Development of palliative care research in Switzerland. Insights from the NRP 67 «End of Life»

Tit.-Prof. Dr. Markus Zimmermann, Department of Moral Theology and Ethics, University of Fribourg, former President of the Steering Committee of the NRP 67 “End of Life”

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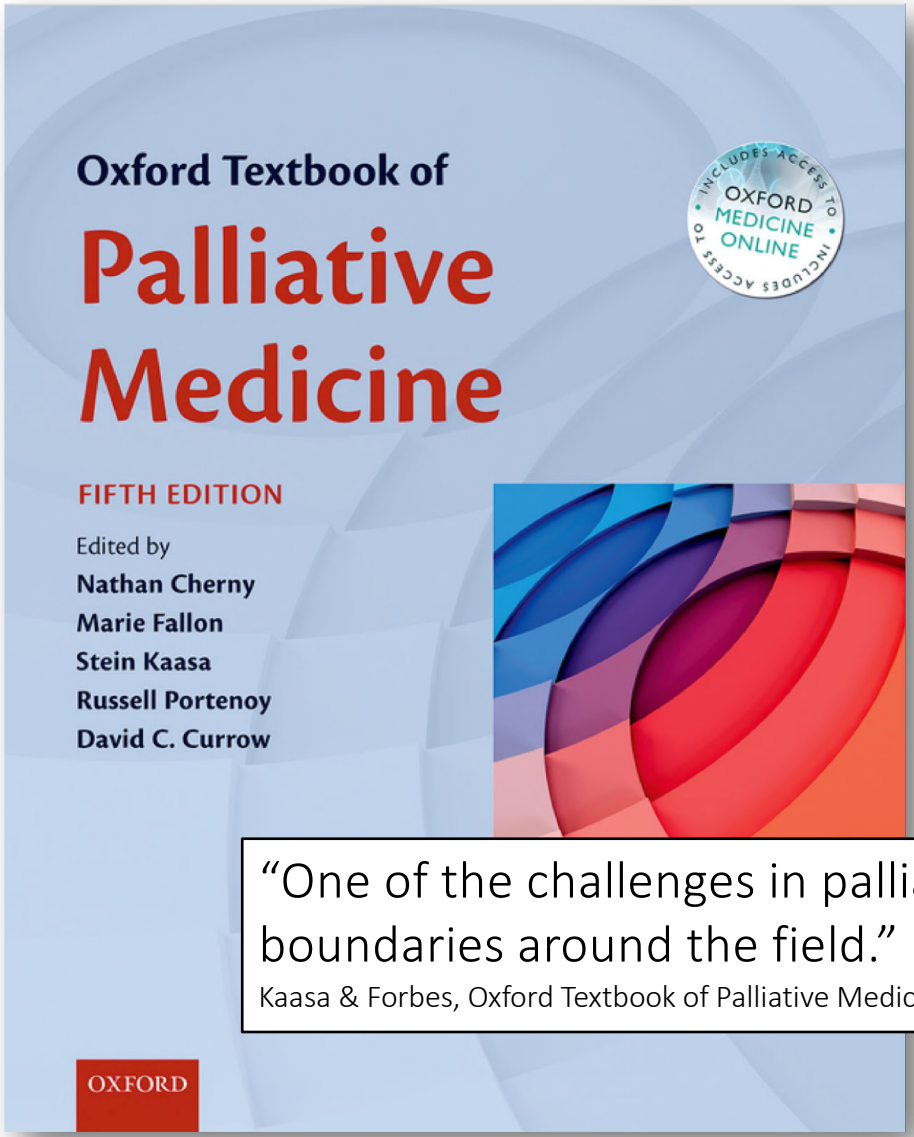
1. Challenges
2. Experiences
3. Next steps
4. Conclusion



19.1

Research in palliative care

Stein Kaasa and Karen Forbes

Ignorance has risks, but they are largely unseen and unnoticed. Gaining knowledge has risks which are noticed, but largely unpredictable, and it is very costly (though less so than prolonged ignorance). It focuses blame, whereas ignorance dispels it. So, maintaining ignorance often seems more attractive than gaining knowledge. (Vere, 1981)

Vere, D., Controlled clinical trials: the current ethical debate, *Journal of the Royal Society of Medicine*, Volume 74, Number 2, pp. 85–8, Copyright © 1981 by The Royal Society of Medicine. Reprinted by Permission of SAGE.

Introduction to research in palliative care

Duncan Vere was Professor of Clinical Pharmacology and Therapeutics at the London Hospital and one of the key advisors to Cicely Saunders when she founded St Christopher's Hospice in 1967. Vere is an expert in clinical trials and analgesic clinical pharmacology and was one of the first people to undertake and supervise research in a hospice setting. The quotation is taken from a paper he presented at the Royal Society of Medicine in London in 1981 in a debate about the ethical aspects of randomized controlled trials (RCTs). He was not talking specifically about research in palliative care but making a general point that it was easy to be deterred from undertaking rigorous scientific research in a clinical setting. He went on to highlight that such research is crucial to the advancement of reliable knowledge.

We have used Vere's quotation to open this chapter on research in palliative care in all four of the previous editions of this textbook because it is an apposite comment on the relatively slow progress of research in palliative care. The initial enthusiasm and urgency to gain a basic understanding of the physiology and pharmacology of the dying or severely ill patient and to evaluate the care provided and the treatment that was given did

tice in palliative care that are founded on clinical experience and anecdote rather than high-quality evidence, and this has applied even to core activities such as the control of pain.

Recently a debate about whether the Liverpool Care Pathway (LCP) is relevant for routine use in palliative care has been ongoing (Fainsinger, 2008). One element in the debate is the lack of scientific evidence supporting the content of the pathway, and there has been a lack of scientific evidence in the effect of implementation of the pathway into clinical practice until recently (Costantini et al., 2014).

This frustrating state of affairs has changed and is changing (Fainsinger, 2008). During the last decade there have been major developments in palliative care research in terms of funding, and the development of infrastructure and support for academic teaching and research. Substantial investment in departments that have the critical mass and facilities to allow high-quality research to be undertaken would take research in palliative care a quantum leap forward. During the last decade, in different parts of the world, new funding streams for palliative care research have become available.

Obstacles to research in palliative care

It has taken much time for research to become embedded within

re versus the 'greatest happiness of
ught sharply into focus in palliative
n to privilege the patient's best inter-
t of medical practice which is given
are. However, the physician also has
acquisition of scientific knowledge.
real conflict and raise difficult ethi-
ared, daily clinical practice, patient
nce over research.
in attracting high-quality research-
s partly a consequence of the uncer-
tain career structures and a relative lack of training opportunities (which reflects the lack of funding and investment). The need for academic palliative care researchers affiliated to formalized research

"One of the challenges in palliative care research is setting boundaries around the field."

Kaasa & Forbes, Oxford Textbook of Palliative Medicine 2015, p. 1147

DE GRUYTER

Michael Anderheiden, Wolfgang U. Eckart (Hrsg.)

HANDBUCH STERBEN UND MENSCHENWÜRDE

Unter Mitarb. v. Schmitt, Eva / Bardenheuer, Hubert / Kiesel, Helmuth / Kruse, Andreas / Wassmann, Jürgen

The field of palliative care research should be focused on issues like

- clinical effectiveness,
- acceptability,
- quality of care,
- eol decision making,
- health care provision.

JOURNAL OF PALLIATIVE MEDICINE
Volume 9, Number 5, 2006

Maslow's Hierarchy of Needs: A Framework for Achieving Human Potential in Hospice

ROBERT J. ZALENSKI, M.D., M.A.[1,2] and RICHARD RASPA, Ph.D.[2,3]

ABSTRACT

Although the widespread implementation of hospice in the United States has led to tremendous advances in the care of the dying, there has been no widely accepted psychological theory to drive needs assessment and intervention design for the patient and family. The humanistic psychology of Abraham Maslow, especially his theory of motivation and the hierarchy of needs, has been widely applied in business and social science, but only sparsely discussed in the palliative care literature. In this article we review Maslow's original hierarchy, adapt it to hospice and palliative care, apply the adaptation to a case example, and then discuss its implications for patient care, education, and research. The five levels of the hierarchy of needs as adapted to palliative care are: (1) distressing symptoms, such as pain or dyspnea; (2) fears for physical safety, of dying or abandonment; (3) affection, love and acceptance in the face of devastating illness; (4) esteem, respect, and appreciation for the person; (5) self-actualization and transcendence. Maslow's modified hierarchy of palliative care needs could be utilized to provide a comprehensive approach for the assessment of patients' needs and the design of interventions to achieve goals that start with comfort and potentially extend to the experience of transcendence.

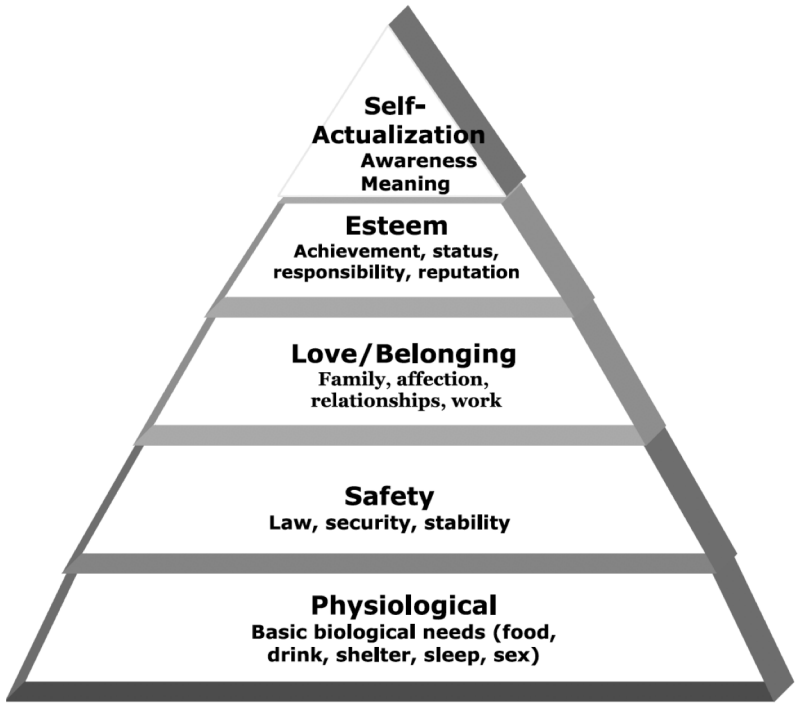


FIG. 1. Maslow's Hierarchy of Needs. The figure diagrams the dependence of higher on lower needs; the apex of the pyramid suggests that higher needs are less frequently realized.

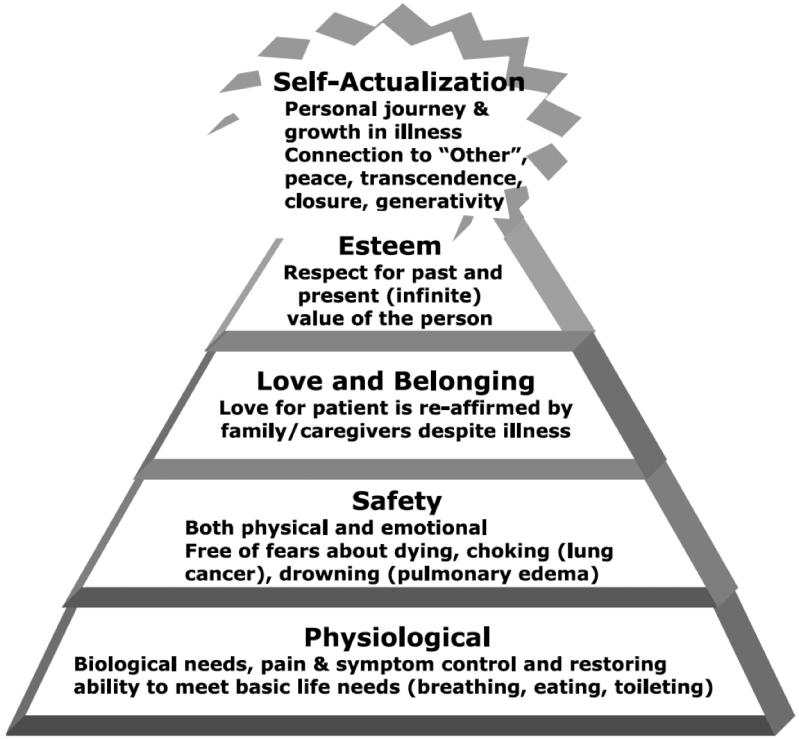


FIG. 2. Maslow's hierarchy adapted to hospice and palliative care. The figure diagrams the dependence on lower needs; the apex of the pyramid suggests that higher needs are less frequently realized.

Schwabe: Basel 2019

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ORIGINAL ARTICLE

WILEY European Journal of Cancer Care

Missing life stories. The narratives of palliative patients, parents and physicians in paediatric oncology

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Institute for Biomedical Ethics, University of Basel, Basel, Switzerland

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Funding information
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Illness narratives have become very popular. The stories of children, however, are rarely ever studied. This paper aims to provide insight into how children, parents and physicians make sense of progressive childhood cancer. It also explores how this meaning-giving process interacts with cultural dominant stories on cancer and dying. The
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determines the way in which children and adults relate to the minor's death, it also constitutes an obstacle to children's participation in decision-making.

KEYWORDS
dying, lived experience, narrative, paediatric oncology, palliative care, stories

The possibility that the child could die was either ignored or briefly contemplated, but then immediately pushed away. Except for one patient, children never directly addressed the topic of death. The way in which death was presented raises important questions about how the social discourse on dying is framed in terms of choice, autonomy and individuality.

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4. Conclusion

Darmstadt 2019

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Simon Peng-Keller, Eckhard Frick, Christina Puchalski, John Swinton (Hrsg.)

STUDIES IN SPIRITUAL CARE

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ISSN: 2511-8838
e-ISSN 2511-8846

Zielgruppe:
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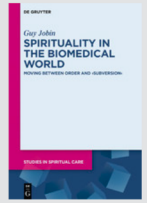
DE GRUYTER

Guy Jobin

SPIRITUALITY IN THE BIOMEDICAL WORLD

Moving between Order and "Subversion"



The need to take the spiritual experience during illness into account is part of a broader trend in Western societies—a fascination with the practical uses of

Studies in Spiritual Care 5
180 Seiten, 8 Tabellen (sw)

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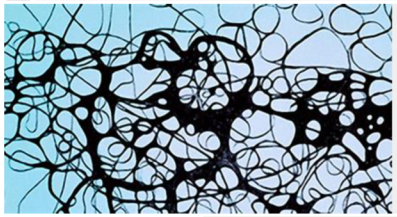
SPIRITUAL CARE

Zeitschrift für Spiritualität in den Gesundheitsberufen

Hrsg. v. Eckhard Frick, Simon Peng-Keller

«Das Jenseits kommt früh genug», sagt Simon Peng-Keller. Foto: Thomas Egli



Conclusion of NRP 67

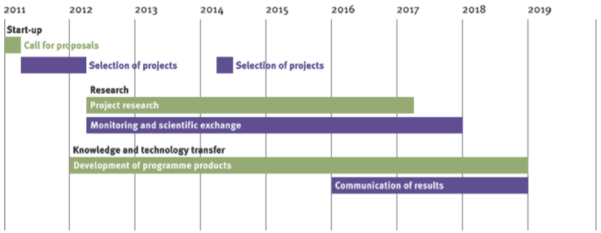
The eight-year National Research Programme NRP 67 "End of Life" was concluded in March 2019.

NRP 67 synthesis report | Conclusion of NRP 67 | "End of life in Switzerland" book available now!

Within the NRP "End of life" (NRP 67), 33 research teams studied aspects of the end of life in Switzerland from a variety of different perspectives. The results offer information useful to guiding decisions and practices at the end of life. This knowledge has been made available to decision-makers in the health care system, as well as to politicians and professionals involved in the care of individuals at the end of life. This research was performed between 2012 and 2017. The research programme was completed end of February 2019.

Organisation Events

Programme timetable

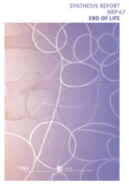


Publications

The book "Das Lebensende in der Schweiz"

Podcasts

NRP 67 Synthesis report



White Paper on geriatric palliative care in French-speaking Switzerland

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18.3384

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CHRONOLOGIE

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PLOS ONE

RESEARCH ARTICLE

Recollection of participating in a trial: A qualitative study of patients with severe and very severe chronic obstructive pulmonary disease

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Competing interests: The authors have declared that no competing interests exist.

Abstract

Background

Despite having similar palliative needs to patients with lung cancer, advanced chronic obstructive pulmonary disease (COPD) patients are less likely to receive palliative care. To evaluate the effect of introducing specialized palliative care with severe to very severe COPD patients, a randomized controlled trial (RCT) was conducted in Switzerland.

Aim

To explore COPD patients' recollection of the trial, their needs and the usefulness of the palliative care interventions.

Design and setting

Qualitative study with advanced COPD patients who participated in a specialized palliative care intervention, conducted in a general hospital.

Method

Eighteen patients with severe to very severe COPD were interviewed about their experiences. Interviews were transcribed and thematic content analysis was performed.

Results

Patients had poor recollection of the trial and difficulties understanding the palliative care intervention. No major differences were observed between patients who received the specialized intervention and those who did not. Content analysis emphasized that although they experienced disabling symptoms, participants tended to attribute their limitations to problems other than COPD and some declared that they were not sick. Patients reported restrictions due to oxygen therapy, and the burden of becoming dependent on it. This dependence resulted in intense anxiety, leading participants to focus on the present only. A strong feeling of perceived helplessness emerged from the patients' interviews.

Conclusions

Our findings suggest that poor recollection and understanding of the palliative care intervention act as barriers to the conduct of clinical trials with severe and very severe COPD patients. Their cognitive difficulties, perception of COPD, functional limitations, overwhelming anxiety, focus on the present and perceived helplessness also seem to hinder the implementation of such care.

1. Introduction

Chronic obstructive pulmonary disease (COPD) is a progressive lung disorder that causes important mortality and morbidity worldwide [1]. Severe COPD is associated with disabling physical symptoms, emotional distress, social isolation and poor quality of life [2, 3]. The illness trajectory of COPD has been described as one of long-term limitations with recurrent exacerbations that can result in death [4]. Within 2 years after admission for an acute exacerbation, mortality rates are between 36–50% [5].

The unpredictable illness trajectory of COPD makes it difficult to determine prognosis and can be a barrier to the provision of palliative care for these patients [6]. Despite having similar palliative needs to patients with lung cancer, studies have shown that COPD patients are less likely to receive palliative care than patients with lung cancer [2, 7]. Many COPD patients have limited access to palliative care services [2, 8–10]. Furthermore, patients with moderate to severe COPD often report infrequent and poor-quality communication about end-of-life care with their physicians [11, 12].

A randomized controlled trial (RCT) was conducted in Switzerland to evaluate the effect of introducing specialized palliative care for patients with severe and very severe COPD [13]. The primary objective of this study was to assess the impact of early specialized palliative care on hospital, intensive care unit and emergency admissions of these patients. Preliminary results show no significant differences between the intervention and control group in terms of exacerbation, hospital and intensive care unit admissions, or on scores for anxiety and depression. The results of the trial will be presented elsewhere.

Little is known about the views of advanced COPD patients on palliative care. To better understand the experiences of these patients with a specialized palliative care consultation, we undertook a qualitative study as a supplement to the above-mentioned RCT. More specifically, we investigated their recollection of participating in the trial and their particular needs at this stage of the disease. The results of this study could provide insights as to how patients suffering from this life-threatening lung disease remember and benefit from palliative care interventions and, conversely, on the possible barriers to the conduct of clinical trials and the introduction of such care with these patients.

2. Material and methods

2.1 Design/Sampling

The randomized controlled trial [13] was a 3-year single center study with a 2 arms parallel groups design. Inclusion criteria were patients with COPD defined according to the Global

3.2 "Nothing was done for me"

A majority of participants related a lack of understanding of the purpose of the study and questioned its usefulness. The patients in the intervention group mainly remembered completing study questionnaires but did not seem to remember and/or acknowledge the palliative care consultation as such.

3.3 "I'm not sick"

Although they suffered from advanced COPD with disabling symptoms, participants tended to talk more about other health problems they suffered from than about their COPD. Moreover, some attributed their functional limitations to aging rather than their illness and 5 patients even declared that they were not sick.

3.4 Functional limitations

Most patients expressed suffering from restrictions in daily activities. In particular, all but 2 participants reported difficulties in moving from one place to another because of dyspnea, oxygen therapy and/or aging. With the worsening of COPD, patients then mentioned the burden of becoming dependent on others and on oxygen to help them function.

3.5 Overwhelming anxiety

Throughout the patients' interviews, a strong feeling of living in a constant state of anxiety emerged. Anxiety was related to the fear of running out of oxygen (with oxygen therapy), having a respiratory distress, the aggravation of their COPD and death.

3.6 Focus on the present

It appeared through the interviews that the patients tended to focus on the present and avoid talking about the future.

3.7 Perceived helplessness

A strong feeling of perceived helplessness emerged from the patients' interviews. COPD was described as an incurable affection that caused a progressive and inevitable deterioration of their lungs.

PLOS ONE

RESEARCH ARTICLE

Recollection of participating in a trial: A qualitative study of patients with severe and very severe chronic obstructive pulmonary disease

Claudia Véron[1☯*], Sophie Pautex[1☯], Catherine Weber[1☯], Jean-Paul Janssens[2☯], Christine Cedraschi[3,4☯*]

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PLOS ONE | https://doi.org/10.1371/journal.pone.0204701 September 27, 2018 1 / 13

Some further obstacles

- Patient care will always take precedence over research.
- Uncertain career structures and a lack of training opportunities.
- Symptom control research is always likely to be less attractive than molecular genetics.
- Interdisciplinarity is still a challenge by looking for funding.
- Support for palliative care research largely depends on the valuation of a social issue, and not on scientific developments.
- Specialization and fragmentation determine still the field of health care.

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Future-proofing Dame Cicely Saunders' Centenary of Change: Integrating research, education and clinical care.

Professor Higginson writes: I was honoured to give the keynote lecture at the 10th World Research Congress of the European Association for Palliative Care, in honour of Professor Vittorio Ventrafridda, especially in this the centenary year of Dame Cicely Saunders. Vittorio's centenary year will be 2027. I hope then, that in 11 years' time, we will be celebrating even more achievements.

Integrating research, education and clinical care

We face a changing landscape of care and treatment. Achieving the best for patients and families requires the best in care, and this means delivering evidence-based practice. However, evidence is often lacking. When robust evidence for a symptom is lacking clinicians often provide medicines 'off-label' (i.e. use pharmaceutical drugs for an unapproved indication or in an unapproved group, dosage, or administration), rather than do nothing. One study, in a highly regarded palliative care unit, found that around one third of prescriptions were 'off-label'; breathlessness was one of the most common indications for off-label prescribing (n = 449, 20%).Yet, as we have learned from recent research, some medicines that have been widely promoted have limited or no effectiveness.

There are also many examples where clinicians and policymakers have implemented services and tools locally, nationally and even internationally, without evidence, on the basis that the intervention 'seems like a good idea,' or on small, single reports, often arguing that 'something must be done'.

We need innovation to be backed up by proper study; without both, the best for patients and families will not be realised. Otherwise we risk diverting resources from other things that would be effective, and potentially risk causing harm to patients and families.

But there is an even more basic reason for conducting research: evidence finds that *research-active healthcare services deliver better care, even for people who are not recruited into studies*. Thus, if clinical services want to offer the best in care, research should be a core part of their activity. Many issues that we are already tackling in palliative care are relevant elsewhere in health and social care; issues that we have grappled with for a long time, like complexity, multimorbidity and patient and family choice. The science of palliative care, the science that puts the person before their disease, coupled with its clinical innovations, has much to offer the wider 'ologies'. We have many approaches, measurement tools, knowledge and skills that are relevant.

Extract published with permission from a longer article first published on the EAPC Blog **eapcnet.wordpress.com**

What we need (Kaasa & Forbes 2015)

- To establish multidisciplinary research groups of sufficient strength and size.
- Long term planning.
- International and national collaboration.
- The long-term goal for clinical palliative care research should be to move from descriptive to interventional studies.
- New research initiatives as well as the establishment of new academic chairs of palliative medicine and palliative care nursing.
- The most urgent needs: Groups of sufficient size, national and international funding and the training of a sufficient number of clinicians and scientists.

What could that mean for us in Switzerland?

- Research should be centered on clinical and epidemiological aspects.
- It’s necessary to create more experienced research teams.
- Collaboration with research teams in oncology, intensive care or other disciplines.
- Interventional studies.
- Possibility to die at home.
- Practical hints for young researchers on the EACP-blog (Joni Gilissen et al. 2018).
- Research in the expanding field of assisted suicide in Switzerland.
- Establishing palliative care itself.

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The Blog of the European Association for Palliative Care

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From well-equipped cohort to future research leaders: Preparing the next generation palliative care researchers

Posted on August 6, 2018

In light of the ever-ageing palliative care work-force, including research, a critical question relates to the development of research capacity. There is an urgent need to consider how we prepare the next generation researchers (Philip Larkin et al., 2016).

Joni Gilissen, Robrecht De Schreye, Arno Maetens, Lenzo Robijn, Steven Vanderstichelen, Romy Van Rickstal *and* ***Maarten Vermorgen*** *represent a group of 27 PhD candidates [1] working in palliative care research in Belgium. In this blog post, they shout out to you, highlighting how they feel junior researchers can be optimally prepared in order to advance palliative care in their future careers.*

To improve future research in the palliative care domain, recruiting young potentials is not enough. Junior researchers need appropriate training to be future leaders in the field. In 2015, Professor Catherine Walshe wrote an EAPC blog post advocating for people to engage in a PhD in palliative care. Besides the

Clockwise: Joni Gilissen, Steven Vanderstichelen, Robrecht De Schreye, Arno Maetens, Lenzo Robijn, Maarten Vermorgen and Romy Van Rickstal.

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Home > Joni Gilissen

Joni Gilissen

Junior Researcher
MSc - Social Work and Social Policy
Promotor: prof. dr. Lieve Van den Block & prof. dr. Chris Gastmans (KU Leuven)

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Joni (*1990) holds a degree in Social Work (2011, KHLeuven), a master's degree in Social Policy (2013, KULeuven) and an additional postgraduate degree in Social Profit and Public Management (2014, Ghent University). She is currently working within the inter-university and interdisciplinary End-of-life Care Research Group on a project funded by FWO (Research Foundation – Flanders) in which she will develop and evaluate an Advance Care Planning intervention in the nursing home setting. Furthermore, she coordinates the Twitter page of the research group and is responsible for the monthly newsletter.

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https://eapcnet.wordpress.com/2018/08/06/from-well-equipped-cohort-to-future-research-leaders-preparing-the-next-generation-palliative-care-researchers/

Development of palliative care research in Switzerland.

Insights from the NRP 67 «End of Life»

1. Challenges
2. Experiences
3. Next steps
4. Conclusion

Three tasks in the years to come

- To promote a narrow definition of palliative care research and to prioritize projects that have direct connection to practice and planning.
- To become aware of the ideals, assumptions and values of palliative care in a pluralistic social context.
- Both to create research groups of sufficient size and to search for national and international funding.

“We should never forget that palliative care research always puts the person before their disease.” (Irene Higginson)