



# POTREBE BOLNIKA IN NJEGOVIH BLIŽNJIH V DOMAČEM OKOLJU *THE NEEDS OF PATIENTS AND THE RELATIVES LIVING IN HOME ENVIRONMENT*

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## **Povzetek**

Pomoč bolnikom in njihovim sorodnikom postaja v socialnem delu vedno bolj prepoznavno področje. V mednarodnem okolju je kvalitativno raziskovanje specifičnih vidikov pomoči bolnikom in njihovim sorodnikom veliko bolj prisotno kot pri nas. Zasedimo raziskave, ki proučujejo stališča žalujočih sorodnikov o primernosti oskrbe bolnikov v domačem okolju, raziskave, o prepoznavanju specifik pri oskrbi, ki jo sorodniki zagotavljajo družinskim članom v zadnjem obdobju življenja in raziskave o pomenu komunikacije strokovnjakov in neformalnih oskrbovalcev z bolniki.

V Sloveniji nimamo nacionalnih raziskav na tem področju, zato smo se na Fakulteti za socialno delo odločili, da samoiniciativno izvedemo poizvedbo o teh temah. Prvo raziskovanje smo izvedli leta 2019 in od takrat z raziskovanjem nadaljujemo vsako študijsko leto. Cilj raziskovanja je spoznati, katere teme so najbolj pereče pri zagotavljanju oskrbe bolnikom, kakšne so potrebe bolnikov in sorodnikov, kako so njihove potrebe zadovoljene in kakšno pomoč bi v zadnjem obdobju življenja potrebovali. Za namen tega prispevka predstavljamo rezultate raziskovalnega vprašanja, ki se nanaša na potrebe bolnikov in njihovih sorodnikov v domačem okolju.

Bolniki menijo, da je njihova oskrba doma, v domačem okolju edina sprejemljiva, da ni bilo potrebnih večjih prilagoditev prostora, ki bi imele tudi finančne posledice. Navajajo manjše spremembe pri ureditvi bivalnega in spalnega prostora, uporabo bolniške postelje, preselitev iz nadstropja v pritličje, uporabo dvigala, prilagoditev kopalnice in stranišča. Na drugi strani pa sorodniki menijo, da je bolj primerna oskrba v domovih, ker se izognejo preveliki emocionalni vpletenosti v oskrbo, ki jo povzročajo: šok, nesprejemanje bolezni, bolečina, obremenitve.

Finančni vidik oskrbe ni več v domeni bolnikov, skrb zanj prevzamejo sorodniki v celoti. Stroške oskrbe zakonci pokrivajo z obema pokojninama, tudi prihranki, zmanjka jim sredstev za vzdrževanje nepremičnine. Partner/ka opravi večino vsakodnevne pomoči,

kar bolniki tudi pričakujejo. Partnerji pa tožijo o tem, da imajo premalo pomoči, da bi se razbremenili. Razbremenitev predstavljajo različni socialni stiki, tudi pomoč strokovnjakov palitivnega tima. Obiski prijateljev, sorodnikov, znancev potekajo na domu bolnika. Dnevne rutine so prilagojene bolniku in spremembam zdravstvenega stanja. Sorodniki nimajo časa za zadovoljevanje svojih potreb. Več se zadržujejo doma in manj časa namejnajo vzdrževanju socialnih stikov, ki so jih vzpostavili pred boleznijo partnerja.

Bolniki izražajo zavist zdravim ljudem, svoje življenje pa razumejo kot čas brez upanja na ozdravitve. V zadrego jih spravi vsiljevanje pozitivizma, upanja, pogovori o smrti. Imajo občutek, da so domačim v breme. Sorodniki podobno kot bolniki doživljajo to obdobje življenje kot brezupno, dodajajo še občutke nerazumevanja bolnika in širše družine, travm iz otroštva. Ponekod so se družinske vezi okrepile, prav tako samozavest oskrbovalca/ke. Skrbi jih čas po smrti.

Raziskovanje potreb se tako kot v dolgotrajni oskrbi tudi v paliativni oskrbi kaže kot pomembno področje za razvoj socialnega dela. Slišati, spoštovati in upoštevati uporabniško perspektivo so koncepti, ki predstavljajo stičišče med socialnim delom in paliativno oskrbo.

### **Abstract**

*Supporting patients and their families is an increasingly recognised area of social work. Qualitative research on specific aspects of supporting patients and their relatives is much more widespread internationally than in Slovenia. We can follow research that explores bereaved relatives' views on the appropriateness of caring for patients in the home environment, research that highlights the specifics of caring for relatives for family members in the last phase of life, and research on the importance of communication between professionals and informal carers and patients.*

*In Slovenia, there is no national research in this area, so the Faculty of Social Work decided to conduct an initiative survey on these issues. The first survey was conducted in 2019 and we have continued it every academic year since then. The aim of the survey is to find out what issues are most pressing in patient care, what patients' and relatives' needs are, how their needs are met, and what kind of help they would need in the last phase of life. In this paper we present the results of a research question on the needs of patients and their relatives in the home environment.*

*Patients consider that their care at home, in their home environment, is the only acceptable one and that no major spatial adaptations are required, which would also have a financial impact. They mention minor changes in the living and sleeping arrangements, the use of a hospital bed, moving from the first floor to the ground floor, using a lift, adapting the bathroom and toilet. On the other hand, relatives believe that institutional care is more appropriate because it avoids too much emotional involvement in care caused by shock, non-acceptance of the illness, pain and strain.*

*The financial aspect of care is no longer the responsibility of the patient, but is taken over entirely by the relatives. The costs of care are covered by the pensions of both spouses.*

*es, including savings, and they run out of funds to maintain the property. The spouse provides most of the daily help, which is expected of the patients. But the partners complain that they do not have enough help to relieve themselves. Relief is provided by various social contacts, including help from palliative care team professionals. Visits from friends, relatives and acquaintances take place in the patient's home. The daily routine is adapted to the patient and to the changes in his or her state of health. Relatives do not have time to meet their needs. They stay at home more and spend less time maintaining the social contacts they had established before their partner's illness.*

*Patients are envious of healthy people and see their lives as a time without hope of recovery. They are ashamed of the imposition of positivism, hope and talk of death. They feel they are a burden to their families. Relatives experience this stage of life as hopelessness, as do patients, adding childhood trauma to the feeling of being misunderstood by the patient and the wider family. In some places, family ties have strengthened, as has the self-esteem of the carers. They worry about the time after death.*

*As in long-term care, exploring needs in palliative care is proving to be an important area for social work development. Listening to, respecting and considering the user's perspective are concepts that represent the interface between social work and palliative care.*