Publishable summary

Project context

New knowledge is not necessarily readily applied in medicine, even when there is evidence of its effectiveness. As a result of the gap between knowing and doing, policy makers, professional care providers, patients and their families have benefited too little from new developments. Implementation research has developed models for stepwise implementation but it is still unclear which strategies are effective for whom and which factors influence the effectiveness of implementation strategies.
From the point of view of implementation sciences changing palliative care is a major challenge, since adequate organisation of palliative care requires collaboration between a range of different professionals and healthcare organisations. Besides, as a consequence of the ageing population, the number of people in need for cancer and dementia palliative care will rise. Therefore we focused on implementation strategies in palliative care.
The overall aim of this project was to develop optimal implementation strategies for using quality indicators to improve the organisation of palliative cancer and dementia care in Europe and to study factors influencing the effectiveness of the strategies. We focused on the implementation process and concentrated the work packages on: the organisation of palliative care, the development of a set of setting-specific implementation strategies including an interactive website and instruction by consultants, the evaluation of the use of selected strategies to improve the organisation of palliative care and factors influencing the effectiveness of the implementation strategies.

Main objectives

The objectives of this project were: to find optimal strategies for implementing quality indicators to improve the organisation of palliative cancer and dementia care in Europe, and to pilot study the effectiveness of these strategies, and factors influencing their effectiveness. This information was used to build a conceptual implementation model applicable across diverse healthcare settings and that allows rigorous assessment of the effectiveness of implementation strategies. By this means we aimed to improve knowledge on how and to what extent health interventions can fit within real-world clinical practice, including knowledge whether the implementation remained faithful to the original conceptualisation and intent of the quality indicator.

7th Framework Programme, HEALTH-2010-two stage,
Grant Agreement No: 258883

Therefore we took the following steps to develop implementation strategies:
1. We developed a set of quality indicators for the organisation of palliative cancer and dementia care from the sets of indicators developed in several European projects and Dutch projects in the past few years. This selection step was important, as feedback from users and giving users a feeling of ownership are among the most powerful implementation prerequisites (Grol et al 2005). This set of indicators functioned and will function as a tool to assess palliative care organisation on the international, national, setting, team and individual level, respectively.
2. We identified barriers and facilitators to the potential use of the indicators, stratified by participating country, patient group (suffering from advanced dementia or advanced cancer), setting and in the transitions between settings.
3. We developed a toolkit of implementation strategies including training of consultants and users and a web-based system to register and feed back the assessment of the organisation of palliative care.
4. We pilot tested the effectiveness of the implementation strategies.
5. We studied factors influencing the effectiveness of implementation strategies for new knowledge.
6. We build a conceptual implementation model that should be applicable across diverse healthcare settings and that will allow rigorously assessment of the effectiveness of the selected implementation strategies.
7. We added the information to our own and other relevant websites (EAPC; Interdem). This information is accessible to the general population, care providers and policy makers, with information on quality indicators for the organisation of palliative care and how to implement them.

A description of the work performed since the beginning of the project and the main results achieved

All Work Package leaders have reached their milestones and submitted their deliverables on time.

- An analytic framework to characterise models of palliative care for both patient groups (patients with severe dementia and patients with progressive cancer) across Europe has been developed;
- The variation in the European healthcare systems and healthcare delivery patterns considering palliative care for cancer and severe dementia patients with regard to the national context (macro-level), the available workforce (meso-level), and the settings and professionals (micro-level) has been described;
- A literature study has been performed on strategies to improve the organisation of palliative care;
- A set of quality indicators (QIs) to be used in WP4 has been developed in a scientifically sound manner;

- Main and setting-specific barriers and facilitators to apply QIs for the improvement of the organisation of palliative cancer and dementia care have been described;
- Barriers and facilitators in national policy (policy makers, (results from WP2) health care insurance, scientific bodies) regarding the application of QIs for the improvement of the organisation of palliative dementia and cancer care have been described;
- All deliverables are posted on the website (publications, workshop reports, information concerning the organisation of meetings, other public events and public relations).
  A consortium-restricted section is available and allows the consortium members to share official communications, documents and reports and allows to share the work in progress and to exchange information and news about the project;
- The website has been made interactive;
- A method for the analysis of the implementation strategies used and an inventory with the factors influencing implementation of improvements in palliative care have been developed.
  All these steps, mostly started in the previous reporting period, have been finalized in this final period. Besides, much output has been generated (presentations at international conferences, posters, scientific publications, tools, a DVD, a declaration).
- The IMPACT and EURO-IMPACT consortia joined forces to emphasise the need they felt to involve policy-makers and influence the political agenda towards the implementation of policy recommendations by 2020. A charter was created, consisting of policy recommendations, which was signed by policy-makers and the European Association for Palliative Care (EAPC), to ensure high-quality palliative care in an ageing society in Europe (and beyond).

Work Package 2

In the final year of the IMPACT project the team working on Work Package 2 has:

1. Published 7 papers or scientific letters from WP2's findings:

- Raymond M, Warner A, Davies N, Iliffe S, Manthorpe J, Ahmedzai S: Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers. Dementia 2014 Jan 1;13(1):96-110. doi: 10.1177/1471301212450538.

- Raymond M, Warner A, Davies N, Baishnab E, Manthorpe J, Iliffe S for the IMPACT research team: Evaluating educational initiatives to improve palliative care for people with dementia: a narrative review Dementia 2014; 13(3): 364-379

- Davies N, Maio L, Vedavanam K, Manthorpe J, Vernooij-Dassen M, Iliffe S for the IMPACT research team: Barriers to the provision of high quality palliative care for people with dementia in England: A qualitative study Health & Social Care in the Community 2014;22(4):386-94

- Davies N, Maio L, Iliffe S: Quality end of life care for dementia: What have family carers told us so far? A narrative review Palliative Medicine 2014; 28(7):919-930
- Davies N, Maio L, Van-Riet-Paap J, Mariani E, Jaspers B, Sommerbakk R, Grammatico D, Manthorpe J, Ahmedzai S, Vernooij-Dassen M, Iliffe S for the IMPACT research team Quality Palliative Care across Europe for Cancer and Dementia: some common challenges. Aging & Mental Health 2014; 18(4):400-10
- Raymond M, Warner A, Davies N, Nicholas N, Manthorpe J, Iliffe S for the IMPACT study: Palliative and end of life care for people with dementia - lessons for clinical commissioners PHCR&D 2014; 15; 406-17 (published online 2013; doi:1017/S146334236130039X)
- Davies N & Iliffe S: Compassion in healthcare - lessons from a qualitative study of the end-of-life care of people with dementia J R Soc Med 2014 107: 134 DOI: 10.1177/0141076814527870

2. Presented findings from WP2 at academic conferences:

- Talking about death with family carers of people with dementia: a taboo within a stigma SAPC Regional conference, Madingley Hall, 30th January [ORAL PRESENTATION]
- Quality End of Life Care for Dementia from a Families Perspective: A Narrative Review European Association of Palliative Care June 5-7th 2014, Lleida, Spain [POSTER PRESENTATION]
- The Experience of Living with and Caring for Someone with Dementia at the End of their Life European Association of Palliative Care June 5-7th 2014, Lleida, Spain [POSTER PRESENTATION]
- Family carers' experiences of admiral nursing Alzheimer Europe Conference, Glasgow, October 2014 [POSTER PRESENTATION]

3. Discussed themes from WP2 at policy conferences:

- Models for organisation of palliative care in patients with cancer and patients with dementia at the 'Towards integration of palliative care in an age-friendly European Union' conference, Brussels 15th October 2014 [KEYNOTE PRESENTATION]
- Evidence for care co-ordination for people at the end of life with dementia National Council for Palliative Care Annual conference, 10th December 2014, London [KEYNOTE PRESENTATION]

7th Framework Programme, HEALTH-2010-two stage,
Grant Agreement No: 258883

4. **Completed the analysis of palliative care services in different European countries**, framed in terms of macro-, meso- and micro-level characteristics.

In addition, the WP2 researcher, Nathan Davies, successfully defended his PhD at University College London. His thesis title was: *Quality end of life care for people with dementia: the views and experiences of family carers*

The research team of WP2 has continued to collect data about national differences in the organisation of palliative care services in Europe, has recruited care homes, community services, hospices and hospital wards for the intervention phase of IMPACT, and has continued to publish findings. The original models of national palliative care systems (in the UK, Norway, Germany, Holland and Italy) have been augmented by data from Poland, France and Belgium, and the models continue to evolve.

Work Package 3

WP3 continued their work on the identification of strategies used to improve the organisation of palliative care, barriers and facilitators related to such strategies and a set of quality indicators that can be used to assess the current organisation of palliative care and hence initiate quality improvement projects. This has led to two scientific publications: a publication about the quality indicators related to the organisation of palliative care and a publication the barriers and facilitators of strategies used to change the organisation of palliative care. Besides, the quality indicators developed in this WP, have been used by an Indonesian PhD student and validated for Indonesian hospitals too (please refer also to attachment ‘indicators Indonesia’).

Work Package 4

WP4 completed the intervention phase in eight services in Germany. A method for the analysis of the implementation strategies used was developed. The results of the analysis undertaken by WP4 are presented in a table of strategies (deliverable 4.05). Due to delays of the intervention phase in some countries, a finalized version of this table of strategies was submitted after the end of the previous reporting period in August 2014. Another revised version was completed in the current reporting period, containing only the services that completed the posttest (3 dropouts). The posttest data from all countries have been cleared and analyzed, as required. The remaining services implemented 1-3 quality indicators each; addressing in total 21 of the 24 indicators from the quality indicator set. The top 3 indicators were: QI 7b (Bereaved professionals involved in the care of a person in need of palliative care are offered support during the bereavement process if they need or wish to have support – 13x), 20 (There is a regular assessment of pain and other symptoms using a validated instrument – 13x), and 24 (The file of the person in need of palliative care contains documentation of a discussion with the person or representative (if the person lacks capacity e.g. is unable to communicate) about: medical condition; goals for treatment; the physical, psychosocial and spiritual needs of the person and family caregiver; an advance directive or advanced care plan; end-of-life

7th Framework Programme, HEALTH-2010-two stage,
Grant Agreement No: 258883

decisions; the intention to return home or to another facility from the place where the person is currently staying - 11x). A detailed comparative analysis and interpretation of the results is provided (MS 21), as well as a database with the pre- and posttest results (MS16).

The clearing and analysis of the pre- and posttest data showed that there was a need for adapting the operationalisations of the quality indicators in order to simplify the analysis process. Therefore the questionnaires for the tests to be used by interested services after the end of the IMPACT project were adapted thoroughly in collaboration with the researcher from WP3.
WP4 researchers have been presenting results of their work at national and international congresses and meetings, contributing to the tasks of other WPs as required, and to publications. Manuscripts for publications of WP4 issues are in working process.

Work Package 5

The posttest has been completed in all 8 services participating in Norway, and the services have been given feedback on the results. The posttest data has been checked and sent to WP4. Data collection for the two WP5 studies has been completed by all countries. In the first study, representatives from all services have been interviewed about the challenges filling in the online questionnaires in the pretest and the posttest. For the second study, data for an extensive process evaluation has been collected using questionnaires and semi-structured interviews with managers and staff members who have worked on improving the quality indicators. An inventory with the factors influencing implementation of improvements in palliative care has been developed. The results can be used to tailor improvement projects in other services not connected to the IMPACT project.

Work Package 6

The following dissemination tools have been developed during the third and last period of the IMPACT project:
- On the general public and healthcare settings level: A DVD in English has been developed in English with subtitles in Dutch, Finnish, French, German, Italian, Norwegian, Polish and Spanish. It shows the main steps that characterize the IMPACT process. A Manual with the details on how to implement the IMPACT process has also been published in eight languages: Dutch, English, French, German, Italian, Norwegian, Polish and Spanish. These tools have been developed with the aim to support the implementation of quality indicators by professionals willing to improve the organization of palliative care within their healthcare settings. Both tools have been uploaded on the IMPACT website and on mass storage devices distributed during conferences and meetings.
- On the researchers level: Other papers have been published in international journals and the IMPACT researchers have attended European conferences and symposia holding poster and oral presentations to disseminate the project results to the scientific community. The results achieved so far have been presented during the final conference of the IMPACT project, organised in collaboration with the EUROIMPACT project, in Brussels in October 2014.

The expected final results and their potential impact and use (including the socio-economic impact and the wider societal implications of the project so far)

A set of QIs has been developed and has been published. This set of QIs has been used in the pilot test we have performed in five countries (NL, DE, UK, IT, NO), in four types of settings (hospitals, hospices, nursing homes, primary care). In each of these settings, a consultant invited the professional team to assess the quality of their organisation with the help of the set of QIs and to chose improvement topics and aims. Based on quality improvement steps (Grol et al) the teams improved the organisation of their setting. Finally, the effects were measured with the QI set. The results of this implementation study will be available in 2015. We now have a set of QIs to assess the quality of the organisation of palliative care in all kind of settings and countries; an overview of barriers and incentives with regard to implementing quality improvement projects in the organisation of palliative care as well as effective implementation strategies. In the future, also other countries can use our set of QIs with the help of the available manual that describes how to use them and how to start improvement projects.

We do know that often professionals want to change, but do not want to be changed. For that reason, the use of QIs should always start as a way to provide internal mirror information: as long as using QIs and transparency are no daily practice, the QIs should not be used by external parties to make judgements, but should be used by the professionals themselves.

Our project has contributed to a better understanding of implementation strategies by systematically studying the process of implementation of quality indicators and improvement projects in a specific field of an urgent societal problem; the organisation of palliative care for the rapidly growing group of patients with cancer and patients with dementia. Our ‘case’ of palliative care for this specific group of patients can also be used as a starting point for QI development and implementation in other groups of patients.

Now the IMPACT project has ended, we want to collect data of those settings that will use our set of QIs. A larger data set will enable comparisons, case-mix adjustments and further studies on this rich material.

We will also strive for dissemination in other European countries, and other continents. Our set of QIs has already been used in Indonesia, and parties from several Asian and African countries have shown interest to cooperate and use the QIs. The project leaders Dr. Yvonne Engels and Prof. Dr. Myrra Vernooij-Dassen have made a successful trip to the Unites States (New York and Boston) to disseminate the project findings and indicators.

During the final conference of the project on October 15, 2014 in Brussels, a lively debate with policy-makers, key stakeholders, clinicians and patient representatives was held to build a better future for palliative care, including the integration, education and use of newly available tools.

A declaration was created, consisting of policy recommendations, which was signed by policy-makers and the European Association for Palliative Care (EAPC), to ensure high-quality palliative care in an ageing society in Europe (and beyond). Already over 1000 people have signed the declaration. (www.palliativecare2020.eu) Currently, the declaration has been translated into Dutch, German, Polish, Norwegian, Italian, French and Spanish in order to increase further dissemination throughout Europe.

Public website address

www.impactpalliativecare.eu
www.palliativecare2020.eu/declaration

7th Framework Programme, HEALTH-2010-two stage,
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