

Public Health Research in Palliative Care: Shifting the Paradigm

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Abstract book

Thursday 25 October

Oral presentations

Men and Family caregivers' experiences of advanced prostate cancer in Ghana: A qualitative serial interview study

Salifu, Y., Almack, K., Caswell, G.

Background: Family caregivers who assume the responsibility of care for patients living with advanced diseases could have challenges especially in resource-poor settings. The bulk and responsibility for care are predominantly provided by the family caregivers within the informal sector. The family caregivers, therefore, could be described as the 'general practitioners' of the patients at home. Using a qualitative study, the experiences of the family caregivers caring for men with advanced prostate cancer were explored.

Methods: Using serial qualitative approach, 23 in-depth individual and dyad interviews were conducted. Patients and their caregivers participated in repeat interviews approximately 2 months apart, across a period of up to 6 months. Transcribed interviews were analysed using thematic analysis.

Findings: This paper focuses on the experiences of family caregivers in the light of inadequate resource for care. Two main themes emerged from the data: Challenges and burden of care, and the support and coping strategies adopted. The family caregivers expressed the overburden nature of the care, 'feeling of being alone in the middle of a deep sea', disruption of their lives, and unhappiness and the fear of an unknown future. On the other hand, they rely on the support of the social network of the extended family, their faith in God, and the positive aspect of living helped to mitigate some of the challenges. The belief in reciprocity and 'giving back' through caring for their loved ones were highlighted by participants.

Conclusion: Generally, the informal social network helped in the care at home. However, the magnitude of the adverse changes in their lives and challenges associated with the caring role was dependent on factors such as the level of care required, financial and other resources available, and the coping mechanisms in place. Efforts to enhance existing social support systems are recommended.

Trends in the timing and uptake of palliative home care support: a register-based study using full-population national databases from 2010-2015

Maetens A., Beernaert K., Deliens L., Van den Block L., Cohen J.

Background: There has been a growing evidence and awareness of the influence of using and timely initiating palliative home care (PHC) support on the quality of care. However, evidence is lacking on whether this has translated into increased and earlier use. This study evaluates the trends in uptake and initiation of PHC support in Belgium between 2010 and 2015 within the full population with possible palliative care needs.

Methods: Eight routinely collected population-level databases were linked, covering all deaths in Belgium between 1 Jan 2010 and 31 Dec 2015 (n=634,445). We selected a population comprising deaths from underlying causes that can be considered as indicative of a need for a palliative care approach, as identified through mixed-methods research. Using reimbursement codes registered in the database, we measured the use and timing of initiating PHC support in Belgium: multi-disciplinary PHC team, PHC nursing or physiotherapy, allowance for PHC patients. To describe trends in the uptake of PHC support, we plotted actual and standardized rates from 2010-2015, standardizing for age, sex and cause of death. To describe trends in the timing of uptake of palliative home care support, we performed a survival analysis with left censoring.

Results: Comparing 2010 and 2015, the proportion of deaths in Belgium that were of home-dwelling people dying of an illness indicative of palliative care needs did not change significantly (respectively 36.2 vs 36.0%). The proportion of those using any PHC support increased about 3 percent points between 2010 and 2015, with a small difference between actual (31.7 to 35.1%) and standardized uptake (31.7 to 36%), demonstrating that the increase in uptake was not influenced by changes in decedent age-gender-cause of death composition. Between 2010 and 2015, the timing of initiating PHC support in median number of days increased from 41 days (mean=100.7; IQR=99) to 46 days (mean=115.8; IQR=119) before death.

Discussion: This study found a slight increase in the uptake and timing of initiating PHC between 2010 and 2015 among people with possible palliative care needs. The increase is modest when considering the recent increase in political, societal and scientific awareness for palliative care in Belgium.

Dying in long-term care facilities in Europe: the PACE epidemiological study of deceased residents in six countries.

Honinx, E, van Dop*, N., Smets, T., Deliens, L., Van Den Noortgate, N., Froggatt, K., Gambassi, G., Kylänen, M., Onwuteaka-Philipsen, B., Szczerbińska, K., Van den Block, L. ; on behalf of PACE*

Background. By 2030, 30% of the European population will be aged 60 or over and those aged 80 and above will be the fastest growing cohort. An increasing number of people will die at an advanced age with multiple chronic diseases. In Europe at present, between 12% and 38% of the oldest people die in a long-term care facility. The lack of nationally representative empirical data, either demographic or clinical, about people who die in long-term care facilities makes appropriate policy responses more difficult. Additionally, there is a lack of comparable cross-country data; the opportunity to compare and contrast data internationally would allow for a better understanding of both common issues and country-specific challenges and could help generate hypotheses about different options regarding policy, health care organisation and provision. The aim of the study was to describe the demographic, facility stay and clinical characteristics of residents dying in long-term care facilities and the differences between countries.

Methods. Epidemiological study (2015) in a proportionally stratified random sample of 322 facilities in Belgium, Finland, Italy, the Netherlands, Poland and England. Facility manager, nursing staff member and treating physician completed structured questionnaires for all deaths in the preceding three months

Results. Of 1,384 residents the average age at death ranged from 81 (Poland) to 87 (Belgium, England) ($p < 0.001$) and length of stay from six months (Poland, Italy) to two years (Belgium) ($p < 0.05$); 47% (the Netherlands) to 74% (Italy) had more than two morbidities and 60% (England) to 83% (Finland) dementia, with a significant difference between countries ($p < 0.001$). Italy and Poland had the highest percentages with poor functional and cognitive status one month before death (BANS-S score of 21.8 and 21.9 respectively). Clinical complications occurred often during the final month (51.9% England, 66.4% Finland and Poland).

Conclusion. The population dying in long-term care facilities is complex, displaying multiple diseases with considerable cognitive and functional impairment and high levels of dementia. We recommend future policy should include integration of high-quality palliative and dementia care.

Treatment patterns and associated factors in patients with advanced epithelial ovarian cancer: a population based study between 2008 and 2016.

Zijlstra M., Timmermans M., Franssen H.P., Reyners A.K.L., van de Poll-Franse L.V., Raijmakers N.J.H.

Background Ovarian cancer is the fifth most common cancer in women and is often diagnosed in an advanced stage, leading to a poor prognosis. A significant proportion of women do not receive cancer-directed treatment (CDT). Limited research has been devoted to this group. This nationwide study aims to gain insight into the trends in treatment patterns in patients with advanced epithelial ovarian cancer (EOC) and main reasons for withholding CDT.

Methods All Dutch patients diagnosed with advanced stage (FIGO IIB-IV) EOC, including peritoneal and fallopian tube carcinoma, between 2008 and 2016 were identified from the Netherlands Cancer Registry. Trends in the number of patients who received CDT were analysed. Logistic regression analysis was used to identify factors associated with CDT. In addition, the main reasons for no CDT (as reported in medical charts) were analysed.

Results A total of 9,303 patients were included. Of these patients, 13% (n=1,227) received no CDT while 67% (n=6,218) received a combination of cytoreductive surgery and chemotherapy and 15% (n=1,396) received chemotherapy only. The remaining patients received hormonal therapy only or surgical treatment only. The proportion of women receiving no CDT was higher in 2014-2016 (15%, n=486) compared to 2008-2010 (11%, n=331, $p<0.001$). Associated factors with withholding CDT were higher age (mean age no CDT 78 years versus CDT 66 years), more often FIGO stage IV, a lower socioeconomic status and more often comorbidity (all $p<0.001$). The main reasons not to start CDT were patient's choice (40%) and a poor condition of the patient (28%).

Conclusion The proportion of patients with advanced EOC not receiving CDT has increased in the last decade. Patient's choice was the main reason not to start CDT, followed by a poor condition of the patient. The latter may be supported by the observations of a higher age, more often FIGO stage IV and more concurrent comorbidities in this patient group. These results might indicate advancements in the process of choosing wisely, for both patients and physicians.

The quality of primary palliative care for the oldest-old in three European countries: A mortality follow-back study

De Nooijer K., Pivodic L., Deliens L., Miccinesi G., Vega Alonso T., Moreels S. & Van den Block L.

Background Populations are ageing, with the oldest-old (aged \geq 85 years) as the fastest growing group. Serious chronic conditions become more common with age, therefore many of the oldest-old experience complex health problems. Palliative care is indicated for the majority of them; however, there is a lack of population-based data on the quality of palliative care for this population. We aimed to examine the quality of primary palliative care for the oldest-old in three European countries.

Methods Nationwide representative mortality follow-back study. Data were collected by epidemiological surveillance networks of general practitioners (GPs) in Belgium (BE), Italy (IT), and Spain (ES) (2013 - 2015). GPs registered all deaths in their practice. We applied a set of nine quality indicators developed through literature review and expert consensus. We excluded people aged $<$ 85 years, and who died sudden judged by GPs. Analysis included generalized linear mixed models.

Results GPs registered 1203 non-sudden deaths of people aged \geq 85 years (BE n=690 IT n=342 ES n=171). The scores in BE (reference category) significantly differed from IT and ES for acceptance of death (BE=62.8% IT=49.1% ES=38.8%), patient-GP communication about illness (BE=46.9% IT=9.4% ES=32.8%), GP awareness of patient preferences (BE=34.3% IT=11.6% ES=11.2%), repeated multidisciplinary consultations (BE=38.4% IT=13.1% ES=10.0%), and involvement of specialized palliative care services (BE=60.5% IT=18.3% ES=77.3%). Regular pain measurement (BE=45.1% IT=14.8% ES=46.6%) and patient death outside the hospital (BE=74.9% IT=72.4% ES=67.3%) significantly differed between BE and IT. No differences were found for relative-GP communication and bereavement counseling.

Conclusion Considerable cross-country differences were identified in the quality of primary palliative care. Yet, there is room for improvement, especially in achieving GP awareness of patient preferences and regular multidisciplinary consultations.

Experience of bereavement and grief support: An Irish population study

Roberts A Keegan O Weafer J

BACKGROUND Information about how contemporary grieving is experienced and supported through time in Ireland is scarce. This study set out to bridge some of the knowledge gaps by exploring the bereavement experiences and support profiles of bereaved Irish adults.

METHODS This study is a population-based cross-sectional study of bereavement experiences and entailed a telephone survey of a random sample of 908 adults in the Republic of Ireland.

RESULTS Bereaved participants' (n=767) who reported deterioration in one aspect of wellbeing (i.e. physical health, mental health and financial situation) were more likely to report deterioration in another aspect. A vulnerable group who did not receive sufficient support were identified. They were more likely to report a deterioration in wellbeing, rate support from family/friends negatively and more likely to access community or professional supports. Overall, the 'helpfulness' of community and professional support varied with many more likely to be rated negatively.

CONCLUSION Developing standards for bereavement care in Ireland which provide a framework for services, providing guidance on level of service provision, associated staff competencies/training needs may be a first step to address these issues. In addition, the development of a public health approach to bereavement care is needed to support 'everyday assets' in the community who care for the majority of the bereaved.

Findings from a DöBra Feasibility Study: A Conversation-based Intervention for Clarifying Values and Preferences for End-of-Life in the Advance Care Planning-naïve Swedish Context

*Tishelman, C., Henriksson, M., Menkin, E. & Lindqvist, O.**

Olav Lindqvist led the project

reported here until his death in March 2018

Background and Objectives: Sweden today has no systematic advance care planning (ACP), nor judicial means of recognizing a proxy to advocate in end-of-life (EoL) situations. In the SweACP project in the DöBra program, we focus on an ACP approach that engages stakeholders in active conversations about preferences for future EoL care, rather than one that is driven by legal aspects or documents. In this presentation, we discuss results of a feasibility study testing this conversation-based structured ACP approach among older adults in the general public in Sweden.

Research Design and Methods: After initial testing in pilot focus groups (4 groups/16 participants), a Swedish version of GoWish cards, DöBra cards, and Eco-mapping were used in a structured intervention to catalyze discussions on what and who matters at the end-of-life. The 66 people interviewed individually or in couples were recruited from across Sweden. They actively contacted the researchers, volunteering to participate after receiving information through national patient-or retiree organizations.

Results: The DöBra cards were positively received by participants; the great individual variation in prioritization of the 37 card items about preferences for EoL care and the use of personally formulated wild cards suggest it to be a feasible tool for stimulating person-centered conversations on preferences for future EoL care. Eco-mapping was met with less enthusiasm but was useful in depicting a social context often taken-for-granted.

Discussion and Implications: In the Swedish ACP-naïve context, having a hands-on tool rather than just talking, raising concrete issues otherwise not considered, and wild cards opening up for conversations on possibly taboo subjects were noted strengths of the DöBra cards. How to communicate these values and preferences further, particularly for the vulnerable and growing group who lack family or other advocates, is a topic which needs to be addressed in future work.

Navigating power and responsibility in developing an intergenerational and arts-based program about death and loss as part of the Swedish DöBra Research Program

Kleijberg, M., Macdonald, A. & Tishelman, C.

Background Age-segregation and a lack of community involvement in issues related to the end of life (EoL) motivated us to collaborate with community organizations to develop Studio DöBra, an intergenerational and arts-based initiative to support conversations about the EoL and develop intergenerational meeting places. The involved organizations were a library, an activity center for elderly, an artistic organization for children, and a school. Representatives from these organizations formed a project group with the first author to develop Studio DöBra: 5 weekly 2-hour workshops with 8 children (9 y/o) and 8 elderly (65+) participating together in a variety of artistic projects (e.g. collage, drawing, performance) with different themes related to death and loss. We aim here to explore challenges in and approaches for navigating the collaborative process of developing this initiative.

Methods This study was guided by principles of community-based participatory research. Data was generated through documentation of the development process (audio-recordings); observations; and follow-up interviews with members of the project group, participating elderly, children, and their parents. These data were analyzed in an inductive qualitative process.

Results We found that members of the project group – the ‘adults-in-between’ the participating children and elderly in age – have both power over and feel a sense of responsibility for these two age groups. These dynamics can either enable or serve to block, avoid, or silence intergenerational conversations about the EoL. We illustrate this here by focusing on challenges in developing ways to raise EoL issues in this intergenerational context, and how collective reflection was used to deal with this.

Conclusion We found that the manner and extent to which the adults-in-between, reflected on and shared their own experiences about the EoL, was related to how they approached their roles in facilitating conversations with other age groups.

Exploring a conversation tool for reflection about the end of life in elder care

Johansson, T. (1), Tishelman, C. (1, 2, 3), Eriksson, L.E.(1), Cohen, J. (4), Goliath, I. (1)

Background Residential care homes (RCHs) are a major site for end of life (EOL) care in Sweden. RCH staff with least formal education often have most contact with dying elderly, but are generally untrained in supporting residents and families in communicating about EOL matters. Opportunity to reflect with others on issues related to death and dying –including one's own mortality– is suggested in research literature as one means to help staff prepare to support RCH residents at the EOL.

Objectives The aim of this study is to explore, together with elder care staff, how a conversation tool – the DöBra cards, a translated and adapted version of the GoWish cards – can support reflection and discussion about what matters at the EOL.

Methods This action research project is part of the DöBra research program. Data was collected through 6 series of 4 consecutive focus group discussions (FGDs) with staff (n=39) at 6 elder care facilities in Stockholm. The Swedish DöBra cards, consisting of 37 statements covering physical, practical, social and existential matters at the EOL, were used to facilitate discussions about death and dying.

Results Preliminary analysis of FGD transcripts indicates that using the DöBra cards promoted sharing of professional and personal reflections and experiences about death and dying, in particular staff's own, residents' and relatives' values and preferences for the EOL. Staff reported that opportunity for reflection increased their sensitivity for EOL matters, sense of preparedness for, and comfort with, engaging in conversations about EOL with colleagues, residents and relatives. Staff also generated ideas for improvement of EOL care provision within the RCHs.

Discussion In this presentation, we will focus particularly on staff's own suggestions and initiatives to support conversations about values and preferences for EOL care in elder care, e.g. using the DöBra cards in group discussions with colleagues and introducing them to residents and relatives.

Where lies the potential role of public health in shaping equity of access of palliative care services for homeless individuals?

Joss K.

Background: Homeless individuals are widely regarded to be some of the most vulnerable members of any given society, corresponding to higher rates of complex comorbidity and early mortality. However, these individuals also often fail to access quality palliative care services, and relatively little research and surveillance in this area has thus far led to a perpetuating cycle of societal neglect. By exploring the nature of the complex needs of homeless individuals and the access barriers they experience, this study aimed to question our understanding of public health's key responsibilities, and investigate how these interact with the health and social inequalities at play.

Methods: This review employed MEDLINE, PubMed, Cochrane Library and Scopus to produce 37 studies outlining staff and homeless individuals' experiences of, and attitudes towards, palliative care. Several relevant reports from UK-based organisations, including St Mungo's and Marie Curie, were also included. A thematic analysis highlighted access barriers, which were compared with core public health services as outlined by the Institute of Medicine and also the Good Life, Good Death, Good Grief initiative. These two literature areas have not previously been co-examined.

Results: This study found that access barriers for homeless individuals stemmed from poor availability and acceptability of existing services, with regard to their unique and complex needs. Issues were highlighted at both service and structural levels, corresponding to serious negative consequences for the wellbeing of both homeless persons and the frontline staff who supported them. These gaps correlated strongly to key aspects of public health approaches, encompassing poor societal assessment, assurance and policy development in this area. As such, it is thus argued that key aims of public health approaches may play a critical role in shaping future equity of access for this population.

Conclusion: This study concludes that public health approaches focusing on societal empowerment around topics of death and dying, and the fostering of service compassion and collaboration, have the ability to lessen the steep gradient in palliative care accessibility, through shaping service acceptability and availability.

Making The People's Charter on Dying, Death and Bereavement in Ireland

Foley S., McLoughlin K., Edghill A., Lloyd R.

BACKGROUND The Irish Hospice Foundation (IHF) has worked for over 30 years to support the best care at end of life and in bereavement for all. Our national 'Have Your Say' campaign aimed to explore what is most important to our citizens about living with life-limiting illness, death and bereavement. From the responses we sought to reflect these views in a Charter on Dying, Death & Bereavement in Ireland. Informed by these voices the Charter belongs to the Irish people. The project aimed to develop the Charter through:

- A national online survey tool to capture the views of the Irish people
- An extensive marketing campaign and publicity strategy to maximize completion of the survey.
- Four Death Café Conversations

METHOD To promote awareness of the survey, engaging stories from 23 people on their experiences of dying, death, loss and grief were captured on the streets of Irish cities. An online survey tool was developed asking 6 open-ended questions along with basic demographic information. It was promoted via (1) ongoing social media campaign (2) promotion of survey during palliative care week when #Haveyoursay trended on Twitter through @Ireland handle; (3) poster and leaflet campaign; (4) hard copy questionnaires to key stakeholders including NGOs, libraries, politicians, students, health conferences, Death Café Conversations in 4 locations nationwide (5) radio interviews and publications. The Survey Monkey tool was open for 11 weeks. Data thematically analysed provided key areas for development of wording for the Charter.

RESULTS 2563 responses received with demographic breakdown largely in line with population distribution in Ireland. 84% female. 41% 45-59 years old. Survey is the largest known such study of Irish opinion on this topic at this time. Analysis indicated that most people want to be pain-free, to be treated with and to die with dignity, to feel comfortable and cared for, ideally at home.

CONCLUSIONS The Charter will inform our work including advocating change in public policy; supporting the dying, caregivers and the bereaved; educational outreach to help communities address social and spiritual needs. We will actively enhance a public health approach to palliative care by creating supportive networks, resources and assistance to the citizens of Ireland.

Friday 26 October

Oral presentations

Criterion validation of a simple tool for early identification of palliative care patients (ID-PALL): preliminary results

Teike Lüthi F., Bernard M., Gamondi C., Vanderlinden K., Ramelet A.-S., & Borasio G.-D.

Background Early identification of patients requiring palliative care (PC) is a major public health concern. A growing number of tools exist to help professionals to identify palliative patients, but none of the available tools has been thoroughly assessed for criterion validity so far. In addition, available tools do not differentiate between patients in need of general or specialized PC, and are primarily intended for physicians' use. ID-PALL was developed to address these questions.

Objective Establish the criterion validity of ID-PALL, a short questionnaire for early identification of patients in need of general or specialised palliative care, for use by health care professionals without specific palliative care training.

Method Criterion validity of ID-PALL was tested in the French and Italian speaking regions of Switzerland. Sample size was calculated based on: sensitivity of 0.9, precision of 5% and $p \leq .05$. Patients were assessed between day 2 and 5 of their hospital stay in internal medicine wards by nurses or physicians using the tool. The ID-PALL results were compared with the clinical assessment by pairs of specialised palliative care nurses and physicians: the current gold standard for identification.

Results 837 patients were included between March and June 2018 (45% women, median age 76 yrs, 23% oncological patients). Preliminary analyses show a good sensitivity and a moderate specificity of the tool part that identifies patients with general PC needs. The part for specialised PC showed a good sensitivity and a moderate to good specificity. Updated results will be reported at the congress.

Discussion Data collection will be completed by the end of 2018. Our preliminary results suggest that ID-PALL may be more precise in identifying patients in need of specialised PC than those in need of general PC. These results await confirmation and further statistical analyses are required to identify the reasons for this variance.

**Four profiles of informal caregivers who provide care to patients at home at the end of life:
A Q-methodological study into informal caregiver' support needs**

Bijnsdorp F.M., Pasman H.R.W., Boot C.R.L., van Hooft S.M., van Staa A. & Francke A.L. Bijnsdorp F.M. (1), Pasman H.R.W. (1), Boot C.R.L. (2), van Hooft S.M. (3), van Staa A.(3,4) & Francke A.L. (1,5)

Background: Informal caregivers of patients at the end of life often experience care-related burden. To prevent overload and to enhance the capacity to provide care it is important to have insight in their support needs.

Objective: To identify profiles of informal caregivers who provide care to patients at the end of life at home. **Design and methods:** A Q-methodological study in which informal caregivers ranked 40 statements on support needs and attitudes towards their care situation. They were asked to motivate their ranking in an interview. By-person factor analysis was conducted to identify corresponding ways in which informal caregivers ranked the statements. Informal caregivers with the same views shared the same factor. The factors were interpreted as informal caregiver profiles.

Participants: A sample of 41 informal caregivers with a variety on background characteristics who currently or recently provided care for someone at the end of life at home were included.

Results: Four distinct profiles of informal caregivers were identified; (1) those who want appreciation and an assigned contact person, (2+) those who are positive about sharing care or (2-) wish to share care but are not able to or unsatisfied, (3) those who want information and practical support and (4) those who need time off. These profiles reflect different needs and experiences with support and different attitudes towards being a co-worker or a co-client in the care situation.

Conclusions: Informal caregivers of patients at home at the end of life have varying support needs and one size does not fit all. The profiles are relevant for healthcare professionals and volunteers in palliative care as they provide an overview of the main characteristics and support needs among informal caregivers of patients near the end of life. This knowledge can help healthcare professionals giving support.

Self-management of patients with advanced cancer: a systematic review

Van Dongen S1, de Nooijer K2*, Cramm JM3., Francke A4,5., Oldenmenger W6., Korfage I1., Witkamp E7., Stoevelaar R1., van der Heide A1. & Rietjens J1.*

Background Patients with advanced cancer are increasingly expected to self-manage their health and care. However, studies on this topic are heterogeneous regarding the self-management strategies and populations examined. We present an overview of the self-management strategies of patients with advanced cancer, and the attitudes of patients, relatives and healthcare providers towards self-management of patients with advanced cancer.

Methods We systematically searched Medline (Ovid), Embase, Cochrane Central, PsycINFO (Ovid), CINAHL (Ebsco), Web of Science Core Collection and Google Scholar for observational studies on self-management of patients with advanced cancer published until February 2017. Study selection and quality appraisal of included studies were performed by two researchers independently. Data were extracted with a pilot-tested extraction form. We used a qualitative thematic framework approach to categorize self-management strategies into broader domains.

Results The search yielded 1342 studies, of which 27 studies (i.e. seven quantitative studies and 20 qualitative studies) were relevant for this review. Twenty-six studies assessed the perspectives of patients, they were found to use self-management strategies in seven domains: medicine and pharmacology, lifestyle, psychology/mental health, social support, knowledge and information, navigation and coordination, and decision-making. Within each of the domains, strategies were often highly individual and sometimes ambivalent and mainly aimed to optimize patients' own and/or their loved ones wellbeing. Two studies addressed the perspectives of healthcare providers, most of them perceived self-management as both desirable and achievable if based on sufficient skills and knowledge and solid patient-professional partnerships.

Conclusion Self-management of patients with advanced cancer spans many domains. Patients use highly individual and sometimes seemingly contradictory strategies. Self-management support programmes could benefit from an individualized approach and embedding in solid partnerships with relatives and healthcare providers.

Stakeholder engagement in the development of complex interventions

Gilissen Joni1, De Nooijer K1*, Pivodic L1. & Van den Block L12. *Contributed equally*

Background Stakeholder engagement is considered integral to develop effective health interventions and encouraged across all phases of the research cycle. However, there are few tools to facilitate such engagement, especially during intervention development. We describe how the Theory of Change (ToC) method was used to engage stakeholders in developing two complex interventions: advance care planning in nursing homes and specialist palliative care for older people in primary care.

Methods Both studies used the ToC method, defined by Aspen Institute as “a theory of how and why an initiative works which can be empirically tested by measuring indicators for every step on the hypothesised causal pathway to impact”. Following two systematic reviews, both studies organised stakeholder workshops to develop these theories. The process started by reaching agreement on the intended impact (eg quality of care) of the intervention, then ‘worked backwards’ to determine intermediate outcomes (eg staff has sufficient skills) necessary to achieve the impact. A ToC map presents how, why and under what circumstances the intervention is expected to be effective in the specific context.

Results Both studies organised 2-4 workshops with stakeholders (n=11-27; patients, family, healthcare providers, policymakers). The resulting maps display a plausible, implementable and testable theory. Stakeholder engagement helped to identify key intervention components; implementation issues; outcomes; and under which circumstances (eg high turnover) the intervention affects different levels (eg patient).

Conclusion ToC is a systematic method to process views of stakeholders, and was found to be feasible and useful in developing interventions. Workshops enabled stakeholders to share knowledge, debate the intended change process, and articulate assumptions about future implementation barriers. The maps will serve as monitoring and data collection framework during process evaluation of the research.

Support for family carers in specialized palliative care: a cross-sectional survey study in 34 palliative care services at home and in the hospital

Vermorgen M., De Vleminck A., Leemans K., Van den Block L., Van Audenhove C., Deliens L. & Cohen J.

Background: Family caregivers are the main providers of end-of-life care. Practical and emotional support from healthcare providers addressing their various needs may help to support their caregiving role and reduce or prevent some of the burden and negative consequences of caregiving at the end of life. This study aims to evaluate to what extent bereaved family caregivers of persons supported by palliative care services have received adequate information, support and aftercare and whether their evaluation varies with patient characteristics, type of palliative care service and length of enrolment.

Methods: A national cross-sectional survey was conducted in Flanders among the prime family caregivers (n = 1,504) of persons who had died under the guidance of a specialized palliative care service. Respondents were recruited through 3 mobile palliative home care teams, 17 palliative care units and 14 palliative support teams in hospitals between November 2014 and May 2016.

Results: The majority of family caregivers indicated that they were frequently asked by professional caregivers how they were feeling (77.7%) and what caring for the ill person meant to them (66.8%). They also affirmed to have received the support required to provide care for their relative (86.1%). A majority indicated having received the right amount of information about the patient's condition (75.3%), impending death (74.2%) and the pros and cons of treatments (75.5%). More than half (56.1%) were notified of available bereavement support and 91.4% felt supported by professional caregivers immediately after the bereavement. Family caregivers of persons who died in a palliative care unit indicated to have received more information, support and aftercare than those of persons dying with support of a mobile palliative home care team or a palliative support team in a hospital.

Conclusion: Family caregivers of persons supported by palliative care services seem to have a positive evaluation of the assistance received at the end of life and during bereavement. However, this evaluation was substantially more positive when care was received in a palliative care unit where palliative care professionals are available 24/7. The family caregiver support in this setting could become a benchmark for all health care services providing care for dying persons.

Post-graduate palliative care education for all healthcare providers in Europe: Results from an EAPC survey

1 Paal, P., 1 Brandstötter, C., 1 2 Lorenzl, S., 3 1 Larkin, P. & 4 Elsner, F.

Background: Palliative care training at basic, intermediate and specialist levels, recommended by the World Health Organization (WHO) is challenging to access in resource-poor countries and regions. Providing support in this regard would seem a moral imperative for all countries with established palliative care education systems and a strong resource base. In collaboration with WHO European Office and European Association for Palliative Care (EAPC) this paper looks into the educational requirements in palliative care at post-graduate level within Europe.

Methods: A survey was specifically designed to gather opinions and comments on elements of palliative care education from European experts. Participants were invited to assess the EAPC core competencies (Gamondi, 2013) on a 5-item scale and to define essential learning goals. Survey data was statistically analysed using IBM SPSS Statistics Software. Qualitative data was thematically analysed.

Results: 195 data sets were recorded, 82 were completed fully. The statistical analysis revealed a high agreement regarding the key elements of palliative care education. The thematic analysis indicated that at post-graduate level all health care providers have to (1) comprehend the palliative care philosophy (2) be able to demonstrate the complex symptom assessment and management competencies (3) be able to design care plans based on patients and families wishes integrating multi-professional and interdisciplinary approaches, and (4) be able to listen and self-reflect.

Conclusions: According to the WHO, inadequate skills and capacities of healthcare workers is one of the four barriers hindering the access to palliative care. This paper contains a new and comprehensive list of learning goals essential for multidisciplinary post-graduate palliative care education. Besides highlighting the relevant competencies, the article provides best-practice toolboxes with teaching and assessment methods. The article comments on WHO's palliative care definition and underpins the importance of the role of the education in knowledge development and skills acquisition.

Poster presentations

The place of palliative care (PC) in jurisdictions permitting assisted dying: a public-health issue

Bernheim JL., Deliens L.

Background. Officially, for the EAPC and the IAHP, euthanasia and/or assisted suicide (EAS) are “incompatible with the very foundations of PC”. Yet, in ever more jurisdictions, now covering 250 million people, EAS was de-penalised and in many others it is on the legislative agenda. In EAS-permissive environments PC organisations have three options: exclude EAS from PC, as in the Netherlands leave involvement in EAS to individual caregivers’ conscience, or, as in Belgium, embed EAS in PC.

Aims. Informing this debate. Methods. Review of 1) the essentialistic (epistemological, historical, doctrinal, conceptual, ethical) objections to EAS embedded in PC and 2) the empirical data from EAS-permissive jurisdictions.

Results. Objections to involvement in EAS are the inalienable privilege of individual caregivers and nowhere disputed.. However, at the societal level, public-health issues arise. 1) Some of the essentialistic objections to EAS embedded in PC are problematic or contradict the PC tenet of patient-centredness. 2) Empirically, in the Netherlands, PC workers are free to engage in EAS or not. In Oregon and Washington and in Flanders (Belgium), over 70% of cases of EAS are preceded by professional PC. In Flanders, EAS occurs three times more after a professional PC trajectory than after non-specialised end-of-life (EOL) care. The Belgian model of ‘integral EOL care’ consists of legally ordained, mainly demand-driven universal access to both PC and EAS. This model enjoys strong professional and public support and was in 2015 largely emulated in Québec’s comprehensive end-of-life care bill.

Discussion. Ethically, the PC tenet of patient-centredness is overruled when caregivers give priority to personal or doctrinal values over the patient’s. Pragmatically, if in future EAS-permissive countries jurisdictions EAS is excluded from PC and performed only in settings that are less competent for EOL care, this may entail adverse public-health consequences. First, patients who desire the possibility of EAS may tend to shun professional PC and hence not receive optimal EOL care. Second, EAS will likely be less practiced in a spirit of ‘total care’. Thus, the quality of all EOL care stands to decline.

Conclusion: If PC organisations do not with open minds confront these ethical and practical issues, they may be marginalised by societal developments and the overall quality of EOL care may suffer.

Understanding implementation strategies to support the delivery of palliative care in long term care facilities (LTCFs): a scoping review from the PACE study

Collingridge Moore D., Payne S., Ling J., Van den Block L., Froggatt K.

Background: The number of older people dying in long-term care facilities (LTCFs) is increasing and represents a public health challenge. Palliative care provision can be poor. Interventions to improve palliative care in LTCFs have been shown to be effective but little is known about their implementation. The aim of this review is to identify facilitators and barriers to implementing palliative care interventions in LTCFs and to describe the nature of implementation strategies

Methods: A scoping review was undertaken: electronic databases including MEDLINE, EMBASE, PsycINFO, CINAHL, Proquest, the Cochrane Library and Web of Science were searched to identify studies published between January 2007 and January 2018. Controlled studies, non-controlled studies, qualitative studies and evaluations on the implementation of interventions to improve palliative care in long-term care facilities were included. Studies that met the inclusion criteria were selected and data extracted on key variables including, the implementation of the intervention and reported facilitators and barriers to implementation.

Results: The review identified 8,071 abstracts, from which 55 studies were included in the review. Implementation strategies varied in four areas; internal and external facilitation, intended audience, extent of joint working and delivery of education/training. Support from managers, stakeholder involvement, flexibility in delivery of the intervention and adopting a 'whole home' approach to involvement were facilitators to implementation. High staff turnover, lack of physician involvement and failure to adopt changes into routine practice were identified as barriers to implementation.

Conclusion: Limited implementation of interventions may lead to inequalities in palliative care among older adults who may benefit from it. The characteristics of palliative care interventions compared to their implementation can be difficult to separate and are often underreported. Further research is needed to understand the extent to which implementation can facilitate the uptake of palliative care interventions in long-term care facilities.

Appropriate end-of-life care from a public health perspective: measuring population level quality indicators for people with Dementia

De Schreye R., Smets T., Deliens L., Annemans L., Gielen B., Cohen J.

Introduction Large-scale evaluations of the quality of end-of-life care in people with Alzheimer's disease are lacking. By means of a validated set of quality indicators, this study aims to: 1. Assess appropriateness of end-of-life care in people dying from Alzheimer's disease, 2. Examine variation between care regions, 3. Establish performance standards.

Methods We conducted a retrospective observational study of all deaths from Alzheimer's disease in 2015 in Belgium, using data from administrative population-level databases. QI scores were risk-adjusted for comparison between care regions.

Results Our results are not yet available with 2015 data, but are expected during the course of July 2018. The following conclusion is based on results of data of 2012.

Conclusion Our study found indications of inappropriate end-of-life care in people with AD, including high percentages of potentially inappropriate medication, and ED and hospital admissions. We also found high risk-adjusted variation for multiple QIs, indicating opportunity for quality improvement in end-of-life Alzheimer's disease care.

Appropriateness of end-of-life care from a public health perspective: measuring population level quality indicators for people with COPD

De Schreye R., Smets, T., Deliens L., Annemans L., Gielen B., Cohen J.

Background Large-scale evaluations of the quality of end-of-life care in people with COPD are lacking. By means of a validated set of quality indicators, this study aims to: 1. Assess appropriateness of end-of-life care in people dying from COPD, 2. Examine variation between care regions, 3. Establish performance standards.

Methods We conducted a retrospective observational study of all deaths from COPD (ICD10 codes J41-J44) in 2012 in Belgium, using data from administrative population-level databases. QI scores were risk-adjusted for comparison between care regions.

Results 4,231 people died from COPD. During the last 30 days of life, 60% was admitted to hospital, 11.8% received specialized palliative care. Large regional variation was found in specialized palliative care use (4.0% to 32.0%) and diagnostic testing in the last 30 days of life (44.0% to 69.7%). Based on best performing quartile scores, relative standards were set (e.g. $\leq 54.9\%$ for diagnostic testing)

Conclusion Our study found indications of inappropriate end-of-life care in people with COPD, such as high percentages of diagnostic testing and hospital admissions and low proportions receiving specialized palliative care. Risk-adjusted variation between regions was high for several QIs, indicating the usefulness of relative performance standards to improve quality of end-of-life COPD care.

Satisfaction with care of hospitalised patients with incurable cancer in the Netherlands

Engel M., Brinkman-Stoppelenburg A., Nieboer D., van der Heide, A.

Background: We aimed to assess the level of satisfaction with hospital care of patients with incurable cancer and its association with quality of life, patients' demographics and disease characteristics.

Methods: In nine hospitals patients were included who were admitted to the hospital with incurable cancer, aged 18 years or older and for whom the attending physician answered "no" to the Surprise Question. Participants were asked to fill out the EORTC INPATSAT-32 questionnaire, measuring patient satisfaction, and the EORTC QLQ-C15-PAL, measuring quality of life. General satisfaction was our primary outcome. Factor analysis was performed to identify underlying patterns in satisfaction. Regression analysis was performed to get insight in the association between satisfaction patterns and quality of life, patient demographics and disease characteristics.

Results: 105 patients participated in the study. The mean general satisfaction score was 72 and the mean overall quality of life score was 59, both on a scale from 0 to 100. Factor analysis identified three factors: satisfaction with nurses (explaining 62.1% of the total variance), satisfaction with physicians (7.7%) and satisfaction with hospital services (5.3%). Associations were found between global health and general satisfaction ($\beta = 0.35$, $p = 0.01$) and between emotional functioning and satisfaction with hospital services ($\beta = 0.016$, $p < 0.01$). Further, diagnosis of breast cancer was associated with satisfaction with physicians ($\beta = 1.06$, $p < 0.01$) and dyspnoea with satisfaction with hospital services ($\beta = 0.007$, $p = 0.03$). Patient demographics were not associated with general satisfaction and the three factors. Quality of life was not associated with satisfaction with nurses or satisfaction with physicians.

Conclusion: Patients with incurable cancer are reasonably satisfied with hospital care. Satisfaction with hospital care in patients with advanced cancer as measured with the INPATSAT-32 mainly measures satisfaction with nurses and exchange of information. Global health status was the only patient characteristic that was associated with general satisfaction. Our findings confirm the assumption that patient satisfaction with care and quality of life represent distinct outcomes of hospital care in patients with advanced cancer.

Quality of collaboration and information transfer in palliative care: a survey study on the perspective of nurses in the southwest region of the Netherlands

Engel M., van der Ark, A., Tamerus R., van der Heide, A.

Background: Palliative care at the end of life is often provided by health care providers from different disciplines and different settings. The aim of this study was to get insight in the quality of collaboration and information transfer in palliative care from the perspective of nurses.

Methods: We performed a cross-sectional regional survey study among nurses working in different settings. Nurses were recruited for participation via professional networks and media. Respondents were asked questions about collaboration in palliative care in general and about the last deceased patient they had cared for.

Results: A total of 933 nurses filled in the questionnaire. The mean score (on a scale from 1 to 10) for the quality of collaboration with care providers from other organizations was 6.8, with the lowest mean score reported by nurses in nursing homes (6.0) and the highest score reported by home care nurses (7.1). 13.3% gave an insufficient score (≤ 5). Nurses that regularly participate in meetings with care providers from outside their own organization gave more often a score of 6 or higher compared to nurses who do not participate in such meetings. 506 out of 933 nurses (54.2%) received at least once a handover of information upon the transfer of this patient into their care. The mean score (scale 1 to 10) for the quality of information transfer was 7.0. From the 402 nurses who (totally) agreed with the statement that the information transfer was there in time, 91.5% gave a sufficient score (≥ 6) compared to 69.6% of them who did (totally) not agree. A higher score was also positively associated with completeness of the information and if the patient was well informed about his or her disease and perspective. We also found a positive association between the score for the quality of information transfer and the score for collaboration ($r=0.19$, $p<0.01$, $n=409$).

Conclusion: Nurses report that structural collaboration between settings and information transfers in palliative care can be improved. Besides timeliness and completeness of the information, an important aspect in information transfers is that patients are well informed about their disease and perspective. Furthermore there is a strong association between the score for the quality of the information transfer and experiences with transmural collaboration in a broader sense.

Database Development for Different Care Settings: Experience of the Palliative Care Clinic in Ticino

Fusi-Schmidhauser T., Oriani A., Bordonni A., Gamondi C., on behalf of the Palliative and Supportive Care Clinic

Background Standardized data are crucial to generate evidence that can influence goals of clinical practice and electronic databases allow to describe the epidemiology of patients accessing care. The Palliative and Supportive Care Clinic in Ticino consists of a mobile team covering seven public hospitals, four ambulatories, two integrated care wards and one acute inpatients unit.

Aim and objectives To explore the experience of a database development for different palliative care settings.

Methods After an extensive literature review, an electronic database was developed in 2014 and implemented for data collection in 2015. The databank consists of a set of common data and a specific dataset relevant to hospital and ambulatory settings. A further database development was implemented for data collection in two integrated care wards. The Palliative Care Team tested the electronic database. Data collection was completed by the caring team and the entire database was managed by one administrator. OpenClinica© was used for data storage and statistical analysis.

Results At the end of 2017, more than 2500 patients have been registered in the database, thus generating a high volume of information, both epidemiological and clinical. The electronic system showed to be easy and feasible to use in all settings. Palliative care provision across all available services was traceable and care trajectories according to patients' complexity were identifiable.

Conclusion Routinely collected data are the main source of information to generate evidence about the effectiveness of treatments and interventions. The rigorous collection, analysis and interpretation of these information can be used to improve care for patients in a palliative care setting. Future priorities will include missing data management, improve the quality of data collection and foster data linkage to extrapolate multivariate analysis for clinical and epidemiological purposes.

The implementation of a screening tool to identify palliative patients in Ticino public hospitals

Gamondi C., Fusi-Schmidhauser T., Oriani A.

Background Palliative Care (PC) is characterized by interdisciplinary care of patients with life-limiting diseases. Too often PC is restricted to terminal care and to cancer patients. Many tools have been created to increase teams capacity of identification of patients with PC needs both in early phases of disease and in non-oncologic settings. In Southern Switzerland a Cantonal Strategy was initiated in 2014 and an urgent need for a screening tool emerged.

Aims To create a tool to: a) early identify patients with PC needs. b) identify the complexity of PC patients in need of specialist care.

Methods A comprehensive literature review was performed. Screening tools from different international settings (Gold standard Framework, Supportive and Palliative Care IndicatorsTool (SPICT), the NECesidades PALiativas tool NECPAL CCOMSICO©) informed the development of the initial draft of the tool. A consensus building procedure was used, involving stakeholders active in general and specialist PC. Three consensus conferences were established to reach consensus. The hospital mobile team then initially tested this tool.

Results The tool consists of four steps, three of them to detect general PC patients and a fourth one to identify those in need of specialist care. The three steps consist of the “surprise question”, of general indicators of decline and disease specific criteria. The fourth one consists of 11 criteria to identify situations that need referral to specialist PC. During the pilot test phase more than 2000 patients were screened by the hospital mobile team. The tool was fast to complete and capable to distinguish complex PC patients. 70% of the screened patients met criteria for specialized PC.

Conclusion The flowchart is currently presented in post graduated educational courses and it is diffusely used to screen the population in palliative care settings in Ticino.

Palliative Care: Knowledge, Attitudes and Perceptions of Young People at University.

Mallon, A., McIlfatrick, S., Hasson, F., Casson, K., Slater P.

Introduction: Global calls for a societal response to the unprecedented demand for palliative care enabled by a public health approach, assumes an informed and engaged public. Yet there is a dearth of empirical evidence as to the public's understanding and perception of palliative care and therefore their ability or appetite to contribute a response.

Aim and Study Population: The beliefs regarding palliative care of young people at university, a significant sector of the young public, have not been gauged. This study has two main aims; to determine knowledge and attitudes to palliative care among young people at university and to explore the perceptions of palliative care of this population within the context of a public health approach.

Methods: A two-phased sequential explanatory mixed method design was adopted. Phase one reported here involved an online survey guided by socio ecological theory and underpinned by the Theory of Planned Behaviour. This population based survey of young people at university sought to assess the knowledge, beliefs and intention regarding palliative care which may identify possible targets for future public health initiatives. The knowledge component of the survey was measured by the 13 item Palliative Care Knowledge Scale (PaCKS) devised by Kozlov et al (2016). Questions determining attitudes experience and demographic variables comprised sections 2 and 3. The second phase of the study involved in-depth interviews with a purposive sample of young people to further explore perceptions and identify what might enable or inhibit their engagement with palliative care.

Findings: In phase one 911 responses were obtained. Analysis revealed a young public that sees palliative care as relevant to them (66% n=563) and can identify its core concerns. Despite a perceived lack of media attention, 68% (n=583) of the young people wanted further information on palliative care, especially as it relates to their community (52%, n=446). The biggest predictors of intention to engage in discussion and seek information regarding palliative care related to peer acceptance, experience of end of life care and knowledge of palliative care.

Caregivers' understanding of palliative care in dementia in nursing homes: results of the EU FP7 PACE cross-sectional study in six EU countries

Miranda R, Smets T, Froggatt, K, Pasma R, Kijowska V, Gambassi G, Kylänen M, Deliens L, & Van den Block L

Background. While the European Association for Palliative Care (EAPC) widely recommends palliative care as an approach highly applicable for people with dementia, we know little about how caregivers view this recommendation. Hence, we examined the caregivers' understanding of palliative care in dementia in nursing homes in six EU countries, studied the differences between countries, and explored potential factors associated with this understanding.

Methods. Cross-sectional survey in representative samples of nursing homes in Belgium, Finland, Italy, Netherlands, Poland, and United Kingdom (2015). We distributed questionnaires to nursing staff (nurses/care assistants) working in the facilities during the survey. We assessed their extent of agreement with two statements: (1) Alzheimer's disease or dementia is a disease you can die from and (2) Palliative care is important to older people with Alzheimer's disease or dementia, using a 5-point Likert scale truncated to 'agree', 'neutral', and 'disagree' categories. Additionally, we assessed eight factors that can be associated with this understanding (e.g. age and receipt of formal palliative care training).

Results. In the 322 participating nursing homes, 3392 nursing staff were surveyed with response rates of 68%. The percentages of nursing staff who agreed with statement 1 ranged from 46% (Belgium) to 76% (Finland), while for statement 2, the percentages ranged from 62% (Belgium) to 85% (Finland). We also found that the nursing staff who received a formal palliative care training are more likely than those who did not to agree with statements 1 (OR=1.51; p-value=0.005) and 2 (OR=1.69; p-value=0.008).

Conclusion. Contrary to the EAPC recommendation, the remarkable cross-country differences in the caregivers' understanding of palliative care in dementia suggest varying views on the applicability and importance of palliative care for people with dementia. Our study also indicates that undergoing a formal training in palliative care may improve the caregivers' understanding of palliative care in dementia.

Team Palliative Care Week 2017

O'Hara B., Charnley K.

Background All Ireland Institute of Hospice and Palliative Care (AIHPC) has held an annual Palliative Care Week campaign since 2014 aimed at increasing awareness and understanding of palliative care among both the public and health care professionals. The theme for the 2017 campaign was: Palliative Care, What have you heard?

Methods For 2017, three members of the public, all with direct palliative care experience, agreed to be the public face of the campaign. John, Evelyn and Claire shared their experiences to increase understanding and reduce fear around palliative care. They had their video stories, photographs and personal experiences of illness and palliative care featured in campaign materials and through media engagement for Palliative Care Week 3-9 September 2017.

Results Important campaign messages were personalised. It was very powerful for these words of John to be heard by the public: "I would have been afraid of palliative care... now I would have no fear". In a contribution to one media news website, more than 33,000 people viewed Evelyn's story, and very positive comments were received. More than 50 media interactions during the campaign included three TV interviews, four national and nine regional radio interviews, coverage in four national newspapers, 10 online pieces of coverage and items in 19 regional newspapers. John, Evelyn and Claire's stories were prominent in promotional materials, including videos and social media clips, more than 10,000 leaflets and posters distributed to a range of locations and for events across the island of Ireland. Not only did John, Evelyn and Claire participate in traditional media activity they promoted the campaign through their own social media channels. They were ambassadors in their communities, for example, through the distribution of promotional materials to health facilities, pharmacies and community centres.

Conclusion The vast majority of media activity for Palliative Care Week 2017 featured Evelyn, Claire or John, and AIHPC believes that this high level of media interest was due to their involvement. The personal stories enabled the public to connect with the campaign and to learn more about the quality of life benefits of palliative care.

Innovative Models of Palliative Care Delivery: Integrated Palliative Care in Internal Medicine Hospital Department

Ottolini L., Fusi-Schmidhauser T., Oriani A. & Gamondi C.

Background Internal medicine departments (IMD) are recognized to be caring for a high number of palliative care (PC) patients, including those in need of specialized PC. These patients should be cared for in PC units where available. The availability and the accessibility to these units for complex patients is reduced, due to logistical and geographical reasons. The modality of PC delivery in acute hospitals outside PC units is that of mobile consultation (MC). For these patients with complex needs and their families, the MC may partially respond to their needs. In Southern Switzerland, 1200 patients are seen each year by the MC team and 65% of those hospitalized in the IMD present complex needs. Therefore, a new model of PC delivery within an internal medicine ward was developed and tested.

Methods The model is based on a collaborative partnership between IMD and PC team, with shared responsibility of the patients that are hospitalized within the internal medicine ward. The responsibility for primary care is guaranteed by the IMD, while the PC team is responsible to: - provide a state-of-the art symptom management - conduct family meetings - manage end-of-life care - organize complex home discharges - discuss advance care planning with patients and families - coordinate the interdisciplinary team (composed of dietician, physiotherapist, chaplain and social worker) - share legal and ethical responsibility of complex decision-making (e.g. withholding/ withdrawing treatments, resuscitation)

Results The pilot project started in September 2017 and more than 200 patients have been included until May 2018. A database has been created to monitor the project outcomes and to collect clinical and epidemiological data.

Conclusion The integrated model resulted feasible and well accepted by both teams. As a result of this project, other wards are interested in implementing this innovative model.

Discontinuation of medications at the end of life. A population study in Belgium, based on linked administrative databases.

Paque K., De Schreye R., Elseviers M., Vander Stichele R., Pardon K., Dilles T., Christiaens T., Cohen J., Deliens L.

Aim: To examine Potentially Inappropriate Medication (PIM) use in relation to time before death, to explore if PIMs are discontinued at the end of life, and the factors associated with this discontinuation.

Methods: We conducted a population-based retrospective cohort study of all deceased in 2012 in Belgium, aged at least 75 years at time of death (n=74368), using linked administrative databases. We used STOPPfrail to identify PIMs delivered during the period of six to twelve (T1) and the last four months (T2) before death.

Results: Mean age was 86 at time of death, 57% female, 38% was living in a nursing home, and 16% was admitted to hospital two years to four months before death. Overall, 69% received at least one PIM at T1 and/or T2. PIM delivery increased towards death for all PIMs. At least one PIM was discontinued during the last 4 months before death for 20% of the population, 49% had no discontinuation, 31% did not receive any PIMs. Being hospitalized during the period of two years to four months before death, living in a nursing home, and female gender were associated with discontinuation of PIMs (respective OR(95%CI): 2.89(2.73-3.06), 1.29(1.23-1.36), 1.26(1.20-1.32)).

Conclusion: PIM delivery was relatively high: 69% received at least one PIM - and increased towards death. At least one selected PIM was discontinued between T1 and T2 for only 20% of the population. People who were admitted to hospital during the period of two years to four months before death, nursing home residents and women had more chance of discontinuation of PIMs.

Palliative Care Coaching for Family Caregivers & Patients with Rare Advanced Lung Disease

Piamjariyakul U., Smothers A., Stephanie Y., Krupp E., Smith C.E.

Background: Nearly 15 million Americans and greater than 10% of West Virginia (WV) residents live with and eventually die from rare advanced lung disease (R-ALD), including pneumoconiosis (i.e., dust, asbestos, silica), and idiopathic pulmonary fibrosis. The aim of this study is to pilot test the nursing care intervention FamPALcare with patients and family members managing home supportive end-of-life palliative care (EOLPC) for R-ALD in rural Appalachia.

Methods: This study uses a random control group comparison design to test the implementation of the FamPALcare intervention with R-ALD patients and their primary family caregivers (N=40). Our empirically based coaching model guides the implementation of FamPALcare. The intervention group receives all standard care plus two sessions of home EOLPC coaching by community nurses experienced in EOLPC. Nurses use the national "Conversation Ready" pamphlet to initiate discussions of R-ALD symptoms and EOLPC preferences, demonstrate strategies to improve breathlessness and decrease anxiety, and encourage use of community resources. The nurse will coach the patient and family in selecting EOLPC options to manage R-ALD home care based on their preferences. Nurses will encourage completion of advance directives at the next physician appointment. "Teach-back" strategies are used to verify understanding at the end of each session. Telephone follow up will be conducted at one month and 3 months post-intervention to answer any questions, allowing sufficient time for family members to discuss their ELOPC decisions.

Results: Intervention implement and data collection are in progress. Group comparisons and preliminary findings on patients' and caregivers' outcomes will be determined.

Conclusion: This is an initial study of home-based palliative R-ALD care coaching in rural Appalachia. The findings could benefit WV by providing evidence-based nursing care with early planning for family preferences and supportive EOLPC.

Palliative care elements in public policies on health care for older people: a documentary analysis in 12 countries

Pivodic L., Smets T., Gott M., Sleeman KE., De Groot Z., Kodba Čeh H., Arrue B., Hrdá K., ten Koppel M., Cardenas Turanzas M., Wilson D., Rhee YJ., Nakanishi M., Lo TJ., Van den Block L.

Background: Palliative care is poorly integrated in the continuum of care for older people. Improving this may require integration of palliative care elements in broader health policies. We studied whether elements of palliative care are included in public policy documents concerning health care for older people in 12 countries with steep ageing projections.

Methods: Directed content analysis of public policy documents (legislation, policies/strategies, guidelines, white papers) published since 2010 in NZL, SGP, JPN, CAN, MEX, NDL, CZE, AUT, ESP, SLO, ENG, BEL. We broadly included documents covering health care for older people. We excluded documents on specific treatments, specific diseases and stand-alone palliative care strategies. Country experts identified documents and completed a detailed data extraction form for each document. The form covered 9 core elements of palliative care, based on essential practices for palliative care (WHO 2016) and quality indicators for palliative care (Leemans et al. 2017).

Results: We identified 53 policy documents in 12 countries. Only one country (NZL) addressed all elements of palliative care in relevant documents. At least one document in each country addressed 'communication/care planning', 'coordination/continuity of care' and 'ethical and legal aspects'. 'Care for family' was mentioned in all but one country (CAN). 'Symptom management' was mentioned in all but two countries (CZE, SLO). 'End-of-life care' was addressed in all countries except CAN, ESP, SLO, BEL. Of the 10 countries that mentioned palliative care explicitly (all except CAN, AUT), 4 mentioned eligible patients but none specified who is responsible for palliative care provision. Stand-alone palliative care strategies were referred to in policy documents of 5 countries (out of 9 countries with palliative care strategies).

Conclusion: Public policy documents of only one country addressed all core elements of palliative care. Elements not exclusive to the end of life (e.g. communication) were more commonly addressed than elements related to end-of-life care. Inclusion of palliative care elements relevant to the whole continuum of care, and referral to palliative care strategies in general health policies for older people may support the integration of palliative care in routine health services.

Enhancing bereavement care in Ireland: a scoping study

Roberts A. McLoughlin K. Keegan O.

BACKGROUND: Approximately 30,000 people die in Ireland annually. Varying estimates indicate that between four to ten people are significantly impacted by each death, yet there is a dearth of national data and policy to guide how bereavement is best supported in childhood through to old age in Ireland. Organisations with a focus in bereavement care and support gathered at two national forums in 2016 and 2017. These fora overwhelmingly called for a nationally coordinated approach to bereavement care. Stemming from this, an independent study to enhance bereavement care in Ireland was commissioned by the Irish Hospice Foundation.

METHODS: The study methodology included: a systematic literature review, interviews with national/international stakeholders, focus group discussions with stakeholders involved in the provision of bereavement care and support across four locations in Ireland and analysis of recent population-based survey data of bereaved people in Ireland.

RESULTS: The findings highlight the need for bereavement to become a national priority at government policy level, together with the need for the development of a framework, guidance and standards for services offering support.

CONCLUSION: This study will contribute to a vision for a national approach to bereavement care and develop an implementation framework for enhancing bereavement care nationally.

Are use and timing of palliative home care associated with appropriate end-of-life care for end-stage COPD patients?

Scheerens C., Faes K., Beernaert K., Pype P., Cohen J., Deliens L., Chambaere K.

Background: Previous studies have reported inappropriate end-of-life care for end-stage COPD patients such as frequent hospitalisations and emergency room visits. Palliative home care, especially when provided early, could lead to improved outcomes and more appropriate end-of-life care, such as home death. To study this, population-level evaluations on the possible association between use and timing of palliative home care and appropriate end-of-life care for COPD are highly informative.

Methods: We conducted a population-level retrospective observational study of all COPD decedents in Belgium between 2010-2015 to assess the association between use and timing of palliative home care on appropriate end-of-life care, using a validated set of quality indicators. We linked eight full-population databases on health care use, COPD diagnoses, and demographic and socioeconomic variables.

Results and conclusion: Results will entail percentages and timing of referral of COPD patients to palliative home care services and the association with quality indicators consisting of 23 items pertaining to 4 domains of care (aggressiveness of care, pain and symptom management, place of treatment and place of death, and coordination and continuity of care). We will use both univariate and multivariate statistical procedures, controlling for various sociodemographic variables. Results will provide useful information for public health and policy interventions on palliative home care and end-of-life care for COPD. In-detail results and discussion will be presented during the congress as they are not available yet.

Family carers' behaviours and related determinants regarding palliative care initiation

Scherrens A.L., Beernaert K., Magerat L., Deliens L., Cohen J. & Deforche B.

Background. Most research on initiation of palliative care focuses on health care services and professional carers. However, also family carers can play a role in initiating palliative care for seriously ill persons with whom they have close relationships.

Aim. To identify behaviours of family carers regarding the initiation of palliative care for their seriously ill person and the determinants of these behaviours.

Methods. A qualitative study using semi-structured face to face interviews with 16 family carers of deceased persons who received palliative care was conducted. Thematic content analysis was used to identify groups of behaviours that influenced palliative care initiation and related determinants. The behavioural determinants were fitted in concepts of behavioural theories (eg 'attitude' of the Theory of Planned Behaviour). A behavioural model was developed.

Results. Most reported behaviours regarding palliative care initiation were related to communicating with the seriously ill person, other family members and professional carers; seeking for information and supporting the seriously ill person with processing information from professional carers; and organizing and coordinating care. Determinants both facilitating and hindering these behaviours included awareness (eg of poor health); knowledge (eg about palliative care); attitude (eg negative connotation of palliative care); social influence (eg important others' opinion about palliative care) etc..

Conclusion. This study identified relevant family carers' behaviours and related determinants such as attitude and knowledge that can contribute to palliative care initiation. As these determinants are modifiable, the palliative care behavioural model that resulted from this study can serve as a basis for behavioral interventions to promote timely palliative care initiation.

Challenges affecting family caregivers in Lithuania

Staras K., Juodaite-Rackauskiene A., Ciurlionis M.

Background Family as caregivers providing care to people with life threatening illnesses, due to high medical needs of care, often suffer physically and psychologically. In addition to this, family caregivers have to cope with financial burden while providing best possible care to the ailing family members. Approaching palliative care for each family caregiver may bring different experiences. In this study we aim to gain understanding of what are the biggest struggles for family caregivers in Lithuania.

Methods The empirical research was focused on the experience of family caregivers, observations were analyzed using a qualitative method. The findings are based on 14 in-depth research interviews with family members providing care to their loved ones. The study was conducted in an urban area on homecare patient's family members. The gathered data turnout showed an overall view of palliative caregivers reality in Lithuania.

Results The qualitative results provided relevant understanding of a primary caregiver, a close family member daily experiences. One of the main findings was that caregivers very often feel unprepared to deliver this type of care at home. Insecurity and insufficient role of healthcare providers in homecare was revealed to be a colossal challenge for family members. Nonetheless, this study exposed that a great stressor is to care for a dying person with partly reimbursed healthcare and it often leads caregivers to neglecting their own life. Especially taking into account the fact that the "medication and supplements" in Lithuania for palliative care are compensated inadequately or aren't compensated at all.

Conclusion The issues expressed by caregivers show unpreparedness of general population for palliative care and death, followed by deficient professional care, as well as economic instability caused by partial state reimbursements. Further analysis is needed to identify challenges of personal growth and lack of professional help in order to find ways to support family caregivers.

Using participatory co-design to create supporting end-of-life environments in elder care - An example from a residential care home in Sweden

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Residential care homes (RCHs) are common places for end-of-life care (EoL) in Sweden. While discourse about dying and death in RCHs often has a negative focus, in this project we work with constructive change processes, which can better support quality of life and death in RCHs. This action research project, part of the DöBra research program, uses a variety of approaches to: develop personal skills; create supportive environments; and reorient health services in relation to EoL care. We aim to better understand what residents, family, and staff experience as important in an RCH setting and apply this understanding through co-design processes to enhance the experience of the EoL care environment from these different perspectives. Our transdisciplinary research team works in partnership with residents, family and staff at Sweden's largest RCH in participatory co-design groups. Recruitment began in January 2018 at 2 units. A total of 39 people participated—16 residents, 3 family members, 14 staff, and 6 researchers have attended one or more of 11 joint discussions. We worked with techniques to explore experiences, to formulate prioritized areas for change. These became: Communication & sensitivity, Togetherness, Too little/too much time, Meaningful everyday life, and Bodily care & sensory experience. These discussions seemed to enable residents, often physically and cognitively frail, their relatives and staff to work in partnership and exchange knowledge. We are now forming co-design teams including all stakeholder perspectives to suggest and test potential improvements to co-create more supportive EoL environments in the RCH. We found that the aspects participants together prioritized related to their impact on relationships and organizational practices. Expertise, ideas and insights from all stakeholder perspectives in the RCH setting has proven to be crucial in researching and actualizing change processes with potential to have sustainable impact on the EoL setting.

Experiences with the Action Research method for developing complex interventions in palliative care

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Aims: Action Research (AR) aims to improve practice through a collaboration between research and practice, while also contributing to scientific knowledge. Whether AR can live up to these expectations in palliative care, or under what conditions this may be the case, is not yet clear. Therefore, we aim to share preliminary findings on the strengths and limitations of the AR approach when applied to the development and implementation of complex interventions that aim to support inter-organizational collaboration.

Methods: Our project uses a bottom-up approach, which means that each of 7 participating teams choose, develop and implement their own intervention to improve inter-organizational collaboration in palliative care. Because of this bottom-up approach, a flexible AR protocol was developed, based on existing AR methods.

Results: Challenges we encountered so far: - Team formation and achieving consensus on intervention choice can be a slow process due to the complexities involved (1-2 years). - Pace and content are mainly set by the team, not the research protocol. - Bridging the gap between science and research demands creativity from both care professionals and researchers, due to differences in speed, language and aims between science and practice. - For the researcher, preserving a fine balance between contributing to project aims while avoiding overdue influence on team dynamics or project ownership is key. Strengths we perceived: - AR provides close-up, longitudinal insights in inter-organizational processes and mechanisms. - AR improves direct links between science and practice which can also be beneficial for other collaboration projects. - AR inspires researchers to reflect on the practical relevance of their work and inspires practitioners to reflect on the evidence base of their work.

Conclusions: AR appears to be a challenging and time-consuming method when applied to inter-organizational settings developing complex interventions, probably more so than when it concerns less complex, intra-organizational projects. On the other hand, the use of AR in this project promises to provide valuable and unique insights into complex intervention development and implementation in palliative care, and inter-organizational dynamics in daily practice.

Use and timing of referral to specialized palliative care services for people with cancer: a mortality follow-back study among treating physicians.

Vanbutsele G., Deliens L., Cocquyt V., Cohen J., Pardon K., Chambaere K.

Background Referral to specialized palliative care services (SPCS) occurs often late in the illness trajectory but may differ across cancer types. We examined differences between cancer types in the use and timing of referral to specialized palliative care services (SPCS) and in the reasons for non-referral.

Method We conducted a population-based mortality follow-back survey among physicians who certified a representative sample of deaths in Flanders, Belgium. We focused only on sampled death cases of cancer (n=2392). The questionnaire asked about the use of the existing types of SPCS and the timing of referral to these services.

Results Response rate was 58% (1394/2392). Patients who died from breast, respiratory, head and neck, genitourinary or gastrointestinal cancer had higher chances of using SPCS compared to hematologic cancer patients. The latter most often received treatment with the aim of life prolongation/curation in the last week of life (24%). The most prevalent reason for non-referral was that regular care sufficiently addressed palliative and supportive care needs (51%). This differed significantly between cancer types ranging from 77,8% for breast cancer and 42.1% for hematologic cancer. A second prevalent reason for not using SPCS was that it was not meaningful (enough) (23.9%), particularly for hematologic malignancies (35,1%) and only in 5.3% for breast cancer.

Conclusion Differences in referral across different types of cancer were found. Referral is more often delayed or not initiated for patients with hematologic cancer, possibly due to differences in illness trajectory. An influencing reason is that physicians perceive palliative care as not meaningful or not meaningful enough for these patients which may be linked to the uncertainty in the disease trajectory of hematologic malignancies.

The liminal space of palliative care volunteers: A qualitative study of volunteer roles among volunteers, patients, family and professional caregivers

Vanderstichelen S., Cohen J., Van Wesemael Y., Deliens L., Chambaere K.

Background Volunteers have an important role in palliative care, both specialized and generalist. They positively influence quality of care for seriously ill patients and their loved ones and provide a link to the community. However, it is not well understood what volunteers mean to palliative care provision, nor how they can be adequately supported. This study therefore aims to describe palliative care volunteer roles across care settings through the perspectives of those closely involved in the care for terminally ill people.

Methods A qualitative study was conducted using focus groups with respectively volunteers, nurses and psychologists, and family physicians and individual semi-structured interviews with patients and family caregivers. Participants were recruited from specialist palliative care units, family medicine and community home care services.

Results 79 people participated in the study. Analyses of their narratives indicated a volunteer role of 'being there' for the patient. They represent a different, more approachable face of care, focused on psychological, social and existential care and building up relationships. A second identified important volunteer role was that of a 'liaison'. Volunteers occupy a unique, liminal space between the professional and the family domain, through which they pick up on and communicate patient needs missed by other caregivers. Barriers to volunteer role performance were lack of communication opportunities with professional caregivers and lack of volunteer coordination. Patient-volunteer matching was a clear facilitator for role performance.

Conclusion Volunteers complement professional caregivers by 1) occupying a unique space between professionals, family and patients and hence providing a liaison function, and 2) being a unique face of care for patients. Healthcare services and policy can support volunteer role performance by ensuring frequent communication opportunities and volunteer coordination.

End-of-life communication in advanced cancer: international trends from a mortality follow-back study between 2009 and 2014

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Background Communication at the end of life as a key component of good palliative care has received increasing policy attention over the last years in European healthcare systems. This study aimed to evaluate if conversations about end-of-life care with cancer patients in general practice have become more frequent between 2009 and 2014 in three European countries, and whether or not trends were associated with specific patient characteristics.

Methods We used data collected via a mortality follow-back study in 2009, 2010, 2013 and 2014 in Belgium (BE) and the Netherlands (NL), and in 2010, 2011, 2013 and 2014 in Spain (ES). Participating general practitioners (GPs) continuously registered every deceased patient (aged ≥ 18 years) in their practices. We included all non-sudden cancer deaths. GPs were asked if the diagnosis, preferences for medical treatment in the last phase of life and preferences for a proxy decision-maker had been discussed with the patient.

Results Overall, 2306 decedents were included (BE: 1233, NL: 729, ES: 344). Only Belgium showed a significant increase in the proportion of people with whom the diagnosis was discussed between 2009 and 2014 (84% to 94%). The increase was largest in those aged ≥ 85 and those who lived in a long-term care facility during the last year of life (both 25 percentage point). Awareness of a preference for medical treatment increased significantly in BE (41% to 53%) and in NL (62% to 70%) between 2009 and 2014. The largest increase was seen in those who died in a palliative care unit or hospice in both BE (21 percentage point) and NL (34 percentage point). BE (20% to 28%) and NL (32% to 52%) showed a significant increasing trend in awareness of a preference for a proxy decision-maker, which in BE was largest in those who died at home (21 percentage point), and in NL in males (35 percentage point). ES did not show a significant trend for any of the three communication variables over the years.

Conclusion The increases in the frequency of GP-patient communication on end-of-life care related topics show that significant change is possible in a relatively short time-span, although international differences seem to persist over time.

Family involvement in end-of-life decisions: A nationwide mortality followback study

Vermorgen M., De Vleminck A., Deliëns L., Spruytte N., Van Audenhove C., Cohen J. & Chambaere K.

Background: Almost half of all deaths in Flanders are preceded by potentially life-shortening end-of-life decisions (ELDs) such as limitation of treatment and intensified symptom alleviation. Involving family in these ELDs may positively influence multiple psychosocial aspects for both patients and their family members. To date, little is known about how often family members are involved in ELDs. This study aims to investigate the proportion of ELDs in which family is involved and to examine the characteristics of the patients and the decisions associated with family involvement.

Methods: A questionnaire survey was conducted in 2013 among physicians attending a large and representative sample of deaths ($n = 6,188$) in Flanders.

Results: Family was involved in 72.3% of all ELDs. In 30.2% of the ELDs that were not discussed with the patient, family was not involved either. In a palliative care unit (PCU), ELDs were discussed with family in 64.1% of cases. Family was more likely to be involved when ELDs were discussed with the patient (OR = 1.33, 95% CI = 1.01-1.75), when the ELD was made in an ICU as compared to at home (OR = 3.15, 95% CI = 1.83-5.39), and if specialized palliative care services were involved in the patient's care (OR = 1.79, 95% CI = 1.38-2.33).

Conclusion: Involving family in end-of-life decision making does not seem to be standard practice and appears to depend on where these decisions take place and whether specialized palliative care services are involved. Our findings suggest a need for more family-oriented approaches to end-of-life care in a variety of care settings.

Palliative care in a home care setting; the development of a guideline for district nurses and nurse assistants

Verschuur E.M.L., van der Sande R., Francke A.L.

Background In the Netherlands district nurses and nurse assistants have a pivotal role in palliative care at home. Partly due to aging of society, an increase of palliative care is expected. Related to this trend, we developed a guideline Palliative Care at Home, especially for district nurses and nurse assistants providing palliative care to patients at home.

Methods This guideline is developed following the standard of the Dutch AQUA-Advisory and Expert Group. To assess the bottlenecks in daily practice, face to face focus groups as well as online focus groups with district nurses and nurse assistants were performed. Seven predefined questions were answered by a systematic international literature review of existing systematic literature reviews and evidence-based guidelines in the field of palliative care at home. The AMSTAR and the AGREE II criteria were used to assess the methodological quality of the included reviews and guidelines, respectively.

Results The 39 recommendations covered four themes: the support of self-management among patients; the identification of the palliative phase and needs assessment; advance care planning, coordination and cooperation and the competences of district nurses and nurse assistants. All four themes are structured as follows: predefined questions, recommendations including the level of evidence, results of the literature review and other considerations. To obtain overall agreement on each recommendation, all recommendations were thoroughly discussed in the multidisciplinary project group and advisory group with representatives of key stakeholders in palliative care. This resulted in both evidence-based and consensus-based recommendations. One example of recommendations is: District nurses and nurse assistants discuss the outcome of the 'surprise question' with the general practitioner if the answer to that question is: 'No, I would not be surprised'.

Conclusions This guideline provide recommendations concerning key aspects of palliative care at home by district nurses and nurse assistants. These recommendations should serve as a reference standard for providing palliative nursing care and for collaboration with the interdisciplinary team of healthcare professionals around patients, in particular with the general practitioner.

Advance Care Planning in palliative care for people with intellectual disabilities

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Background Advance Care Planning (ACP) is a process in which patients and relatives, together with professionals, discuss wishes and preferences for future care and treatment. The purpose of the study was to investigate the ways in which ACP has been carried out for people with intellectual disabilities (ID), and learn about barriers and facilitating factors for ACP.

Methods The study was done in four institutions providing care for people with a mild to severe ID. Data from medical records were analysed of a total of 15 patients in the palliative phase and 15 deceased patients. Patients in the palliative phase were identified by their doctors with the surprise question. Additional semi-structured interviews were conducted with their relatives (n = 30) and professionals (n = 30).

Results Nearly all (93%) patients had a do-not-resuscitate declaration. In a smaller group other (medical) decisions were reported, mainly the absence of treatment or hospitalization (43%). In the interviews, all relatives stated they were satisfied with the information they received about the expected course of illness and possible treatment options. Due to low cognitive and communicative abilities, most patients were not involved in ACP. Relatives and professionals experienced difficulty in deciding on behalf of someone else.

Conclusion In the records, mainly medical decisions were reported. Professionals should be informed about the need to register medical as well as nonmedical decisions and learn about the content and benefits of ACP. The importance of intensive collaboration between professionals, relatives and patients with ID for ACP should receive attention. In addition, there is a need for training professionals in communication skills to discuss wishes and preferences for future care with patients with ID and/or their relatives.