Governance and organisation of palliative care in cancer care in Sweden - cancer care leaders’ perspectives

Anna O’Sullivan R.N., PhD [1,2] , Joakim Öhlén R.N., professor [4,5,6], Stina Nyblom MD, PhD [6,7],
Anneli Ozanne R.N., associate professor [8,9], Carl-Johan Fürst MD, professor [10,11] , Cecilia Larsdotter R.N., professor [1]

ID: 211

Conclusion

- Governance and organisation of palliative care differs regionally, locally and between cancer diagnoses in the country
- The result indicate that prerequisites for palliative care vary within the country in ways that may hinder equity in palliative care
- Increased knowledge about palliative care and early integration of palliative care is required, to enable the possibility to die in one’s preferred place, and especially at home

Aim

Governance and organisation of care is driven by policy and inclusion of palliative care in policy has been encouraged internationally. The aim of this study was to investigate cancer care leaders’ perspectives on governance and organisation of palliative cancer care in Sweden.

Methods

Participants in this study were nurses, physicians and other professionals who are cancer care leaders and patient representatives on a regional level in the national cancer care organisation representing different regions and cancer diagnoses. There was in total 36 participants in 16 interviews: six group interviews with 3-6 participants in each and ten individual interviews. Data analysis was performed based on interpretive description.

Results

Conceptualisations of palliative care

The interview discussions mainly involved the late phase of palliative care, the very end of life when disease-specific antitumoral treatment has ceased. Early integration of palliative care parallel to disease-specific treatment was however desirable but considered not possible due to the organisation of care.

Results continued

A lack of knowledge about palliative care amongst decision-makers was expressed, but also amongst healthcare professionals, patients, family and general public.

> “…we have perhaps a great deal of work out there with the public to change the view of palliative care… there is fear around this concept in public because you don't have knowledge about it”

Perceptions of governance and organisation of palliative care

Regional, as well as local differences in the governance and organisation of palliative care were highlighted. Locally between hospitals, between clinics within hospitals and between cancer types. It was expressed that what drives palliative care is "enthusiasts“ - but also that it is difficult to influence governance and organisation of care and what ultimately rules is politics and resources.

> “It very much depends on the local organisation; the availability of palliative care can differ from one street to the next in a city. I think it is very much dependent on individual people who take action and that is the most important reason for the difference. Politicians and resources – I don't think that is the most important reason, but I think the most important reason is above all people in the profession, both nurses and doctors and how committed you are to making it work”

A better collaboration between advanced specialised home care and the oncology clinic could contribute to increased knowledge and earlier integration of palliative care, enabling death in one’s preferred place – especially at home death.

Consequences for care – lack of early integration of palliative care

Lack of governance, lack of knowledge and resources for palliative care means that early integration of palliative care does not take place. This is partly due to a culture in oncology of active treatment late in the course of the disease, and the consequences of this for patient care and care giving were highlighted.

> “Decisions about palliative care are often made late and it is very unfortunate when we have seriously ill and difficult cancer patients when it comes to hospice care and they only have a week left to live. I don't like the fact that we refer them so late to palliative care, and that's a lot to do with not stopping oncology treatment in time”

1. Sophiahemmet University, Department of Nursing science, Stockholm Sweden
2. Marie Cederschiöld University, Department of healthcare sciences, Stockholm Sweden
3. Department of Palliative care, Sahlgrenska University Hospital and Institute of Health and Care Sciences, University of Gothenburg, Gothenburg Sweden
4. Centre for Person-Centred Care, University of Gothenburg, Gothenburg Sweden
5. Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg Sweden
6. Palliative Centre, Sahlgrenska University Hospital, Gothenburg Sweden
7. Sahlgrenska Academy, Institute of Medicine, University of Gothenburg, Gothenburg Sweden
8. Institute of Health and Care sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg Sweden
9. Department of Neurology, Sahlgrenska University Hospital, Gothenburg Sweden
10. Faculty of Medicine, Department of Clinical Sciences Lund University, Lund Sweden
11. The Institute for Palliative Care, Respiratory Medicine, Allergology and Palliative Medicine, Lund University, Lund, Sweden

Corresponding author: Anna O’Sullivan, , email: anna.osullivan@shh.se

UNIVERSITY OF GOTHENBURG

LUND UNIVERSITY

MARIE CEDERSCHIÖLD UNIVERSITY

SOPHIAHEMMET UNIVERSITY