need them in the future
8. Help people to become more familiar with end of life and death through education, conversations, or experiences
9. Invest in the community the awareness that at some point we may have to take care of someone and be prepared for when this happens
10. Improve the quality of patient care by getting closer to patients, listening to them, respecting their autonomy, supporting them, and addressing their needs

11. Make people reflect on life and the future, including old age, illness and death and to become more accepting of them
12. Provide access to centralized information about other institutions and what to do in each case to direct people to someone who can take the lead
13. Change (improve) regional and cultural attitudes, including attitudes towards vulnerability, illness, and death
14. Generate spaces (and give tools) to talk about grief, normalize it and address it from the community so as not to depend on health professionals
15. Foster research in Compassionate communities
16. Empower citizens, including underserved and forgotten populations, to recognize and demand what they need
17. Recognize the wisdom of the community and ancestral peoples, learn from it and embrace it
18. Identify volunteers (including as caregivers) of different ages who have time and resources to support care



The Compassionate City Charter

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People who live with life-threatening or life limiting illness, their caregivers, and the bereaved are segmented social groups, forced to experience lifestyles that are commonly socially hidden and disenfranchised from the wider society. Outside of the health services that deal specifically with their immediate problems, these populations suffer from a range of other troubles that are separate but linked to their health conditions or social circumstances – loneliness, isolation, job loss, stigma, depression, anxiety and fear, or even suicide. These populations also suffer from a range of other debilitating health problems often caused by their social and psychological troubles - insomnia, cardiac arrhythmias, chronic fatigue and headaches, hypertension, and gastric-intestinal disorders.

THE COMPASSIONATE CITY

- A CHARTER OF ACTIONS -

Follow a strategy
The Bern declaration

Go for action
The compassionate city charter

The Bern experience

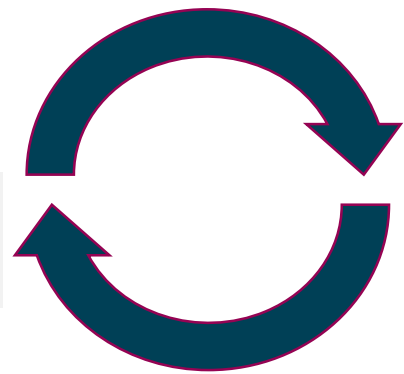
Define goals/ benefits
Core & local/ regional

AWARENESS & INFORMATION

- 5. Instill a collective responsibility in the society
- 6. Make the compassionate community visible
- 8. Help people to become more familiar with end of life, death & bereavement



Follow a strategy
The Bern declaration



Go for action
The compassionate city charter

Last night approximately 80.000 people died worldwide



Congratulations! It didn't hit you.



What matters to you in the remaining lifespan?



Join the cityfestival!



Let Bern burn: keep the momentum of compassion



From a firelighting event
to a long lasting, warming fire



Spread the message of compassion – go for action



- Create and further develop your Compassionate Communities
- Get inspired by worldwide models such as from Rwanda, Uganda, Kerala, Thailand, Japan, Canada, UK or Australia.....
- Host the next PHPCI conference and attract the community by organizing a cityfestival alongside
- Share pictures and tell stories
- Join PHPCI

And a final comment

Mankind explores the space by astronauts

What about exploring the **interrelational** space?



why not **compassionauts**?

***compassionaut (f,m,queer):** a human being dedicated to believe in Ubuntu principles and exercising compassion on a daily basis (Felber 2022)*

Towards a world of compassion

Why not 'World leading compassionauts'?





Building Bridges – reality not a dream


**Bärn
treit**

GEMEINSAM
BIS ZULETZT

**Endlich.menschlich.
Ultimately human**