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Palliativversorgung - kein Luxus, sondern ein Menschenrecht und wesentliches Element einer universellen Gesundheitsversorgung (UHC)

Lessons learned from two pilot municipalities in Bosnia-Herzegovina

Mobilizing resources to improve end of life care at home

Von Sigiriya Aebischer Perone, Emira Dropic, Dejan Sredic, Thomas Vogel, Bruno Lab, Caroline Matis, David Beran, Sophie Pautex and François Chappuis

Worldwide, many patients at the end of their life express a preference for spending their last days at home. As in many other low and middle-income countries, the current situation in Bosnia-Herzegovina makes it challenging for such a desire to be a reality. To better respond to the needs and expectations of terminally ill patients, we assessed the needs they had at the end of their life, trained health care workers and volunteers, and developed a coordination mechanism to mobilize available resources around the individual. We wish to present our participative approach, share the tools we developed, and the lessons learned from our experience in two pilot municipalities.



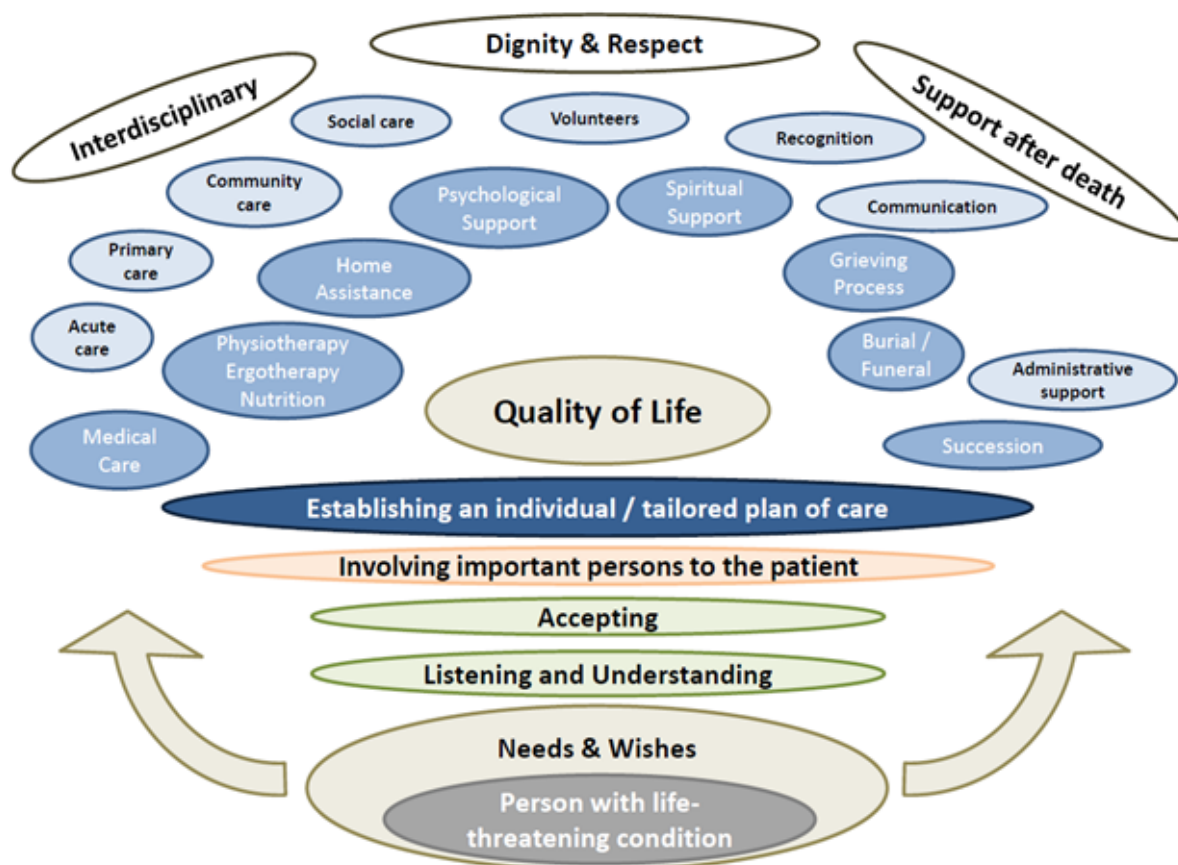
Patient at home. Photo: © Emira Dropic

The management of the Primary Health Care Center (PHCC) of the municipality of Dobož, Republika Srpska, Bosnia-Herzegovina (BiH) approached the Fondacija fami, a local non-governmental organisation, and the Geneva University Hospitals (HUG) in 2016 to improve the provision and the quality of services to terminally ill individuals living at home. Thereafter, a project proposal was submitted to the HUG for funding.

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As in most transition countries, terminally ill individuals are often unheard, and their needs are rarely covered by existing health or social services. Collecting reliable information and making sure that care providers know what is important for the individual and their families (**Figure I**) is a basis to initiate change to support new efforts to better address the needs of terminally ill individuals (WHO 2016).

Figure I: Areas of support to consider to improve quality of life of terminally ill patients



Therefore, to design an acceptable, affordable and sustainable solution, we engaged people and their families allowing us to explore the current barriers and existing useful resources.

Project to improve care and support for terminally ill patients in Bosnia and Herzegovina (BiH)

The three partners (PHCC, Fondacija fami and HUG) conducted the exploratory, preparatory, implementation and replication phases together:

Exploratory phase (phase I): Identifying lack of information, symptom management and attention

During the **exploratory phase** (phase I) we used individual semi-structured interviews with 62 patients to collect qualitative information about their experience and to assess their perceived needs and expectations. Participants were purposively recruited to represent the spectrum of terminally ill individuals and to ensure that age and gender distribution was representative of the population registered at the PHCC in Dobož. The results showed the following key issues to be addressed.

- **First**, there appeared to be a lack of information provided to patients about their condition and the existing available support, resulting in feelings of helplessness and lack of control over their condition.
- **Second**, patients described the need of better symptom management by health care providers (essentially for pain and for signs of anxiety/depression), often leading them to

take their own decisions and self-medicate.

- **Third**, they often expressed feelings of isolation with lack of attention and consideration, overreliance on their family and stigma. Finally, many felt that their care givers were exhausted. These findings emphasized that there was a wide gap between what patients and their relatives expected from end-of-life care and support and the services provided by the system in place at the time of the initial assessment (Aebischer S. et al, 2018).

Preparatory phase (phase II): Mapping of local resources and Identification of potential barriers

During the **preparatory phase** (phase II) we approached all relevant actors in Doboj municipality and the region. Thereafter, we mapped local resources and identified services to be provided as well as potential barriers to be lifted through focus group discussions. Based on the expectations collected from the patients' interviews (phase I) and the propositions formulated during the focus group discussions (beginning of phase II) we facilitated several inter-professional and inter-institutional meetings, inviting representatives of the Municipality, Ministry of Health and Social Welfare, health insurance fund, health professionals, patient's associations, NGOs, the Red Cross, social services, religious leaders, to participate as strategic partners. Together, they identified and designed a comprehensive patient centred model for end of life care and support to be rapidly implemented.

Implementation phase (phase III): Establishing of an integrated network of services

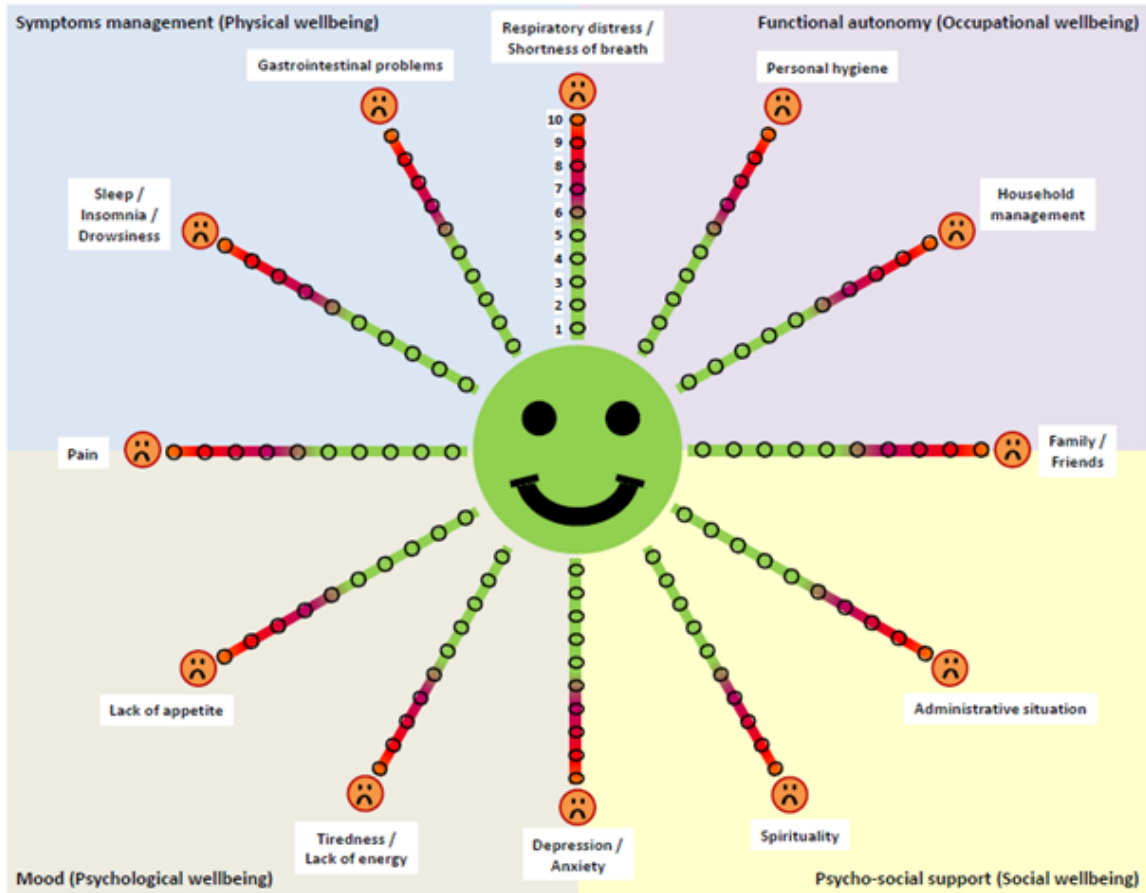
The **implementation** of an integrated network of services for terminally ill individuals (**phase III**) was divided in several steps.

- **First**, we set up an *inter-institutional network* of providers under the responsibility of the municipality and with the approval from the Ministry of Health and Social Welfare. Each institution or partner organisation wrote a letter of intent to participate in the network.
- **Second**, a *services' coordination function* was defined so that each identified person could benefit from the available services.
- **Third**, we established a suitable *institutional, professional and administrative work environment* by ensuring the necessary tools and equipment for home visits to become operational:

(i) we proposed a shared care and support plan including medical, social and spiritual needs of the patients to reach what we called a **“quality of life agreement”** (Figure 2); (ii) we adapted existing symptom management tools for end of life care (WHO 2004, Zulian 2007, Pirnazarova 2015); (iii) in collaboration with the PHCC management, we revised the job

description for nurses providing care at home; (iv) delivered inter-professional trainings for health workers; (v) provided psychological support to all actors involved through team meetings, and individual counselling.

Figure 2: Interprofessional patient's needs assessment tool



Physical wellbeing		Occupational wellbeing	
<u>Remarks</u>		<u>Remarks</u>	
<u>Therapeutic objectives</u>	<u>Patient's objectives</u>	<u>Beneficiary's objectives</u>	<u>Support objectives</u>
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<u>Remarks</u>	<u>Remarks</u>		
Psychological wellbeing		Social wellbeing	

Finally, **we had the opportunity to replicate** the same experience in a municipality of the Federation of Bosnia-Herzegovina (FBiH), as its Ministry of Health expressed the wish to have the same approach applied in the municipality of Orasje.

Not simple copy and paste: The obvious need for a tailored contextual approach

This second initiative allowed us to identify similarities and differences between two municipalities of the same country, highlighting the fact that a tailored contextual approach needs to be privileged over a simple copy and paste.

In Orasje, the identified priorities were:

- the set-up of a coordination mechanism for all actors;
- the need for better symptom management and access to opioids;
- a dedicated scheme for the care of destitute patient;
- availability of transport means from home to PHCC and to secondary and tertiary health facilities.

These priorities were addressed through an inter-institutional collaboration under the guidance of the municipality and the Ministry of Health by:

- the development of de-centralised prescription and delivery of opioids;

- the implementation of a dedicated transport solution for the patients to the PHCC or hospital;
- the delivery of trainings for volunteers;
- the adoption of tools and processes previously developed for the municipality of Dobož.



Inter-institutional collaboration in Orasje: signing of collaboration agreement. Photo: © Emira Dropic

Between April and September 2019 in Dobož 1827 home visits were provided by 12 nurses for terminally ill patients and, during the same period, 232 visits were performed by 10 nurses in Orasje (beginning of the project, which started later).

Finally, and to cope with the current situation, the pre-established network and inter-professional collaboration and coordination allowed both municipalities to respond to the needs not only of end of life care patients but also to the needs of other vulnerable groups hit by the Covid-19 pandemic that emerged during the 1st quarter of 2020.



Old couple, husband holds wife. Photo: © Emira Dropic

The positive impact of collaborative work

Both municipalities started to implement a person centered inter-professional and inter-institutional coordination mechanism which showed its importance to respond to the needs and expectations of terminally-ill patients.

To support the coordination and to assign respective objectives to the health and social services providers, we developed a common assessment tool, exploring the medical, social, spiritual and administrative needs of the beneficiaries. The results then led to individual and

agreed care and support plans setting joint clinical and social objectives.

The supportive network surrounding the patient is the starting point and helps the organisation of patient centered end of life care and support services at home. Our project shows the positive impact of collaborative work that engages communities, mobilizes existing resources, addresses a shared concern and aiming at an acceptable, affordable and sustainable response.

The **Division of Tropical and Humanitarian Medicine (DTHM)** at the **Geneva University Hospitals (HUG)**, established in 2007 is a rare example of a division within a public hospital dedicated to improving health globally. The staff of the DTHM comprises medical doctors, nurses, public health specialists, health economists and project managers. Currently the DTHM has ongoing projects in close to 20 countries. The DTHM provides technical support to a variety of humanitarian and development actors by serving as a resource or a link to further expertise within the HUG or the University of Geneva. Finally, the DTHM is a WHO Collaborating Centre for Humanitarian Medicine and Disaster Management.

Le Service de médecine tropicale et humanitaire (SMTH) des **Hôpitaux universitaires de Genève (HUG)** a été créé en 2007. Il constitue un exemple rare de dévouement d'un hôpital public à l'amélioration de la santé dans le monde. Les collaborateurs du SMTH sont issus de nombreuses disciplines : médecine, soins infirmiers, santé publique, économie de la santé et gestion de projets. A l'heure actuelle, les collaborateurs du SMTH sont actifs sur des projets humanitaires et/ou de coopération dans une vingtaine de pays, pour lesquels ils/elles fournissent de l'assistance technique ou des liens vers une expertise pointue des HUG ou de l'Université de Genève. Enfin, le SMTH est Centre collaborateur de l'OMS pour la médecine humanitaire et la gestion de catastrophe.

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