QOL-10. THE MAKING OF ‘GOINGS-ON’ - A QUALITY OF LIFE MONITOR APP FOR CANCER PATIENTS AND FAMILIES
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BACKGROUND: My late husband, father of our 3 children of then 8, 6 and 2 years old, was diagnosed with a bi-frontal glioma in 2009. His prognosis was 2 to 20 years with behavioral and cognitive problems. He died in 2012 after in his own words a good life of still 40 years old. In an effort to minimize the effect of the tumor on our family I’ve initiated the ‘ReMind’ app. ReMind is based on Dr. Karin Gehring’s SNO quality of life awarded cognitive rehabilitation research, that was no longer available. The app and game are tested later this year both in the US and the Netherlands. I’m now working on quality of life monitor app ‘Goings-On’ for cancer patients with most probably a fatal diagnosis and their families. The concept has won the Achmea Open Health Community Award. Goings-On helps determine and monitor patient and family goals and functioning. Physician, patient and family can select their own specific items to monitor either via quantified self, photo’s or easy scales to better determine if cancer - and palliative treatments are desirable and effective. METHOD: As part of my PhD research in medical decision making I’ve attended several consultations with oncologists and other cancer related physicians inside and outside of the Netherlands, used available literature and input and feedback from physicians, other medical staff and patient advocates both at and outside the Society for Neuro Oncology Annual Meeting to determine the concept, draft screens and now a clickable prototype. RESULTS: The clickable prototype and reasoning behind design choices will be presented. CONCLUSION: The clickable prototype combined with feedback is to result in a randomized controlled trial for effects on treatment choices, health outcomes, quality of life and efficiency.