



Espacio Salud: an integrated model for palliative care

By Jorge Ferreruela Diaz and Rafael Fernández Manda. *RAIS*

HOMELESSNESS AND HEALTH IN SPAIN

The determining role that social factors have on health is an indisputable fact which is based on innumerable scientific evidence. The **World Health Organization (WHO)** defines the social determinants of health as the circumstances in which people are born, grow up, live, work and age.

Living without a home is a constraint on the health status of people. The three dimensions of well-being (i.e. physical, mental and social), identified by the WHO as a good state of health, are threatened by the experience of homelessness.

Although there is no specific research in Spain on the impact of homelessness on the health of people who experience it, some data from the **Survey of Homeless Persons conducted in 2012 by the National Institute of Statistics**¹ indicate the worst health status and the worst conditions of life that can favour it:

- 41.4% of people in a situation of homelessness considered that their state of health is not good.
- 30.7% of people experiencing homelessness claimed to have a serious or chronic illness.
- 19.8% of people experiencing homelessness reported not having a health card, this implies a barrier to their access to the health system, proper care and monitoring of health.

The barriers that hinder the access to health services as well as the monitoring of a homeless person's health are many: The complexity of access to health rights, the lack of accommodation that guarantee a space for rest and medical recovery, the lack of a family network and/or support that provides assistance and emotional support, the affordability of medicine, the inflexibility of care networks which usually make it difficult to access combined profiles (convalescents, drug addicts, mental health, etc.). This highlights the need for flexible resources to promote timely responses to the complex health needs of this group.

The perceived health of people indicates the important impact that homelessness has on physical well-being. It is difficult to have healthy habits concerning food, hygiene and rest when a person is in this situation. These same conditions obviously influence the possibility of facing the end-of-life process of palliative people in conditions of dignity and quality.

The control of symptoms, which is key for the intervention in palliative care and convalescence, is very difficult to deal with if the patient does not have an address. The homeless, once discharged from the

hospital, usually return to a shelter or similar or to the street and in none of these cases can the specific and necessary support for their final life process be provided. Mostly, these situations involve difficulties in adhering to treatment since continuous care is abandoned, the patient relapses and keeps returning to the emergency services.

ESPACIO SALUD (HEALTH SPACE)²

The service

In 2011 **RAIS** observed a reality that has not been addressed neither by the public sector nor by civil society organisations that worked with homeless persons in these processes. Due to the lack of attention to this group RAIS has developed a campaign with the slogan "The hospital discharge is bad news if you live in the street" which is a project that first opens in Madrid – including palliative care in 2014- and will be replicated further in the cities of Murcia and Córdoba.

Espacio Salud is a programme which responds to the detected needs. It applies a methodological change in its approach and implements an innovative housing model. Both aspects are aimed at acting as a bridge between social and health care networks, improving the health (symptoms) and care for palliative homeless people as well as promoting improvements in their general situation through a process of rising social mobility.

It is being developed in apartments, avoiding the concept of a centre, in order to be as close as possible to the idea of a traditional apartment. Although the apartments are located in social action centres, each one of them has an individual and independent entrance from the shared community space to promote the feeling of belonging to the community. It is not a parallel resource to the hospital centres, but we make use of the network of standardised health services such as citizenship in general.

Palliative care and the end-of-life stage

Persons under **palliative treatment** need references within which they can move while at the same time the functioning of the programme has to be consistent with their treatment and degree of autonomy. It is necessary to match those aspects of their lives that can give them an identity with those that challenge their mourning process at the end of their lives. With a person-centred model, working to improve the quality of life, responding to individual needs as required, without losing the intervention focused on the present, on the experience of now. Based on an absolute **respect** for autonomy during the end-of-life stage and on the **belief** that all persons have a dignified life/death, the right to equal treatment and non-discrimination. Guaranteeing access to and exercising

¹ <http://www.ine.es/dynt3/inebase/es/index.htm?padre=1870&capsel=3249>

² <https://raisfundacion.org/en/right-health>



“The control of symptoms, which is key for the intervention in palliative care and convalescence, is very difficult to deal with if the patient does not have an address.”

of citizenship rights and generating a sense of social belonging.

In order to prepare the end-of-life process, we are providing for all the needs of the fundamental dimensions: symptom control, psychological, spiritual, emotional support and grief support with the aim of achieving and maintaining the highest quality of life for those who need it. It is important that each person is the protagonist of his or her process, making decisions that they consider appropriate, choosing the best way to spend the last moments of their life with support and closeness. According to this focus, it is necessary to start the palliative treatment well in advance, not delaying it to a near-death phase of the disease.

The wish expressed by people who learn about the prognosis of their terminal illness requires professionalism, moral maturity and extraordinary sensitivity so that the patient's request can be fulfilled. We ensure that each person can freely control their body and their life when freely choosing the way to die. To carry out this work, a **professional multidisciplinary team is required**:

- From a **health perspective**: registered nurses and nursing assistants address symptom control, search for comfort, pain relief, nutrition, supervision of pharmacological treatments, mobilisations, accompaniment, etc.
- From a **social perspective**: professionals in psychology, occupational therapy and social work provide person-centred support in order to develop and accept grief respecting each person's pace, recognising their state of mind, helping to overcome fears, being readily available, providing all possible comfort, listening, creating areas of reflection concerning family relations and, whenever possible, facilitating family reunions.

Furthermore, at **community level**, we are developing a network that joins the forces of other services and entities at our disposal. Continuous coordination with the home-based health care teams (ESAD) for symptom and treatment control, and with the Spanish Association Against Cancer where people participate in workshops and support groups with psycho-oncologists.

The intervention is not a product of intuition, nor of the state of mind at a particular moment, but

rather of a cautious and informed reflection which is discussed and shared among all team members, considering and aware of the preferences of each person. It focuses on:

- Offering a secure space providing comfort care;
- Ensuring health monitoring, adherence to treatment and pain control;
- Guaranteeing access to resources and services made available by the public health system for citizens for the home-based treatment of people receiving palliative care;
- Psychologically and emotionally accompanying the gradual acceptance of the patient's palliative reality;
- Supporting the resumption and/or improvement of family relations and other support;
- Guiding leisure time activities;
- Informing about and supporting in the preparation of advance instructions to choose which type of medical care patients would like to receive at their end-of-life stage;
- Guiding on economic and legal arrangements;
- Encouraging areas of autonomy.

Main results and challenges for the future

In **Espacio Salud**, 25 people have been accompanied in their end-of-life process; during this time, they have spent an average of 3.4 years on the street. The percentage has been shared equally between men and women. The palliative processes were cancer related. According to the National Institute of Statistics, life expectancy at birth in Spain is at 83 years; seven people have died before reaching the age of 50 years and 16 have died before the age of 66 years, which indicates a decrease in life expectancy of almost 20 years.

As a challenge for the future, this programme has to be reinforced and expanded across Spain by providing a **specialised response that combines social and health intervention**, offering a space of security, rest and stability that contributes to the improvement/stabilisation of health. In doing so, space is essential to ensure the coordination between social and health services in order to guarantee accessible and continuous treatment of patients in palliative care. It is necessary to accompany the patients during their end-of-life process respecting the principles of security, dignity and stability.