



HELSE BERGEN

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Regional Centre of Excellence for Palliative Care, Western Norway



The Institute for Palliative Care, Lund University and Region Skåne (Palliativt Utvecklingscentrum, Universitet i Lund og Region Skåne):

Evaluation after the first five years, 2013-2017

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SUMMARY

The Institute for Palliative Care at Lund University and Region Skåne was established in 2013 to conduct research, provide education, and support and strengthen the clinical palliative care services in Skåne. The evaluation was commissioned by the two owners to evaluate research, care development and educational activities in the first five years of operation. Mixed methods comprising the study of written materials, a site visit and 13 interviews were employed. Results are summarized in a SWOT analysis and discussed. In conclusion, activities within care development, education, and cooperation with the specialist clinical services are mostly very satisfactory, while research efforts need to be more focused, with a clear strategy. A number of recommendations are given.

INTRODUCTION

Background

In 2012, a new strategy for palliative care in Region Skåne was approved. The strategy included a reorganisation of the clinical services, and a call for a stronger academic foundation. As a result, the Institute for Palliative Care was established in 2013 in cooperation between the Faculty of Medicine, Lund University, and Region Skåne. The vision for the centre was to strengthen research in palliative care, promote evidence based implementation of knowledge, secure equivalent quality of care and strengthen the standing for palliative care within hospital and community health and care services.

The centre's mission was described in the signed Agreement between the two partners Lund University and Region Skåne (Agreement parts 2.1-2.2):

- Conduct research, care development and education with the aim to improve the quality of general as well as specialist palliative care in Region Skåne

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- Through research and implementation of research findings obtain a leading position nationally and be acknowledged internationally
- Contribute to timely, evidence-based palliative care practice

The agreement stated that the Institute should have four central areas of work (2.3):

1. Research about general and specialist palliative care
2. Educational and care development for palliative care staff in Region Skåne and community services; the latter should be based on specific agreements
3. Contribute to educational programs at Lund University and University Colleges in Skåne
4. Be a leading centre nationally for quality development in palliative care

The centre's research activities should include the following:

- Develop and establish a long-term research strategy with prioritized research areas within palliative care research. These areas should be cutting edge nationally and internationally.
- Strengthen the development and use of registry data as a basis for research and quality improvement
- Recruit, educate and supervise PhD candidates and young researchers interested in research and palliative care
- Establish cooperation with other research groups regionally, nationally and internationally. Palliative medicine and palliative care nursing are two central research perspectives, but the interdisciplinary cooperation should also include other professional areas.

The requirements for activities linked to education and care development were less specific, but several recommendations were given, e.g. to implement the Swedish Palliative Care Registry in Region Skåne, establish clinical networks, develop, promote and implement clinical tools and care programs, develop web resources for health care practitioners and the public, educate palliative care professionals, and initiate patient and public engagement events.

Evaluation purpose and questions

Lund University and Region Skåne commissioned an evaluation of the Institute after five years of operation. This coincides with the end of the strategic plan for the development of palliative care in Skåne (2013-2018).

The aim of the evaluation was to assess to what degree the centre had fulfilled its goals as stated in the Agreement, and to identify areas with potential for improvement. The board and staff of the Institute would use the report as a basis for further strategic planning.

The evaluation should examine the following areas:

1. Research, care development and educational activities during the period 2014-2017
2. Cooperation with the clinical services
3. Support for the development and implementation of evidence-based palliative care
4. National and international cooperation

Evaluation scope and process

The evaluation took place in February-March 2018. A mixed methods design was applied, comprising the following parts:

1. Study of written materials and web resources, described in Appendix 1
2. Visit at the Institute, 22nd-23rd February 2018
3. Interviews, performed during the visit or by telephone shortly after. List of interviewees, Appendix 2.
4. Synthesis of information and writing of report.

Limitations of the evaluation are that it is carried out by just one individual over a limited time period. (The Director of Research at Region Skåne tried to recruit another researcher, but unfortunately did not succeed.)

Positive aspects are that the chosen evaluator understands Swedish, spoken and in writing, and has carried out similar projects before, e.g. an evaluation of the Danish Knowledge Centre for Palliative Care, and a report on the organisation of palliative care in the other Nordic countries for the Norwegian government (2017). In addition, she is head of a similar centre in Western Norway, covering a comparable population and number of services.

EVALUATION

Description of the Institute and its main areas of work

Staff and infrastructure

Since the establishment in 2013, the centre has constantly been growing and has per March 2018 18 employees, adding up to 13.6 full time equivalents. Staff members by background represent medicine, nursing, physiotherapy, public health, psychology, education, coaching, epidemiology and human ecology.

Apart from the Director, 3 staff members work with administration, one works as course developer, one as quality manager (care plan developer/coordinator), and one as outreach coordinator; the rest are research staff.

One special feature of the Institute, unique for Sweden, is the combination of academic chairs in palliative medicine (from December 2012) and palliative care nursing (from 2014).

The Director has a small management/leadership group. There is a common meeting for all staff members twice per month, regular research meetings, and seminars for the whole staff a few times per year.

The centre has very nice facilities in Medicin Village in Lund.

Overall strategic plans

The Institute does not have a written strategic plan apart from the guidance and mandate given in the Agreement. However, the activity report 2013-2017 states that the Institute initially prioritized activities with short delivery time such as education and courses for generalist and specialist staff, while later turning to activities with a longer time perspective, i.e. developmental and research projects.

The Institute has a board with three representatives from each of the partners.

It does not have a reference group, but the regional group for research, development and education has many of the functions of a reference group.

Funding

The Institute is funded by the two partners, but external funding from private donators has been crucial for its development. Major grants have been received from the Crafoord Foundation, the Kamprad Family Foundation and Mats Paulsson Foundation.

Research

The Institute is engaged in a broad range of research activities and projects. I have tried to categorise these under a few headings:

1. Studies on early integration of palliative care and oncology

The "ALLAN" study (randomized controlled trial, gastrointestinal cancer) and the study on multidisciplinary team meetings for patients with oesophageal cancer

2. Registry studies

Mostly studies linked to the Swedish Palliative Care Registry, but also a study on patient pathways in palliative care in the Southern Health Care Region.

3. Bereavement studies: Losing a parent as teenager

A PhD project based on a comprehensive questionnaire survey.

4. Core Outcomes and Quality Indicators

Development of a Core Outcome Set for care of the dying is an international multi-centre project of the International Collaborative for Best Care for the Dying Person. A similar, local project is a qualitative study to identify preferences and priorities for end of life care.

5. Patient care: Studies to improve clinical services and patient care

Examples are a multi-centre study on existential loneliness in frail and seriously ill elderly persons, and an international, comparative study on patient experiences on the way to diagnosis and treatment of lung and colorectal cancer.

6. Studies on educational interventions

Implementation of evidence based palliative care for elderly persons living in nursing homes. Studies on the effects of communication training. A new project around the concept of 'embedded training' is being planned in Kronoberg county.

7. Studies on the effects of implementation of palliative care tools

Validation and implementation of IPOS (Integrated Palliative Care Outcome Scale). Studies on the experiences and effects of using the National Care Plan for Palliative Care.

Some of the completed or ongoing studies cannot be defined as palliative care research, such as 'Individual rehabilitation after breast cancer surgery' and partly the study on patient experiences listed above (5).

Two overarching themes for the research are **care of the dying** and **communication**.

The Swedish Registry is a registry for care of the dying. The Core Outcome Set is for studies on care of the dying, and the National Care Plan started out with a module for the last 48 hours.

Communication training has been the main educational activity of the Institute.

Supervision of Master and PhD candidates

Five candidates have completed a one year Master thesis (Magisteruppsats, 60 credits) at the Institute, and six a two year Master (Masteruppsats 120 credits). Two of the latter, one physiotherapist and one psychologist, have continued as PhD students at the Institute. One additional PhD student has recently entered.

The PhD candidates are offered regular supervision. The candidates have presented results from their projects at national as well as international courses and conferences.

There are no completed PhD degrees at the Institute so far, but the professors have been involved as co-supervisors for several candidates at other institutions.

National and international collaboration

The Institute has cooperation and links to a number of international institutions and organisations / work groups, among them University of Seattle, Harvard University, University of Oxford, University of Liverpool, University of Århus, University of Bern, Kings College London, European Association for Palliative Care (EAPC) and International Collaborative for Best Care for the Dying Person.

Nationally the Institute has connections to all other major palliative care centres and several universities and university colleges, and is part of several research networks. The Director and other staff members have a number of commissions of trust and leadership roles in national and international committees and organisations.

Collaboration with specialist palliative care services in Region Skåne

The Institute has built a close collaboration with the clinical palliative care services in the Region. This collaboration includes

- Teaching on courses arranged by the Institute
- A weekly Directors' meeting
- Common responsibilities for doctors in training and student selective
- Research, with the clinical services recruiting patients and collecting data
- Dissemination of research findings
- A common Group for Research, Development and Education; common seminars
- Quality improvement projects

The medical advisor position at the Institute has been instrumental in establishing the links with the clinical services.

Development projects

The National Care Plan for Palliative Care (**Nationell vårdplan för palliativ vård, NVP**) has been the main development project for the Institute. It started as a planned revision of the Swedish version of Liverpool Care Pathway, an integrated care pathway for care of the dying, but has been extended to also include modules on (initial) assessment of palliative care needs and decision support for palliative care interventions. The development of the plan was a three-year project with three

rounds of testing, the last round in 30 units all over Sweden, and a project group with 90 members, including public and patient representatives. The final product has since 2016 been implemented in 170 services across Sweden, mostly in community services. The next phase of the project concerns sustainability and a research-based evaluation.

The National Board of Health and Welfare (Socialstyrelsen) has a link to the NVP on their homepage, but rather hidden and not identifiable through their search option.

Another development project, linked to NVP, is the translation and validation of the assessment tool **IPOS**, Integrated Palliative Care Outcome Scale. After pilot testing, the tool has been introduced to specialist palliative care services in the region through an implementation project. The project is now being evaluated, and one has started to disseminate the tool to community services.

Educational activities

During the first years, the Institute offered a wide range of courses and educational activities. During the last years, they have concentrated on a few central educational activities:

- **The Necessary Conversations** (De nödvändiga samtalen, DNS), originally for physicians, but a similar course for nurses has recently been developed. More than 700 physicians have been trained, and trainers have been educated. 13 certified course facilitators are presented on the home page. The concept builds on acknowledged international communication training programs and uses role plays with professional actors.
- A five week student selected module in palliative medicine for medical students. This has been offered to 15 students twice each year (not run autumn 2017 and spring 2018 due to low number of applicants). This elective course is the only education in palliative medicine offered to medical students at Lund University.
- Educational days on the National Care Plan
- Web course in basic palliative care, 90 minutes times two. Participants register for the course, and information on completed courses is sent to clinical managers.

In addition, regular seminars are arranged by the regional Group for research, development and education.

A thoroughly planned course on leadership for palliative medicine physicians had to be cancelled due to lack of applicants.

Dissemination

The Institute has a well-structured and informative **web site** with information about the main projects, news, courses, staff etc. Several instructive films are presented. The newest addition to the website is the part Death Ed (Death Education). Death Ed is published in Swedish and English, while other parts of the website are only offered in Swedish.

A monthly newsletter is sent to 4,000 recipients.

The Institute was local organiser for the Swedish National Palliative Care Conference in 2015 and has several contributions at this year's conference in Stockholm. In 2017 a full day seminar was arranged as part of Lund University's 350 years anniversary.

Several staff members have been interviewed by media. The Journal of the Swedish Medical Association has had a special issue presenting the Necessary Conversations.

Publications

The number of publications has increased over the years, with about 20 publications in international, peer-reviewed journals the last year. Publication channels include all the major palliative care journals as well as Nordic journals. Some of the international projects have resulted in publications in prestigious, high impact journals.

Evaluation

I have chosen to present the evaluation as a SWOT analysis, presenting the Institute's strengths, weaknesses, opportunities and threats as I perceive them from the interviews and the materials studied.

Strengths

- Enthusiastic, interdisciplinary, action-oriented staff with strong expertise
- Variation in methods and approaches
- Good working environment and collaboration, with a lot of good discussions on a daily basis
- Part-time coworkers bring impulses from other settings
- International collaboration and contacts
- Wide net of contacts within Sweden, especially within education and research institutions
- Promotion of palliative care within Skåne, giving it a firm foundation, 'placing it on the map'
- Development and implementation of the clinical and educational tools: the National Care Plan, IPOS and the Necessary conversations
- The regional Group for research, development and education
- The web course in basic palliative care
- The student selective in palliative medicine for medical students
- The close collaboration with the clinical specialist palliative care services
- Successful dissemination activities
- Flexibility and readiness to seize opportunities and explore new ideas
- Financial support

Weaknesses

- Lack of clear goals and a clear research strategy
- Still not in a position to compete for prestigious national research grants, has not reached 'critical mass'
- Lack of a strategy to strengthen basic palliative care in community and hospital services
- Lack of a palliative medicine curriculum in the undergraduate medical education
- Strong dependency on Director

Opportunities

- Good potential for further academic development

- Potential for stronger integration of the different activities of the Institute, e.g. research and development
- Recruitment of coworkers: Ample opportunities for research and professional development for the right persons
- Possibility to employ present senior persons part time when retired
- Quality improvement agents have been appointed in the primary care services – use these to reach community services?
- Expand catchment area to the whole Southern Health Care Region, not only Region Skåne
- Expand the studies related to the National Palliative Care Registry – unique coverage

Threats

- The constant work required to keep a standing
- The close link to clinical oncology
- The three senior persons all close to retirement
- Strategic plans too closely linked to individuals and not the Institute as a whole
- High degree of flexibility may give a lack of focus and a loose structure
- More resources necessary for a stronger integration of research and development
- Combining course development and marketing may give rise to conflicts
- Having individuals working on very different projects creates vulnerability
- Part-time staff may threaten unity and cohesion

Discussion

Five years is a short time span in the life of an academic institution. Even so, the Institute for Palliative Care has already managed to achieve a standing within Region Skåne and Lund University, a national reputation as a leading palliative care centre, and a broad international network. This is brought about by a dynamic Director and an active, enthusiastic, skilled interdisciplinary staff.

The Director has both nationally and internationally long been recognized as one of the national leaders in palliative care in Sweden, and his reputation and network have naturally represented considerable advantages in the establishment of the Institute. Other strong assets in this first period have been the ability to recruit excellent coworkers, and a great flexibility. The flexibility has made it possible to pursue 'hot' trends in palliative care, e.g. early integration and death education, ensuring that the Institute responds to timely and relevant challenges.

However, being flexible and building upon individual coworkers mean that the formal structures for the Institute are less strong, creating a certain vulnerability. Most of the coworkers work on their own projects without colleagues as backup, and without pursuing a clearly stated, common strategy and goal. At the moment, the common goal for the Institute is more like the sum of individual goals. This may be acceptable in a construction phase involving a certain degree of trial and error to find projects with the most potential, but time has now probably come to set a clear direction for the future: What should be the priorities and goals for the next five years? This clarification is likely to imply a narrower scope for the research efforts, but more depth.

The National Care Plan for Palliative Care and the educational program the Necessary Conversations are examples of projects that have been rooted and firmly developed within the Institute. These projects are nationally acknowledged and having an impact. The communication program has been linked to a PhD project, and there are plans to launch a more integrated model, targeting several administrative and management levels to have the communication program 'embedded' within an organisation. The National Care Plan should also be subject to a research program; the lack of international publications on its development so far is a weakness.

Linking research activities to the main educational and clinical development projects is a smart way of uniting areas of expertise within the Institute, and a necessity for credibility and evidence based development. However, communication and care for the dying are two demanding and rather poorly defined research areas, with limited 'hard', quantitative data.

The Institute has managed to establish a close cooperation with the clinical specialist care services in Region Skåne. The Group for Research, Development and Education has been an important facilitator for this cooperation, which includes research, quality improvement, education and training. However, it is still a challenge to involve the more distantly placed units to the same degree as the ones in close proximity to the Institute.

The Institute does not have the same close links to the 'ordinary' hospital and primary care services as to the specialist palliative care services. From a strategic viewpoint, starting with the specialist services was a wise decision, as the Institute is dependent on highly skilled clinical collaborators for education and training purposes. However, dissemination of palliative care skills and knowledge to non-specialist services is also part of the Institute's mission, and the next step could be to develop a strategy for this work together with the specialist clinical services.

The Institute is recognized as a leading palliative care centre in Sweden and has links to the other major palliative care centres in the country. Staff members are involved in international collaboration with several leading palliative care institutes.

The Institute is engaged in several high quality research projects, but has not yet managed to establish an internationally acknowledged research profile within one specific area of palliative care. Participation in a major international research or innovation project would be a logical next step, both to focus attention and as a basis for further cooperation and networking.

RECOMMENDATIONS

My recommendations are based on the SWOT analysis. In principle they are to nurture the strengths, strengthen the weak areas, consider the opportunities and oppose the threats.

The Institute has a lot of strengths. These are the main investment for the future.

The opportunities should be carefully considered, and the best ones pursued.

Specific recommendations:

- Develop a strategic plan for the next five years, with a clear research strategy
- Aim for stronger integration of research and development
- Consider participation in at least one major international research or innovation project
- Strive to reach 'critical mass' to be able to compete for national research grants

- Try to have a balance between PhD students, post-docs and established researchers; make use of European exchange programs to have international guest researchers
- Develop a strategy to strengthen basic palliative care in community and hospital services
- Strive to establish a palliative medicine curriculum for the undergraduate medical education

Appendix 1

List of written materials and web resources that were studied as part of the evaluation:

- Cooperation Agreement for the establishment of an Institute for Palliative Care for Research, Development and Education, between Region Skåne and Lund University, April 2013 (Samarbetsavtal avseende inrättandet av ett Palliativt centrum för FoUU, mellan Region Skåne och Lunds universitet («Avtalet»), dnr M 2013/445, april 2013)
- Strategic plan for specialist palliative care and other advanced home care. Committee for health and care services, Region Skåne, March 2013 (Strategisk plan för specialiserad palliativ vård och annan avancerad sjukvård i hemmet. Hälso- och sjukvårdsnämnden i Region Skåne, mars 2013)
- Activity report June 16th 2017: The Institute for Palliative Care 2013-2017 (in Swedish)
- List of publications December 2012 to March 2018
- Selected conference participations and external commitments
- List of educational activities of the Institute for Palliative Care 2015-2018
- A selection of published articles not accessible via PubMed
- List of Master of Science candidates 2013-2017
- List of PhD candidates 2013-2017
- List of staff as per February 2018
- Information about the Palliative Care Group for Research, Development and Education (Palliativa FoUU-gruppen) 2015-2017
- Clinical studies and projects for service development within specialist palliative care services in Region Skåne: Procedure for Assessment of Proposals by the Palliative Care Group for Research, Development and Education
- Regional knowledge groups in Södra sjukvårdsregionen: Knowledge management (October 2012)
- Application: Care skills and communication in palliative care. Family Kamprad Foundation.
- Project draft: Conversations in serious illness – the Kronoberg Model.
- Compilation of Mattias Tranberg's activities as a PhD student in medical psychology at the Institute for Palliative Care
- Powerpoint presentation about the Institute, 21st February 2018
- Folder: The palliative care doctor as leader. A development project for leadership skills.

Appendix 2

List of interviewees

- Carl Johan Fürst, Director, Lead Consultant and Professor of Palliative Medicine
- Birgit Rasmussen, Professor of Palliative Care Nursing
- Bengt Sallerfors, Medical Advisor
- Ingemar Petersson, Chair of the Board
- Ingrid Vesterberg, Head of Service
- Maria Schelin, Epidemiologist
- Rose-Marie Stiller, Administrative Coordinator
- Camilla Jönsson, Education Coordinator (left the Institute end of January 2018), (telephone)
- Mattias Tranberg, Psychologist, Ph D candidate
- Anette Duarte, Registered Nurse, Care Plan Developer
- Ingela Beck, Registered Nurse, Lecturer
- Marlene Malmström, MD, PhD, researcher
- Anders Danielsson, Course Developer (telephone)