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# Where are the forgotten people in palliative care?

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# Questions to consider

- Who is forgotten and why
- Why is this a problem for palliative care?
- How can we address such inequality?

# Case study' Eric '

Eric, a 60-year-old homeless man, is found confused, distressed and taken to hospital. His feet and legs are swollen and covered with ulcers and dead tissue - he has osteomyelitis, chronic obstructive pulmonary disease (COPD), chronic foot infections and alcoholism. Clinicians found a mass in Eric's lung that could be either TB or cancer. The infections in his legs are so severe that a double amputation is also recommended.

What questions does this pose for palliative care?

# Caring for marginalized and excluded persons

- For some, marginalisation and exclusion is the whole life experience
- Poverty, in all its forms, is an overarching theme
- Exclusion leads to conflict and destructive behaviour
- **Palliative care is not immune to this**

# The significance of the vulnerable 'other'

- To be vulnerable is to be human
- Vulnerability carries risks and harms
- Vulnerability becomes more visible when a person is ill because they are unable to defend themselves against it.
- Vulnerability can also enable people to make important changes in their lives to live better and longer.

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# Vulnerabilty is a global experience

- "Vulnerability is not just the experience of a disadvantaged minority, but is part of our universal human condition"
  - Stienstra D, Chochinov H. Vulnerabilty and Palliative Care. *Pall Support Care* 2012, 10: 1-2.

# Vulnerability - a public health message?

- Multiple descriptions
- Variable by country and politics

National Collaborating Centres for Public Health

Centres de collaboration nationale en santé publique

«Vulnerable populations are groups and communities at greater risk of ill health because of barriers to social, economic, political and environmental resources, as well as limitations due to disease or disability»

www.nccdh.ca

National Collaborating Centres for Public Health

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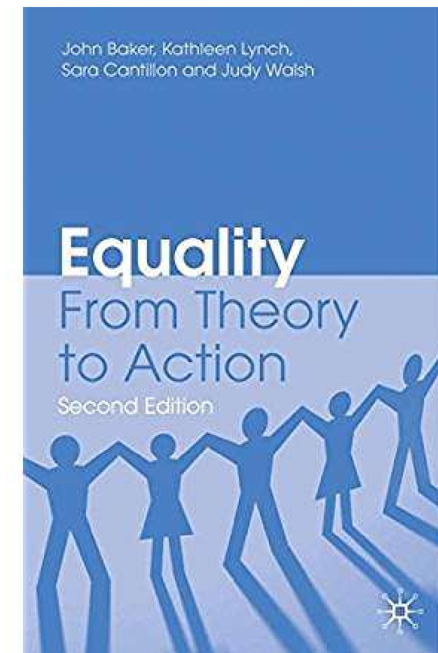
# Marginalised and underserved populations

- *Marginalised populations are groups and communities that are discriminated against and excluded (socially, politically and economically) because of unequal power relations between the economic, political, social and cultural dimensions.*
- *Q. Do we live in a society that unconsciously divides its citizens?*
- *Q. Health - a system that unconsciously divides its citizens?*

# The risks of social exclusion

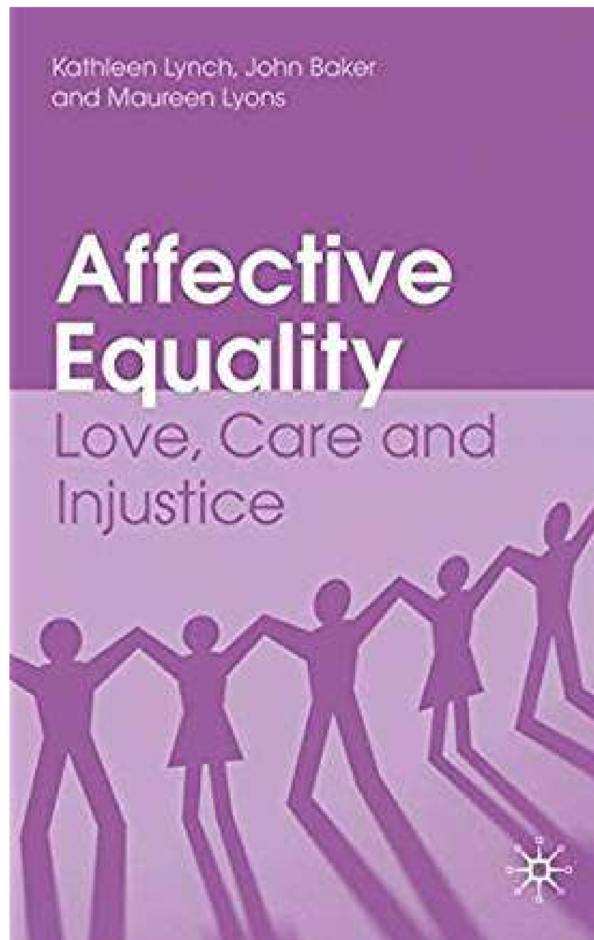
- Unemployment
- Low income
- Housing poverty
- High crime
- Family breakdown
- Addiction
- Mental health problems



# Social exclusion in palliative care – we are not immune!

- People with mental health problems
- People living with Intellectual Disability
- The palliative care needs of those in prison
- Chemical dependency

# Three determinants of inclusion




- Love - a sense of value and belonging
- Care - a fundamental prerequisite for human development, skills and behaviour
- Solidarity - interdependence on each other

***The absence of any or all of these leads to emotional inequality***

# Mental Health

# Serious and persistant mental Illness ( SMPI)

Significant impact on quality of life and curative options unlikely

Co-morbidity common

Benefit of a palliative care intervention considered valuable

May need to consider models of shared care

Pathway to palliative care unclear or possibly ‘blocked’.

Place of care

BMC Psychiatry

RESEARCH ARTICLE Open Access

## Acceptability of palliative care approaches for patients with severe and persistent mental illness: a survey of psychiatrists in Switzerland

Manuel Trachsel, Martina A. Hodel, Scott A. Irwin, Paul Hoff, Nikola Biller-Andorno and Florian Riese

**Abstract**

**Background:** Some patients develop severe and persistent mental illness (SPMI) which is therapy-refractory. The needs of these patients sometimes remain unmet by therapeutic interventions and they are at high risk of receiving care that is inconsistent with their life goals. Scholarly discourse has recently begun to address the suitability of palliative care approaches targeting at enhancing quality of life for these patients, but remains to be developed.

**Method:** A cross-sectional survey asked 1311 German-speaking psychiatrists in Switzerland (the total number of German speaking members of the Swiss Society for Psychiatry and Psychotherapy) about the care of SPMI patients in general, and about palliative care approaches in particular. 457 (34.9%) returned the completed survey. In addition, participants were asked to evaluate three case vignettes of patients with SPMI.

**Results:** The reduction of suffering and maintaining daily life functioning of the patient were rated as considerably more important in the treatment of SPMI than impeding suicide and curing the underlying illness. There was broad agreement that SPMI can be terminal (93.7%), and that curative approaches may sometimes be futile (e.g. 72.4% for the anorexia nervosa case vignette). Furthermore, more than 75% of the participating psychiatrists were in favour of palliative care approaches for SPMI.

**Conclusions:** The results of the present study suggest that the participating psychiatrists in Switzerland regard certain forms of SPMI as posing high risk of death. Additionally, a majority of respondents consider palliative care approaches appropriate for this vulnerable group of patients. However, the generalizability of the results to all psychiatrists in Switzerland or other mental health professionals involved in the care of SPMI is limited. This limitation is important considering the reservations towards palliative care in the context of psychiatric illness, mainly because of the association with death and futility. Palliative care approaches, however, are applicable in conjunction with other therapies intended to prolong life. A next step could be to involve service users and develop a consensus of what palliative care might encompass in SPMI. A framework for identifying which patients might benefit from palliative care, should be explored for the future development of care for SPMI patients.

**Keywords:** Severe and persistent mental illness, Goals of care, Quality of life, Treatment-refractoriness, Futility, Palliative care, Palliative psychiatry

BMC

# Prisoners

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# Prisoners

- Ageing population
- Issue of care versus custody
- Environment
- Issue of timely ongoing access
- Use of inmate volunteers
- Healing relationships/compassionate release
- Commitment to care
- Prioritizing the person not the prisoner

# Migrant and transient populations

# Migrant and transient populations

- 3.5% of the world's population are displaced and live outside their country of origin
- Definition is confusing and discriminatory
- Access varies widely across health systems and countries
- Migration exacerbates health problems
- People from ethnic groups are less likely to avail of PC services than those from the national community

# Why a problem in palliative care ?

Access impeded at a system, community and individual levels

Poor communication strategies

Preferences

Lack of resources in palliative care to manage the wider needs of the population.

Understanding of cultural humility as a tool to strengthen models of care.

## Palliative Care Utilization Among Non-Western Migrants in Europe: A Systematic Review

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**Abstract**

The paper aims to identify and describe the European evidence on opportunities and barriers to access and utilization of palliative care among non- western migrants. A systematic review in accordance with PRISMA guidelines was conducted in June 2020, searching Medline, CINAHL, PsychINFO and EMBASE databases. PROSPERO# CRD42020193651. Studies included empirical research published between 2011 and 2020. Search words were, for example, ethnic groups and palliative care. Thematic analysis was used to analyze data. Twenty nine qualitative and six quantitative studies were included. Four main themes were identified: communication and language; knowledge and awareness; patient preferences, cultural and religious issues; and lack of resources at different levels of palliative care service provision. Migrants' access to palliative care is impeded at system, community and individual levels, yet, recommendations are mostly at the individual level. Closer attention is required to these different levels when designing future palliative interventions for migrants.

**Keywords** Palliative care · Non-western · Migrants · Europe · Systematic review

### Introduction

International migration is increasing globally, with an estimated 272 million people (3.5% of the total world population) living outside their country of origin [1]. Since the Second World War, the continent of Europe has become more ethnically and culturally diverse [2]. In 2019, 21.8 million people (4.9% of the total population) living in Europe were born elsewhere [3]. As a result, the European healthcare system is serving an increasingly diverse population of patients [4]. All migrants in Europe have the right to equal access to health services from prevention to treatment, rehabilitation and palliative care (PC) without discrimination. This common goal of the continent towards provision of PC among migrants motivated our search to be conducted within Europe [5, 6]. Since palliative care is multidimensional, multiple settings including home, hospitals, long-term care facilities, cancer centers, and hospices are involved in the provision of care [7].

In Europe, migrants are defined diversely within several categories, including labour migrants, refugees and asylum seekers, family members of existing migrants, victims of trafficking, and returnees [4, 8]. In this review the term 'migrants' will be used as an overarching term inclusive of refugees, asylum seekers and other migrants [4] (Table 1). Due to different welfare systems within Europe, the right to access health care varies according to the migration status of the migrant. Within Europe, for example, undocumented migrants have the right to access free of charge, more than emergency care in five countries, only emergency care in twelve countries and only first aid in ten countries [9]. It is anticipated that legal aspects of migration status can influence access to and provision of palliative care among various migrant groups within Europe [10]. Although in this review non-western migrants will be named as a common group, they represent a variety of languages, religions and cultures originating from different continents of the world [11]. Migrants will not be categorized according 1st generation or 2nd generation migrants in this review.

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# Conclusions

- The forgotten people are in front of us – if we open our eyes and the eyes of others
- Populations underserved by misunderstanding
- Limited opportunities for communication enforced by misplaced professional roles and functions
- Leaving the comfort zone for the learning zone
- Seeing care as an element of social justice.

# The message of the spinning wheel

- *"The message of the spinning wheel is much wider than its circumference. Its message is one of simplicity, service of mankind, living so as not to hurt others, creating an indissoluble bond between the rich and the poor, capital and labor, the prince and the peasant."*

Mahatma Ghandi

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