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

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Traditional oncology integrated care models tend to only consider integration between providers, for example hospital care and palliative care.

Where is time spent from diagnosis to death in the neuro-oncology field?

Eva was diagnosed with Glioblastoma on the 1st of Sept 2014. During her first year with a brain tumour, she spent 364 hours in healthcare (red) and had 30 hours of social care (yellow). Eva also spent 7,651 hours in selfcare (blue) and 720 hours managing herself with the help of her husband Wilmar (green).

During Eva’s second year with a brain tumour, she spent 2,880 hours in healthcare (red) and had 210 hours of social care (yellow). During her last nine months, she needed help from her husband Wilmar to manage herself for 3,750 hours (green). Eva died on the 25th of May 2016.
A day in a patient's life require professional and organizational integration, the care need also changes over time.

4 Dec 2014

Jan’s motor skills have deteriorated and she has now difficulties to button her pants and keep her balance, so her friends and Karin step in. The meeting with her neurologist went well and they want to make a new cognitive assessment as a basis for the home care service. Jan’s employer is very understanding, and she now works 25%. At night Jan is looking for possible studies to participate in.

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Jan had several seizures during the day and needs help with both eating and going to the toilet. Karin is caring for Jan full time and during the day and social care has been there four times. The Palliative Mobile HealthCare Team also came by in the afternoon and did an examination. The children find it difficult to see their father so ill so their grandfather took care of them in the afternoon.
In neuro-oncology there is a need to take a broader perspective regarding the perspective of care. We suggest that patient self-care, support of informal caregivers/actors and other formal 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.

Fully integrated care model including co-care

- Patient focuses on quality of life, overall survival, self-care and co-care
- Other important informal actors focus on supporting quality of life and self-care, and help in coordinating care
- Next of kin focus on supporting quality of life and self-care, and help in coordinating care
- Other informal actors focus on supporting quality of life and the new life-situation of the patient
- Social care focuses on quality of life and practical support
- Healthcare focus on life-prolonging or curative treatment
- Other formal actors focus on practical tasks, including financial support
- Palliative care manages symptoms and improves quality of life
- Another type of social care focus on quality of life and practical support
- Next of kin also becomes more and more informal caregivers and take a greater part in coordinating life for the patient
- Due to the characteristics of a brain tumor the capacity for self-care and co-care can decline
- Due to the characteristics of a brain tumor the capacity for self-care and co-care can decline
- Death
Fully integrated care requires efforts from policymakers, health - and social care practitioners to organize care services differently, but also a new mindset

Continue and increase patient and informal caregivers/actors involvement in healthcare....but

Continue to treat the tumour according to best practice care and clinical guidelines....but

... also start to involve healthcare and other formal actors into the lives of patients and informal caregivers (co-care)

... also start to see, coordinate and strengthen roles and relationships in order to better handle the possibilities and challenges caused by a brain tumour, both for patient, informal caregivers and professionals
So we started to develop a complex intervention that we called: CareMap-CareMapping

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And we started simple, with pen and paper and some instructions....

**Instructions**

1. Draw figure/figures next to you if you as a patient live with someone else in the house in the middle of the map.
2. Write their names in the light green table and write what role / roles they have.
3. Continue to write down the name and role / roles in the various tables that help you to feel good and handle challenges related to your (patient's) health and illness. Keep in mind that there may also be people who help you with challenges in life caused by the disease, such as paying bills, shopping and more.
4. You as next of kin, feel free to also fill in people who help you with challenges linked to the disease but also linked to you to feel good and feel free to put a little * behind these names.
5. Reflect on all these roles and relationships regarding how important they are right now (last month) for you to feel good and be able to handle the challenges that the disease leads to.
6. Feel free to reflect on what would happen if someone who is very important could not contribute more or as much and how you can possibly prevent it.
7. Reflect on how you / you feel that very important roles / relationships have developed over time (last month).
8. If you have very important roles / relationships that have changed and been strengthened or weakened over time, reflect on how and why you think the roles have changed and how and why the relationship has been strengthened, weakened or developed into a new type of relationship. **Note that roles and relationships change and it is not uncommon to have a different picture of how roles and relationships change.**
9. Delete the roles and relationships that have no longer been active or take a new blank CareMap and draw the ones that are currently in effect.
Joint combinations of talents; patients – next of kin – professionals and researchers in close collaboration

- Ongoing: Several workshops with patients-next of kin and professionals
- Ongoing: Qualitative study with patients and next of kin (no1), qualitative study with next of kin (no2), qualitative study with bereaved next of kin (no3)
- Ongoing: Scooping review for interventions for to see, coordinate and strengthen roles and relationships (no 1) Scooping review on capturing lived experience from bereaved next of kin
Findings so far

- Fully integrated care, co-care and caremapping requires a new mindset regarding how to organize care, but also broaden the definition of care to involve the patients whole life situation.

- For a fully integrated, co-care and caremapping to happen, representatives of all stakeholder groups need to be onboard and challenge more traditional mindset about how to collaboration between patients, informal caregiver, organizations, professionals. Less of silo thinking regarding respsibility.

- Fully integrated care as team work involve all stakeholder perspectives. Every perspective counts.

- Researchers need to stop recruiting patients to their studies and, instead, collaborate closely with patients/next of kin and professionals and doing research together. By identifying research questions relevant to all stakeholders, design and carry ot the research the more relevant the results are more likely to be implemented and contribute to both practice and science.

- Design the study intervention to stimulate a change in mindset and praxis to have higher impact on clinical outcomes, comparable to that of new drugs or medical equipment - but...

- ... a new mindset and new way of working require endurance, support, a clear why and NEW reimbursment schemes.

- Frequent communication and spread of findings – so more people will join and contribute.

- Think big, start small and move fast

- Have fun and be proud
We call for published/un-published data that strengthen what we have present, please help us in our important work

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