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HENKO NET

MAP: DIPBI

Map description	**SCOPE SUMMARY** Journey map from the perspective of patients, family members and healthcare professionals				
Key phases	**KNOWING THE PATIENT** — KNOWING THE PERSON WITH NEEDS AND THEIR ENVIRONMENT	**DIAGNOSIS** — DIAGNOSIS-COMMUNICATION IDENTIFICATION	**CARE & EVALUATION** — COMPREHENSIVE CARE & EVALUATION	**FOLLOW-UP, COORDINATION, TRANSITION** — FOLLOW-UP - COORDINATION - TRANSITION	**END OF LIFE - EXITUS** — END OF LIFE - EXITUS
Illustration					
Activities of the patient	It is not the patient who arrives late to palliative care but the professional. The socio-family environment and administrative situation are decisive.	He wants clarification on what is going on with him. "I don't know what I have to do... in the hospital they told me two things in a hurry and nothing else... besides I was alone and I got a bit nervous".	There are different needs and the itineraries must be different: - People with frailty - People Chronic process - People with Dementia - Oncological processes. The socio-familial environment and administrative situation is a determining factor, there are people in social exclusion with little support... "(...) we went to look for the best, even though it was private, we were looking for quality of life, so that there would be no side effects (...) to lead a dignified life.	Find more practical information on what you need to do at home. When people go to the emergency room, the moment of discharge causes rejection because they don't know what to do. "I told him I wasn't taking him, and the doctor said I was (...)". Thanks to me being a donkey, he spent 33 days in a specialised palliative care centre, being treated as a person (...).	Many prefer a nursing home or a hospital at the last resort. "We were asked where to sedate her and I chose the hospital".
Activities of the professionals	We are talking about clinical diagnoses and not about knowing the person in their desires and preferences.	Encodes (Code zSIS with NECPAL) primary care and hospital only (Osabide Global). Activation of resources: ARINGARRI HOSPIDOM Psychosocial care teams Emergencies Health advice PIA can be done from "Osabide integra". Social and community entities Partnerships. Sometimes, professionals are overwhelmed by talking to the patient. Fear of making the situation worse, of the person sinking...	Complexity. Planning	"The person tells 'their stories' to different professionals who do not always coordinate with each other". NEEDS: Work from case management model, development Community connectors, Home visits LOOKING FROM GLOBALITY	Identification final phase. Supports (important emotional support...) Last days of care. Care in agony, sedation...
Thoughts	The patient is overwhelmed by everything that is happening, ideas are not clear. Desires and preferences. Values and imaginings of a good death. Each person has his or her own values and imaginary of the good death. Desires and preferences differ. "Who can help me? I want to have a professional reference"	The question is: "Who decides when it's over? Can I decide too" Confusion: No one has sat us down to tell us clearly what I have and what processes I can have. "We were brave enough to ask that communication be fluid, both on our part and on theirs (professionals), and that everything that could be discussed about the disease, the process, the treatments... we wanted frank communication and I think that this is what is fundamental (...)". "It is a disease that is difficult to detect when it is terminal (...) Relative of Alzheimer's sufferer". "They want to have enough material to do studies (ALS), (...) my wife is a "guinea pig", but they treated us well".	"(...) there was no way to include her in a palliative care programme (...) she told me that she was not ready to die, (...) I thought that it doesn't matter, palliative care is not for dying,...in fact, from the moment you are diagnosed you can enter palliative care. Once I told her that if it's not for her, then it should be for me (...) I told her that palliative care is also for the relatives. (relative of patient with AD)" "In public institutions we should promote (...) more psychological support to help you live without fear, without uncertainty, doubts, fears...".	The patient needs four things clear. Information that all professionals should know. "So far we have heard (...) and when they go there there is no hope (...) I think that at a social level there is this stigma of palliative care equals death (...) I don't know how to start from schools (...) to teach (...) to broaden that palliative care goes beyond the final phase of life". "In the caregiver care courses (...) there is nothing about palliative care on (...) I could see that there was a relationship between the three (attending physicians) (...) the only place we felt bad was in the emergency room. Our primary care doctor told us that these people see a lot of very extreme cases, but that doesn't justify not treating them well".	(...) I could see that there was a relationship between the three (attending physicians) (...) the only place we felt bad was in the emergency room. After 8 p.m., and especially at the beginning, we felt insecure, afraid that it would get out of control. "I need to be informed about practical things if my relative dies at home". "He was admitted with pain and they were already proposing the issue of sedation (...) without external symptoms, with pain, but with morphine it stopped, there was no recognised suffering, that was what the reports said". (...) they do give us some privacy, they tell us that they are going to move him to a single room (...) where we will be able to spend the night with him, his son and me. We thought: how nice, not to be bothering the roommate (...).
Feelings	Feeling of being late "I wish I had been sent to hospital earlier". You want to have a professional reference, in the face of ignorance, fear, uncertainty, ... Who can help me, don't treat me like a number! Life is a road of good and bad experiences, and within that you have to learn. "(...) At this time, especially in the family, the word that is most often used is uncertainty (...)".	No understanding of language: "Discharge reports are like "sheet music" for someone who doesn't know solfège". This year I was diagnosed with ALS (...) I was already referred 3-4 years ago, but I have symptoms from before (...) I think the diagnosis has been very late.	Lack of communication "We have been encountering everything without anyone telling us, or warning us, about anything". "We really know that doctors don't know which way to turn and so they have to experiment" (person with ALS). "(it would be necessary) (...)a transversal unit with doctors specialised in different diseases that can degenerate at the end of life, who would attend in a certain way...". "We had a telephone service from 9:00 to 16:00 (...) but if something happens to you in the afternoon or at night you have to call an ambulance or go to the hospital". "They offered us psychological support (...) it was great (...) The support they give you goes up to a point (...) There is little psychological support".	Displacement in transitions, loss of reference points: - CHANGES OF ADDRESS - SPECIFIC UNITS - FROM HOSPITAL TO RESIDENCE - OF HOME EXACERBATIONS - ... "From time to time health institutions should take better care of people (...) If I go to the medical services, it is so that they can take care of me, not to tell me that you are in a surplus (...) you are an oncology patient and we are treating you for a common illness (...)". "As a society we have a problem with death in general, we don't talk about it (...)".	"Knowing that you can always call someone who knows what you're talking about and can make very safe decisions to be able to stay at home". "(...) sometimes that lack of humanity on the part of some professionals, (...) I didn't ask for affection (...) but I did ask for a bit of sugar when it came to saying things. Given the situation we were in at the time (with a 15 year old son) I don't think it was the best way to tell us that if you don't sedate him I'm going to send him home". "That's the problem, when is the moment (...) They tell me, do you think he doesn't suffer (...) That's the main thing, that he doesn't suffer".
Experience	fear	apprehension	annoyance	vigilance	grief
Pain Points	There are complex cases in which the designed circuit does not cover certain socio-health needs. People living at home and in palliative care do not always feel that they have sufficient professional support (uncertainty of treatment, fear of an unexpected event at home, discharge from hospital without continuity of care, ...). They look for professionals who are referents and are involved "they know what you are looking for, who know you and treat you as a person (they don't make you feel like a number) and accompany you".	There is a need for more TRAINING among various professionals (health, social ...) in identifying palliative needs and what this will imply for the agents around the patient. To agree on the identification of the factors that help to assess each case with regard to the necessary SUFFICIENT SAFETY NETWORK to be able to cope with care at home. watch out for inconsistencies between verbal and body language: restless patient, nervous, grateful for the attention and the doctor serious, wanting to finish the process of giving. Patient and doctor are in different emotional situations: patient needs time and information, doctor wants to close the episode as soon as possible.	Both the patient and the doctor are in a different emotional state. The patient needs time and information, while the doctor seeks to close the episode as soon as possible	What is needed when the patient enters the hospital is for the specialist to speak with the primary care physician and maintain communication between them, so that there is bidirectional communication. Understanding professional performance from people's transitions: Home (Primary care), changes of address Residencies and Coordination with their teams Hospital Specific units	You can only die at home if there is a socio-familial infrastructure to support it. "Palliative care at home needs a lot of support". The process, the timing of each step (sedation, etc.) is important.
Ideas and Opportunities	Advancing interoperability. Faced with the reality of people in situations of exclusion, it is necessary to move forward with MICROPROJECTS of flats with support (e.g. leaving prison...) and to complement the absence of family and social support.	"The duty of palliative care should be to prevent, not to 'palliate' when one has already suffered a lot (...) Who is responsible for my mother's unnecessary suffering?" **RESOURCE MAP/RELEVANT PROFESSIONALS UPDATED** knowledge of the potential for each case (good practices in palliative care): Increased knowledge among professionals of different resources and services so that we can tell the patient who can help you.	There should be some computerised mechanism that allows, at the very least, direct notes or notices to be left between hospital and primary care professionals. Plans adapted to the different life itineraries (chronic, dementia, oncology). Life Plan Support plan Care plan Referral hospital Community projects with COMMUNITY CONNECTORS, who have professionals, volunteers, ... who approach the different cases, generate confidence and make people and families feel that they know them, know what is important to them, bring them together, create spaces for communication... it is necessary to extend it to more territories.	**Case manager/community connector** (visits at home, residence, hospital, follow-ups...) **etxeTIC** can become a community reference service and extend its focus to people with palliative needs, pilot the predictive system that anticipates people who will transition from home care, train staff in palliative needs and maximise its socio-sanitary coordination	That the patient feels safe and protected in the hands of good professionals. There is a **need for INTERMEDIATE SOCIO-HEALTHCARE RESOURCES**, which already know the person, have access to planning, have 24-hour nursing, can make direct admissions without having to go through the emergency, with quick exits and entrances".