The MyPal project: Electronic Patient Reported Outcomes to Foster Palliative Cancer Care

L. Koumakis[1#], G. Zacharioudakis[1], M. Chatzimina[1], P. Argyropaidas[1], M. Tsiknakis[1] and K. Marias[1]

[1] Foundation for Research & Technology – Hellas Heraklion, Greece

Presenting and Corresponding author: Lefteris Koumakis, email: koumakis@ics.forth.gr

ABSTRACT

Palliative care is specialized medical care offered along with primary treatment to improve the quality of life (QoL) of the patient by relieving the symptoms and stress of a serious illness (such as cancer). As per modern definitions, palliative care is appropriate at any age and at any stage of the illness, regardless of the eventual outcome. Patient-reported outcomes (PROs), i.e., health status measurements reported by patients or their proxies, e.g. family members, and their availability in electronic form (ePROs), are gradually gaining popularity as building blocks of innovative palliative care interventions.

We present MyPal, an EC-funded project aiming to foster palliative care for people with cancer by leveraging PRO systems through their adaptation to the personal needs of the person with cancer and his/her caregiver(s). MyPal aspires to empower people with cancer and their caregivers in capturing more accurately their symptoms/conditions, communicate them in a seamless and effective way to their healthcare providers and, ultimately, foster the time for action through the prompt identification of important deviations in the patient's state and QoL. MyPal will demonstrate and validate its intervention in two different patient groups, i.e. adults with hematologic malignancies and children with solid tumors or hematologic malignancies. In order to assess the adult intervention, MyPal will design and conduct a multi-center, interventional, unblinded, 1:1 randomized controlled trial (RCT) with an estimated enrollment of 300 participants diagnosed with chronic lymphocytic leukemia (CLL) or myelodysplastic syndromes (MDS) from 4 clinical sites in Europe. The eHealth platform of MyPal will be administered to the intervention group, while the control group will receive usual palliative care at the corresponding center – if desired. The currently considered endpoints of the RCT are: (i) Improvement in QoL (primary endpoint), (ii) Symptom reduction, (iii) Pain reduction, (iv) Improvement in psychological and physical functioning, (v) Increase in patient involvement, (vi) Increase in satisfaction with care, (vii) Overall survival, and (viii) Improvement in cost-effectiveness. To assess the child intervention, MyPal will design and conduct a multi-center, observational, non-interventional study of 100 participating children and their parents from 3 clinical sites. The currently considered endpoints of the study are: (i) Improvement in QoL, (ii) Improvement in satisfaction with care for parents, (iii) Improvement in parental strain experience, (iv) Improvement in symptom burden for children.

Overall, the foreseen advancement through MyPal reflects a paradigm shift from passive patient reporting based on conventional PRO approaches to active patient engagement and a closed-loop approach (bridging the gap between patient reporting and timely as well as personalised actions performed by healthcare providers to address the varying patient needs) to cope with the palliative care for cancer.

MyPal is coordinated by Dr Vasilis. Koutkias of the Centre for Research and Technology Hellas, Greece. Other partners are: Fraunhofer Institute for Biomedical Engineering, Germany; Foundation for Research and Technology Hellas, Greece; International Observatory on End of Life Care, Lancaster University, UK; Central European Institute of Technology, Masaryk University, Czech Republic; Karolinska Institute, Sweden; Vita-Salute San Raffaele University, Italy; University Hospital of Heraklion, Greece; Hannover Medical School, Germany; University Hospital Brno, Czech Republic; Saarland University, Germany; Promotion Software GMBH, Germany; Atlantis Healthcare, UK; European Association for Palliative Care; International Children's Palliative Care Network; National School of Public Health, Greece.