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Initiatives to raise awareness of paediatric palliative care in Sweden

BESA HAJZERI & CHARLOTTE CASTOR



Aim

To describe initiatives for raised awareness, increased knowledge and formalized Paediatric Palliative Care (PPC) in the Southern Region of Sweden.

Background

Awareness, knowledge and ability amongst healthcare professionals to raise concerns and face difficult situations in (PPC) is urgent.

Development of three interventions

To support an implementation of a national healthcare program in the southern part of Sweden a three-year regional project was launched.

A questionnaire amongst healthcare professionals and a literature review supplemented by workshops identified needs which were transformed into three prioritized interventions.

An Interprofessional Regional Team Consulting in PPC consists of members with specialized expertise, complementary backgrounds and skills offering education

- **Nurse** – Leads and supports the team, increases knowledge and helps customizing treatment based on individual health needs in complex care situations.
- **Physician** – Provides information/education about disease, symptoms and symptom management. Initiates diagnostic workups, treatment and evaluations of response.
- **Dietitian** – Supports nutritional management of patient's diet, adapting changes in nutrition needs throughout the illness process.
- **Physiotherapist** – Guidance on how to maintain physical health and independence, optimise functioning ability and participation
- **Occupational therapist** – Support assessment on the patients' functional abilities and enable daily activities and routines. Educate in energy saving strategies, and support meaningful activities by adjusting the environments or with different types of aid.



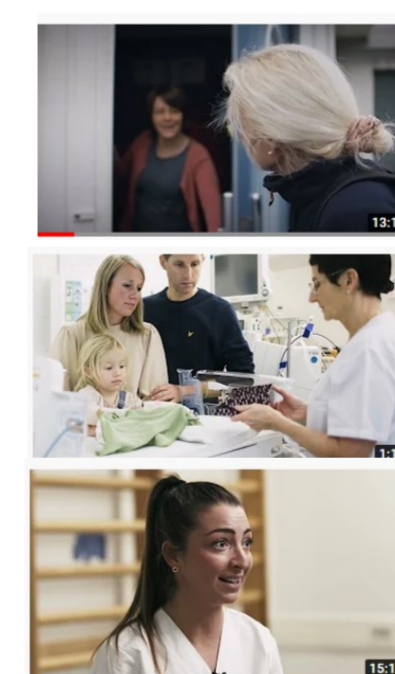
- **Psychosocial Counsellor** – Assess needs of psychosocial intervention including legal issues, and guides during the whole illness-trajectory. Provides counselling and education on; crisis support, the grief process after loss and bereavement and how to impact the family's ability to cope during a traumatic event.
- **Psychologist** – Attention on individual emotional reactions, increase understanding and knowledge about reactions at different ages and stages, based on cognitive and emotional maturity and previous life experiences. Education and support on how to understand emotions, how to respond and offer psychological support.
- **Child life specialist / Special educator** – Advice on identifying the needs of recovery and coping. Education on how to create conditions for play and creative activities in a safe environment for the whole family.
- **Chaplain** – Guidance in spiritual health, balancing aspects such as psychological, physical and social. Focusing on family members different needs of rituals and reliefs during and after the illness-trajectory.
- **Sibling supporter** – Attention on including and highlighting siblings needs throughout the process. Advices on adjusting information and support during and after the illness-trajectory.

Consulting program: Guidance, counselling, collaboration and support via telephone, video conferences and website (under construction).
Outreach program: Auscultation, study visits and educational intervention.

Regional Steering group with members appointed by the southern healthcare management consisting of healthcare providers and managers from various paediatric and PPC settings.

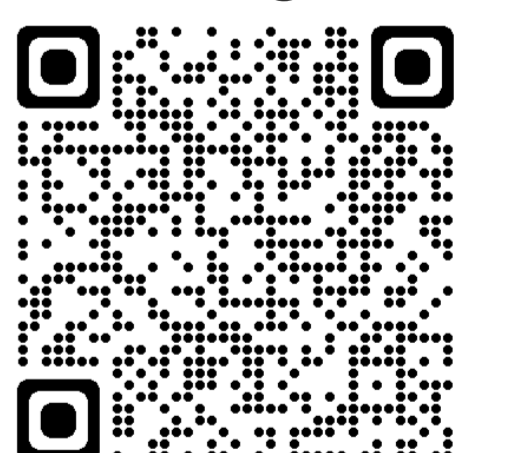
Identifies and discusses common or overarching organisational or policy related PPC issues within the region on a regular basis.

Bilateral communication and collaboration with the regional team to optimize implementation.



Five digital films introducing PPC aiming at raising awareness and willingness to act. Each film is 12-16 minutes with a specific sub-theme targeting. The films are produced in collaboration with Regional Cancer Centre Skåne University Hospital, Palliative care and Advanced Home Care Services Lund, Hospital Church in Lund by MASONIT / Dualongo.

Free to view on YouTube:



Conclusion

This project is ongoing with positive clinical response and aiming at increased child centered, equal, accessible, and effective PPC. Evaluation will include interviews, postintervention questionnaire and process report and will support future research proposals.

References

Cheng et al. 2019; Nilsson et al. 2019; RCC Stockholm. 2021; WHO. 2018

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