



PROJEKT »METULJ« - PRIPRAVA INFORMATIVNIH VSEBIN S PODROČJA PALIATIVNE OSKRBE V SLOVENSKEM JEZIKU

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Namen: O paliativni oskrbi (PO) je bilo do nedavnega v Sloveniji le malo pripravljениh vsebin, zlasti tistih namenjenih splošni populaciji. Namen projekta »Metulj« je bil približati PO vsebine v slovenskem jeziku bolnikom z neozdravljivimi boleznimi in njihovim bližnjim.

Metode: Specialistični več poklicni tim s področja paliativne oskrbe je v prvih korakih projekta pripravil nabor vsebin s katerimi se bolniki z neozdravljivo boleznijo in njihovi bližnji najpogosteje soočajo. Nato so v projekt povabili različne strokovnjake iz različnih strok in zdravstvenih ustanov širom Slovenije.

Rezultati: V projektu je sodelovalo 42 strokovnjakov, iz petnajstih različnih ustanov z vseh nivojev zdravstvenega sistema (20 zdravnikov, 12 medicinskih sester, 5 socialnih delavcev, 2 psihologa, 2 ponudnika duhovne oskrbe in 1 fizioterapevt). V skupinah se je pripravilo 20 informativnih vsebin, ki jih lahko razdelimo v pet glavnih skupin: telesni simptomi (bolečina, balonska samokrčljiva črpalka, težko dihanje (dispneja), slabost in bruhanje, nemir in delirij, utrujenost, izguba apetita, zaprtje, skrb za osebno higieno in urejenost, preprečevanje razjed zaradi pritiska (preležanin), nega oteklin (limfedem), suhost ust), psihološki problemi (otrok/mladostnik ob hudo bolnem, podpora svojcem v paliativni oskrbi, kako se pogovarjati s hudo bolnim), socialni problemi (pomoč na domu, kam, ko oskrba doma ne bo več mogoča), duhovna podpora in zadnji dnevi življenja. Vsebine so bile objavljene v tiskani in spletni obliki v času Svetovnega dneva paliativne oskrbe in hospica 2014. Tiskane vsebine so bile razposlane po zdravstvenih ustanovah, ki so za to zaprosile. Spletno stran www.paliativnaoskrba.si pa je v slabem letu dni obiskalo čez 5.400 uporabnikov, ki so stran obiskali 7.200 krat.

Zaključek: Projekt Metulj je vseslovenski projekt, ki je nastal v želji po boljšem prepoznavanju vsebin paliativne oskrbe. V letu dni od prvih objav je prepoznavnost spletne strani močno narastla, tako da se informacij, objavljenih na njej, bolniki in njihovi svojci že samostojno poslužujejo.

PROJECT »BUTTERFLY« - A PROVISION OF PALLIATIVE CARE INFORMATION IN SLOVENIAN LANGUAGE

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Aim: In Slovenia, up until now, there was almost no written information available for general population about palliative care. The aim of the project »Butterfly« was to prepare informative contents about palliative care in Slovenian language for patients and their caregivers.

Methods: A specialist multi-professional palliative care team has prepared a list of problems and difficulties with which the patients with incurable disease and their caregivers have to deal with most commonly. They have also invited different specialist from different professions and health institutions across Slovenia to participate in the project.

Results: A total number of professional that participated in the project was 42 from 15 different institutions from all the levels of health care (20 doctors, 12 nurses, 5 social workers, 2 psychologists, 2 spiritual providers, 1 physiotherapist). Divided into teams they prepared information for 20 different topics divided into five main groups - physical symptoms (pain, subcutaneous pump, dyspnoea, nausea/vomiting, delirium, fatigue, loss of appetite, constipation, patient hygiene, ulcer prevention, lymphedema, dry mouth), psychological problems (child/teenager close to palliative patient, self-care for caregivers, how to talk to a patient), social problems (home care, institutional help), spiritual support and last days of life. The prepared topics were released as flayers and a web page at the time of the World palliative care and hospice day 2014. The flyers have been together with a memo send to all the health institutions that asked for it. The web page www.paliativnaoskrba.si has been visited in the previous year by over 5.400 users that visited the site 7.200 times.

Conclusion: Project "Butterfly" is a national project, which arose from the wish for better recognition and understanding of different topics from palliative care. In the year since the first publications the recognition of the web page has strongly increased, so the patients and their caregivers already use the information on the web page on their own.