





### **Care in Connection**

## A Participatory Action Research (PAR) project on family-focused care in oncology

L. Van Humbeeck, MSc, PhD; L. Dillen, Mpsych, PhD; R. Piers, MD, PhD; N. Van Den Noortgate, MD, PhD

Ghent University Hospital, Ghent, Belgium Contact: liesbeth.Vanhumbeeck@uzgent.be

#### **BACKGROUND**



Cancer is a complex family issue affecting both patient and his loved ones. Although health care providers (HCPs) are aware of this rippling effect, the actual implementation of family-focused care (FFC) is not straightforward. There seems to exist a gap between theory and practice.

Our project *Care in Connection* aims at bridging this gap by developing or strengthening FFC tailored to three participating wards: the palliative care unit, the head and neck cancer unit, and the acute geriatric ward of the Ghent University Hospital.

#### METHOD

Bridging this gap requires a change in culture of care, in thinking about care models (levels of family-involvement) and in personal attitudes. To enable such a transformation a participatory action research (PAR) approach was used.

#### PAR is characterized by

- (1) a systematic and cyclic process of reflection (or diagnosis), planning (or construction of plan of action), action (or executing the plan of action), observation (of action) (see Figure 1);
- (2) an appreciative inquiry approach;
- (3) co-creation by HCPS, stakeholders and project staff;
- (4) acknowledgment of local knowledge (of the wards and specific HCPs) and prescriptive knowledge.

# Reflect Plan Observe Act Plan

Figure 1
Systematic process of PAR

#### **RESULTS**

PAR CHARACTERISTIC	GERIATRIC WARD	HEAD AND NECK CANCER UNIT	PALLIATIVE CARE UNIT
REFLECTION	Shadowing of HCPs     Questionnaire on FFC completed by HCPs     Reflection exercises in small workgroup FFC	<ol> <li>Shadowing of HCPs</li> <li>Questionnaire on FFC completed by HCPs</li> <li>Reflection exercises in small workgroup FFC</li> </ol>	<ol> <li>Shadowing of HCPs</li> <li>Questionnaire on FFC completed by HCPs</li> <li>Reflection exercises in small workgroup FFC</li> </ol>
PLANNING GOAL SETTING	GOAL = strengthening the welcoming of family members at a specialized unit for patients with delirium and/or behavioral disturbances.  (1) Revision of welcome leaflet (2) Design of a family conversation guidance document  (3) Registration of information from (2) in the electronic patient file, multidiscplinary consultation, and a summarizing board at the headbed.	GOAL = developing a communication trajectory for head and neck cancer patients and their family (1) Establishing tipping points for patient and family in the disease trajectory (2) Constructing information leaflets for patient and family about these tipping points (3) Multidisciplinary discussion of use of leaflets	GOAL = developing a vision statement on FCC at a palliative care unit.  (1) Discussion on central values in FCC  (2) Writing a vision statement with three central values and two overarching care attitudes  (3) Translating vision statement in concrete everyday care actions.
Action	DOING the conversation with families and recording the information. ASKING families about their experiences.	STARTING conversation between disciplines on communicating with families. ASKING families about their experiences.	STARTING the actions to make the vision statement tangible in everyday care. ASKING families about their experiences.
REFLECTION	Reflecting on and adapting tools.	Reflecting on and adapting tools.	Reflecting on and adapting actions.
COCREATION	A process of collaboration between two 0,5 FTE project staff members and a multidisciplinary workgroup per ward. Project staff facilitated and structured the process, while the workgroup gave content input and were owners of the process.		

#### **CONCLUSION**

PAR has the strength of inducing ownership, long-term sustainability and local theory. Conversely, PAR presents with the challenge of tenacious reflection on considerations in each PAR-cycle while ensuring collaborative decision-making and open communication with all stakeholders.