

CASE STUDY

Development of social and health services of the civil society organisations as a support system based on beneficiary needs - palliative care of elderly and ill persons “Ruhama” Zenica

COUNTRY: BOSNIA AND HERCEGOVINA

Year: 2016

Prepared under the project: “Improving the provision of Social Service Delivery in South Eastern Europe through the empowerment of national and regional CSO networks”

Reference:
EuropeAid/20132438/C/ACT/Multi



This project is funded by
European Union

CASE STUDY

**Development of social and
health services of the civil society
organisations as a support system
based on beneficiary needs -
palliative care of elderly and ill
persons “ Ruhama “ Zenica**

COUNTRY: BOSNIA AND HERCEGOVINA

Table of content

1. Introduction and rationale	3
2. Description of the innovative and sustainable example	4
3. A qualitative assessment of the local social realities	5
4. Means-tested analysis of the ‘clients’	6
5. Reference to relevant EU policies and domestic strategic documents and laws	7
6. Experience in country and neighbouring country	8
7. Qualitative assessment on the up scaling potential	8

1. Introduction and rationale

The World Health Organisation has defined palliative care as the active tool care of patients whose disease is not responsive to curative treatment. From the day to day the need for this type of care in Bosnia and Herzegovina increases due to extension of lifetime, the increased number of patients with malignant and other chronic incurable diseases, as well as changes in family structure and social isolation of elderly and ill people. The palliative care is a term deprived from Latin word pallium meaning „to cloak“. It refers to specialised medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain and stresses of a serious illness — whatever is the prognosis.

The need for palliative disposal are primarily patients suffering from malignant diseases, but they also suffer from cardiovascular diseases, Respiratory diseases, suffering from multiple sclerosis, Alzheimer’s disease, motor neuron diseases, HIV / AIDC and other diseases.

Palliative medicine is recognized as a separate medical specialty and palliative care movement itself grew out of the modern hospice movement. The first hospices in Europe appeared in France in the mid-19th century and were intended for dying patients. The modern history of palliative care began in 1967, when. St. Christopher’s Hospice, a pioneer in this area, was founded by Dame Cicely Saunders in London and it connected the clinical care, research and education. Hospice movement had great importance in the development of pain and symptoms of dying patients, the mode of communication with the patient and family, as well as the manner of announcing bad news to a patient (unfavorable diagnosis, treatment and prognosis of unfavorable development of the disease). Hospice usually means specialized institution which, in accordance with the definition of palliative care provides the best possible care for patients. Hospice care and palliative care are synonymous. Hospice care does not imply compulsory care in the hospice building itself, but the way it cares for these patients regardless of whether they are at home, in hospitals, homes for the elderly or in the hospice.

The subject of the case study is humanitarian organization Ruhama, the member of IRIS BiH network, established in November 1993 starting with project “Home Care”. Ruhama’s mission was to provide the best quality services and long term support to elderly persons above 60 years old, with the highest priority group of ill people who do not have relatives. Today Ruhama has a Centre for Professional Health and Palliative Care with 24- hour supervision and care, health and hygiene assistance to elderly and disabled persons and high-quality and professional care based on humane principles.

IRIS BiH network established by ASB and LIR CD National Partner for BiH and funded by EC continuously provided technical assistance to Ruhama through four year funded project “Improving the provision of Social Service Delivery in South Eastern Europe through the empowerment of national and regional CSO networks” in the development of the social services and its sustainability, building the capacities through the educational process thus improving social services, transfers of experience and knowledge to support beneficiaries and strategic positioning between the civil, public and private sectors of this service.

Ruhama established cooperation with Regional IRIS network such as Caritas Sabac, Caritas Valjevo and other members of Konekta IRIS network in Serbia for the exchange of knowledge, joint planning activities to support beneficiaries and establishing this types of services. The Protocols on cooperation were signed with the Cantonal Hospital in Zenica, University, Medical School, Faculty of Education and the Polyclinic.

The experience of Ruhama and transfer of good practice are used by the members of the IRIS network of BiH: Društvo Gerontologa Bijeljina, Caritas biskupije Banja Luka, Udruženje “Krajiška suza” Sanski Most that are providing services to elderly persons and other members of the network that provide services to people with disabilities, youth at risk, gender based domestic violence and migrants.

2. Description of the innovative and sustainable example

The introduction of integrated beneficiary support, the medical support within the social welfare services is an innovative approach to look after the elderly and ill persons that Ruhama applied as a new approach model of a services in the region. This model has been applied on the basis of experiences from the European Union.

The service “Home care”, offers a fast and efficient help and is aimed to satisfy the needs of elderly and ill persons, in order to return the lost dignity of every person, making their lives better.

The mobile team is an additional activity of social service provision, with over 240 local and foreign volunteers (doctors, nurses, lawyers, social workers and other necessary staff) specially trained to provide professional support and quality implementation of social services to protect beneficiaries.

The Palliative care through the program “Home care” with “Health-Hygiene-Humanitarian program” carries out its activities in parallel in Ruhama Center, Centre for Professional Health and Palliative Care and directly in the homes of patients. Those activities are divided into three separate programs:

The medical program includes nursing, physical examinations, laboratory services, ECG machine heart control, changing catheters, changing decubitus wounds, injections and many other medical activities for 382,000 elderly people in the period of ten years.

The another program consider maintenance of the patient hygiene and within the last decade has been recorded 397,200 cases. This program includes personal hygiene of patients, such as bathing, dressing, haircut and shave, hygiene in the area where the patient resides, washing and laundry feeding and fostering patients. This program is being implemented at the Centre as well as directly in the homes of patients.

The final program consider an Additional program that includes transport of patients on hemodialysis, chemotherapy or other destinations required to perform basic life functions such as administrative payments. The Additional program includes social workers visits and volunteers in order to meet the basic daily needs of the elderly people, such as: grocery shopping, paying utilities and even to establish the conversation. The Additional program also includes ‘master of the house’ and painting works. This program supports 91,380 beneficiaries.

In addition to the above activities, the recreational activities of patients are an integral part of the program of the Centre.

For the implementation of the project activities “Home Care” with “Health-Hygiene-Humanitarian program” special mobile teams are defined as follow:

- » Medical expert team required to treat and monitor the health status of patients, prescribes and implement treatments;
- » The team for the nurturing the patients, nurses, taking care of personal hygiene of the elderly, changing bed linen and clothes;
- » Team of housewives;
- » Other teams of volunteers.

The Mobile team includes about 240 local and foreign volunteers (doctors, nurses, lawyers, social workers, housewives, etc.)

In order to facilitate the work of the Mobile Team, Ruhama has procured adequate equipment financially supported by various international and local donor, as follows: special vacuum suction apparatus, equipment for ironing, washing machines and dryers, hair dresser salon equipment, laboratory equipment with special, most modern devices for analyzing blood counts and other devices necessary for quality service delivery. In addition, Ruhama has its own car park which is also necessary for the execution of various functions within the projects

and those are: Landrower, Lada niva, Ambulances, Nissan patrol, Golf, Opel cadet etc. However, the organization is looking forward to expand their daily range of services in order to provide better working conditions for the mobile team and consequently provide better services to patients.

IRIS network provides continuous support to Ruhama on education of professional workers and volunteers, as well as ensuring the financial sustainability of services through the help of writing the project proposals.

Within the framework of grant support ASB/IRIS BiH network, Ruhama was Partner in the project “LIVING WITH DIGNITY TO THE VERY END” to Drustvo Gerontologa Bijeljina, member of the IRIS BiH network, which has developed the concept for the establishment of palliative care in Bijeljina. The aim of the project was to present a new model of social protection in Bijeljina and creating conditions for palliative care for the elderly people. During the implementation of the project a round table was held for the presentation of the prepared Study on the need for organizing palliative care in presence of relevant key stakeholders where Ruhama presented its model as an example of good practice and after that initiative was launched with a proposal that the recommendations and conclusions of the studies should be implemented.

Also, within the project activity-advocacy campaign a strategic document was created “Plan for the establishment and improvement of social welfare services in the city of Bijeljina for the period 2016-2018” where this service is defined as a priority. In the future, based on the created and adopted Plan it is expected the establishment of these services in Bijeljina.

3. A qualitative assessment of the local social realities

In everyday practice, primary health care services are covered by municipal health centres throughout the whole territory of BiH (basic medical services, rehabilitation, home health care - when the health centre has patronage. Likewise, in the municipal Centres for social work elderly people exercise their rights to social security benefits (welfare benefits, allowance for assistance and care, one-time assistance, home care, placement in an institution). The cooperation between Health Centres and Centres for social work at the local level is riddled with difficulties, thus, there is a lack of coordination and patients are not supported according to individual needs and in one place. Taking care of severely ill patients after discharge from hospital is family responsibility and the experience on a local level show that those families facing a very difficult problems and they do not have adequate support.

Elderly users of palliative care services, due to their condition are not able to use the services in an efficient manner going from one to other institution, therefore it is necessary to have a support in one place. The civil society sector in BiH, particularly CSO social service providers such as Ruhama, recognize the beneficiary specific needs that require a combination of provision of medical, nursing and social services. As a dedicated social service provider and a key stakeholder in the local community Ruhama perceived that protection system of the elderly and chronically ill persons need to assess individual needs and provide holistic services. This is based on an assessment of individual needs and requires to offer a coordinated, structured, tailored, specific and continuous protection.

With this innovative approach Ruhama has opened the door for systematic set up of integrated socio - medical services through new legislation, thus contributing to the improvement of patient protection. Model of integrated long-term social and health care, developed by dedicated civil society organizations, social service providers in BiH allow developing the new services, aiming to respond to the needs of elderly people and development of their disease and the possible social risks that can occur. More importantly, Ruhama supports continuity between the care at the local community, hospital care for acute patients and social support, complementing primary care and specialized hospital care levels.

4. Means-tested analysis of the 'clients'

Palliative care service is specific in a way that emphasise the patients not the diseases, it is not important diagnose its essential patient and family needs, it is insignificant the length of patient life it is important quality and dignity of life. And then, when the cure is impossible, at least something can be done that will make patient feel better. For the implementation of these human activities multidisciplinary teams of professionals of different profiles is included (doctors, nurses, social workers, psychologists, priests) or trained volunteers, the patient himself and his family. The Teamwork is essential in the management of all aspects of total pain which includes physical, psychological, spiritual and social suffering from the family and to the patients in need.

Decades of Ruhama's presence in Zenica-Doboj Canton manifests working on the ground distributing the humanitarian assistance to most vulnerable populations, elderly and ill persons, with the aim to ensure high quality services and long-term support to elderly persons.

Up to date Ruhama recorded 1,750,000 visits and provided services, and thus has saved a huge number of human lives, which is worth mentioning and above all appreciated. Based on these activities, the needs of the target groups are defined and how the community should be organized to support the elderly and ill persons.

For all this time, hundreds of young volunteers aged 12 - 22 years, opened the door to forgotten and disabled elderly people, abandoned by society and their families to the mercy. They helped them to overcome the difficult situation and to understand that they are not completely forgotten. Each volunteer is served by an average of 10 elderly people helping them regardless of the rain, snow and war, carried them the food from one distance to another and to remote villages. In the patient houses the will prepare firewood, light a fire, clean the house and the bad, prepare meals, shave them and offered them psychological support. The medical team follow up each patients, write the reports and review and determinate the treatments carried out on the spot. Further, the team of nurses take care of the patient hygiene, that the bed and their cloths are clean. The connection, trust and friendship between the younger and older population gave it the strength, durability and support for future survival of patients. In this way a competent group of professional workers, assistants and volunteers are formed, who are at a given moment were able to be integrated into a comprehensive system service and responded to patient needs and provided adequate support.

Today the number of patients who receive the services and home visits is 3,650 weekly and on the monthly level average is 11,000 persons.

It is important to note that the programme approach focus on the person needs, thus includes not only the methodology how to work with the patient, but the patient participatory approach in creating service plan for independent living.

The main tasks of the service as a full and sustained support of the target groups are:

- » Continuous work on improving the quality of services in accordance with the individual needs of beneficiaries,
- » Improving the service capacity and financial sustainability of the established program services,
- » Impact on policy and legal framework of social protection at the national, cantonal and local level with the aim of positioning system of innovative socio-health services,
- » Continuous exchange of knowledge and good practice with other social service providers in BiH and the region in order to develop these services in all parts of BiH.

5. Reference to relevant EU policies and domestic strategic documents and laws

The Committee of Ministry on 12 November 2003 adopted Recommendation Rec (2003) 24 on the organisation of palliative care and recalling to Article 11 of the European Social Charter on the right to health protection, and recalling that Article 3 of the Convention on Human Rights and Biomedicine (ETS no. 164) requires that contracting parties provide equitable access to health care of appreciate quality, that Article 4 requests that any intervention in the health field, including research, must be carried out in accordance with relevant professional obligations and standards, and that Article 10 emphasis the right of everyone to know any information about his or her health.

Further, recognizing that the health care system should be patient orientated and that patient should necessarily participate in decisions regarding their health care. Recalling in this context the recommendation of the Committee of Ministries Recommendation no R (2000) 5 on the development of the structure for citizens and patients participation in decision-making process affecting health care. Also, it is important to convince that respect and protection of the dignity of a terminally ill or a dying person implies above all the provision of the appropriate care in a suitable environment enabling him or her to day with dignity. Recalling in this context Recommendation 1418 (1999) of the parliamentary Assembly on the protection of the human rights and dignity of the thermally ill and dying. Further, recalling Recommendation No. R (89) 13 on the organization of multidisciplinary care for cancer patients and recognizing that palliative care needs to be further develop in European countries and in this respect recalling Poznan Declaration (1998) on palliative care in Eastern Europe.

Based on the above recommendations, a draft Strategy for the Development of palliative medicine in the Federation of Bosnia and Herzegovina has been prepared. It is important to mention that there is no special law on palliative care in Bosnia and Herzegovina, but is mentioned in the Laws on Health Care in both Entities and Brcko District and Primary Health Care Strategy of the Republic of Srpska.

The Development Strategy of palliative medicine in FBiH is a document of national importance and instrument for activation and mobilization of the health sector, government institutions, NGOs, scientific, educational and training institutions, local and religious communities, social and humanitarian institutions and volunteers who participate in the programs of palliative care. The strategy was prepared in accordance with the recommendations of the Committee of Ministers of the Council of Europe (Recommendation Rec (2003) 24 years). For solving the problem of palliative care for population in need, it is necessary active participation of the state, the Ministry of Health and Ministry of Social Welfare, which would, in cooperation with medical professionals (at all levels of health care), non-governmental associations, patients and their families, define the strategic development goals of palliative medicine and care and in cooperation with the Ministry of education and educational institutions provide educational programs at the secondary and higher medical education. For the implementation of the strategy and the inclusion of palliative medicine and care in the health care system it is necessary:

- » to educate health policy makers, health professionals, patients, families, local communities and the general public about the principles, objectives and importance of palliative care,
- » to provide adequate legislation and ensure sustainable financing models,
- » to provide integration services and units of palliative care in the health care system (from primary to tertiary level),
- » to provide education of medical professionals at different levels of palliative care, and non-professionals (volunteers, humanitarian organizations, etc.),
- » to ensure the availability of drugs (opiates and other medicines) used in palliative treatment and put them on the list of essential medicines.

The Primary health care Strategy defines palliative care as an integral service that will provide organizational forms of primary care health centers which is not yet in force.

6. Experience in country and neighbouring country

In the Federation of Bosnia and Herzegovina, palliative care for patients is organized in two cities: Tuzla and Zenica. Palliative care in Tuzla was organized in 2003 as part of the University Clinical Centre – Tuzla. Within the Center for Palliative Care it is organized a Day Hospice for adults that is intended for psychological and spiritual support to persons suffering from cancerous diseases, and works on the basis of external patients with a capacity of 12 patients per day. Also in Tuzla in 2009 was opened Children's Hospice as part of Palliative Care Centre supporting chronically ill children providing them physical treatment necessary for them. The Center for palliative care has two vehicles, enabling the transport of patients to hospice and home. The Center for Palliative Care was financed by different donors. The Palliative care in Zenica is organized by the NGO "Ruhama" which is subject of this study.

In the Republic of Srpska this type of health care was introduced five years ago for the first time at the Hospital Gradiska, while until then, patients stayed in hospital intensive care units or even were sent abroad, which significantly increased the cost of their health care, but a large number of patients stayed with families to take care of them. In addition to the Hospital Gradiska, the health insured persons receive palliative care services in hospital Nevesinje. Disposal of the departments of palliative care in hospitals Gradiska and Nevesinje is approved by the Health Insurance Fund based on recommendations from the hospitals where patients are treated.

The project "Development of Palliative Care in Serbia" is a joint project of the Ministry of Health and the European Union and is funded by the European Union for the period 2011-2014. In the framework of this project palliative department are open in 4 medical institutions in Belgrade, and it is envisaged that in the future every hospital has a unit for palliative care. Also it is organized service of home care by a team consisting of a doctor, five medical nurses, visiting nurse, social worker and the priest. These teams are formed at community health centers, so that for every 25,000 inhabitants there is one team. The Government of Serbia adopted the Strategy for Palliative Care.



7. Qualitative assessment on the up scaling potential

The Experts recognize that the number of people needing palliative care is growing and believe that differences in accessibility and quality of palliative care in Europe and likewise in BiH and in neighboring countries must be bridged with better interstate cooperation. They are aware that the goal of palliative care is achievement of the best possible quality of life for patients and their families. They also emphasize that palliative care is an integral part of the health care system and an indisputable element of citizens' rights to health care and therefore, it is the responsibility of the government to guarantee palliative care and make it accessible to anyone in need. The development of palliative care should be carried out in a humane way, to make it an essential part of health care for patients at the end of life. The palliative care, like all other medical care, should be patient-oriented, guided by their needs, taking into account their values and preferences, and the dignity and autonomy of concern for patients who need palliative care.

SUCCESS STORY

Success story: RUHAMA Zenica - Will for Life and dedication of medical staff brought extraordinary results

Two middle-aged women brought their mother from Sarajevo, 70 km away from Ruhama Centar in Zenica. They sought the assistance for her mother, who had a severe stroke, fed with feeding tube and was in a semi-conscious state. They were stressed and through tears explained what doctor said: "mother will live just one or two more weeks". Specialists from Ruhama promised to these two ladies that they will do everything in their power to help their mother, but with a touch of suspicion, because the old lady was really in a very difficult situation with all forms of long-term complications of decomposition (decubital wounds, thrombosis, pneumonia).

After standard admission procedures in Ruhama, physicians reviewed patient medical records, opened a medical card and prepared health plan for this 72 years old lady.

Every day the therapy was consisted of an adequate diet that is made for individuals who were fed on the tube. Continuously, every day medical staff in a light and calming atmosphere talked to patient even though she was in a semi-conscious state. Eventually the old woman opened her eyes first and began responding to their inquiries. Thanks to physical therapist she slowly started sitting and learning to walk again. Defectologist was also part of the medical team and tried to eliminate speech disturbances, because she had aphasia (damage of the speech center). Complete treatment, which lasted a year, has led to the health improvement of this old lady: she talked, walked up and started to react on what is happening around her and on surrounding effects.

The lady was declared as medical phenomena and a good example of Will for Life.

Recommendations:

1. Adopt policies, laws and other measures necessary for a coherent and comprehensible national policy framework for palliative care, which does not exist in BiH,
2. Commit to the principles of palliative care and take into account the specific national features,
3. Promote international and regional networking between organizations, research institutions and other activities that are active in the field of palliative care,
4. To support the expansion of Recommendations and memoranda-Recommendation Rec (2003) 24 Years

The humanitarian organization organization Ruhama supported by IRIS BiH network will specifically seek to provide:

- » respect, autonomy, dignity, choice, privacy and independence of patients in the process of activities service development,
- » continuous staff education and purchase of necessary equipment e.g. ambulance for emergency cases
- » to be focused on patient lives based on their needs,
- » to pay attention on the importance of the surrounding environment or the community and connect all relevant systems to be responsible for the life of each resident.

The humanitarian organization Ruhama daily expands the range of its activities and strives to improve the working conditions of its mobile teams and strengthen the cooperation of Health centers and Centers for social work at the local level. The ultimate goal has not yet been outlined, but the main goal set at the very beginning even today it is respected: TO HELP PEOPLE IN NEED. The plans for the future is to build the Geriatric Centre where the health-hygienic services would be provided adequately and professionally to elderly and ill people in one place and would be based on the principles of democracy, voluntarism and humanity.

References:

Social protection in the FBiH - 2014 (2015), Bulletin of the Federal Office of Statistics, Sarajevo .

Stanje i perspektive razvoja sistema socijalne zaštite u Republici Srpskoj, (2008), Banja Luka, Ministarstvo zdravlja i socijalne zaštite RS.

Status and prospects of development of the social protection system in the Republic of Srpska, (2008), Banja Luka, Ministry of Health and Social Welfare.

Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organization of palliative care, report of the Council of Europe on the organization of palliative care.

World Health Organization. 1990. Cancer pain relief and palliative care. Report of a WHO Expert Committee (WHO Technical Report Series, No. 804). Geneva: World Health Organization.

Draft Strategy for the Development of palliative medicine in FBiH, FBiH Ministry of Health.

Primary Health Care Strategy of the Republic of Srpska, 2008, the Ministry of Health and Social Welfare of the Republic of Srpska, Banja Luka.

www.ruhama-bih.org

<http://ruhama-bih.org/v2/ruhama-knjiga-bih/>

<http://www.coe.int/cm>

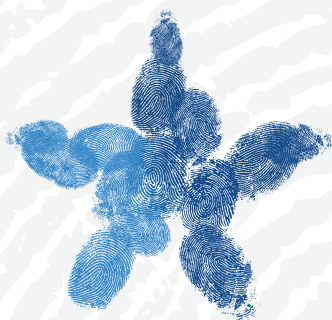


This project is funded by
European Union

IRIS NETWORK IS A UNIQUE REGIONAL NETWORK THAT BRINGS TOGETHER MORE THAN 160 CSOS, SOCIAL SERVICE PROVIDERS IN SOUTH EAST EUROPE. BASED ON VISION OF EQUAL RIGHTS AND OPPORTUNITIES FOR DECENT LIFE FOR ALL, THE NETWORK HAS BEEN CREATED TO ENSURE SOCIAL INCLUSION AND STRENGTHEN THE ROLE AND CAPACITIES OF NON-PROFIT SOCIAL SERVICE PROVIDERS THROUGHOUT SEE. MEMBERS OF THE IRIS NETWORK PROVIDE NECESSARY SOCIAL SERVICES TO OVER 10000 BENEFICIARIES DAILY.



Author:
Irena Spasojević



Contact us and keep in touch with our activities!



iris@iris-see.eu



[/IRISsNetwork](https://twitter.com/IRISsNetwork)



[/irissnetwork](https://facebook.com/irissnetwork)

www.iris-see.eu



The publication has been produced with the assistance of the EU. The contents of this publication are the sole responsibility of LIR CD and can in no way be taken to reflect the views of the European Union.