
CONFERENCE ABSTRACT

Closing the organizational gap between formal- and informal care in neuro-oncology to achieve fully integrated care.

ICIC20 Virtual Conference – September 2020

Eskil Degsell¹

1: Karolinska University Hospital, Solna, Stockholm Sweden

Fully integrated care between all stakeholders and more flexible transitions between services (hospital care, palliative care and advanced medical care at home, social care) and informal care and patient self-care are vital for neuro-oncology patients. Cultural differences, lack of communication and collaboration between all stakeholders that hinder fully integrated care are to be identified and dealt with.

Traditional oncology integrated care models do only consider integration between hospital care and palliative care but in neuro-oncology there is a need to think broader. We suggest that informal caregivers and other informal support must be considered as an integral part of the care process when dealing with patients with brain tumors, due to the complexity of the disease.

Such an approach calls for efforts from policymakers and health and social care practitioners to organize care services differently, but also a new mindset. Current systems are rigid which makes it difficult to respond to changes in care needs and the great variety in patients' life situations.

The necessary practice change requires a new way to work in a fully integrated way, and most importantly, driven by the perspectives of patients and next of kin. The project investigates how care providers can better be organized to provide a fully integrated care fulfilling these requirements. We involve all stakeholders in piloting and implementing the project. We apply integrated care and implementation theories.

The process started in 2015 with the change of organizational model at Karolinska University Hospital and with the Regional Cancer Center engaging patients and next of kin in priority setting. In 2016 the team joined the Co-care research program at Karolinska Institute. In 2019 we created a new model of co-care in neuro-oncology which is now starts to get implemented. The project will continue during 2019-2024 and ultimate aim is to contribute to a change of culture and reach a fully integrated person-centered approach service.

The project aims to achieve:

- Strengthened role for patients and informal caregivers.
- Routines for observation, communication, interventions and transitions between all levels of care.

- Flexible and integrated structure for collaboration between all stakeholders at the right level.
- Changes in policy regulations and reimbursement.
- Formal training/education of all stakeholders to optimize skills in brain tumor care.

All stakeholders acknowledge the need to change their practice and have an emphasized focus on quality of life. As patients and next of kin/informal caregivers are integrated in the project, the management of their daily lives will form a powerful stimulus to continuous and sustained improvement.

The lessons learned can be transferred to other regions in Sweden.

By developing a fully integrated response to the care needs of this patient group, quality of life can be improved both for the patients, next of kin and for the professionals.

The project is ongoing and findings will be presented and discussed at the conference.